

The lived musical experiences of individuals living with Williams Syndrome: an interpretative phenomenological analysis

E Erasmus
21161046

Dissertation submitted in fulfilment of the requirements for the
degree *Masters* in *Musicology* at the Potchefstroom Campus of
the North-West University

Supervisor: Dr L van der Merwe

November 2014

Abstract

This study was inspired by my experiences with a Williams syndrome child, which drew my attention to the meaningful experiences that children with Williams syndrome might have with music. The problem of the study can be defined in terms of five aspects. Firstly, individuals diagnosed with Williams syndrome suffer medically, socially and cognitively (Levitin & Bellugi, 1998:358-359) and music seems to be an aspect of their lives that could make things easier for them. Secondly, those suffering from Williams syndrome seemingly struggle to adapt to their social surroundings (Bellugi *et al.*, 1994:5). The third aspect that defines the problem is that families of individuals with Williams syndrome in South Africa do not have sufficient access to educational facilities that are equipped to work with their children. This forces them to home school their children without the ability to educate them optimally. Fourthly, the research problem also stems from the lack of awareness about the lived musical experiences of individuals living Williams syndrome. It becomes clear that heightening awareness of the lived musical experiences of Williams syndrome individuals has not been addressed in research. Lastly, researchers have yet to undertake in-depth qualitative studies on the meaning of musical experience for the learning experiences of those suffering from Williams syndrome.

The purpose of this interpretative phenomenological analysis (IPA) is to understand the lived musical experiences of individuals living with Williams syndrome in Southern Africa¹. Williams syndrome is defined as a rare genetic disorder which presents when around 20 genes are deleted on chromosome 7 at conception (Bellugi *et al.*, 2007:98).

This study follows an IPA approach and aims to gain insight into how participants understand their lived musical experiences. The theoretical foundations for IPA are based on “three key areas of philosophical knowledge, namely phenomenology,

¹ Of the three participants taking part in this study, two are from South Africa (Eastern Cape and Free state) and the third is from Namibia.

hermeneutics and idiography” (Smith *et al.*, 2009: 11). For this study data were collected by conducting in-depth semi-structured interviews with three purposefully selected participants. The interview transcriptions were then analysed separately using ATLAS.ti 7 computer software. After each interview transcript was analysed individually, superordinate themes emerged from a cross-case analysis.

The results of the study revealed four superordinate themes regarding the musical experiences of the three Williams syndrome participants: a passion for performing, fostering friendships, lightens the load and dependent on music. The study found that music contributes to the overall well-being of the three participants in a way that allows them to feel accepted by others and to escape the label of being diagnosed Williams syndrome.

Key words: Williams syndrome, lived experiences, musical experience, interpretative phenomenological analysis

Acknowledgements

I would like to start by thanking my supervisor, Dr L. van der Merwe, for her guidance and wisdom during the course of my study. Her passion for research and music education was a true inspiration and the motivation for the entire process of completing my dissertation. Thank you also for every bit of advice and your belief in me. You always inspire me to go above and beyond.

I also want to thank the three participants who agreed to share their stories with me. I learned so much from you and it was a humbling experience for which I shall be eternally grateful.

I would also like to thank my parents and in-laws for their love and support over the past two years. I really do appreciate every phone call, message and prayer. Thank you also for your patience and understanding when I did not always reply to phone calls or messages immediately or at all.

Lastly I would like to thank my husband, Hans, for his unfailing love and support. For all your patience and motivational talks I am truly grateful. Thank you for always being there and making sure that everything in our lives stayed on track over these last two years. I would not have been able to do this without you.

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CHAPTER ONE: INTRODUCTION

This study was inspired and shaped by my experiences with a Williams syndrome child while conducting a case study for my fourth year mini-dissertation. During the time spent with a Williams syndrome child I noticed that the child has an intense love of, and need for, music in everyday life and presented an unusual attentiveness to, and grasp of, music. This observation alerted me to the meaning music has for individuals living with Williams syndrome and the possible significance of this in their education.

The problem of this study can be defined with reference to five aspects. Firstly, individuals diagnosed with Williams syndrome suffer medically, socially and cognitively (Levitin & Bellugi, 1998:358-359). Music seems to be an important aspect of their lives that could make things easier for them. Secondly, those suffering from Williams syndrome struggle to adapt fully to their social surroundings (Levitin, 2006:2). The third aspect is that families of individuals with Williams syndrome in South Africa do not have sufficient access to educational facilities that are equipped to work with their children. This forces them to home school their children without the ability to educate them optimally, especially if musical experiences are to be used as part of the children's learning process (van der Merwe, 2012:21). Fourthly, the research problem also stems from the lack of awareness about the lived musical experiences of individuals living with Williams syndrome. It becomes clear that heightening awareness of the lived musical experiences of Williams syndrome individuals has not been addressed in research. Lastly, researchers have yet to undertake in-depth qualitative studies on the meaning that musical experience has for those suffering from Williams syndrome.

Although little, if any, research has been done on the lived musical experiences of individuals living with Williams syndrome, there have been studies that highlight some characteristics of individuals suffering from the syndrome that could prove useful in trying to understand not only the syndrome itself, but also the lived musical experiences of individuals living with Williams syndrome. These studies discuss

mainly four aspects of individuals diagnosed with Williams syndrome: medical conditions, physical traits, cognitive manifestations and sociability. Studies that are important – not because of any direct similarity to this study, but rather because they lead to a better understanding of Williams syndrome – highlight certain medical conditions and physical traits associated with the syndrome. Some of the medical conditions present in individuals with Williams syndrome are cardiovascular abnormalities, digestive problems, hypercalcemia and curvature of the spine (Levitin & Bellugi, 1998:358-359). Furthermore, physical traits that help identify Williams syndrome sufferers include a slender build, broad forehead, sunken nasal bridge, puffy blue eyes, wide mouth, long upper lip, prominent lower lip, small widely spaced teeth, small chin and poor digit independence between the third and fourth fingers (Levitin & Bellugi, 1998:358-359).

Unlike the studies on medical and physical traits of Williams syndrome individuals, studies that mention several common cognitive manifestations present in people suffering from Williams syndrome are of greater relevance as far as the current study is concerned. Levitin (2005:2) found that Williams syndrome sufferers have an IQ range of between 40 and 100, impaired spatial and reasoning abilities, poor hand-eye coordination and a short attention span. An unusual neuropsychological profile affecting the behavioural patterns of those diagnosed is also present in Williams syndrome individuals. As far as Gestalt theory is concerned, Williams syndrome individuals do not look at the bigger picture (Levitin & Bellugi, 1998:361), but rather focus on every detail as if removed from the whole. This could have an influence on this study when considering the way in which Williams syndrome individuals interpret and understand music.

According to Levitin and Bellugi (1998:359), people who are diagnosed with Williams syndrome exhibit exceptional language development which facilitates their sociability (Bellugi *et al.*, 2007:100). This is an important quality when studying the musical experiences of individuals living with Williams syndrome, since they perform optimally in social settings. Studies done by Levitin *et al.* (2004:226) show that Williams syndrome children have higher levels of sociability than typically developing

children of the same age. This was found in a study on the rhythmic capabilities of children with Williams syndrome compared to other special needs children. Williams syndrome children showed fewer capabilities in rhythmic tasks than other children when using recorded music, but their scores improved immensely when someone played the material on an instrument during the test. The study emphasises their need for, and love of, social interaction in that Williams syndrome children function optimally in social settings, even when taking tests (Levitin *et al.*, 2004:226).

There are a few studies that are fairly directly related to this research that could be used for guidance in trying to understand the lived musical experiences of individuals living with Williams syndrome. Levitin *et al.* (2005:516) conducted a study on *hyperacusis*, which is presented in individuals suffering from Williams syndrome. They identified different levels of hearing sensitivity, which include the ability to detect soft sounds, lowered pain threshold for loud sounds, the display of fear when hearing sounds not usually regarded as aversive, a pathological state leading to a feeling of pain with stimuli not usually perceived as painful, and also a fascination with certain sounds. Researchers have found that individuals with Williams syndrome seem to be drawn toward listening to and making music on a very frequent basis. These individuals exhibit an intensely emotional engagement with music and a good musical memory.

Levitin *et al.* (2004:236) are of the opinion that there is a possible correlation between the social and musical drives presented by Williams syndrome individuals and the gene deletion present at conception. They also argue that Williams syndrome sufferers seem to be “consumed by their affective reactions to music”. Levitin (2005:3) found that several orthogonal factors such as “musical complexity, production, sensitivity, musical theory and achievement, listening, habits, positivity and emotions” form part of Williams syndrome individuals' musical phenotype. The assumption that when Williams syndrome sufferers engage with music they do so with extreme emotions seems to be borne out when taking into consideration a study done by Levitin *et al.* (2004:238), where a little girl wept after hearing just a couple of notes at a Mozart concert. Afterwards she commented to her mother: "There are two

kinds of Mozart, the kind that hurts and the kind that does not hurt." This level of emotional engagement with music could prove to be a key factor in the current study, as it could possibly influence the meaning that these individuals ascribe to their musical experiences.

In another closely related study conducted by Levitin (2005:6), Williams syndrome individuals presented higher than expected musical abilities. This was seen when Williams syndrome children were asked to clap rhythmic patterns presented to them. While they did not necessarily clap the exact patterns as required, they did clap patterns that were musically compatible with the phrase given. When referring to melodic reproduction, on the other hand, Levitin (2005:7) found that Williams syndrome children performed well when asked to repeat a melodic phrase, but did not perform as well when asked to complete a melodic phrase. When these children's rhythmic and melodic audiation was tested, the Williams syndrome children scored high marks, indicating that the discrepancy between rhythmic and melodic production is not influenced by rhythmic and melodic audiation (Levitin, 2005:8).

This study differs from existing research as it focuses on the individuals' experiences rather than on diagnosis of the syndrome. This study will be the first of its kind providing insight to parents, teachers and therapists working with children suffering from Williams syndrome. This study could also provide academics with the needed information to conduct further research in this field.

1.1. Purpose statement

The purpose of this interpretative phenomenological analysis (IPA) will be to understand the lived musical experiences of individuals living with Williams syndrome in Southern Africa. Williams syndrome is defined as a rare genetic disorder which presents when around 20 genes are deleted on chromosome 7 at conception (Bellugi *et al.*, 2007:98).

1.2. Research questions

1.2.1. Central question

The main question guiding this study is: How do individuals suffering from Williams syndrome understand their lived musical experiences?

1.2.2. Sub-questions

The first sub-question, which will provide a textural description of the problem, thus asking what the participants experienced, is: What do individuals living with Williams syndrome experience when engaging in music?

The second sub-question, which aims to provide a structural description, asking how the participants experienced the phenomenon, is: How do individuals living with Williams syndrome experience music?

1.3. Delimitation

In this study I shall not be focusing on cases of individuals with Williams syndrome outside of Southern Africa. While conducting this study, I shall not draw on information gathered through interviews with the parents of individuals suffering from Williams syndrome. The objective of this study will not be to create a new theory or solve any problems, but to heighten awareness of the lived musical experiences of individuals diagnosed with Williams syndrome.

1.4. Research design

The research design that shapes this study is qualitative, aiming to gain an understanding of how people interpret their lived experiences (Creswell, 2013:43; Merriam, 2009:5), how they understand the world and what meaning they ascribe to their experiences. Interpretive research takes as its point of departure that reality is socially constructed and assumes that there is no single

fixed reality but different interpretations of the same event (Merriam, 2009:8). This dissertation will take the form of a holistic study, as it will acknowledge the interaction between social context and biography in answering questions about people's lives and the circumstances in which they live.

As a qualitative researcher I try to understand the world from the perspective of those “often not listened to” (Merriam, 2009:6), “giving voice” (Creswell, 2013:44) to people marginalised by society. This type of research places a strong emphasis on thick description and interpretation (Creswell, 2013:44), whilst demanding that I remain aware of my personal biases in order not to allow my preferences to influence my findings (Bresler, 1995:4). While conducting my research I shall construct knowledge from discovery-oriented findings (Merriam, 2009:7) in the process of using different interpretive techniques seeking to “describe, decode, translate and come to terms” with phenomena in a natural social world. The reason for undertaking this qualitative study stems from the lack of existing research about the lived musical experiences of individuals living with Williams syndrome.

1.4.1. Research approach

For this qualitative study I shall follow an interpretative phenomenological analysis (IPA) approach providing a description of how individuals living with Williams syndrome experience music (Lester, 1999:2). The theoretical foundations for IPA are “based on three areas of philosophical knowledge, namely phenomenology, hermeneutics and idiography” (Smith *et al.*, 2009: 11). This study will objectively describe the essence of the meaning that individuals with Williams syndrome ascribe to certain lived musical experiences (Colaizzi, 1978:53; Creswell, 2013:76). I shall thus discuss the key factors of the participants' lived musical experiences in terms of what they have experienced, how they experienced it (Creswell, 2013:79) and how they understand these experiences (Smith & Osborn, 2003:53). Seeing that phenomenology is one of the three philosophical areas associated with IPA research, my study focuses

on lived experience and can only be grasped reflectively as past presence (Bresler, 1995:8).

From a hermeneutic point of view, human experience is context-bound and expresses happenings in a social world. For this study, experience will be treated as text (Bresler, 1995:8) in order for me to interpret the meaning of a whole. In line with what Van Manen (1990:6) and Bresler (1995:8) posit, I have to study the meanings that persons generate and emphasise the uniqueness of these individual meanings in the sense that persons are irreplaceable, unclassifiable and incomparable. In order to remain true to the idiographic nature of IPA, I shall focus on each interview separately during data analysis before moving on to searching for similarities and differences across the three interview transcriptions. Therefore, this study is phenomenological, hermeneutic and idiographic in nature, because it studies the musical experiences of Williams syndrome individuals, while focusing on the uniqueness of each participant and the meanings that each individual generates.

1.4.2. Research method: interpretative phenomenological analysis (IPA)

IPA aims to explore the meanings that participants ascribe to their lived experiences (Reid *et al.*, 2005:20). According to Reid *et al.* (2005:20), a successful interpretative analysis of lived experiences is transparent and plausible, creating a balance between what is distinct and shared in terms of the lived experience and the meanings generated by each individual. Typical IPA data collection and data analysis strategies will now be discussed.

a. Data collection

The main instrument for conducting IPA research is conducting in-depth semi-structured interviews (Reid *et al.*, 2005:22). I shall conduct one-to-one interviews (Reid *et al.*, 2005:22), seeing that this will help me make sense of

the topic by identifying and interpreting relevant meanings. Collecting data through interviews will be possible, seeing that Williams syndrome individuals display extraordinarily well developed language and social skills. Thus the data collection method for this IPA research will aim to encourage and facilitate reflection. By conducting semi-structured interviews, the interviewees can follow streams of thought themselves, while exploring often unformulated in-depth lived experiences revealing personal meaning (Bresler, 1995:10). I shall thus ask the appropriate questions in order for me to gather descriptive data about the lived musical experiences of individuals diagnosed with Williams syndrome. This study will benefit from detailed engagement with three purposefully selected participants and will access the phenomenon from more than one perspective, through creative and reflective conversations with participants.

I thus aim to design data collection events which prompt thoughts, descriptive stories and feelings from the participants (Smith *et al.*, 2009:56-57). When planning my interview schedule I shall focus on incorporating questions exploring sensory knowledge into the interview schedule, seeing that people experience the world, and music, through their senses. The success of the interviews relies on the extent to which the questions explore the uniqueness of the participants' experiences (Colaizzi, 1978:58).

b. Data analysis

The IPA process that I shall follow when analysing my data is inductive, subjective (Moustakas, 1994:9; Van Manen, 1990:20) and reflective, allowing interpretations that encompass meaning, affect and cognition (Reid *et al.*, 2005:20-21). During this process I shall use techniques of organising, coding, integrating and interpreting data to make sense of the participants' experiences (Reid *et al.*, 2005:22). ATLAS.ti 7 computer software will assist me in the organisation of my data when I start the analysis process (Creswell, 2013:203).

During the analysis stage of my research I shall analyse the lived musical experiences of Williams syndrome individuals to identify superordinate themes (Bresler, 1995:14; Reid *et al.*, 2005:23), which will be organised in such a way as to provide structure when writing up my findings. It is necessary that I work transparently in order for the reader to see how I have arrived at my interpretations (Lester, 1999:2). Smith and Osborn (2008:72) emphasise, however, that it is important that I check my own understandings against what the participants actually said, taking care to stay true to the participants' story, so that phrases that support the identified themes can be highlighted.

The data-analysis process necessary for a successful IPA study follows an idiographic approach by starting with the particular examples and then moving on to more general claims by analysing the transcripts case-by-case (Smith & Osborn, 2008:34, 168). I shall thus start by concentrating on each single case in its own right and only after each case has been analysed, independently from each other, shall I move to the other cases in a case-by-case process. The analysis process associated with IPA research has often been described as inductive and iterative (Smith *et al.*, 2009:79; Willig, 2010:187).

Smith *et al.* (2009:81-103) give step-by-step guidelines for successful data analysis, which I used to guide my analysis process. I shall also follow this process for data-analysis using ATLAS.ti 7 computer-aided qualitative data analysis software, saving the different stages of my progress. The six steps explained by Smith include:

- i. *"Reading and re-reading"*
- ii. *"Initial coding"*
- iii. *"Developing emergent themes"*
- iv. *"Searching for connections across the emergent themes of each separate case"*
- v. *"Moving to the next case"*
- vi. *"Looking for patterns across cases"*

c. *The participants*

IPA research normally studies a small group of participants who are carefully selected, share certain qualities or lived experiences, and who are able to speak in depth about their experiences (Smith & Osborn, 2008:56). For this study I shall identify three participants. The participants whom I shall select for this study must all be individuals with Williams syndrome who have had a musical experience of some sort or another and who are able to articulate their lived experiences (Creswell, 2013:150; Colaizzi, 1978:58; Reid *et al.*, 2005:22). According to Reid *et al.* (2005:22), typical IPA participants chosen for a study range across the sociocultural spectrum, range between the ages of 10 and 83 years, and are distributed across gender categories.

d. *The role of the researcher*

When conducting qualitative, and in this case IPA research, the researcher takes on the role of primary instrument for data collection (Merriam, 2009:18). According to Bresler (1995:4), it is important that, as the researcher, I must be aware of my own biases and prejudices in order to monitor them while collecting and analysing data during a qualitative study. In the current study I shall take on the role of attentive listener (Bresler, 1995:10) during interviews and conversations, while facilitating the attempts by the participants to articulate their nonverbal experiences. Smith and Osborn (2008:53) emphasise that the researcher in IPA has to understand and interpret the participant's experiences from an insider's perspective. Thus I shall draw on personal experiences in order to make sense of the participants' world through interpretation. As an IPA researcher I must also initiate inquiry by an examination of my own approach and presuppositions about the topic. Following Moustakas's (1994:35) suggestion, I shall draw on my intuition to interpret the lived musical experiences of Williams syndrome individuals as part of my wish to grasp the structural essences of their lived musical experiences.

1.5. Validity

The first strategy that I shall use for validity is member checking (Colaizzi, 1978:61; Creswell, 2013:252) after my findings have been written in order to ensure that all the findings are accurate and trustworthy. I shall further ensure the validity of my research through imaginative variation by viewing my data from various perspectives (Merriam, 2009:26). Another approach for validating my research will be to corroborate my findings with the data. Finally, I aim to provide a rich, thick description (Creswell, 2013:252) of the lived musical experiences of individuals living with Williams syndrome by presenting many interconnected details that could enable the reader to transfer information to other settings and to determine whether the information can in fact be transferred because of shared characteristics.

1.6. Ethics

The first ethical concern of my research is informing the potential participants of the purpose of the study and then obtaining permission (Creswell, 2013:58, 154) from the participants whom I have identified to be studied. Seeing that the participants whom I choose for this study are mentally impaired, it is necessary for me to obtain permission from both the participant and his or her parents/legal guardians. Each participant's parent/s will thus be asked to complete a form providing proof that permission has been given for access to the vulnerable Williams syndrome participants (Creswell, 2013:154). This will be done at the outset of the study to protect the participant, myself and the North-West University. Another ethical issue that I shall keep in mind during my study concerns the privacy of the participants (Merriam, 2009:29). I shall respect the privacy of the participants by not publishing information they deem private and by ensuring their anonymity. As researcher I undertake to ensure that no participant will be harmed at any stage during the research and that participants have the right to withdraw from the study at any given time.

1.7. Chapter division

This dissertation will consist of five chapters. The first chapter will provide an introduction to the study. Chapter Two will discuss the relevant literature on Williams syndrome while Chapter Three explains the research design for this study. Chapter Four will include the results and Chapter Five ends the dissertation with a discussion of the results and a conclusion.

1.8. Significance of the study

This study will contribute towards heightening awareness of the meaning and value of lived musical experiences for individuals living with Williams syndrome, thus giving a voice to a group of individuals overlooked and often ignored by society. This insight could lead to parents, educators and therapists having a better understanding of the way in which individuals with Williams syndrome experience music. In turn, this understanding could help parents, educators and therapists create more suitable environments in which the Williams syndrome individuals could have musical experiences. Such awareness could contribute towards greater pedagogical thoughtfulness and tact (Van Manen, 1990:154,155).

The next chapter of this dissertation is the literature review. The second chapter gives a broad overview of existing literature on Williams syndrome, thus defining the syndrome and giving insight into what it means to be diagnosed with the syndrome.

CHAPTER TWO: LITERATURE REVIEW

Introduction

In recent years Williams syndrome has drawn the attention of many researchers in the field of neuropsychology. This could be ascribed to the fact that the syndrome presents a unique neuropsychological profile (Bellugi *et al.*, 1994:102-103) exhibiting strengths and weaknesses that might, at first glance, seem to contradict one another. Individuals living with Williams syndrome also tend to display unusual musical interest and skills.

Existing research on Williams syndrome and music focus mainly on the neuropsychology of the musical perception and cognition of people living with Williams syndrome, but not on the essence of their musical experiences. Some of the psychophysical features associated with the syndrome include an uncanny sensitivity to certain sounds, loud noises and timbre (Bellugi *et al.*, 1994:6; Levitin, 2005:18). Furthermore, extensive research has been done on the cognitive, language and social abilities of Williams syndrome individuals. Research also shows that children with Williams syndrome appear to be drawn to music in an unusual way and are more emotionally responsive to music than comparison groups (Dyken *et al.*, 2005:16-18; Salk Institute, 2006:10; Thornton-Wells *et al.*, 2010:8). When studying the literature on Williams syndrome and music it becomes clear that most Williams syndrome individuals have an affinity for music and that they present high levels of talent and musical skills (DuFour, 2008:6; Levitin, 2005:9; Levitin *et al.*, 2003:7; Martens *et al.*, 2010:6; Martens *et al.*, 2011:4).

Yet very little research, if any, has focused on the meaning that Williams syndrome individuals ascribe to their musical experience and its importance in their lives. When considering the vast research field of music education and music therapy, it would seem that musical experience potentially has deep meaning in the lives of

Williams syndrome individuals. Researchers are yet to conduct in-depth research on the topic, specifically related to Williams syndrome individuals.

Reynolds and Prior (2003:1) conducted a study, not directly related to Williams syndrome but relevant for this study, which revealed that art helped chronically ill participants to maintain a healthy self-image and also to foster friendships. The study further found that art assisted participants in coping with struggles brought on by illness. According to Reynolds and Prior (2003:5-6) art provided participants with stress relief while enhancing their quality of life by decreasing feelings of depression and anxiety. Reynolds and Prior (2003:6) also state that art was a means through which participants could cope with their chronic illness by distracting their thoughts. Through art, these participants were able to momentarily create a seemingly normal life free from the limitations brought on by their illness (Reynolds & Prior, 2003:11). Another study that has relevance to this research project is one by Heath *et al.* (2006:40, 42) which studied “children’s assessment of participation and enjoyment” and found that children experienced feelings of success and social satisfaction when engaging in extra mural activities. Their study revealed that disabled children formed friendships and were able to enhance positive self-esteem when experiencing successful participation which led to fun, success, socialisation and self-growth (Heath *et al.*, 2006:44).

This review could prove helpful to researchers aiming to embark on qualitative studies on Williams syndrome in drawing attention to the important role that music plays in the lives of those living with the syndrome. Furthermore, this literature review will draw conclusions on the musical experiences of people living with Williams syndrome and could thus be valuable for researchers undertaking phenomenological studies. The current research will give caregivers, educators, researchers, therapists and parents an insight into Williams syndrome, whilst raising awareness about the strengths and impairments associated with the syndrome.

The aim of this literature review is firstly to gain an understanding of what Williams syndrome is. Secondly, this review synthesises the literature on the musical

experiences or musical perception of individuals diagnosed with Williams syndrome. Therefore this study should provide insight into the syndrome and highlight the need for a study that focuses on the meaning that musical experience has in the lives of people living with Williams syndrome. The review was done by analysing 56 primary documents by coding the collected literature using ATLAS.ti 7 computer software.

The review starts with a section defining Williams syndrome in broad terms. The syndrome will then be discussed under the following eight themes derived from the literature as shown in *Figure 1*: neuropsychological profile, Williams syndrome and emotion, cognitive phenotype, language, sociability, auditory perception, auditory abnormalities and, finally, Williams syndrome and music.

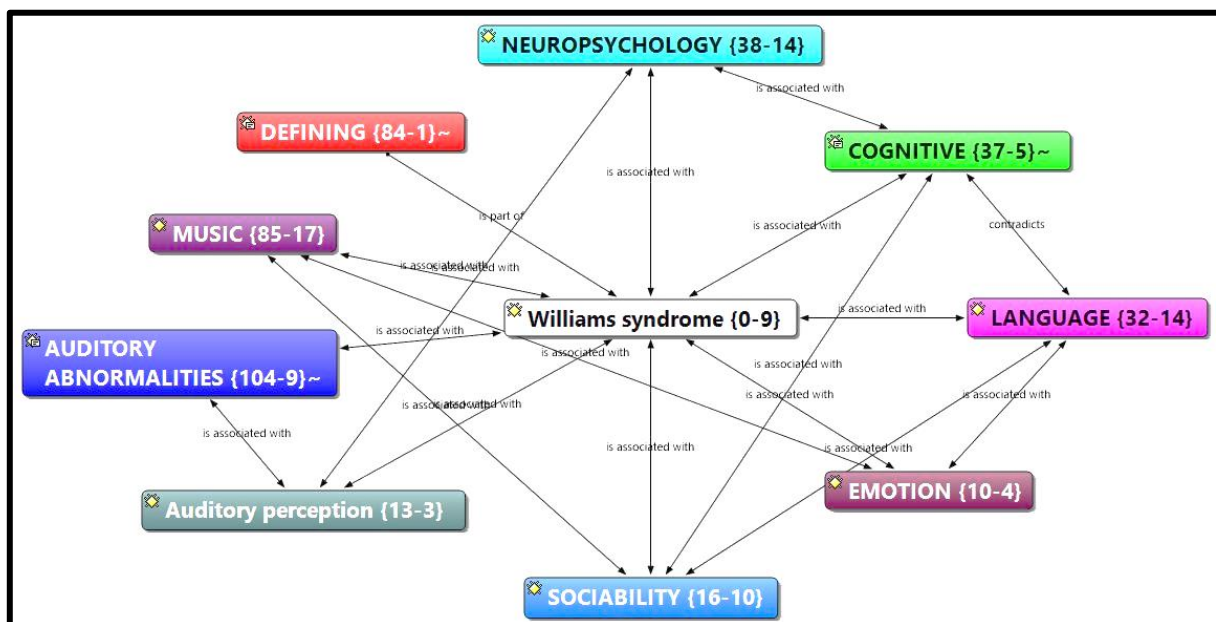


Figure 1: Structure of this chapter²

² The numbers at the end of the code in the network view refer to the groundedness and density of the codes in ATLAS.ti 7. The term groundedness refers to how frequently a code word appears in the ATLAS.ti 7 hermeneutic unit. Density refers to the number of links between a specific code word and others.

2.1. Defining Williams syndrome

Williams syndrome is a rare neurogenetic developmental disorder (Levitin, 2005:1; Levitin *et al.*, 2004:5) characterised by a specific neuropsychological profile (Don *et al.*, 1999:15) and presents itself in approximately one out of every 20,000 live births. The syndrome was first discovered by British cardiologist Dr Williams and his colleagues in 1961 (Levitin & Bellugi, 1998:358). Williams syndrome occurs when approximately 20 genes are deleted on Chromosome 7 (Bellugi *et al.*, 2000:7). These genes include those necessary for elastin production and have an impact on the release of neurochemicals, in turn affecting cell signalling during neurodevelopment (Levitin *et al.*, 2004:7-10). The elastin gene is also associated with the vascular abnormalities seen in Williams syndrome (Hopyan *et al.*, 2010:9). Järvinen-Parsley *et al.* (2009:9) state that some of the distinctive social functions associated with Williams syndrome, especially the amplified approachability toward strangers, can be associated with the unique genetic features present in individuals living with Williams syndrome. Barozzi *et al.* (2013:14) claim that the genetic deletion causing Williams syndrome could be responsible for the cognitive phenotype and visual-spatial development associated with the syndrome. Williams syndrome characteristics can be divided into eight categories, which include physical aspects, medical conditions, neuropsychological profile, cognitive phenotype, language, sociability, auditory abnormalities and music.

Individuals with Williams syndrome can easily be identified by certain physical aspects, which include a slender build, broad forehead and a sunken nasal bridge. They also tend to have blue, puffy eyes. Furthermore individuals with Williams syndrome can be identified by their wide mouth, long upper lip, prominent lower lip, small widely spaced teeth and small chin (Levitin & Bellugi, 1998:358).

Those diagnosed with Williams syndrome are also prone to suffer from certain medical conditions. These conditions include cardiovascular abnormalities resulting in a narrowed aorta and scoliosis. They often have renal and digestive problems and perforated intestines. Individuals diagnosed with Williams syndrome further tend to suffer from severe arthritis and struggle with stiff limbs (Sforza *et al.*, 2006:24). Hypercalcemia and curvature of the spine are also among the medical conditions commonly associated with Williams syndrome (Levitin & Bellugi, 1998:358-359). People diagnosed with Williams syndrome, not only suffer from extreme anxiety and fear in everyday life, but tend to suffer from sleep anxiety as well (Ashworth *et al.*, 2013:4). Despite the physical aspects and medical conditions commonly characterising Williams syndrome, individuals diagnosed also present an unusual neuropsychological profile.

Williams syndrome is associated with an abnormal neuropsychological profile which has an effect on the behaviour of those diagnosed. Williams syndrome individuals are intellectually impaired, exhibiting IQs ranging between 40 and 100 with a mean of 56 (Levitin & Bellugi, 1998:358 DuFour, 2008:2). They also show impaired spatial, quantitative and reasoning abilities (Levitin, 2005:9). These individuals do, however, display spared abilities in the domains of facial recognition, language, sociability and music, exhibiting a heightened emotional response to, and affinity for, music (DuFour, 2008:6; Levitin, 2005:9; Levitin *et al.*, 2003:7; Martens *et al.*, 2010:6; Martens *et al.*, 2011:4). In order to better understand Williams syndrome, the neuropsychological profile associated with the syndrome is discussed below.

2.1.1. Neuropsychological profile

Williams syndrome presents an uncommon neuropsychological profile which has an impact on the cognitive functioning and development of those diagnosed (Bellugi *et al.*, 1994:102-138). According to Bellugi *et al.* (2000:137), markers of Williams syndrome include an enlarged neocerebellar vermis, small

paleocerebellum, enlarged neocerebellum and disordered neurons. The relatively good explicit memory skills of Williams syndrome individuals suggest that the mesial temporal structures and hippocampus are intact. Studies done on brain function and morphology show neural abnormalities which distinguish aspects of the Williams syndrome neurobiological phenotype (Bellugi *et al.*, 2000:87). The neuropsychological profile associated with Williams syndrome will be discussed further in terms of neuroanatomical features.

2.1.2. Neuroanatomical features

Bellugi *et al.* (2007:28) conducted a study which revealed that individuals with Williams syndrome have disproportionately large volumes of the amygdala. Williams syndrome is further associated with smaller overall brain size and grey matter volume than typically developing controls (DuFour, 2008:24; Golarai *et al.*, 2010:13). The temporal lobes of the brains of Williams syndrome individuals are normal sized, but the cerebral volume is decreased. Bellugi *et al.* (1994:94) suggest that Williams syndrome presents abnormal development of neural systems impacting on brain function and structure. These abnormalities could provide an insight into the neural systems that underlie the higher cognitive functions observed in people living with Williams syndrome (Bellugi *et al.*, 1994:94).

Focal lesions in the right hemisphere of Williams syndrome individuals tend to preserve key linguistic functions while obstructing spatial skills (Bellugi *et al.*, 1994:100). Research also found differences in cell size and density in the brains of people with Williams syndrome as compared to normal controls. These findings could underlie strengths in auditory phonology, language and music. They may also explain their impaired visual-spatial construction (Salk Institute, 2006). These insights into the neuroanatomical characteristics associated with Williams syndrome then brings us to the cognitive phenotype typically found in individuals living with Williams syndrome.

2.2. Cognitive phenotype

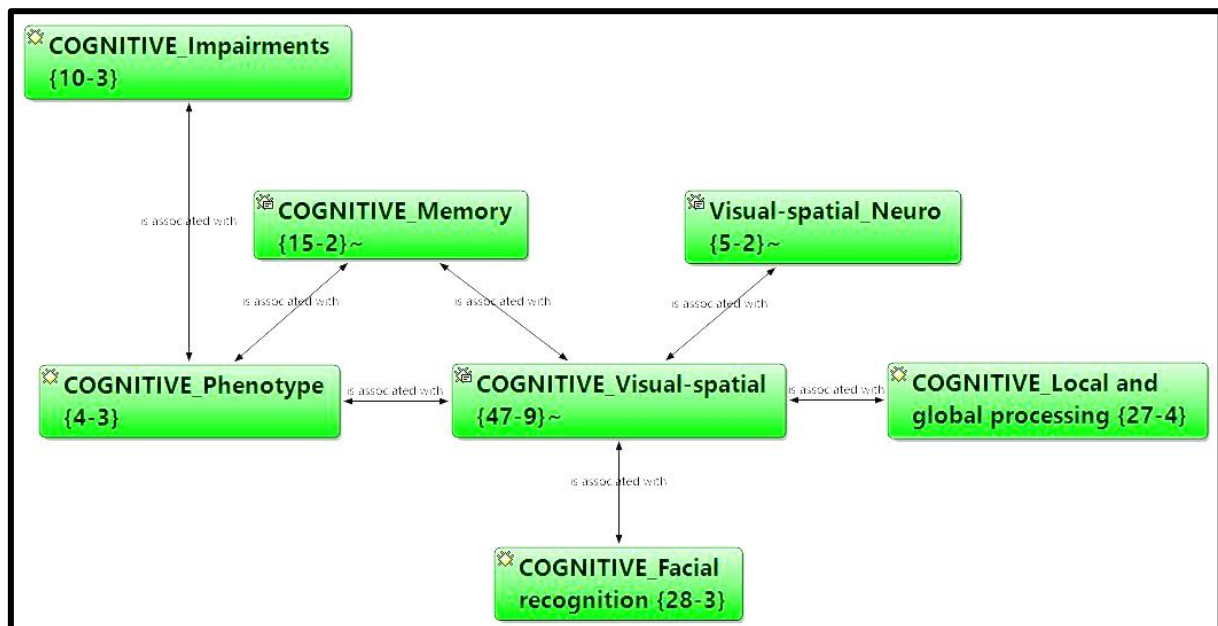


Figure 2: ATLAS.ti 7 network view of the literature review on the cognitive phenotype of Williams syndrome individuals

Williams syndrome individuals present an unusual cognitive profile which features mental impairment (Bellugi *et al.*, 1994:32) and certain dissociations (Bellugi *et al.*, 2007:8). The cognitive profile can also be characterised by a variety of abilities within and across certain cognitive domains (Bellugi *et al.*, 1994:22; Bellugi *et al.*, 2000:90). Williams syndrome individuals tend to show unusually good facial processing abilities, especially when considering that they fail Piagetian tests of conservation skills for numbers, weight and substance (Bellugi *et al.*, 1994:36). Furthermore, those diagnosed with Williams syndrome often have difficulty with coordination (Bellugi *et al.*, 2000:105) as well as with mathematics and its application in everyday life (Bellugi *et al.*, 2000:95). People living with Williams syndrome generally have poor motor skills, which lead to difficulty tying shoes, for example, and poor eye-hand coordination overall (Levitin & Bellugi, 1998:74).

The cognitive profile of individuals living with Williams syndrome include dissociations between general cognitive functioning such as visual-spatial processing, facial recognition and language abilities (Bellugi *et al.*, 1994:92; Bellugi *et al.*, 2000:75; DuFour, 2008:3; Pani *et al.*, 1999:12). Studies have found evidence for the independent functioning of facial processing, spatial abilities and language in human behaviour (Bellugi *et al.*, 2000:82). Don *et al.* (1999:42) argue that the deficits observed in the cognitive profile associated with Williams syndrome could be influenced by systems within the right hemisphere.

Researchers have begun to focus their studies on the short- and long-term memory of individuals with Williams syndrome. Bellugi *et al.* (1994:82) found that individuals diagnosed with the syndrome were able to correctly repeat a sequence of at least four digits. This only holds true for the forward repetition of the digits, seeing that the Williams syndrome subjects only averaged 2.5 digits with backwards repetition. When studying the explicit memory skills of people with Williams syndrome, tests showed that these individuals were able to recall items from different categories (e.g. toys, fruit, clothes) by grouping these items into the selected categories during the recall. Results on the implicit memory skills of those with Williams syndrome show that they do not perform as well when having to draw on collective abilities which include motor skills, perceptual skills and problem solving in order to complete a task (Bellugi *et al.*, 1994:86). Levitin and Bellugi (1998:92), furthermore, found that phonological memory appears to be a relative strength in individuals diagnosed with Williams syndrome. Martens *et al.* (2011:15) suggest that the verbal short-term memory of those diagnosed with Williams syndrome could be relatively strong, while their verbal long-term memory may be significantly impaired. The cognitive impairments associated with Williams syndrome possibly contribute to the fact that these children struggle with academic achievement.

Williams syndrome individuals require special education and their academic performance is far below that of their age-matched peers, even in adulthood.

The consequence of this is that Williams syndrome adults often reside with their parents or in group homes with supervision (Bellugi *et al.*, 1994:34). Another important aspect relating to the cognitive phenotype of Williams syndrome individuals is their unique neuropsychological profile.

2.2.1. Cognitive neurology

Bellugi *et al.* (1994:80) refer to neurobiological studies which found that certain cells in the superior temporal sulcus of those diagnosed with Williams syndrome respond selectively to visually presented faces. This could possibly explain the pattern of abilities associated with Williams syndrome. Holinger *et al.* (2005:4, 21) suggest that the anatomical finding of a smaller brain together with dorsal forebrain activity in Williams syndrome is linked to abnormal visual-spatial function. Taking into account that the Williams syndrome brain presents densely packed, smaller neurons in some primary visual cortex layers, one could reach a better understanding of the unusual visual-spatial profile presented by those with Williams syndrome (Holinger *et al.*, 2005:21).

2.2.2. Visual-spatial development

The visual-spatial functioning of those with Williams syndrome is severely impaired, resulting in individuals having difficulty with simple tests of spatial perception and object tracking (Bellugi *et al.*, 1994:63; Landau & Hoffman; 2005:3-9; O'Hearn; Pani *et al.*, 1999:15). This impairment can also be observed in narratives, where people diagnosed with Williams syndrome tend to make use of incorrect spatial prepositions. This becomes clear in a study done by Bellugi *et al.* (2000:125), when a subject stated that "The dog has the jar in his face" when presented with a picture of a dog with his head in a jar. Their findings are suggestive of problems in using language to describe spatial relations. More examples confirming this finding follow in *Figure 3*.

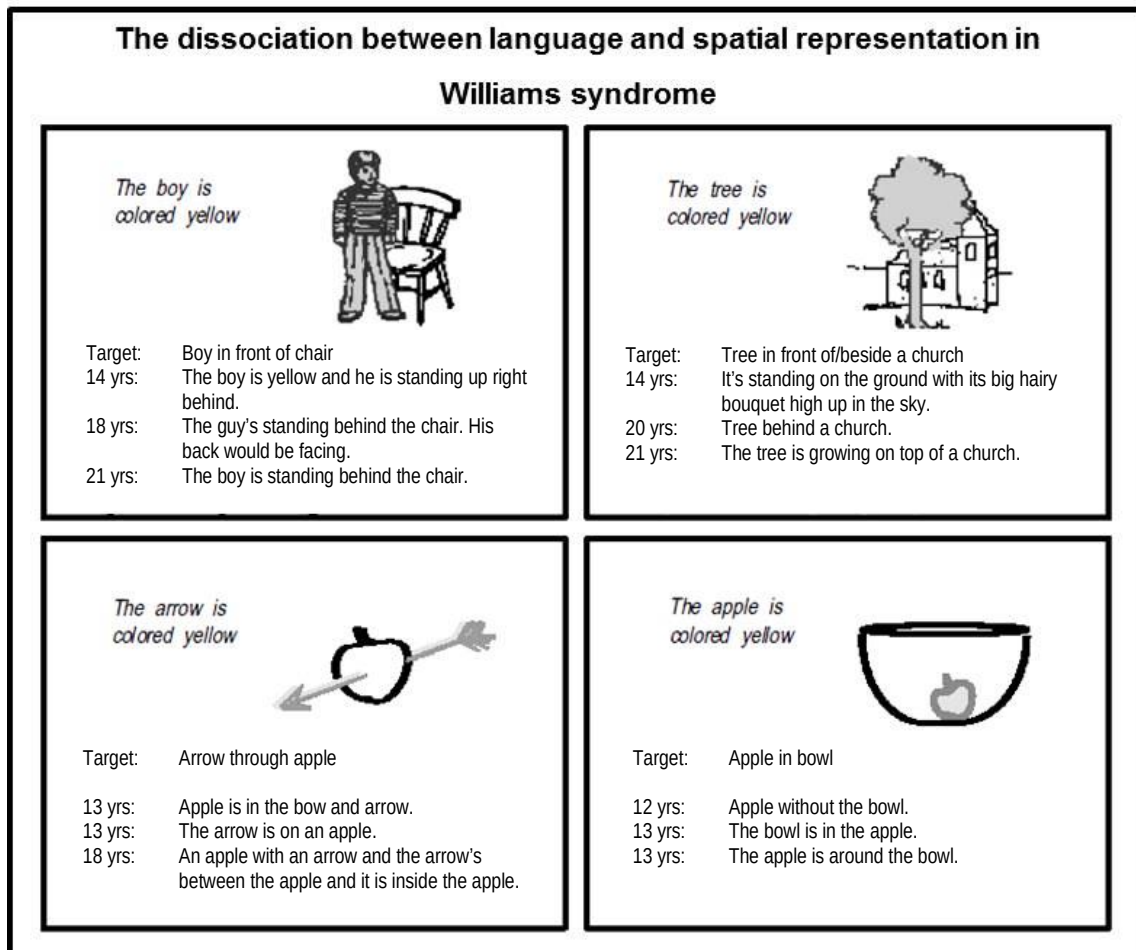


Figure 3: The dissociation between language and spatial representation in Williams syndrome (Bellugi et al., 2000:126)

People diagnosed with Williams syndrome present a bias toward the details of the designs, thus failing to observe global conformations of designs. This behaviour is also associated with individuals suffering from right-hemisphere damage, who exhibit difficulty in perceiving global structures (Bellugi et al., 1994:101). Studies that have been done on the drawing skills of Williams syndrome individuals highlight their visual-spatial impairment, presenting drawings with poor cohesion and a lack of organisation (Bellugi et al., 2000:115). People diagnosed with Williams syndrome are likely to talk their way through their unorganised drawings, expressively describing the objects they aim to draw, despite their drawings being almost impossible to understand (Salk Institute, 2006:15). Through these results it becomes clear that individuals living with Williams syndrome cannot focus on the bigger picture

(Bellugi *et al.*, 2000:120; Levitin & Bellugi, 1998:361; Pani *et al.*, 1999:5). Instead, they focus on every detail as if removed from the whole. This is also demonstrated in a study done by Levitin and Bellugi (1998:362), as seen in the example in *Figure 4*, which shows that Williams syndrome children focus on detail rather than context.

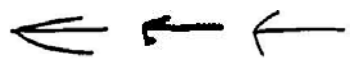
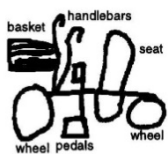
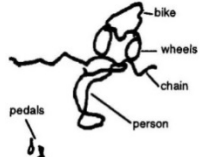
Model	Down's syndrome	Williams syndrome
	 Age 11 Age 13 Age 17	 Age 13 Age 15 Age 16
	 Age 11 Age 16 Age 18	 Age 11 Age 16 Age 18
	 Age 11; IQ 52	 Age 11; IQ 50

Figure 4: Impaired spatial development of Williams syndrome children with specific focus on local and global processing (Levitin & Bellugi, 1998:362)

People living with Williams syndrome tend not to have trouble navigating through and around new buildings and also place objects in containers with ease. The main problem with visual-spatial cognition, then, seems to lie in spatial construction as described by local and global processing (Pani *et al.*, 1999:7). Those with Williams syndrome struggle to recognise global configurations, thus not seeing a flock of birds as flying in a V-shape but rather

seeing each bird individually. Williams syndrome individuals also have difficulty tying their shoes, drawing and building models (Pani *et al.*, 1999:14).

Despite having these difficulties with visual-spatial processing, those diagnosed with Williams syndrome exhibit a good ability when referring to the identification of objects shown from unusual perspectives (Bellugi *et al.*, 1994:72; Bellugi *et al.*, 2000:76). It thus becomes clear that there are certain peaks and valleys within the visual-spatial cognition of Williams syndrome individuals (Bellugi *et al.*, 2000:70).

Despite their other visual-spatial impairments, people living with Williams syndrome present an extraordinary ability to remember and discriminate between unfamiliar and familiar faces (Bellugi *et al.*, 2000:28,123). This ability also holds true when perceiving faces in different lighting conditions and from different angles. Research shows that Williams syndrome individuals employ the same strategy when perceiving faces that they do when perceiving other images, relying on the feature-by-feature processing of faces, thus not focussing on the global structure (Bellugi *et al.*, 1994:136). The performance of Williams syndrome individuals on facial processing stands in strong contrast to their general cognitive impairment, especially in terms of other visual-spatial tasks such as drawing and constructing designs of blocks (Bellugi *et al.*, 2000:80). Research further found that Williams syndrome individuals experience extreme emotions when engaging with music, which could suggest that they are able to focus on the bigger picture where language and music are concerned (Levitin & Menon, 2003:24). This brings us to another characteristic of Williams syndrome that seemingly contradicts their general cognitive development, namely emotion.

2.3. Williams syndrome and emotion

Adolescents with Williams syndrome appear to be overly attentive to the emotional states of others and also often express exaggerated emotions

themselves (Bellugi *et al.*, 1994:59). People diagnosed with Williams syndrome are characterised by their tendency to be animated and vivid in their conduct of everyday life (Bellugi *et al.*, 1994:60).

Järvinen-Parsley *et al.* (2009:48) conducted a study in which they investigated the ability of Williams syndrome individuals to identify emotions displayed by facial expression and scenery. Their study concluded that individuals diagnosed with Williams syndrome executed the task presented to them well, exhibiting abilities similar to normal controls. This was, however, not true for all the emotions presented. Williams syndrome individuals performed well when having to identify happy, fearful and sad facial expressions. When asked to identify these same emotions in visual scenes presented to them they did not perform as well (Järvinen-Parsley *et al.*, 2009:50-53). The study proved that Williams syndrome individuals performed better in social than non-social conditions (Järvinen-Parsley *et al.*, 2009:52), confirming the idea that Williams syndrome individuals are hypersociable.

It thus seems that the degree of intellectual impairment associated with Williams syndrome does not influence their performance of certain tasks in social settings. Järvinen-Parsley *et al.* (2009:52) found that people diagnosed with Williams syndrome tended to perceive the intensity of visual emotion concerning positive facial stimuli as being higher than the control subjects did. This confirms their overall attentiveness to the emotional state of others (Järvinen-Parsley *et al.*, 2009:54-55). The emotional development characterising Williams syndrome is also closely related to, and influenced by, the language abilities of people living with the syndrome.

2.4. Language

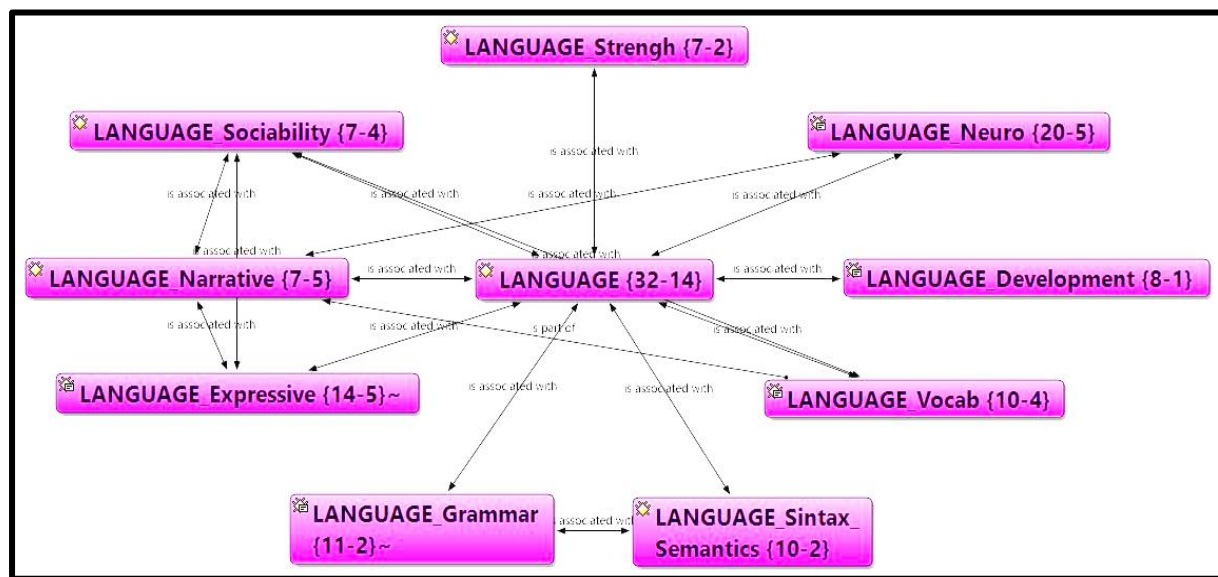


Figure 5: ATLAS.ti 7 network view of concepts on the language development and abilities of Williams syndrome individuals as found in the literature

Researchers suggest that mastering of the concept of conservation is essential for the understanding of passive sentences in language. The visual-spatial profile of Williams syndrome contradicts this argument seeing that Williams syndrome individuals fail conservation tests but show well-developed language skills (Bellugi *et al.*, 1994:76). Bellugi *et al.* (2000:40) further argue that there is a discrepancy between the cognitive impairment and strength in language (which includes ease in using complex syntax in sentences) as seen in people with Williams syndrome.

Although individuals with Williams syndrome present an extreme delay in the production of their first words, their language skills become a relative strength by the time they reach adolescence (Bellugi *et al.*, 2000:38, 55). When Williams syndrome children pass the initial delay in language development, they display grammatical abilities which lead to the dramatic improvement of general language abilities (Bellugi *et al.*, 2000:100-112). Once children with Williams syndrome start to reach adulthood, their linguistic abilities seem

relatively preserved (Bellugi *et al.*, 2000:97) and they swiftly begin to grasp basic morphosyntactic structures (Bellugi *et al.*, 2000:99). This is also true for normally developing children. Don *et al.* (1999:56) emphasise, however, that Williams syndrome individuals perform well with simple language tasks, but that they also tend to perform far worse on complex measures of language involving comprehension.

People diagnosed with Williams syndrome present unusually well-developed narrative and linguistic capabilities resulting in spontaneous fluent speech, good phonology and syntax, good vocabulary and preserved morphology (Levitin, 2005:2). Levitin (2005:13) found that Williams syndrome individuals are, however, likely to use unusual words when engaging in conversation. This could contribute to their inability to understand the world (Bellugi *et al.*, 2007:100). Levitin (2005:15) also mentions evidence of linguistic preservation problems in children diagnosed with Williams syndrome. He led a study which found that Williams syndrome children tend to use words correctly without necessarily understanding the meaning of the word. An example of this is a Williams syndrome boy who spoke about wanting to play steel drums and then later on revealed that he does not know what they look like.

Bellugi *et al.* (1994:78) found that Williams syndrome individuals persistently use exaggeratedly affective prosody in conversations and narratives employing phrases such as “all-of-a-sudden” (Levitin, 2005:14) to grab the attention of their listeners. This shows that those with Williams syndrome are not totally incapable of understanding the world, as affective prosody relies on knowledge of cultural expectations and affective understanding.

Grammar, on the other hand, is less likely to depend on non-linguistic ability. The language profile as seen in Williams syndrome suggests that some language skills may develop independently from general cognitive ability (Bellugi *et al.*, 1994:79-95). The unique language profile of individuals diagnosed with Williams syndrome will now be discussed in depth in terms of

neuropsychological profile, grammar, semantics, syntax and linguistic abilities, expression, and narrative skills.

2.4.1. Neuropsychological profile and language

Although Williams syndrome individuals generally display right hemisphere dependence, there are domains of their language usage that contradict this (Bellugi *et al.*, 1994:110). The existence of well-preserved word fluency, together with volume preservation in frontal brain regions possibly implies that people living with Williams syndrome have a normal neurobiological substrate for semantic function (Bellugi *et al.*, 1994:132). Bellugi *et al.* (1994:142-144) found evidence that frontal brain areas play a role in language, especially lexical and semantic processing. This is supported by the fact that Williams syndrome individuals present relatively good abilities and fluency in semantic tasks.

Despite the overall brain volume of people with Williams syndrome being smaller than normal, the temporal lobe, which is involved in sound, music and language processing, has an almost normal volume (Salk Institute, 2006:16). The brains of Williams syndrome individuals also do not, as with normal brains, show asymmetry, which possibly indicates unusual organisation for language. But this has not been researched in depth (Holinger *et al.*, 2005:18). Levitin and Bellugi (2006:74) found that the hyperconnectivity observed in the brains of Williams syndrome individuals could be related to their reasonably well-developed language and musical abilities (Levitin *et al.*, 2005:60).

The affective and emotional abilities presented by those with Williams syndrome are better than one would expect and suggest relatively good limbic functioning (Bellugi *et al.*, 1994:140). Levitin (2006:63) suggests that the affective processing associated with Williams syndrome could be related to observed vermal, pons and brainstem activation.

2.4.2. Semantics, syntax, grammar and linguistic abilities

Bellugi *et al.* (1994:98) emphasise that Williams syndrome individuals show evidence of both good semantic use as well as deviation from the norm. This could possibly support the notion that semantic organisation may depend on general cognition (Levitin & Bellugi, 1998:44). Most researchers, however, argue that the structural aspects of language are a strength in those diagnosed with Williams syndrome. In a study by Bellugi *et al.* (2000:58) they state that, rather than saying Williams syndrome presents dissociation between language and general cognition, one could argue that the preserved language skills may enable Williams syndrome individuals to reach levels of performance that they otherwise could not. Bellugi *et al.* (1994:37) report that Williams syndrome adolescents perform well in tests on the comprehension of passive sentences, negatives and conditionals. These tests require a grasp of the underlying syntax of the sentences. The ability to reflect upon grammatical form and to comprehend syntactic constraints suggests that Williams syndrome individuals have sophisticated metalinguistic abilities which are remarkable when considering their cognitive profile (Bellugi *et al.*, 1994:39).

Some of the characteristics associated with the language abilities of individuals living with Williams syndrome, as defined by Bellugi *et al.* (1994:39), include the production of grammatically correct sentences, the use of a variety of intricate grammatical forms, conditional clauses, passive sentences and embedded relative clauses. It is important to note, however, that Williams syndrome individuals do not do this flawlessly. They do, on occasion, make grammatical and syntactic errors (Bellugi *et al.*, 1994:41). Bellugi *et al.* (1994:42) found that Williams syndrome individuals have the ability to monitor and correct ungrammatical sentences and that, even though they sometimes make mistakes, they use morphological markers for tense, aspect and auxiliaries. The general conclusion in the existing research is that Williams syndrome individuals display well-developed grammatical abilities.

Although Williams syndrome individuals generally display well developed language abilities, they also exhibit unusual semantic organisation. Studies done by Bellugi *et al.* (2000:23) found evidence for this when Williams syndrome individuals would use sentences such as “I have five fingers on my moon”. When the comprehension of passive sentences was tested, Williams syndrome adolescents performed well, presenting a grasp of the underlying syntax of sentences. Bellugi *et al.* (2000:49-50) further report that Williams syndrome subjects were able to provide and understand definitions compatible with homonyms, providing the same number of primary and secondary meanings for words. The control group, however, provided almost only primary meanings. According to Bellugi *et al.* (2000:110), this is suggestive of anomalous semantic organisation.

Adolescents with Williams syndrome exhibit a large and unusual vocabulary, together with an intricate syntactic structure (Levitin & Bellugi, 1998:26). Studies found that Williams syndrome individuals do not only show preservation of vocabulary but also deviation. This becomes clear in a study conducted by Bellugi *et al.* (1994:45), which found that the spontaneous language of adolescents with Williams syndrome included unusual word choices such as “The bees abort the beehive” – meaning that the bees leave the beehive. Another example of this is a Williams syndrome participant saying “I have to evacuate the glass” instead of “I have to empty the glass”. These are examples of words used for their secondary rather than their primary meanings.

The parents of children with Williams syndrome often report that their children have a wide vocabulary, but that they do not necessarily understand what all the words mean (Bellugi *et al.*, 2000:15). Some even say that Williams syndrome individuals often “talk funny”. It is also true that Williams syndrome children tend to give exotic examples when asked to name different items from the same category. These children would easily name animals such as newts, yaks and ibexes (Levitin & Bellugi, 1998:27). One would not typically expect

these animals in a list from a child, especially one with severe cognitive impairments.

According to Levitin and Bellugi (1998:44), the inordinately good language abilities associated with Williams syndrome suggests that language may not totally rely on general mental function, but could represent an independent faculty. This development is the result of strengths primarily associated with systems in the left cerebral hemisphere (Don *et al.*, 1999:41).

2.4.3. Expression

Williams syndrome individuals tend to use affective prosody very often, especially when telling and re-telling stories (Bellugi *et al.*, 1994:12). The expressive language use of individuals with Williams syndrome is evident in paralinguistic and linguistic affective devices such as “OH, my POOOOOOR little wabbit!”, which are employed to maintain the audience’s attention (Bellugi *et al.*, 1994:51-57). What one should note, though, is that Williams syndrome individuals do not only use these paralinguistic devices during their story telling, but also when engaging in casual conversation.

People diagnosed with Williams syndrome also display a tendency toward expressive language use in their narratives in which they frequently draw focus to the emotional states of the characters in the stories. Bellugi *et al.* (1994:53) confirm this through a study which found that Williams syndrome individuals would often use phrases like “And ah! he was amazed”, “The dog gets worried and the boy gets mad”, “BOOM! Millions of bees came out and tried to sting him” and “He goes, Outch! oh uh get outta here bumblebees!”. When considering studies done by Bellugi *et al.* (2000:62), it becomes clear that Williams syndrome individuals depict not only the emotions and thoughts of the characters in a story, but also those of the storyteller (in this case the Williams syndrome individual telling the story).

It is necessary to emphasise that Williams syndrome individuals do not lose some of their expressiveness when they tell a story for the umpteenth time (Bellugi *et al.*, 1994:62). Instead, they manage to maintain the same level of expressiveness they had when telling the story for the first time. The Salk Institute (2006:6) reported that Williams syndrome individuals exhibit strong empathy together with fluent and exceptionally expressive language abilities. According to Levitin *et al.* (2005:68), people living with Williams syndrome present a tendency to be more spontaneous and expressive on a verbal and emotional level than control groups.

2.4.4. Narrative

People with Williams syndrome generally provide well-structured narratives and are generally perceived as dramatic storytellers (Bellugi *et al.*, 2000:135). In their narratives they establish direction, introduce time and characters as well as the characters' states of mind and behaviours. They also tell stories with clear problems that are resolved in the time the story is being told.

The stories that people with Williams syndrome tell further reveal good grammatical skills and the use of narrative enrichment devices which contribute to the drama of the story (Bellugi *et al.*, 1994:49). Williams syndrome individuals perform well in tasks where they are asked to tell a story from a drawing. They tend to draw on their imagination to tell coherent stories filled with paralinguistic devices such as whispering and exaggeration, and phrases such as "lo and behold", "all of a sudden", "guess what happened next!", to grab their audience's attention (Levitin & Bellugi, 1998:28).

According to Levitin and Bellugi (1998:359), the exceptional language development of people who are diagnosed with Williams syndrome facilitates their sociability (Bellugi *et al.*, 2007:100). Bellugi *et al.* (2007:14) argue that Williams syndrome individuals demonstrate an excessive use of language to facilitate socialisation and that this trait can be observed in their general

conversations and narrative language usage. Williams syndrome individuals are constantly aware of the emotional state of their audience or the person that they are in conversation with, and they will use affective language to keep the listener engaged. This is an important quality to keep in mind when studying the musical experiences of individuals living with Williams syndrome, since they perform optimally in social settings.

2.5. Sociability

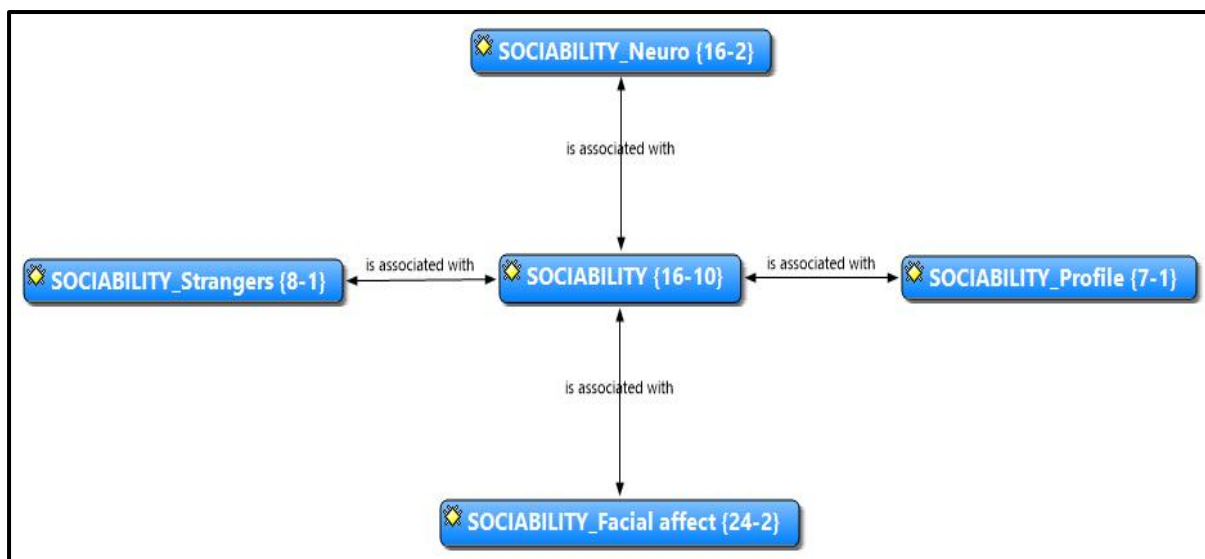


Figure 6: ATLAS.ti 7 network view of sociability categories in the literature on Williams syndrome

Williams syndrome is characterised by hypersociability, which includes over-friendliness and a high approachability toward others, especially strangers (Bellugi *et al.*, 2007:11). Because of this, Williams syndrome individuals also present an inability to discriminate between positive and negative unfamiliar faces (Bellugi *et al.*, 2007:19). Järvinen-Parsley *et al.* (2010:87) found that Williams syndrome individuals also tend towards higher intensity ratings of emotion in social settings.

The hypersociability associated with Williams syndrome was documented in a study by Levitin *et al.* (2004:226), which shows that Williams syndrome children

have higher levels of sociability than typically developing children of the same age. The study was done on the rhythmic capabilities of children with Williams syndrome compared to other special needs children. Williams syndrome children scored lower marks in rhythmic tasks than other children when using recorded music to do the test, but their scores improved immensely when someone played the material on an instrument during the test. This provides evidence that Williams syndrome individuals perform better in social than non-social environments. In another study, done by Bellugi *et al.* (2007:21), researchers set out to collect data on the emotions elicited by Williams syndrome children when a toy was placed behind a barrier in front of the child. They could, however, not collect any data because the children concentrated on the experimenter's face rather than on the toy. These two studies emphasise the need of Williams syndrome individuals for, and their love of, social interaction (Levitin *et al.*, 2004:226).

2.5.1. Sociability and neurology

People diagnosed with Williams syndrome display social behaviour similar to that of individuals who have amygdala damage. The amygdala is therefore important for processing socio-emotional stimuli and appropriate behavioural responses by stimulating the visual domain (Bellugi *et al.*, 2007:29; Levitin *et al.*, 2003:24). Research shows that those diagnosed with Williams syndrome exhibit larger prefrontal brain region volumes than typically developing controls. This could be the reason for the greater use of social affective language that is associated with the syndrome (Järvinen-Parsley *et al.*, 2010:73).

Järvinen-Parsley *et al.* (2010:65) highlight evidence for the atypical pattern of neural activity underlying facial processing in individuals with Williams syndrome. People with Williams syndrome are socially outgoing and often cannot judge the trustworthiness of strangers. Like patients with amygdala damage, Williams syndrome individuals judge all faces as friendly and thus cannot discriminate between friendly and threatening faces (Levitin, 2006:60-

61). It seems that Williams syndrome individuals experience positive social stimuli with greater intensity than normal controls and this could lead to the increased neural activity as seen in neurobiological data (Järvinen-Parsley *et al.*, 2010:86).

2.5.2. Facial recognition and facial affect

The facial recognition skills of individuals diagnosed with Williams syndrome is remarkably well-developed and seems to remain a strength in those with Williams syndrome, even across their age span (Bellugi *et al.*, 2000:37, 81; Bellugi *et al.*, 2007:9). Children with Williams syndrome perform unexpectedly well in tasks for facial recognition, even when comparing their abilities to normal controls. The Salk Institute (2006:5) found that Williams syndrome individuals are not only able to discriminate and remember different faces, but also remember names with ease. DuFour (2008:12) states that those diagnosed with Williams syndrome tend to be very empathetic and adept at reading the positive and negative facial expressions of others.

Bellugi *et al.* (1994:118) found that Williams syndrome individuals meticulously attend to their social partners' faces, while being receptive and responsive to any and all facial cues. The ability that people with Williams syndrome display in terms of facial recognition and remembering faces is unique to the syndrome. Järvinen-Parsley *et al.* (2010:80) suggest that the hypersociability associated with Williams syndrome may be driven by an increased attention to faces. Research has found that Williams syndrome individuals even tend to fixate on people's faces, specifically on the eyes, and that they do not easily disengage from the faces of others (Järvinen-Parsley *et al.*, 2010:83).

The high degree of willingness to approach strangers that Williams syndrome individuals display might be related to their poor ability to recognise facial affect regarding neutral emotions as they struggle to accurately identify these neutral emotions (Bellugi *et al.*, 2007:33; Järvinen-Parsley *et al.*, 2010:61). People

diagnosed with Williams syndrome further exhibit poor performance when asked to identify different emotions from auditory and visual domains, and they tend to perceive all these expressions as positive. Affective expressions are mostly multimodal and thus rely on the ability to integrate auditory and visual stimuli to accurately identify certain emotions (Järvinen-Parsley *et al.*, 2010:39,40). The inability of Williams syndrome individuals to accurately identify certain emotional expressions could be explained by the fact that they experience emotions presented to them aurally as less pertinent than affect presented in a visual manner. When not experiencing anxiety, however, Williams syndrome individuals are in fact able to sufficiently discriminate between happy and sad emotions (Järvinen-Parsley *et al.*, 2010:63). The overall emotional processing profile of those diagnosed with Williams syndrome is mediated by an exaggerated interest in faces and their heightened perception of subjective emotional facial stimuli. The relationship between the identification of emotion from auditory and visual domains brings us to auditory perception as displayed by Williams syndrome individuals.

2.6. Auditory perception

Despite their cognitive impairments, Williams syndrome individuals exhibit areas of strength regarding the perception of sound. According to Lense and Dykens (2013:6), those diagnosed are able to clearly discriminate and separate sound sequences into groups of perceptual units. Levitin *et al.* (2003:17) state that individuals with Williams syndrome are also able to easily distinguish between different musical pieces. Furthermore, they are able to separate different noises from one another and music from noise. Levitin *et al.* (2003:17) even emphasise that people with Williams syndrome do this similarly to, or even better than, normal controls. Thornton-Wells *et al.* (2010:5) found that those diagnosed with Williams syndrome present auditory symptoms which indicate a general heightened auditory sensitivity to sound.

Levitin *et al.* (2005:50) conducted a study of speech discrimination in children with Williams syndrome and revealed that these children were able to discriminate between words in quiet environments and also when noise was present during the test. Their findings suggest that the central auditory processing of Williams syndrome individuals present heightened awareness to sound together with abnormalities in sound perception. This occurs because hyper-excitability to sound is executed by various neural systems in individuals with Williams syndrome, which differs from what occurs in normal controls when they process sound (Levitin *et al.*, 2005:54). Levitin *et al.* (2005:54) emphasise, however, that this is restricted to the auditory domain. The basic auditory pattern perception skills in people with Williams syndrome are often stronger than their working memory or auditory rote learning. The suggestion that rudimentary auditory pattern perception is intact in Williams syndrome, is confirmed by their strength in phonological fluency (Don *et al.*, 1999:82).

According to Don *et al.* (1999:110), the basic auditory-processing abilities of Williams syndrome individuals underlie certain aspects of their music and language skills as well. They suggest that the good auditory-perception abilities of those with Williams syndrome, combined with their large deficit in visual-spatial processing, could make auditory stimuli more notable than other stimuli for children and adults living with the syndrome (Don *et al.*, 1999:130). Don *et al.* (1999:130) argue that basic auditory perception skills could perhaps lead to certain auditory abnormalities.

2.6.1. Auditory perception and neurology

Williams syndrome is associated with an unusual acoustical and musical sensitivity (Levitin *et al.*, 2003:37). Research has found that brainstem responses are normal in Williams syndrome individuals, which possibly indicates that their hyper-excitability to sound is not triggered at brainstem level (Bellugi *et al.*, 1994:122). Bellugi *et al.* (1994:124) instead found that the sensitivity to sound perceived in Williams syndrome may be related to cortical

mechanisms. Levitin *et al.* (2003:16) state that auditory processing in Williams syndrome individuals is possibly executed by different neural systems than in typically developing people and could be characterised by neural hyper-excitability.

The amygdala activation for auditory stimuli, as associated with Williams syndrome, is consistent with individuals who have amygdala damage. When auditory tests were conducted, Williams syndrome individuals displayed variable activations throughout the brain, together with an amplified activation in the amygdala and cerebellum. This provides evidence for neural organisation that differs from that of normal controls (Levitin *et al.*, 2003:26-37). Levitin *et al.* (2003:38) argue that the distinct cognitive and sensory functions associated with the Williams syndrome population could prove helpful in the understanding of their auditory processing (Levitin *et al.*, 2003:38).

Thornton-Wells *et al.* (2010:17) conducted a study on Williams syndrome and found auditory activations in areas of the brain which are normally associated with visual perception, including the occipital lobe. These results suggests that Williams syndrome individuals have something similar to synaesthesia, in which a person sees colour when hearing musical notes (Thornton-Wells *et al.*, 2010:18, 20). Another finding showed auditory activation in areas related to emotional processing. These activations were not only present when Williams syndrome individuals were presented with music, but when hearing sounds in general. Thornton-Wells *et al.* (2010:36) state that cross-modal processing might not be unique to synaesthesia, but that it is only on one end of the spectrum of synaesthesia to which Williams syndrome individuals seem to belong, but to a lesser degree. The theory of synaesthesia plays a role in the understanding of the unique visual response of Williams syndrome individuals to sound (Thornton-Wells *et al.*, 2010:40).

Studies done by Levitin *et al.* (2004:74) found that Williams syndrome individuals showed significantly decreased activation in brain regions which are

typically associated with auditory processing. This may be due to hyperconnectivity. They also found irregular patterns of activations in the cortex and neocortex, along with higher activation levels in the paleocortical amygdaloid complex than in normal controls (Levitin *et al.*, 2004:74). The study done by Levitin *et al.* (2004:80) support the notion that there are anatomical underpinnings for the emotional reaction that Williams syndrome individuals exhibit to sound.

Levitin *et al.* (2005:58) are of the opinion that the preserved language and music skills, together with other auditory functions associated with Williams syndrome, could be related to increased connectivity in the auditory cortex. According to Levitin *et al.* (2005:59), this possibly accounts for specific unusual reactions to auditory stimuli present in individuals diagnosed with Williams syndrome. Levitin *et al.* (2005:64) also confirm that there are neuroscientific findings which support the claim that certain sounds could hold special meaning to those diagnosed with Williams syndrome.

2.7. Auditory abnormalities

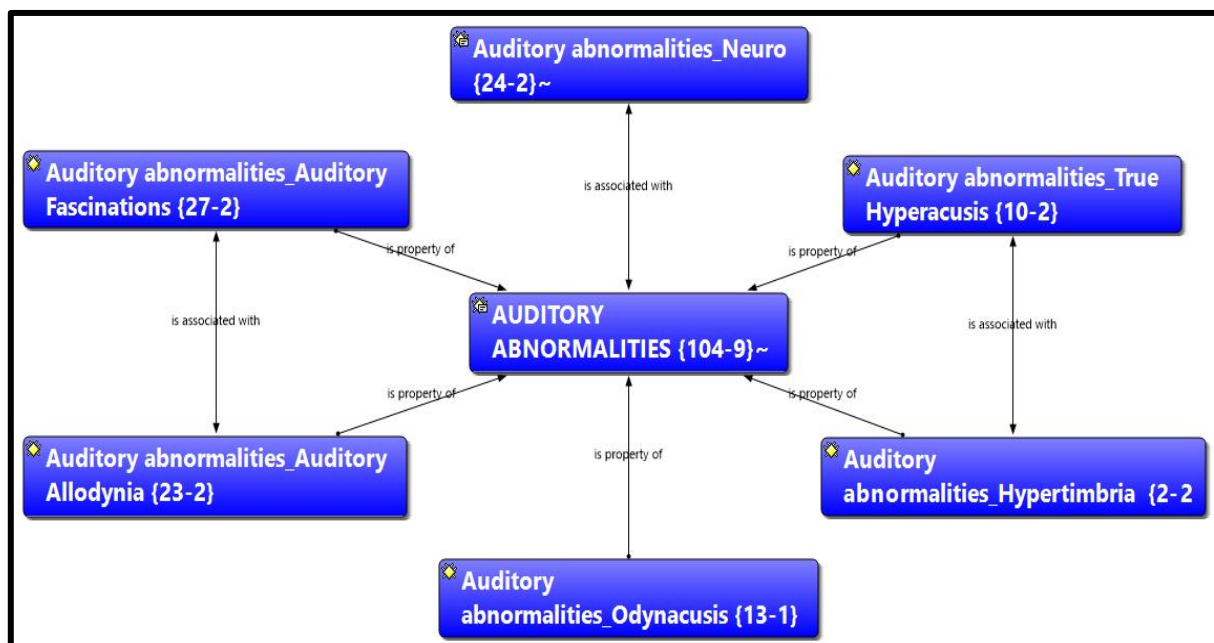


Figure 7: ATLAS.ti 7 network view of the auditory abnormality categories associated with Williams syndrome as identified in the literature

Williams syndrome individuals tend to be overly sensitive to loud noises and timbre and research has found that these individuals seem to have much higher ratings of auditory abnormalities than normal controls (DuFour, 2008:22; Levitin, 2005:27; Levitin *et al.*, 2005:3). This unusual sensitivity to certain environmental sounds is one of the psychophysical features associated with Williams syndrome (Bellugi *et al.*, 1994:6; Levitin, 2005:18). When referring to the auditory abnormalities associated with Williams syndrome, it is important to note that the term hyperacusis has long been used to describe any type of auditory abnormality, when it in fact refers only to an abnormal sensitivity to sound. This means that the term refers only to the ability to detect soft sounds before others or that others normally cannot (Levitin, 2005:22; Levitin *et al.*, 2005:16).

The auditory sensitivities associated with Williams syndrome, as defined by Levitin *et al.*, 2005:70), are divided into four categories, which include a lowered hearing threshold for loud sounds (odynacusis), an awareness of sounds before others (true hyperacusis), an aversion to sounds not usually considered aversive in normal populations (auditory allodynia), and a fascination with certain sounds (auditory fascinations). Auditory fascinations are usually presented together with a type of auditory acuity which allows Williams syndrome individuals to differentiate between different vacuum cleaner brands or lawnmowers (Salk Institute, 2006:2). This often leads to some individuals with Williams syndrome being drawn to sounds that others cannot stand. These concepts of auditory abnormalities help to describe the Williams syndrome phenotype. According to Gothelf *et al.* (2006:4), the onset of these symptoms starts before one year of age and often decreases during adolescence. Before describing each of the four auditory abnormalities exhibited by individuals living with Williams syndrome in detail, the neuropsychology of these abnormalities will be discussed.

2.7.1. Auditory abnormalities and neurology

The hearing abnormalities observed in Williams syndrome individuals could reflect the utilisation of specific mechanisms in the cortical areas for auditory processing (Bellugi *et al.*, 1994:126). People with Williams syndrome show marked increases in the amplitude of certain auditory responses at faster repetition rates than controls. This is suggestive of a shorter refractory period for neurons responding to sound and indicates hyper-excitability (Levitin *et al.*, 2005:52). It is important to note that this occurs in the temporal cortex exclusively and applies to auditory stimuli only.

The acoustic reflex, or the lack thereof, could contribute to cochlear hearing loss, seeing that it depends on the intact transmission of stimuli from the cochlea to the auditory nerve (Gothelf *et al.*, 2006:21). Damage in the auditory nerve could thus explain an acoustic reflex dysfunction. Gothelf *et al.* (2006:26) claim that the onset of hyperacusis and auditory aversion in infancy could suggest a link between the lack of acoustic protection and one of the genes deleted in Williams syndrome at conception. Research also found that cochlear impairment in Williams syndrome is due to inappropriate acoustic reflex protection when exposed to repeated noise stimulation (Gothelf *et al.*, 2006:29).

The amygdala is responsible for the fight-or-flight response and could influence the fear and anxiety Williams syndrome individuals experience when they hear certain sounds (DuFour, 2008:29). Furthermore, hyper-connectivity in the limbic system of people with Williams syndrome could explain their unusual sensitivity to sounds (Holinger *et al.*, 2005:23). When listening to music, Williams syndrome individuals showed activation in the cerebellum, pons and brainstem (Levitin & Bellugi, 2006:57). Gothelf *et al.* (2006:24) found that the lack of elastin production in Williams syndrome individuals could mediate hyperacusis by a peripheral mechanism.

According to Gothelf *et al.* (2006:16) hearing seems to be normal in most cases of individuals who have hyperacusis; however, on pure-tone audiograms subjects with Williams syndrome tend to exhibit cochlear high-frequency hearing loss (Gothelf *et al.*, 2006:16). This hearing loss was mainly linked to high frequency sounds and reflects a dysfunction of the outer hair cells of the cochlea. Gothelf *et al.* (2006:18) state that cochlear hearing loss is often observed together with a heightened sensitivity to the loudness of some sounds. Levitin and Bellugi (2006:48) found that peripheral auditory mechanisms in Williams syndrome function normally, suggesting the hyper-excitability of the cortical neurons presumably mediates both hyperacusis and odynacusis.

2.7.2. Odynacusis

People with Williams syndrome often display inappropriate responses to non-threatening sounds. They also tend to complain about the loudness of sounds not perceived as uncomfortably loud by others. This reaction to sound is characterised as odynacusis (Levitin & Bellugi, 2006:35). It is important to note that odynacusis does not refer to sound that evoke fear in those with Williams syndrome, but only to sounds perceived as uncomfortably loud.

Levitin *et al.* (2005:46) suggest that a shift in the hearing range of Williams syndrome individuals could contribute to their experience of odynacusis. Furthermore, Levitin *et al.* (2005:72), argue that those diagnosed with Williams syndrome possibly cannot focus only on pertinent auditory information and are unable to tune out extraneous sounds. This then, possibly leads to Williams syndrome individuals experiencing discomfort when hearing certain sounds. A further explanation for odynacusis, as provided by Levitin *et al.* (2005:79), is a compressed or abnormal loudness function; in other words, those diagnosed with Williams syndrome possibly have an increased perception of loudness levels. Individuals living with Williams syndrome not only tend to be sensitive to

the loudness of sounds, but they also display a special interest in some sounds. This unusual interest in and sensitivity to sound is called hyperacusis.

2.7.3. True hyperacusis

The sensitivity to and interest in sound presented in Williams syndrome are usually related to specific timbres (Levitin & Bellugi, 2006:23). Individuals with Williams syndrome seem to have something related to perfect pitch and are able to code, recall and label stimuli along the pitch continuum, while also noticing small variations in timbre with finer distinction than others (Levitin & Bellugi, 1998:117). This ability to classify objects based on timbre suggests a highly developed recognition memory in this regard sometimes described as 'hypertimbria'.

Levitin *et al.* (2005:45) report a girl who was sensitive to the sound of only one vacuum cleaner brand. She could hear the specific vacuum from houses away and described the sound as follows: "The sound gets inside my head and reverberates". True hyperacusis is associated with auditory fascinations in the sense that hyperacusis can also refer to an unusually intense affective response to some sound categories (Levitin & Bellugi, 2006:36). Despite this, Williams syndrome individuals also often display a fear of certain sounds not perceived as threatening by others.

2.7.4. Auditory allodynia

Auditory allodynia is also known as phonophobia. This indicates dislike or fear of sounds not typically found aversive (Levitin, 2005:45). This aversion is also associated with a fear of certain sounds. Auditory allodynia include symptoms of auditory aversions among Williams syndrome and seem to decrease over time. In response to these sounds Williams syndrome children would typically display feelings of fear, cover their ears, cry or leave the room (Gothelf *et al.*, 2006:5). Parents of Williams syndrome children reported that the reactions of

their children to these sounds made it clear that they did not necessarily find these sounds too loud, but that they were truly frightened by them (Levitin *et al.*, 2005:31).

Levitin *et al.* (2005:36-38) classified these frightening sounds in different categories which include “broad-band continuous sounds (e.g. blender, vacuum, lawnmower, airplane, cheering, engine), broad-band percussive sounds (sudden onset sounds like fireworks, balloons popping, pulsed fire alarms, thunder, door slam), narrow-band continuous sounds (e.g. dentist equipment, air brakes, power saw, power drill) and human/animal sounds (e.g. babies crying, screams, yelling, dog barking, operatic singing, frequency sweeping sirens, coughing, sneezing)”.

The fear of certain sounds could lead to Williams syndrome individuals avoiding parties because of a fear of the noise of the crowd or of bursting balloons. Gothelf *et al.* (2006:6) refer to a 16-year-old girl who described her suffering by stating that “When I hear the sound of an electric drill, I feel as if it is drilling into my body”. Levitin (2005:28) found that Williams syndrome children often outgrow their fear of certain sounds (auditory allodynia) and that they then become fascinated by those sounds. This is also confirmed by a study done by Don *et al.* (1999:114) that reported a child with extreme anxiety about and fear of the school fire alarm. However, the child displayed an uncanny fascination with that school alarm when he was later put in charge of setting the alarm during fire drills.

2.7.5. Auditory fascinations

Don *et al.* (1999:108) found that almost two thirds of people diagnosed with Williams syndrome present an unusual liking of specific sounds. Their study also revealed that parents of Williams syndrome children even tend to describe this unusual liking as a relationship that their children have with certain sounds. According to Levitin *et al.* (2003:14), one would find numerous anecdotes telling

of Williams syndrome children who would be captivated by music, the sound of leaf blowers, engines and other sounds for hours. They would be able to name the make and models of vacuum cleaners and engines based purely on the acoustic information (Levitin *et al.*, 2005:65). Williams syndrome children seemingly derive the same amount of pleasure from these everyday sounds as from music. Studies done by Levitin (2005:29) found many stories about Williams syndrome children and their auditory fascinations, which include the story of a Williams syndrome child who had a collection of vacuum cleaners and yet asked for a new one every Christmas. There are also stories on children who would describe the sound of lawnmowers or vacuum cleaners as “the most beautiful sound ever”. The fact that Williams syndrome individuals tend to describe unusual sounds as beautiful brings us to Williams syndrome and music.

2.8. Williams syndrome and music

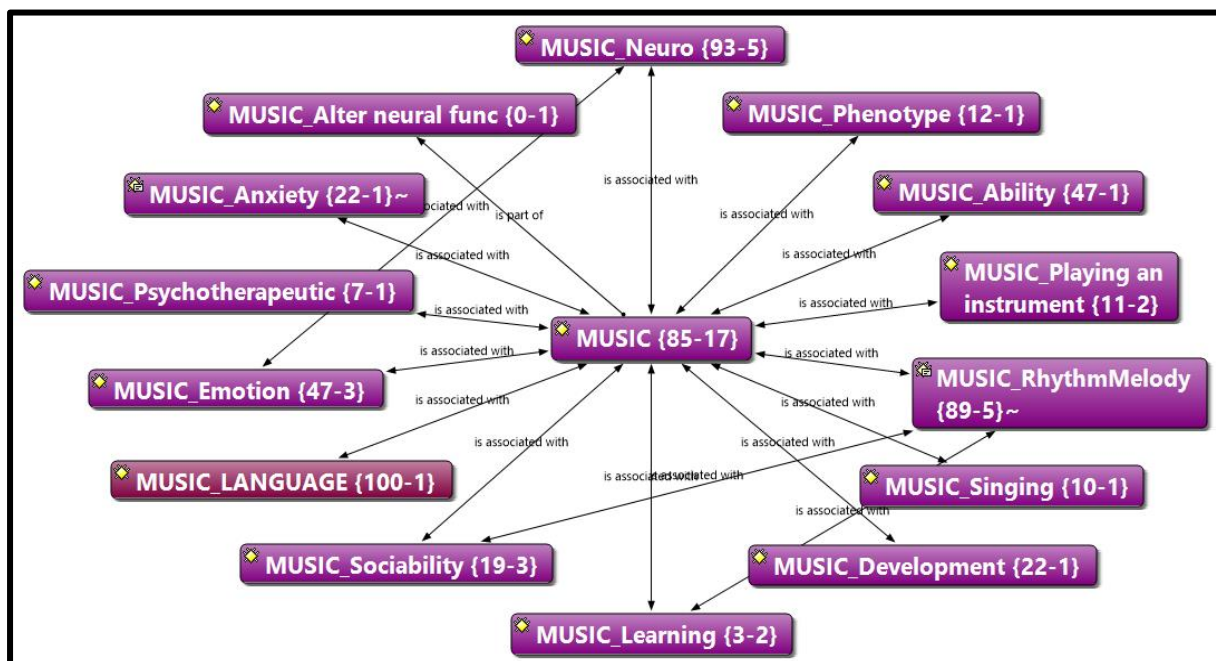


Figure 8: ATLAS.ti 7 network view of music categories identified in literature on Williams syndrome

Studies found that the deletion on chromosome 7, which is a key characteristic of Williams syndrome, is related to the unique musical abilities associated with the syndrome (Thornton-Wells *et al.*, 2010:42). Thornton-Wells *et al.* (2010:7) found that people diagnosed with Williams syndrome often exhibit a distinct musical phenotype. Children with Williams syndrome seem to be drawn to music in an unusual way and will easily spend hours listening to or making music and are more emotionally responsive to music than comparison groups (Dykens *et al.*, 2005:16-18; Salk Institute, 2006:10; Thornton-Wells *et al.*, 2010:8). These children seem to have an affinity for music and present increased musical talent and skill when compared to the control group (Dykens *et al.*, 2005:9). It would in fact not be accurate to assume that all Williams syndrome individuals are musical, seeing that there is the same amount of individuality in the Williams syndrome population as in a normal one. One can say that those with Williams syndrome are more likely to engage in and show a love for music than normal controls (Levitin & Bellugi, 2006:3).

Levitin *et al.* (2004:32) report that Williams syndrome individuals present a higher possibility of being left-handed or ambidextrous than normal controls. What makes this interesting is that this has also been reported among musicians. Williams syndrome and Down syndrome populations have higher than normal rates of left-handedness and, accordingly, also contain a larger proportion of musicians than deemed normal (Levitin *et al.*, 2004:82-85).

DuFour (2008:30) found that Williams syndrome individuals were better at detecting the difference between two melodies when the shape stayed the same and only a single note changed than when the shape of the melody was altered. This is proof that Williams syndrome individuals focus on the local elements of music rather than the global. These findings imply that the visual-spatial impairments displayed by Williams syndrome individuals could influence the way in which they perceive music.

Williams syndrome children present an extraordinary attentiveness and grasp of music (Salk Institute, 2006:8). It seems that music is more than a rich part of the lives of Williams syndrome individuals as it is ever-present in almost all of their everyday lives. This becomes clear in a study conducted by Levitin and Bellugi (1998:120), where a Williams syndrome child said “Music is my favourite way of thinking”. Another child stated that “Music is like soup for the soul, it feels so good”.

Parents of Williams syndrome individuals provide many anecdotes illustrating the fact that music forms a rich part of their children’s lives in reporting that their children often gravitate towards musical toys and that their children would easily create musical toys out of other materials (Lense & Dykens, 2013:35). Williams syndrome and music will now be discussed in terms of neurology, musical phenotype, ability, instruments, rhythm and melody, singing, development and learning, music and sociability, music and language, emotion and music and psychotherapy, anxiety and fear.

2.8.1. Music and neurology

Martens *et al.* (2011:66) found neuroanatomical evidence suggesting that musical training early in life may have a long-term effect on brain organisation. This is supported by enhanced cortical representation in the somatosensory cortex of individuals with Williams syndrome who began taking violin lessons early in their lives. Research has also found that the corpus callosum, which allows the transfer of information between the two hemispheres, is larger in musicians than non-musicians (Schlaug *et al.*, 1995:1050). Martens *et al.* (2011:78) report that there is evidence of cortical thickness in perisylvian regions of musicians. These regions are involved in some elements of musicality. Martens *et al.* (2011:69) also found that the use of musical mnemonics has been shown to have a positive impact on brain regions subserving memory.

According to the Salk Institute (2006:9), the unusual development of the planum temporale of the frontal lobe – which plays a part in auditory perception and processing – in those diagnosed with Williams Syndrome could underlie their unusual language and musical skills. When listening to both music and noise, Williams syndrome individuals often showed interest in the noises presented to them. What is interesting, though, is that the processing of music and noise were much more similar in Williams syndrome than it was in the control group (DuFour, 2008:28; Levitin *et al.*, 2003:18; Martens *et al.*, 2010:19). DuFour (2008:25) found that generally people with Williams syndrome use more parts of their brains while processing music than the controls did. These areas include, among others, the amygdala (Levitin, 2005:35).

Abnormal activation of the amygdala could possibly correlate with the emotional responses to music as observed in Williams syndrome (Levitin *et al.*, 2003:26). The reason for this is that the amygdala is responsible for the storage of emotional events. As discussed in 2.6.1, the activation of the amygdala, however, is associated with visual processing, a field where Williams syndrome individuals seemingly lack ability. According to Thornton-Wells *et al.* (2010:28), some individuals with Williams syndrome activate occipital and early visual areas in response to general auditory and musical stimuli.

Lense and Dykens (2013:26) argue that musicmaking could alter neural functioning. Their argument is supported when considering that the brain areas associated with perceptual-motor coupling are activated when engaging in musical training. The emotional reaction provoked by music has also been linked to temporal fluctuations. Martens *et al.* (2010:16) state that the left planum temporale, which is linked to music processing, was considerably larger in individuals with Williams syndrome who exhibited authentic musical abilities than it was in others. The ability to accurately sing and complete a musical phrase has also been linked to the planum temporale.

According to Don *et al.* (1999:23) and Martens *et al.* (2010:25-26), functional imaging and electrophysiological studies show that the left hemisphere seems to be involved in melodic and rhythmic processing, despite the fact that the right hemisphere has been considered to be responsible for certain musical functions. Don *et al.* (1999:26) further found that people with Williams syndrome process music by employing more varied neural structures than control subjects, activating sub-regions of the amygdala, cerebellum and brainstem. They also state that certain aspects of music and language seem to share the same processor (Don *et al.*, 1999:28). The insight into the role of neuropsychology on the musical abilities and perception in individuals diagnosed with Williams syndrome brings us to the musical phenotype associated with the syndrome.

2.8.2. Musical phenotype

Levitin *et al.* (2004:236) are of the opinion that there is a possible correlation between the social and musical drives displayed by Williams syndrome individuals and the gene deletion present at conception. Individuals diagnosed with Williams syndrome seem to be “consumed by their affective reactions to music”, resulting in their seemingly experiencing music more fully than most. Levitin (2005:3) identified several factors that form part of Williams syndrome individuals' musical phenotype, which include “musical complexity, reproduction, sensitivity, musical theory and achievement, listening, habits, positivity and emotions”.

Williams syndrome children show an interest in music at a significantly young age (Levitin, 2005:20). They also present an above-average musical memory. Parents of children with Williams syndrome have reported that their children get so caught up in musical activities that it seems as if they lose touch with reality, or that they are taken over by the experience (Levitin *et al.*, 2004:91). The fact that people with Williams syndrome show musical abilities beyond what is expected for general music tasks provides evidence for the independence of

music cognition and perception from other cognitive abilities (Levitin & Bellugi, 1998:58).

Levitin and Bellugi (1998:90-122) claim that Williams syndrome individuals do not seem to have difficulty responding to musically based tasks and thus present relatively spared musical abilities for both the production and perception of musical ideas. This provides further evidence for the idea that there are certain patterns of cognitive dissociations found in individuals with Williams syndrome. It would seem that some Williams syndrome individuals are musical savants, displaying unusually good abilities in musical tasks, despite their other mental handicaps (Levitin & Bellugi, 2006:93).

2.8.3. Musical ability

Don *et al.* (2009:9) found that an unusual number of Williams syndrome individuals had perfect pitch. There have also been reports of Williams syndrome individuals who reach extraordinary musical achievements. There is a woman with Williams syndrome called Gloria Lenhoff, who is able to sing hundreds of songs from memory in twenty-five languages that she cannot speak. Another person living with Williams syndrome is a composer who has written several songs that comply with structural rules of harmony and form (Levitin & Bellugi, 2006:98-99). This is not, however, true for all individuals with Williams syndrome who have had musical experiences.

Levitin and Bellugi (1998:58) found that Williams syndrome individuals show preserved abilities for general musical tasks, despite their impairment in other cognitive domains. They argue that these abilities could provide evidence for the independence of music cognition from general cognitive abilities. Even though the majority of Williams syndrome individuals fail tests for conservation, Williams syndrome individuals tend to respond well in musically based tasks for rhythm and melody (Levitin & Bellugi, 1998:122-123; Levitin & Bellugi, 2006:77).

People diagnosed with Williams syndrome often perform well when learning complex rhythms; they tend to find it easy to compose and learn song lyrics (Don *et al.*, 1999:6-7). There are some important aspects of music, however, that are not developed to age-appropriate levels in Williams syndrome individuals. This is consistent with the idea that music is developmentally independent from general cognition (Hopyan *et al.*, 2010:45). Hopyan (2010:56) suggests that music instruction, especially in the initial stages, should focus on musical expressiveness rather than on the acquisition of analytic skills.

A study by DuFour (2008:14) found that Williams syndrome individuals show similar musical abilities to normally developing control groups. The study also revealed that those with Williams syndrome tend to make more 'musical' mistakes during tests than the controls. Some of the Williams syndrome participants even exhibited stronger musical skills than chronological age-, sex- and dexterity-matched controls. When considering music perception skills, those of individuals with Williams syndrome are equal to normal developing controls (Levitin *et al.*, 2004:65). Levitin *et al.* (2003:9) emphasise that this does not imply that Williams syndrome individuals are necessarily very skilful musicians in general, but that their instrumental ability is remarkable taking their cognitive and motor impairments into consideration. It is true, however, that there are cases of Williams syndrome individuals presenting remarkable skill on their chosen instruments.

2.8.4. Instrumental playing

People diagnosed with Williams syndrome are more prone to spend time playing instruments and taking music lessons (Dyken *et al.*, 2005:36) and experience more intense levels of involvement with instruments than the control group (Dyken *et al.*, 2005:27). Levitin and Bellugi (1998:102) report that Williams syndrome individuals execute musical passages which require a fine degree of control on the instrument they specialise in (be it clarinet, piano or

drums) with less trouble than they have walking up a flight of stairs or cutting their food. It is true, however, that these performances lack a certain degree of technique, but this is compensated for by the degree of subjective musicality the Williams syndrome individuals bring to the performance.

When teaching instruments to Williams syndrome children, it is necessary to keep in mind that these children tend to have underdeveloped fine motor skills and not very toned muscles. Instruments like violin or cello would thus probably not be most fitting for these children to start with. Percussion instruments might be a more suitable match (Lense & Dykens, 2013:19; Levitin & Bellugi, 1998:102). Levitin *et al.* (2004:35) found that Williams syndrome children often start playing an instrument five years before they begin to receive musical training. Parents of children with Williams syndrome report that their children often made instruments out of common household items such as pots and pans (Levitin *et al.*, 2004:34), clearly being strongly drawn toward music.

2.8.5. Rhythm and melody

Williams syndrome individuals show strengths in tonal and rhythmical tasks (Dykens *et al.*, 2005:11; Salk Institute, 2006:13). When considering the rhythmic and melodic abilities of those with Williams syndrome, it would be more appropriate to describe their abilities as strengths in the domain rather than areas of preserved functioning (Lense & Dykens, 2013:7). It seems that the rhythmic production abilities of people with Williams syndrome are stronger than their melodic production. This disparity does not apply for their perception of rhythm and melody (Levitin, 2005:36).

Levitin (2005:6) conducted a study asking Williams syndrome children to clap rhythmic patterns presented to them. During the study the children presented abilities which were higher than expected. While the children did not necessarily always clap the exact patterns as required, they did clap patterns that were musically comparable with the phrase given. The Williams syndrome

children also tend to immediately clap back the demonstrations, without missing a beat. They do this so accurately, it seems that their response forms a part of the same rhythmic sequence. Levitin and Bellugi (1998:62) mention that the Williams syndrome subjects who formed part of their study all interpreted rhythmic examples as being part of a general musical set, assuming an implied time signature and tempo, displaying a clear grasp of metre. Those diagnosed with Williams syndrome also display an astounding ability to track changes in rhythmic pulse. It is interesting to note that Williams syndrome individuals do not seem to have any trouble with rhythmic tasks, even considering their visual-spatial impairment.

Individuals diagnosed with Williams syndrome further demonstrate remarkable precision when clapping rhythmic patterns presented to them, even though the activity requires coordination and perception of temporal order and rhythmic organisation (Levitin & Bellugi, 1998:130). Levitin and Bellugi (2006:9) confirmed that Williams syndrome participants performed as well as mentally age-matched controls on rhythmic tasks, but that they showed higher levels of musicality when making mistakes during the tests. When making mistakes, it seemed as if the Williams syndrome participants completed the rhythmic patterns presented to them, thus keeping the musical integrity of the rhythmic piece.

When referring to melodic reproduction, on the other hand, Levitin (2005:7) found that Williams syndrome children performed well when asked to repeat a melodic phrase, but did not perform as well when asked to complete a melodic phrase. When these children's rhythmic and melodic audiation were tested, the Williams syndrome children scored high marks, proving that the discrepancy between rhythmic and melodic production is not influenced by rhythmic and melodic audiation (Levitin, 2005:8).

2.8.6. Singing

Dyken *et al.* (2005:10, 44) state that people with Williams syndrome are perceived as more skilled singers than the control group. Findings reported by the Salk Institute (2006:12) correlate with these findings in the sense that their research shows that Williams syndrome individuals possess a great memory for songs. Don *et al.* (1999:163) conducted a study in which they found that Williams syndrome children performed better in verbal than nonverbal tasks. This also holds true when engaging in musical tasks. The study led Don *et al.* (1999:165) to speculate that the ability of Williams syndrome individuals to process auditory patterns could contribute to their good language and musical abilities. People with Williams syndrome do exceptionally well in tasks where they have to identify certain patterns. This has an impact on their ability to quickly learn a new language and to easily sing songs in different languages (Don *et al.*, 1999:165). It is true, however, that these individuals often sing the correct words with the correct pronunciation without necessarily knowing what they are singing about.

Levitin and Bellugi (1998:104) conducted a study in which they found that Williams syndrome individuals would spontaneously compose songs about a wide variety of topics, complete with verse, chorus and rhyming lyrics. These individuals would also easily compose music for their songs, which they often performed using basic chord structures, mostly in the root position.

2.8.7. Music and learning and development

The development of musical abilities could contribute to the development of a wide variety of other skills. The experience of learning how to play a musical instrument relies on the student's ability to imitate a teacher's sound, as well as fine and gross motor movements (Lense & Dyken, 2013:2). The auditory motor connections in those diagnosed with Williams syndrome could thus be enhanced with greater exposure to musical activities. Levitin and Bellugi

(2006:80) found reports of successful motor action learning sequences, such as tying shoes, when aided by music and taught slowly and gradually.

Musicmaking requires well-developed auditory skills and could assist in the development of visual-spatial abilities in a way that is enjoyable. For optimal development through musical tasks, it is important that one chooses syndrome-specific instruments, taking into consideration the impairments and strengths associated with a specific syndrome (Lense & Dykens, 2013:22). A study by Lense and Dykens (2013:25) reveals that musical activities could contribute to the development of visual, auditory, somatosensory and motor skills. This is possible, seeing that instrumental playing involves the mapping of movement to sound in time and space, while relying on auditory information for guidance.

It seems, then, that instrumental learning might assist the visual-spatial and motor development of those diagnosed with Williams syndrome in a fun and safe context. Musical activities furthermore enhance abilities pertaining to attention, concentration and memory (Lense & Dykens, 2013:31). When Williams syndrome individuals participate in musical activities and performance, they have the opportunity to develop skills they might otherwise not use. These skills, although mentally and logically challenging, include the development of stage presence, the increased consciousness of time and appointment scheduling, and the ability to plan a repertoire (Levitin & Bellugi, 2006:86). The playing of instruments, especially in ensemble contexts, and taking part in group music activities could provide people with Williams syndrome with opportunities for socialisation.

2.8.8. Music and sociability

Researchers have suggested that there could be a link between gene deletion, sociability and music. This is because music played an important role in social bonding and communication during our evolutionary history. There is thus

speculation that the genes selected for sociability are also those involved in musical behaviour (Levitin, 2005:41).

Williams syndrome individuals are extremely focused on connecting with people socially. It would seem that they view music as one of the best ways in which to connect with others (DuFour, 2008:32). Their need for socialisation could possibly be one of the reasons they love music. This statement is supported by a study conducted by DuFour (2008:13), which found that Williams syndrome individuals, because of their extreme sociability, perform better in musical tasks executed by a person than a recording. It could also be true that individuals with Williams syndrome respond not only to the social nature of these tests, but also to the difference in timbre between a recording and the live execution of the test. Those diagnosed with Williams syndrome present high sociability and high musicality, and seem to have fewer inhibitions than most. It could thus be speculated that the high sociability and high musicality displayed by those with Williams syndrome might have an evolutionary basis. The high musicality associated with the syndrome could also be linked to the spared language abilities displayed by individuals diagnosed.

2.8.9. Music and language

According to Martens *et al.* (2011:17), it is believed that it is easier to remember words set to music than spoken words. Music thus serves as a mnemonic device facilitating the encoding and retrieval of information, especially for individuals with special needs (Martens *et al.*, 2011:27). If music is to be used as mnemonic device, it is important that it must provide structure in order for new information to be incorporated into existing knowledge structures. These musical mnemonics must also be easy to utilise and have to provide cues for information retrieval (Martens *et al.*, 2011:18-21). Music has also been found to be useful in memorising unconnected text, because of the rhythmical pattern and repetition.

Learning through music, according to Martens *et al.* (2011:23), may shorten the time that it takes to learn names or lists, especially when using a familiar melody. Martens *et al.* (2011:53) found that when Williams syndrome individuals who have had musical experience learn through music, they enhance the transfer of information to their long-term memory. According to Martens *et al.* (2011:60), musical training could lead to better recall of verbal material by strengthening temporal order processing. It thus seems that musical learning could be associated with improved memory as a result of neural changes through the synchronisation of neural pathways supporting verbal learning memory (Martens *et al.*, 2011:71).

Don *et al.* (1999:30) state that research has found that linguistic prosody processing and music are linked in patients with amnesia. They explain this by stating that speech to infants often includes slow, regular rhythmic patterns and exaggerated prosody, just as in children's songs. Don *et al.* (1999:45) found that there are thus similarities between language and musical skills, suggesting that some aspects necessary for the auditory processing of language and music are shared. Williams syndrome children, along with their relatively good language abilities, exhibit good memory for uncomplicated musical patterns, thus appearing to be focused on the melodies of speech (Don *et al.*, 1999:47-48).

Just as Williams syndrome individuals do not scramble words within a sentence or sentences within paragraphs, they do not scramble the measures and phrases of a musical piece (Levitin & Bellugi, 1998:88). Thus there appear to be similarities between the preservation of local motivic elements in language and music. Williams syndrome individuals, however, do not focus on details in language and music at the expense of the global structure. This, then, seems to be another area of dissociation in considering the general cognitive abilities associated with Williams syndrome as they cannot, in general, focus on global structures as they are able to do in music and language. According to Levitin and Menon (2003:19), musical and linguistic syntax processing possibly share

general neural substrates. The musical elements which give meaning are part of the bigger coherent temporal structure, just as in language. The finding that Williams syndrome individuals engage with music with extreme emotions also suggests that they are able to focus on the bigger picture where language and music are concerned (Levitin & Menon, 2003:24).

2.8.10. Music and emotion

Levitin *et al.* (2005:12) report that Williams syndrome individuals display heightened emotional responses and attraction to music. A study by Dykens *et al.* (2005:12) also found that Williams syndrome individuals present high levels of musical expressiveness, similar to normal controls, but that they expressed a greater love of music and were more emotionally responsive to music than the control group.

The assumption that Williams syndrome sufferers experience extreme emotions when engaging with music seem to be borne out when taking into consideration a study done by Levitin *et al.* (2004:238), where a little girl began weeping after she heard just a few notes at a Mozart concert. Afterwards she commented to her mother: "There are two kinds of Mozart, the kind that hurts and the kind that does not hurt." This intense emotional experience could prove to be a key factor in the current study, as it could possibly influence the meaning that these Williams syndrome children ascribe to their musical experiences. Don *et al.* (1999:65), also provide an anecdote for the extreme emotions with which Williams syndrome individuals engage in music by reporting that one child in their study stated that "music could not make him happy, because it made him more than happy".

Studies conducted by Levitin *et al.* (2004:238) and Don *et al.* (1999:166) show that Williams syndrome individuals engage with music, and sounds in general, with extreme emotion. Levitin *et al.* (2004:234) found that Williams syndrome children are more verbally and emotionally expressive when listening to, or

engaging with, music. It is true, however, that Levitin *et al.* (2003:8) found that Williams syndrome individuals display strong emotional reactions not only to music but also to certain noises. Don *et al.* (1999:66) conducted a study showing that music leads to Williams syndrome children experiencing a wider range of emotions than children in the control group. When asked to rate their feelings when engaging in musical activities, they also exaggerated more. Don *et al.* (1999:117) claim that the emotional sensitivity and auditory perception abilities observed in children with Williams syndrome possibly assist the development of musical skills.

Music listening effects seem to last longer in Williams syndrome individuals than in normal controls. Parents of Williams syndrome individuals also reported more intense levels of emotional engagement with sound in their children than the parents of typically developing children did (Levitin *et al.*, 2004:89,94,97). Järvinen-Parsley *et al.* (2010:28) report that individuals with Williams syndrome were more prone to feelings of sadness when listening to or engaging with music than the controls were. It becomes clear that Williams syndrome individuals seemingly experience music more abundantly than most and that music evokes more extreme emotions in those diagnosed with Williams syndrome than in typically developing controls. Musical experience is not only a means for emotional expression to those diagnosed with Williams syndrome, but also influences their levels of anxiety and fear in everyday life.

2.8.11. Music and psychotherapy, fear and anxiety

Since ancient Grecian times music has been shown to have an astonishing influence on the mood and wellbeing of people from different societies and backgrounds (Dyken *et al.*, 2005:3). Music has also been found to provide comfort in times of distress and has the ability to alter mood (Lense & Dyken, 2013:23; Levitin & Bellugi, 2006:78). This also holds true for individuals diagnosed with Williams syndrome. The affinity that people with Williams syndrome show toward music could be attributed to the fact that music offers

them the opportunity to control time and structure in ways that would otherwise be impossible for them (Levitin & Bellugi, 2006:102). Music, furthermore, is a means of expression for people living with Williams syndrome. Williams syndrome individuals are well suited for studies on the effect of music on mood, seeing that persons diagnosed with the syndrome are prone to problems with anxiety, obsessions, worries, fears and somatic complaints in their daily lives (Dykens *et al.*, 2005:14; Thornton-Wells *et al.*, 2010:6).

Kerchner and Abril (2009:88) state that musical experience plays a role in children's lives not only in terms of communication, but also in helping children realise their feelings and to create a feeling of belonging in the world. This could in turn reduce feelings of fear and anxiety in children while teaching them to display certain emotions calmly. When people spend time listening to music, they tend to show fewer externalising symptoms of fear and anxiety. This also applies to Williams syndrome individuals, as the frequency and skill in making music, together with their emotional response to music, influences their experience of fear and anxiety in their everyday lives (Dykens *et al.*, 2005:2).

A study by Dykens *et al.* (2005:346, 353) showed that Williams syndrome children were less prone to experience anxiety and stress than other children when listening to or engaging in musical activities. Williams syndrome individuals also tend to experience less anxiety when playing a musical instrument or when they develop their singing skills (Dykens *et al.*, 2005:17, 40). The explanation for this could lie in the fact that Williams syndrome individuals appear to have an affinity for music, and show high levels of musical expressiveness and emotional responsiveness to music (Dykens *et al.*, 2005:12).

Dykens *et al.* (2005: 353) found that Williams syndrome children showed lower levels of anxiety and stress when engaging with music. Their study also revealed heightened levels of fear and anxiety in Williams syndrome individuals in that they would say that sad or atonal music makes them feel happy when

tests showed that it did in fact make them experience feelings of fear and anxiety. This could be a sign of denial or the inability to recognise the specific emotion or feeling that they experience when engaging with music. The Williams syndrome individuals who did admit when music made them feel sad, in contrast, showed lowered levels of fear and anxiety (Dykens *et al.*, 2005:33). It thus seems that music, whether it evokes feelings of sadness or happiness, could contribute to the overall wellbeing of people diagnosed with Williams syndrome.

Conclusion

When studying the existing literature on Williams syndrome it became clear that the existing research is still relatively new, thus leaving much to discover still. As one studies the literature, there seems to be a dissociation between the musical and language abilities and general cognitive functioning associated with the syndrome. Although Williams syndrome refers to a cognitive phenotype with severe impairments, individuals living with the syndrome tend to excel musically, linguistically and socially. There is also a dissociation between the language and musical abilities and the visual-spatial development of Williams syndrome individuals, as they cannot focus on the bigger picture in general tasks but are capable of understanding language and musical structure.

Music could possibly play a vital role in various areas of development for those with Williams syndrome, seeing that musical activities promote motor development, reasoning skills, planning, spatial awareness, social and communicative skills. Music could also provide an opportunity for Williams syndrome individuals to feel that they are good at certain things and it allows them to reach goals that they possibly otherwise cannot.

Music may have a positive effect on the overall well-being of those diagnosed with Williams syndrome as it promotes healthy self-esteem, lowers feelings of fear and anxiety, allows individuals with Williams syndrome to experience and react to

different emotions and also to admit to certain emotions and providing a means through which they can express their emotions appropriately. Finally, music is an aspect in the lives of people with Williams syndrome that allows them to engage with others socially through a shared interest. It thus becomes clear that music has a larger role to play than simply assisting in general development. It may allow Williams syndrome individuals to foster healthy self-images while promoting a sense of emotional and personal wellbeing.

CHAPTER THREE: RESEARCH DESIGN

Introduction

The aim of this chapter is to give a detailed description of the research design followed for the study. The chapter starts with an overview of a qualitative research design and an interpretative phenomenological analysis approach. The research procedures, including participants, data collection, data analysis and findings, will then be discussed before the chapter concludes by addressing the ethical and validation issues that were taken into account and dealt with in this study.

The key concern of interpretative phenomenological analysis (IPA) research is to understand what the experience of being human is like and how it matters (Smith *et al.*, 2009:11; Willig, 2010:179). This is in line with the aim of my study, in which I aim to understand the meaning that Williams syndrome individuals ascribe to their musical experiences. This dissertation thus focuses on exploring the personal meaning and sense making of musical experiences for individuals living with Williams syndrome, making IPA the ideal approach for conducting this research.

The reason for my choosing to do an IPA study was that IPA is an approach well suited to gaining insight into the way that individuals experience specific situations that they are faced with (in this case musical experiences), especially when studying uncharted territory (Reid *et al.*, 2005:59; Smith & Osborn, 2008:28) – as is the case of the musical experiences of individuals living with Williams syndrome. IPA is thus an appropriate approach for this research study, especially as there is a lack of literature on the lived musical experiences of Williams syndrome individuals. Another motivation for my choice of this research approach was that Williams syndrome individuals have very well developed language abilities and narrative skills, but present poor visual-spatial skills. This made conducting in-depth, semi-structured interviews an ideal way to collect data from individuals living with Williams syndrome. This is confirmed by Bellugi *et al.* (2000:45-46), who found that Williams syndrome individuals and children display a strong ability to process and answer

conditional questions and that Williams syndrome children, adolescents and adults tend to respond in complete sentences in ways confirming that they have the ability to fully understand questions presented to them.

Figure 9 depicts the research process that was followed for this study on the musical experiences of individuals living with Williams syndrome. The research process will now be discussed in terms of research design, approach to qualitative inquiry, the research method (which includes data collection, data analysis, writing up, the participants, role of the researcher), ethics and validity.

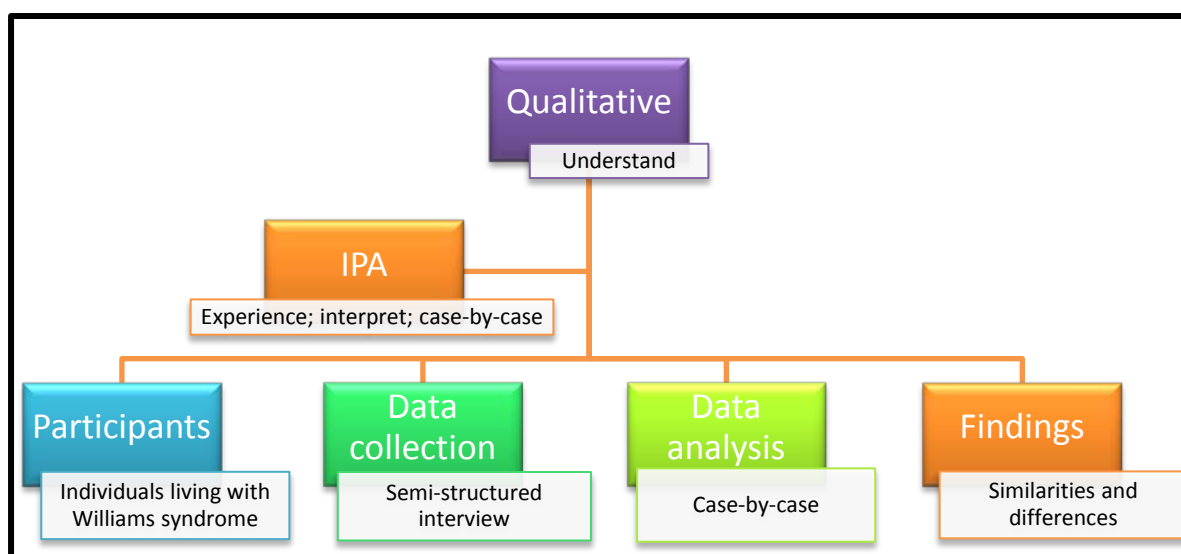


Figure 9: The research design, approach and method followed for this study

3.1. Research design

The research design that shapes this study is qualitative, aiming to understand how individuals living with Williams syndrome interpret their experiences (Creswell, 2013:43; Merriam, 2009:5), what meaning they ascribe to their lived musical experiences and how these meanings help to shape their world (Creswell, 2013:47). I thus assumed that “reality is socially constructed and that there is no single observable reality but rather multiple interpretations of a single event” (Creswell, 2013:36). This dissertation also takes the form of a holistic study (Creswell, 2013:47), as it acknowledges the interaction between

social context and biography in answering questions about Williams syndrome individuals' musical experiences.

As a qualitative researcher I tried to understand the world from the perspective of those often not listened to (Merriam, 2009:6), giving voice to people marginalised by society (Creswell, 2013:44) – in this case individuals living with Williams syndrome. This type of research places a strong emphasis on thick description and interpretation (Creswell, 2013:44), whilst requiring that I remained aware of my personal biases in order not to allow my preferences to influence my findings (Bresler, 1995:4). While conducting my research I constructed knowledge on the basis of discovery-oriented findings (Merriam, 2009:7), at the same time using different interpretive techniques to describe, translate and understand phenomena in the natural social world. The reason for doing this qualitative study arose from the lack of existing research about the lived musical experiences of individuals living with Williams syndrome.

3.2. Approach to qualitative inquiry: interpretative phenomenological analysis

Interpretative phenomenological analysis (IPA) was first introduced by J. Smith and his colleagues in the mid-1990s. The approach is most commonly applied in the fields of counselling, psychology, social and health sciences, and anthropology (Reid *et al.*, 2005:20-22; Smith *et al.*, 2009:3; Smith & Osborn, 2008:21). IPA emphasises active research in which the researcher must play an active role in the research process in order to understand the participants' experiences from an "insider's perspective" (Holmes, 2011:307; Smith, 2003:53; Smith & Osborn, 2008:4, 6). At the start of my IPA study, I aimed to do justice to the whole life experience of each of the participants (Smith & Osborn, 2008:14), letting their voices shine through in the findings.

IPA draws on three "key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography" (Smith *et al.*, 2009:11). IPA is firstly a phenomenological approach in that it calls for detailed examination of

the participants' experiences according to each of the individuals' personal perception of a specific phenomenon (Holmes, 2011:307-308; Smith & Osborn, 2008:3; Willig, 2008:53). In aiming to understand the participants' world and experiences from their point of view, IPA remains true to its phenomenological origins (Smith & Osborn, 2008:11). From a phenomenological point of view, if a person is to have a meaningful experience, he/she has to be conscious of something and must be able to reflect on what he/she saw, thought, felt, remembered or wished. Husserl uses the term "intentionality" to describe phenomenological inquiry referring to a "consciousness of something" (Husserl, 1983:67). Smith *et al.* (2009:13) further emphasise that phenomenology requires that one bracket preconceptions of one's own world in order to truly understand the world of others from an insider's perspective. According to Smith *et al.* (2009:14), researchers undertaking phenomenological studies must analyse data with different lenses in order to become aware of all the possible interpretations for certain specified phenomena. I thus had to analyse the collected data from different perspectives to give an accurate account true to each participant's story.

IPA does not solely focus on the nature of experience, however, but also on the meaning generated from experience (Chapman & Smith, 2002:126). In this sense, Heidegger's philosophy of hermeneutic phenomenology is closely related to IPA. Heidegger (1953:49-50, 54, 56, 185-186, 363) believed that by studying the meaning that people derive from experience, it is possible to uncover significance in experience and in the world. From this viewpoint, we are constantly engaging with the world on an intersubjective level because of our relatedness-to-the-world (Smith *et al.*, 2009:16). This is an important aspect to keep in mind when conducting IPA research in that it focuses on understanding people's focused involvement in the world, while uncovering the meanings people derive from their experiences (Smith *et al.*, 2009:21).

The second knowledge area associated with IPA research is hermeneutics, which refers to the interpretation of texts. Hermeneutics, in this case, also

refers to the interpretation of the musical experiences of Williams syndrome individuals in terms of the stories they tell. When interpreting the meaning that participants assign to their experiences, the researcher not only has to uncover the evident meaning of the experience, but also the hidden meaning of certain experiences that the participants may not be aware of, or that may not be clear during the initial analysis of the interview transcripts. This is in line with Heidegger's theory in which hermeneutic phenomenology is concerned with examining the phenomenon as it appears at the surface, but also with its hidden form (Smith *et al.*, 2009:24). As with phenomenology, where hermeneutics is concerned, the researcher has to be aware of personal presuppositions and biases as interpretation comes first and foremost from an understanding from within. Smith *et al.* (2009:25) argue, however, that these presuppositions must not be given priority over the new conception of the phenomenon that is being studied. As a researcher, I allowed the participants to speak for themselves about their experience and I had to keep an open mind when analysing and interpreting the meanings that they attribute to their musical experiences (Smith *et al.*, 2009:26-27).

Although it was important that my preconceptions did not lead the research process, my own conceptions were important when trying to make sense of the personal world of the Williams syndrome participants through a two-stage interpretative activity or double hermeneutic process (Smith & Osborn, 2008:7-8). This refers to a process where the participants first had to interpret their own lived experiences and then I, as the researcher, interpreted the participants' world from their point of view, letting their voices be heard (Smith & Osborn, 2008:9). The type of interpretation required for IPA studies involves the researcher having to ask critical questions to probe for hidden meanings or emotions in the story told by the participants (Smith & Osborn, 2008:12).

Hermeneutics is concerned with understanding the different parts of the phenomenon being studied by understanding the whole. To gain this understanding of the whole, one has to first understand the smaller parts. This

process is called the hermeneutic circle and plays a key role in the continual analysis process required for IPA studies, where the researcher has to offer different perspectives on the part-whole coherence of text (Smith *et al.*, 2009:28).

The third aspect called upon for IPA studies is idiography (Smith *et al.*, 2009:29; Smith & Osborn, 2008:36). Idiography is concerned with the particular or the specific, individual case. Firstly, it focuses on the detail and in-depth analysis of the particular, and secondly, on the understanding of how the particular phenomena have been understood by certain people (Willig, 2010:183). Idiography, in this case, thus refers to the in-depth analysis of each of the Williams syndrome participants' musical experiences. Furthermore, the researcher has to understand how these experiences are understood by the participants as individuals and how they have meaning in each of their lives. Idiography focuses on one particular and thus I could not analyse all of the participants' accounts simultaneously. In order for me to analyse the data idiographically, I did not import all three interview transcripts into ATLAS.ti 7 simultaneously. Rather, I imported only the first transcript, analysed it completely and then imported the second transcript without comparing it to the first, subsequently doing the same for the third. I also saved my analysis process in stages in order to show the idiographical process that I followed.

Self-interpretation and self-reflection is key for IPA research as it allows people to make sense of their experiences (Colaizzi, 1978:14; Reid *et al.*, 2005:15). These activities also allowed me to enter the research process as analyst when I began to interpret the participants' accounts of their musical experiences and the meanings they associate with them. When following an IPA approach to qualitative inquiry, the participants are considered to be experts and I, the researcher, learn about my participants' "thoughts, commitments and feelings through their own stories, in their own words, in as much detail as possible" (Reid *et al.*, 2005:7). When conducting IPA research, it is important to keep the contextual ground against which the data were collected in mind in order to

make accurate interpretations with respect to meaning, cognition, affect and action (Reid *et al.*, 2005:18).

IPA acknowledges each person as a complex physical, affective, cognitive and linguistic being, exploring connections between their talking, thinking and emotional state. This implies that I had to be aware of the fact that people sometimes struggle to express exactly what they are thinking or how they are feeling (Smith & Osborn, 2008:17-18). There could also be reasons for the participants not wanting to disclose too much about themselves.

IPA does not view experience as a philosophical entity, but rather allows philosophical accounts to illuminate and give insight into lived experience which is tantalising yet elusive (Smith *et al.*, 2009:33). Smith *et al.* (2009:33) state that pure experience is never fully accessible and that our research can only provide findings which are close to the actual experience. IPA is concerned with meaning bestowed on experience by a person as a sense-making creature and therefore represents the participants' experiences by analysing third-person data (Smith *et al.*, 2009:33). It can thus be said that IPA investigates human experience through examination of the meanings people ascribe to it.

IPA analysis thus always involves interpretation of meaningful experiences through a double-hermeneutic process. Although interpretations may be drawn from different theoretical perspectives, I had to develop these interpretations around the core of the participants' accounts of their lived musical experiences in order to answer my main research question (Reid *et al.*, 2005:18, 47-48).

3.3. Procedures

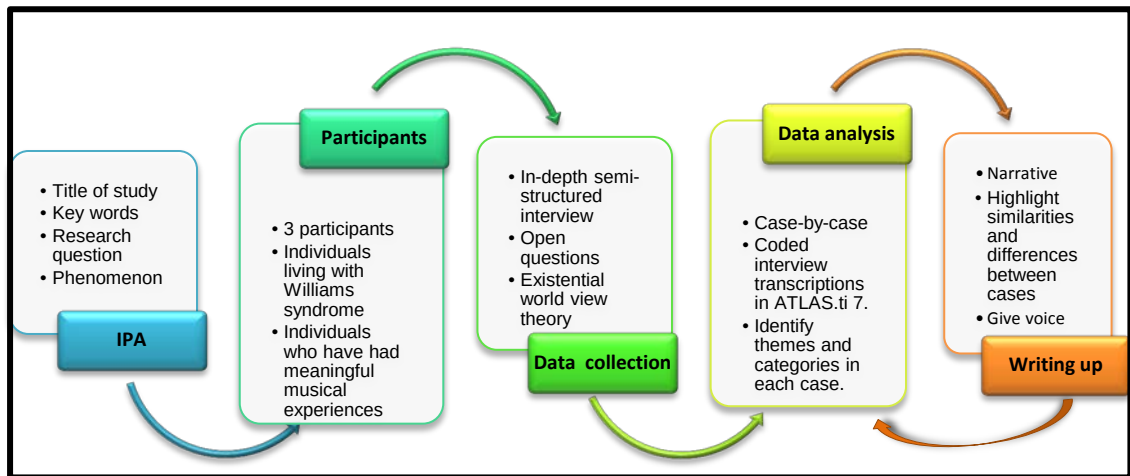


Figure 10: The procedures as determined by IPA

Figure 10 shows the procedures followed when conducting an IPA study. Thus, for this study I conducted in-depth, semi-structured interviews with each of the three purposely selected Williams syndrome participants. I took on the role as active researcher for the study and carefully analysed each of the interviews separately before finally highlighting similarities and differences between each of the cases. When writing up my findings, the meaning that each of the Williams syndrome participants ascribe to their musical experiences became clear. As part of my research process I repeated the data analysis writing-up process three times before finally highlighting similarities and differences between the cases.

3.3.1. The participants

Brocki and Wearden (2006:94) state that, because of the idiographic nature of IPA, the sample sizes are usually small. For Masters-level IPA studies three is treated as the default size for participants (Clarke, 2010:8-9; Smith *et al.*, 2009:51; Smith & Osborn, 2008:54-55). For this study I thus identified three individuals living with Williams syndrome as participants. It is possible to conduct a study with such a small group of participants because of the richness

of the data gathered from each of the in-depth, semi-structured interviews (Smith & Osborn, 2008:49, 56). The participants in an IPA study have to be purposefully selected because of their expertise on the phenomenon being explored (Chapman & Smith, 2002:127; Reid *et al.*, 2005:8; Smith & Osborn, 2008:37) – in this case Williams syndrome individuals who have had meaningful musical experiences. According to Brocki and Wearden (2006:95), the participants identified for IPA research should be able to shed light on the research questions and provide rich, interesting data for interpretation.

I identified potential participants for my study through referral and opportunities provided by my previous studies on the musical experiences of a child living with Williams syndrome. The participants I have selected were willing and able to grant me access to their perspectives of their musical experiences (Smith *et al.*, 2009:48-49). IPA participants usually range from age 10 to 83 years and are selected from across the sociocultural spectrum (Reid *et al.*, 2005:26, 29). All the participants identified for this study present below average levels of cognitive and emotional functioning and are male. Two of the participants are 17 years of age and the third 20. Although the oldest participant is 20 years of age, he has a severe case of Williams syndrome together with low levels of emotional maturity and does not present normal 20-year-old behaviour.

3.3.2. Data collection

The most common data-collection process associated with IPA is conducting in-depth, semi-structured interviews (Chapman & Smith, 2002:127; Clarke, 2010:10; Reid *et al.*, 2005:39; Willig, 2010:188). The aim of the interviews that were conducted for this study was to understand what it is like for the chosen Williams syndrome participants to have musical experiences (Larkin *et al.*, 2006:104, 113; Reid *et al.*, 2005:4). The benefits of conducting one-on-one interviews were that they allowed time to establish rapport with the participants, while also giving the participants enough time to think before answering questions as part of an in-depth, personal discussion (Reid *et al.*, 2005:42).

According to Merriam (2009:88), one-on-one interviews are the preferred method for data collection when working with a small number of participants, as is the case with this study.

Greene and Hogan (2011:8) state that, when doing research on children, one should carefully consider which method will be most effective for collecting data from the selected child participants. Semi-structured interviews were well suited for research on the experiences of individuals living with Williams syndrome, seeing that they tend to make sense of their world through music and language, presenting strength in language development (Bellugi *et al.*, 2000:38,55; Levitin & Bellugi, 2006:2). These individuals are also hyper-social (Bellugi *et al.*, 2007:11; Levitin *et al.*, 2004:226) and love engaging in conversation, which further confirms that conducting semi-structured interviews was a sound method for this research.

a. Semi-structured interview

Semi-structured interviews call for flexibility in terms of the questions asked during the interview (Chapman & Smith, 2002:127; Merriam, 2009:89). The questions planned for the interview should be used only as a guideline for topics to explore during the interview and the ordering of the questions should be regarded as less important (Merriam, 2009:89; Smith & Osborn, 2008:74). For my interview schedule I focused on questions that explore sensory knowledge in order to gain insight into the three Williams syndrome participants' musical experiences. I also used the four life-world existentials mentioned by Van Manen (1990:101) which are "lived body, lived time, lived space and lived relations" when creating my interview schedule. When referring to the types of questions as defined by Merriam (2009:96), my interview schedule included "experience and behaviour questions, questions on feeling, sensory questions and opinion and values questions". I also avoided questions that ask more than one thing per question, leading questions and

questions where the participants would only answer yes or no (Merriam, 2009:99-100).

In order to gain as full an insight as possible into the meaning that participants ascribe to their experiences, it was important that all of the questions asked during my interviews were framed broadly and openly (Smith & Osborn, 2008:31). These types of questions allowed me to explore in a flexible way the essence of the musical experiences (Merriam, 2009:93) of individuals living with Williams syndrome in detail. While conducting the interviews, I remained alert to interesting ideas brought up by the participants (Smith & Osborn, 2008:75) and I probed some of these ideas if deemed necessary or if the participants preferred. As IPA determines that I treat the participants as experts (Brocki & Wearden, 2006:90), I also allowed the participants to determine the flow of the interviews, while allowing them every opportunity to tell their own story (Brocki & Wearden, 2006:90; Chapman & Smith, 2002:127; Smith & Osborn, 2008:81).

b. Conducting the interview

The first important thing to consider when conducting an interview is to establish rapport with the participant and to ensure that the participant is comfortable and treated respectfully (Merriam, 2009:107). It was important that the participants trusted me and that they were aware of the fact that they were the sole focus of my attention (Smith *et al.*, 2009:64). As the interviewer, I also had to ensure that the participants understood the aim and structure of the interview. Before each interview started, I made sure that the interview would be free of interruptions and that the environment was quiet (Creswell, 2013:165). Smith *et al.* (2009:63) emphasise the need to let the participants know that the interview is about them and that their opinions and experiences matter. This goes together with the fact that the participants should be aware that there are no correct or incorrect answers during the interview (Smith *et al.*, 2009:63).

I focused on not saying too much during the interview, allowing the participants to take their time thinking about questions and answering in as much detail as possible. By asking questions calmly and slowly, the participants were able to feel more relaxed during the course of the interviews. Smith *et al.* (2009:63) mention that, as the interviewer, I should aim for an interview environment that resembles the natural interactions of conversation. This helped to promote a calm and relaxed mood during the interview.

The key to conducting a good interview is to ask good questions (Merriam, 2009:95) and to get the relationship between the schedule and the interview right in order to find out as much as possible about the participant's life world. This can only be done by taking enough time to ask questions and to listen to every word of the participant. Smith *et al.* (2009:65) state that some questions will require time for the participant to reflect on them in order to give rich, full answers. It is also true that silences can sometimes speak more than words and Smith *et al.* (2009:67), suggest that these silences must be waited out, as this might encourage the participant to pick up a certain topic again. Good interview technique and resisting the urge to lead the interview develops over time and with practice. As interviewer, I had to pay full attention to the participant's stories and body language, while being aware of stages in the interview where it would be better to move away from certain topics (Larkin *et al.*, 2006:108) or to ask for more details on others.

c. Interview schedule

The aim of the development of an interview schedule was to enable the participants to give a detailed account of their experiences through comfortable interaction. For a semi-structured interview, the questions should be open (Brocki & Wearden, 2006:90), encouraging participants to talk in detail and at length. By starting the interview with a straightforward question on the present, the interviewer provides an opportunity for the participant to get comfortable at the onset of the interview (Merriam, 2009:103; Smith *et al.*, 2009:59, 61).

Merriam (2009:103) argues that it is also a good idea to start the interview with basic descriptive questions in order to prepare the participants for the more intense and detailed questions to be asked later on. In order to ensure that the data gathered from each interview was rich, I included different types of questions (Merriam, 2009:95) which included descriptive, narrative, evaluative, comparative and structural questions. I also prepared prompts and probes (Merriam, 2009:100-101), which allowed me to guide the participants if they did not understand a question fully or to find out more about an interesting topic. I avoided the use of over-empathetic, manipulative, leading and closed questions during the interview to ensure that I did not influence the information gathered from each of the interviews (Smith *et al.*, 2009:60).

I used the following steps to compile my initial interview schedule as suggested by Smith and Osborn (2008:98-103):

- i. Determine the areas to be tackled during the interviews. These areas should investigate a broad range of issues;
- ii. Put the different topics in a logical order. Keep in mind that it would be wise to leave the sensitive topics for later in the interview;
- iii. Generate questions for each of the topic areas;
- iv. Develop possible prompts and probes to be used when necessary;
- v. Draft and redraft the interview schedule until all the questions are well formulated, open and non-leading;
- vi. Learn the interview schedule by heart. This ensures that the researcher can focus on every aspect of the participant's responses during the interview (Smith & Osborn, 2008:109).

As part of the process of finalising my interview schedule, I conducted a pilot interview with the pilot interview schedule presented in Table 1. This interview revealed that my initial interview questions were not open enough and it became clear that some of these initial questions were leading.

Table 1: Pilot interview schedule

Pilot interview schedule
1. Do you like music? 2. Can you tell me what kind of music you like? 3. Why do you like music? 4. When was your favourite musical experience? Could you tell me more about it?
<i>Listening to music</i>
5. When was the last time you listened to music? 6. What do you do while listening to music? 7. How do you feel when you listen to music?
<i>Playing an instrument</i>
8. Do you play any instruments? Which instruments do you play? 9. How did you start playing the instrument/s? 10. How do you feel when playing on your instrument?
<i>Music in general</i>
11. What do you like most about music?
<i>Music in your life</i>
12. Could you please describe how music affects your life? 13. What are the differences between a good and a bad musical experience?
<i>Williams syndrome and music</i>
14. Do you suffer from certain medical or physical problems? 15. Do these problems influence you when you listen to music? 16. Do these problems influence your instrumental playing? 17. Does music help you with some of these problems? How?
<i>Prompts</i>
Are you active when listening to music? (Q3) What emotions do you experience? (Q 4+7) Does music help you with certain aspects of your life (make it easier)? (Q10)

Merriam (2009:95) argues that pilot interviews are essential when developing a good interview schedule and formulating questions that will assist the researcher in gathering rich descriptive data. The pilot interview led me to the decision to start planning my schedule from scratch, this time also using the four life-world existentials mentioned by Van Manen (1990:101), thus focusing on the life-world existentials of the participants. This phenomenological concept states that knowledge about human nature is gained in two ways. Firstly, people learn about reality in a way that transcends time. Secondly, individuals learn about the nature of reality through values and beliefs according to place and circumstance (Heidegger, 1953:49, 50-51; Narasimhan *et al.*, 2010: 1). I also focused on incorporating sensory knowledge into the

final interview schedule, seeing that people experience the world, and more specifically music, through their senses. For the final interview schedule (see Table 2), I used descriptive (Question 2, 5, 7, 8, 11), narrative (Question 1, 4), contrast (Question 6), evaluative (Question 2), circular (Question 3, 12) and comparative questions (Question 9, 10) (Smith *et al.*, 2009:60).

Table 2: Final interview schedule

1. What is the first musical encounter that you can remember?
2. Could you please tell me how you feel about music?
3. Some people would say that music is a waste of time and money. What would you tell them?
4. Tell me about your favourite place for listening to or making music.
5. Would you describe what you think would be the ideal time to listen to or make music?
6. What are the main differences between listening to or making music alone or with other people?
7. Imagine you are having a bad day physically and describe how it would feel listening to or making music.
8. What did you hear, see, taste, smell or sense when you made or listened to music?
9. What would happen if you had to go a day without music? (How would you feel if...)
10. How do you think the world would be different if there was no music?
11. Could you tell me about the ways music affects your life?
12. What do you think other people think when you make music?

During the interviews with individuals that were diagnosed with Williams syndrome, I noticed that the participants had very high expectations of the interviews. They wanted to handle the interviews professionally. In my opinion, the participants viewed the interviews as a way in which they could participate in the adult world as experts on the phenomenon in question. This sometimes led to the participants only briefly answering the questions as they were posed, not necessarily taking the time to tell their stories in much detail. I thus sometimes had to ask certain questions again or ask them from a different angle to get more information from the participants. When interviewing children living with Williams syndrome, as two of the participants in this study are, it could possibly be beneficial not to use the term 'interview' when getting consent

from the children, but rather referring to the interview only as a casual conversation or discussion on a certain topic. I believe that this could also prove helpful when referring to the 20-year-old participant. Even though the interview circumstances were relaxed, rapport was established and the participants and I had casual conversations, they seemed to fixate on the idea of an interview as they understood what the term traditionally means. Despite this, the second interview schedule still proved to be much more successful than the initial schedule. The interview transcriptions are included in Annexure D. For this research I did not need to conduct follow-up interviews with any of the participants and I thus have three interview transcripts. The average duration of each of the three interviews was 30 minutes.

3.3.3. Data analysis

The assumption in IPA is that the analyst wants to learn something about the participants' psychological world. This is accomplished by engaging in an interpretative relationship with the transcripts (Brocki & Wearden, 2006:96; Smith & Osborn, 2008:157-160). The data analysis process necessary for a successful IPA study follows an idiographic approach by starting with the particular examples and then moving on to more general claims by analysing the transcripts case-by-case (Chapman & Smith, 2002:127; Smith & Osborn, 2008:34, 168). I thus started by concentrating on each single case in its own right and only after each case was analysed, independently from the others, did I move to the other cases in a case-by-case process. The analysis process associated with IPA research has often been described as inductive and iterative (Smith *et al.*, 2009:79, Willig, 2010:187). For data analysis I included the three interview transcripts in one hermeneutic unit in ATLAS.ti 7. In order to keep the interviews separate, I created families in ATLAS.ti 7 (Frieze, 2014:77, 119) and worked in stages while analysing each interview separately.

When I analysed the data that I collected from each of the participants, I started by relying on the process of making sense of the musical experiences of the

Williams syndrome individuals first from their perspective and then from my perspective as analyst (Reid *et al.*, 2005:10). Seeing that IPA is an interpretative study, care had to be taken not to analyse the data as facts, but as subjective meanings (Reid *et al.*, 2005:13). When analysing the data, I also had to adopt “the insider’s perspective” to offer an interpretative account of the meaning that the participants ascribe to their experiences in certain contexts (Larkin *et al.*, 2006:104; Reid *et al.*, 2005:45). According to Larkin *et al.* (2006:104), the account given in IPA research is constructed by both the participant and the researcher, where the researcher’s objective is to get as close as possible to the participants’ point of view.

I started my data analysis by reading and re-reading the first transcript commenting on anything and everything that attracts my attention (Chapman & Smith, 2002:127; Smith & Osborn, 2008:170). These comments were attempts at summarising or paraphrasing parts of the transcripts and even commenting on or questioning some of the things that were said in the interviews as part of the process of interpreting the participants’ accounts (Chapman & Smith, 2002:127; Smith & Osborn, 2008:173). At the beginning of the analysis process the entire transcript was treated as data and no sections were regarded more or less important (Smith & Osborn, 2008:185).

IPA involves identifying themes in the transcripts of interviews which are organised and used to find commonalities and/or variations between the different accounts of each of the participants’ experiences (Chapman & Smith, 2002:127; Reid *et al.*, 2005:54-55). Smith *et al.* (2009:81-103), provide a basic step-by-step guideline for successful data analysis which I shall use to guide my analysis process. I also followed this process for data analysis using ATLAS.ti 7 computer-aided qualitative data analysis software saving the different stages of my progress. These six steps are outlined below.

Individual case analysis

i. Reading and re-reading

This step involves reading through the first transcript a few times to become familiar with the bigger picture and content of the transcript (Smith *et al.*, 2009:82).

ii. Initial coding

For this step the analyst has to read through the transcript and assign codes to any and all things which grab the analyst's attention in any way. I focused on affective coding which included: coding for emotion, values, conflicts and judgements (Saldaña, 2013:105-110), labelling the feelings of my Williams syndrome participants in terms of their musical experiences, focusing on the beliefs, conflicts and struggles of each participant.

Emotion codes allowed me to label the participant's feelings thus exploring their personal experiences. These codes typically include terms such as scary, happy, sad, confused and uncertain. When studying a complex phenomenon such as the musical experiences of special needs individuals, one could also use descriptive emotional codes which can be sub-coded or categorised, allowing me to discern which emotions could have occurred when the participants were having certain experiences. When coding for emotion, I had to be aware of the complexity of emotional states, acknowledging that there are, for example, different levels of anger which include irritation, anger and fury, and that this emotion could be triggered by other emotions such as embarrassment, shame, frustration, depression (Saldaña, 2013:105-108).

Value codes distinguish between values (the importance attributed to a thing, idea or person), attitude (the way we think and feel about something) and beliefs, which is a system including attitudes, values and personal knowledge, experiences, opinions and morals. Versus codes refer to personal conflicts and contradictions found in the transcripts (Saldaña, 2013:110-114).

These codes assist the researcher in identifying specific ways in which the participant explains things, while helping the researcher understand the participant's concerns. Affective comments include descriptive comments (describing the content), linguistic comments (exploring specific language use and seeking deeper meaning in metaphoric language use) and conceptual comments (interrogative and conceptual exploration of the interview content). The comments draw attention to the participant's words, emphasising the importance of context within the interview helping to recognise interrelationships (Smith *et al.*, 2009:115-118).

iii. Developing emergent themes

By mapping the exploratory comments on the transcript of an interview, the researcher will begin to notice emerging themes in the data. These emergent themes are assigned to each case individually by bracketing the cases during the three individual case analyses (Chapman & Smith, 2002:127). The identification of these themes starts a process in which the interview is broken down into sections which will come together again in the final write-up. In this stage of the analysis process I began to move away from the participant, including more of myself by closely associating my own experiences with those of the participant. As themes are developed, the researcher starts to capture the essence of the data, reflecting a synergistic process of description and interpretation (Smith *et al.*, 2009:91-92).

iv. Searching for connections across the emergent themes of each separate case

Once the researcher reaches this step, the identified themes are organised into clusters of emergent themes. The themes must also be re-evaluated to identify the most interesting and important aspects of the participant's account. One can look for these connections between themes by grouping themes together under a label for the cluster, or selecting a specific theme that will be seen as the main theme of a cluster with other themes (Chapman & Smith, 2002:127). Themes can also be identified on the basis of oppositional relationships

focusing on differences between themes. Another way of organising the themes of an interview is to group them according to life events or life stages, according to the frequency with which the theme is supported, or by looking at the function and deeper meaning of the themes (Smith *et al.*, 2009:92-100).

v. Moving to the next case

When the first four stages of analysis have been completed and emergent themes have been linked to certain transcript extracts the researcher can move on to the next case, repeating the process. It is important, however, that the analysis of the previous case is bracketed while working with the new case to ensure that the case will be analysed in its own right (Smith *et al.*, 2009:100).

Cross-case analysis

vi. Looking for patterns across cases

Finally, I can start to look for patterns across all the cases. This process involves asking questions about what connects the cases, what themes help illuminate the cases and which themes come across the strongest. The aim is to finally highlight similarities and differences between the cases in terms of their lived musical experiences (Smith *et al.*, 2009:101). The similarities between the cases will be labelled using new meaning superordinate themes and the differences will then be discussed as unique emerging themes which refer to those themes that are not present in all three interviews. When one has completed the data analysis, Smith *et al.* (2009:103) emphasise that the researcher has to be aware of the three levels of interpretation present in IPA research.

The first level refers to interpretation of the obvious experiences or meanings explicitly referred to by the participant. The second level involves the interpretation of metaphors used by the participant when telling his/her story. The final level of interpretation moves to detailed microanalysis of the text, which sheds further light on the transcripts as a whole, strengthening the

argument. Smith *et al.* (2009:105) suggest a fourth level of interpretation, when conducting IPA research, that involves psychodynamic interpretation of the text. These interpretations are guided by the microanalysis of the text and come from within the researcher.

3.3.4. Writing up

IPA calls for research findings to be written up as a narrative providing an exhaustive description of the phenomenon being studied (Chapman & Smith, 2002:127; Clarke, 2010:13; Colaizzi, 1978:11). I thus present the findings from each of the participants in my study in the form of a narrative. According to Colaizzi (1978:12), it is important that I present my findings as a statement that accurately reflects the fundamental structure of the investigated phenomenon. Smith and Osborn (2008:44) mention that a good IPA study must allow the readers to draw links between the findings presented and their own personal experience in terms of the literature presented in the study. The power of IPA research thus lies in the insight it provides within a broader context by translating the superordinate and emergent themes from interviews into a narrative account (Chapman & Smith, 2002:127; Smith & Osborn, 2008:220). Superordinate themes develop from correlating the emergent themes from each interview transcript.

The superordinate themes identified during the cross-case analysis should be adequately explained, illustrated and nuanced when writing up the findings. This can be accomplished using excerpts of raw data and commenting on each superordinate theme. Chapman and Smith (2002:127) explain that the findings of an IPA study must be presented together with tables of themes (Smith *et al.*, 2009:100, 107) and transcript excerpts (Brocki & Wearden, 2006:97) to reinforce the narrative argument, supporting the case, leading to a well planned and executed study. While writing up my findings, I took care to clearly distinguish between what the respondents said and what my interpretations of the accounts are (Brocki & Wearden, 2006:97), ensuring that I remained true to

the participants' voices and stories. One of the strategies that I used to accomplish this was to create comments and memos with personal ideas or interpretations in ATLAS.ti 7 while analysing my data (Frieze, 2014:112, 122, 123, 167). The presentation strategy that I followed for my study was to present the findings of each case together with the similarities and differences between the cases, with the discussion presented separately (Smith & Osborn, 2008:227-229).

3.4. The role of the researcher

Brocki and Wearden (2006:98) emphasise that one of the most important aspects regarding the role of an IPA researcher is that the researcher adopts an interpretative role. According to Colaizzi (1978:1), as an IPA researcher, I must at all times truthfully express whatever I learn from the participants' accounts. IPA thus calls for objectivity. In order to reach the required level of objectivity, I had to acknowledge my own experience before trying to interpret, understand and write about the experience of the participants in my study (Colaizzi, 1978:2-3). When conducting IPA research, the researcher actively takes part in a dynamic process of data collection and analysis (Smith & Osborn, 2008:5). During the semi-structured interview, my role as interviewer was to facilitate and guide the participants rather than dictate exactly what should happen during the interview (Smith & Osborn, 2008:128). Taking on the role of active co-participant during an interview could lead to the interview structure diverging from the planned schedule. As researcher I had to know when to abandon the scheduled structure by following up the concerns of the participant (Smith *et al.*, 2009:64).

One of the participants in this study, Peter, was the case study for my fourth-year mini-dissertation in which I focused on the role music plays in the lives of a Williams syndrome child and on the way Peter reacts to certain musical characteristics. After meeting Peter and his family for the first time, we became friends and I still receive emails from Peter every other week to keep me

updated on his life and adventures. My interest in Williams syndrome comes from my love of psychology, music therapy and special needs education. When I first heard about the syndrome and then met a child living with Williams syndrome, my passion for the subject was ignited and I have been studying the syndrome ever since.

3.5. Ethics

Before starting my research project, my research proposal was approved by the ethics committee of the North-West University and I was given an ethics number (NWU-00180-13-A7) confirming that the study was approved. With regard to the ethical issues that might arise during different stages of my research, it is important to note that the ethical considerations when working with children do not differ greatly from those when conducting research with adult participants (Greene & Hogan, 2011:63). According to Greene and Hogan (2011:63), the main difference between research on adults and children has to do with the ability and power of the participants. Adults tend to be more self-assured than children, which means that children could see an adult researcher as having power over them or the interview. I thus emphasised that the child is the one who was important during the interview and that the participant had the power to lead the interview.

In some cases, there are also differences between the communication abilities of children compared to adults (Greene & Hogan, 2011:63). Seeing that Williams syndrome children, adolescents and adults have abnormally well-developed language skills, this did not have a considerable influence on this research. Children are, however, just as capable of speaking about their experiences as adults and can articulate what they want to express well if the context allows them to (Greene & Hogan, 2011:65). I thus conducted interviews with two children and one young adult living with Williams syndrome in environments that made them comfortable (Greene & Hogan, 2011:72), while

making sure that the participants knew what the study is about and why I conducted interviews with them.

Before starting the data-collection process for this study, I obtained informed consent from the participants and their parents for them to participate in the research project after they had been informed about what they can expect from this study (Greene & Hogan, 2011:65; Smith *et al.*, 2009:53). The consent form (Annexure A, B, C) stipulated what the study is about, how it would be conducted and what the aims for this research are (Creswell, 2013:58; Greene & Hogan, 2011:69). By giving the participants the right to withdraw from the study at any stage of the data-collection process, I further assured the participants that I have their interests at heart (Greene & Hogan, 2011:65; Smith *et al.*, 2009:54). It is important that I assured the participants that their identity shall remain anonymous throughout the study (Greene & Hogan, 2011:65) and also when the findings are written up and/or published.

One of the main ethical considerations when starting any study is ensuring the avoidance of harm to any of the participants (Greene & Hogan, 2011:65). This harm does not only refer to physical harm, but also to trauma experienced when talking about sensitive issues and not respecting the privacy of the participants (Creswell, 2013:58-59; Greene & Hogan, 2011:65). While conducting the semi-structured interviews for the research, I thus had to be aware of the participants' non-verbal behaviour in order to pick up on suggestions that the participants are uncomfortable with a certain line of questioning, especially seeing that I interviewed two children (Greene & Hogan, 2011:67). I also had to be ready to respond to this type of behaviour by rephrasing the question or by backing down (Smith & Osborn, 2008:143). While conducting the interviews I emphasised to each participant that his/her story is what matters. I ensured this by expressing it to the participants and by not leading the interviews. This is a very important aspect when interviewing children, because they are particularly vulnerable to persuasion (Greene & Hogan, 2011:63) and I thus had to make sure that I did not pressure the

children or the young adult into taking part in my study or to answer the questions in a certain way.

Another ethical issue that I had to consider refers to avoiding siding with participants during the data-analysis process. Furthermore, I also avoided disclosing only positive results (Creswell, 2013:59) by analysing both positive and negative comments, and by presenting both perspectives while writing up my findings. To ensure that my study does comply with ethical standards, I gave the participants the opportunity to review my findings before the study was finalised to ensure that they are comfortable with the information that I have used and the way in which the information is presented (Greene & Hogan, 2011:69). When I finished writing my results and concluding chapters I sent my fourth and fifth chapters to the participants in order for them to decide whether or not they are comfortable with what I wrote and if they still wanted to participate in the study.

3.6. Validity

There are different ways in which one can improve the validity of a study. A successful IPA study relies on research that is of high quality and that is conducted with sensitivity to context and the particular phenomenon being studied. Furthermore, as an IPA researcher I had to conduct my study with commitment and rigour, thus implying that I must be thorough while carefully collecting and analysing data (Smith *et al.*, 2009:181). Transparency and coherence of the research results are also important factors in ensuring the validity of IPA research findings (Reid *et al.*, 2005:50; Smith *et al.*, 2009:182). This dissertation complies with this approach, seeing that the different stages of the research process, documented with ATLAS.ti 7 computer software, are described in detail. Additionally, Reid *et al.* (2005:50) emphasise that the interpretation of interviews should be true to each participant's story without being influenced by the ideas and/or biases of the researcher. To ensure that my results are valid, I used member checking, in order to get confirmation from

each of the participants that my findings are indeed accurate, allowing them the opportunity to confirm that I had made valid interpretations of their accounts concerning their experiences (Colaizzi, 1978:13). When I finished writing my fourth and fifth chapters, I sent my findings to the participants and asked them to check what I wrote in order to decide if they are comfortable with my findings, that they agree with what I wrote, and to tell me if they wanted me to change something or leave something out of my dissertation. All of the participants' parents replied to let me know that they and the participants are satisfied with my results and that they still agree to be participants in the study. None of the participants asked me to change anything that I wrote.

Smith *et al.* (2009:183) refer to another principle that contributes to the validity of research, which is impact and importance. The current study is formulated around this principle in the sense that it is the first of its kind in Southern Africa and that this study holds value for educators, researchers, therapists and parents working with individuals living with Williams syndrome.

Conclusion

IPA research therefore requires creativity and precision (Smith *et al.*, 2009:184) in the striving to gain insight into the meaning of certain experiences for participants who have been carefully selected because of their shared lived experiences. The interpretations of IPA research must be true to each individual, and thus not aim to make generalisations but rather to emphasise the similarities and the differences between the cases.

By following a logical system when collecting and analysing data I ensure validity with a step-by-step path through the chain of evidence (Smith *et al.*, 2009:183). It is important to note that the aim of IPA research is not to make the assumption that the account given is the only valid or accurate account. Rather, this study aims to present the research findings systematically and transparently to ensure that the account given is credible (Smith *et al.*, 2009:183). IPA research thus requires

commitment to quality from the onset of the research, during the data-collection and analysis processes through to the publication of the findings.

CHAPTER FOUR: FINDINGS

Introduction

This chapter will discuss the results from analysing the three interviews, thus shedding light on the meaning that the three participants ascribe to their musical experiences. As an IPA study calls for an idiographic approach, I shall first give a vignette for each participant followed by the emerging themes from his interview. Great care was taken to analyse each case separately in ATLAS.ti 7 by working in stages while analysing each participant's interview transcripts (see Chapter 3.2 and 3.3). I then moved on to a cross-case analysis, where similar emerging themes from each case were organised and given new labels as superordinate themes. This process of identifying superordinate themes was done manually, not with ATLAS.ti 7. When similar emergent themes occurred in only two of the three cases, they were not considered superordinate themes and were thus not given new labels. This process is depicted in *Figure 11*.

According to Creswell (2013:251), it is still necessary to report these themes, although they do not fit the general pattern, as this will provide a realistic view of the phenomenon being studied. As part of my negative case analysis and also in order for me to follow an idiographic approach, I shall report on the unique emergent themes of the three participants' stories.

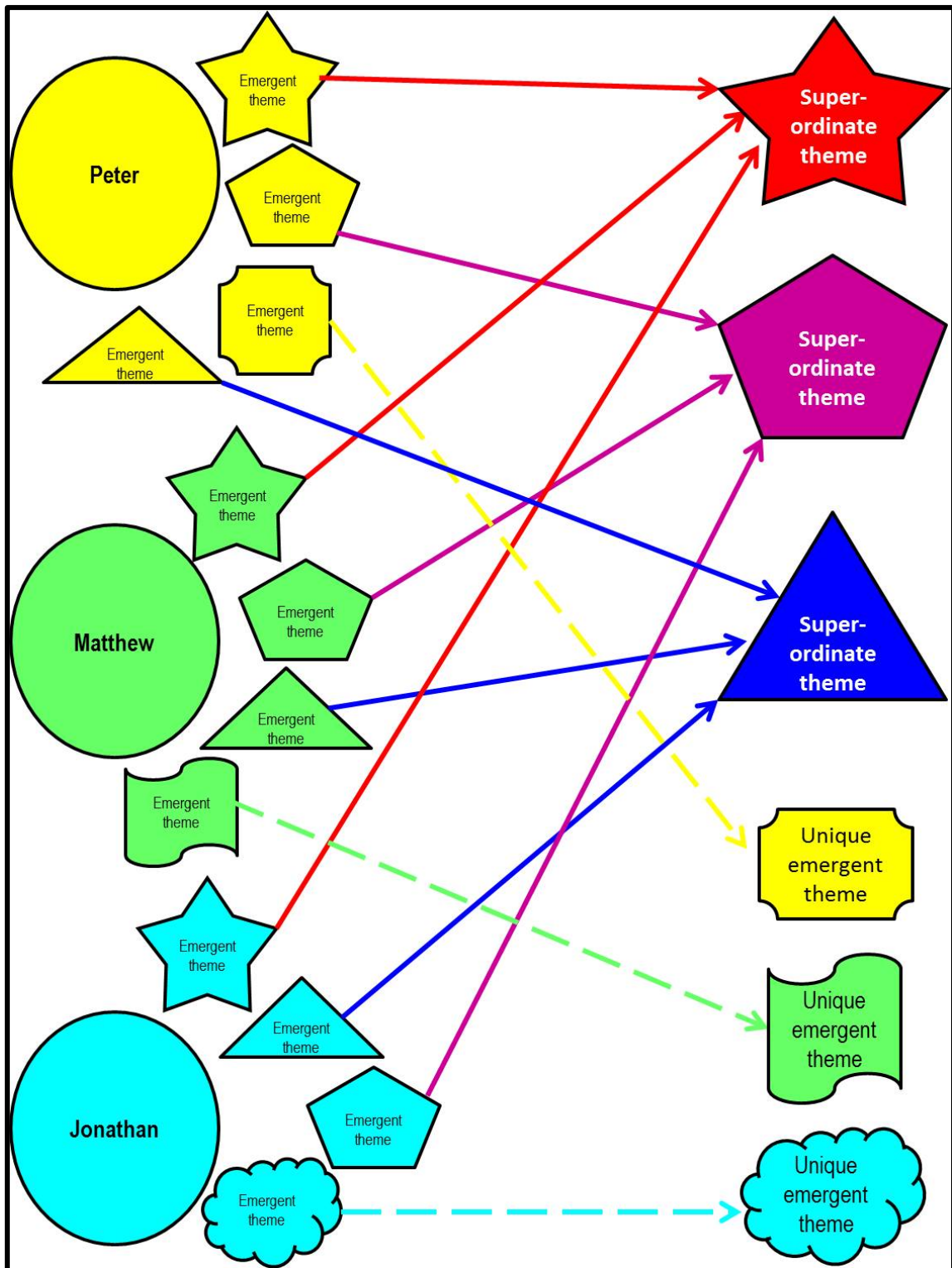


Figure 11: Process followed for identifying superordinate and unique emergent themes

In order to ensure the anonymity of each of my participants, the names Peter, Matthew and Jonathan as used in this study are pseudonyms.

4.1. Peter

Peter was visited by the Reach for a Dream foundation in 2003. The foundation presented him with his first drum set in the same year – a simple act which turned Peter's world around. After Peter had saved every cent of his allowance, he bought himself a 7-piece Maple Drum set seven years later. In 2003, two weeks before the Reach for a Dream foundation visited him, Peter had lifesaving heart surgery at the Christiaan Barnard Memorial Hospital in Cape Town. In January 2011, while in ICU at Panorama Medi-Clinic, the doctors gave Peter's family the news that there was no hope for their child's recovery. This followed a rupture of Peter's colon. Peter also suffers from a severe case of arthritis and constantly has to have blood tests done which are sent to a specialist in the Western Cape. Peter further suffers from high levels of anxiety and fear in his everyday life, especially in unforeseen circumstances, when not knowing what to expect in certain situations and when plans that have been made in advance change suddenly. For Peter and his family, this is but a small part of the journey of a child diagnosed with Williams syndrome, and in this instance, a severe case.

Despite all these hardships Peter works hard to keep his drumming up to standard. When he speaks of himself as a drummer he refers to himself as a professional. Peter did not have the opportunity to attend school and was home schooled by his mother. Part of their unique educational approach was to make use of library books and field trips. Peter learned optimally when observing how machines work and by participating in projects as part of his learning process. The knowledge that he has acquired through years of experience, despite his mental impairment, is astonishing.

As a result of these educational field trips, Peter became involved in his hometown community for 11 years before his family had to move. His involvement included volunteering at the fire brigade, local police station and sea rescue services. It seemed at times that Peter has accumulated more

knowledge on these services than most books can teach us. Peter loves the sound of fire alarms, mist sirens, police sirens and jet engines. Yet at the same time he does not necessarily like loud music – a result of his acute hearing or hyperacusis. Peter's personality and love of people, as with other individuals living with Williams syndrome, has a way of drawing people into his life and establishing friendships that will last a lifetime.

4.1.1. Emerging themes for Peter

Peter's interview revealed five emergent themes and seventeen related categories regarding his musical experiences. Table 3 shows the emergent themes and categories identified in Peter's interview, together with raw data supporting each theme and category.

Table 3: Emerging themes for Peter

Emerging Themes	Categories	Raw data
Music is my life	Being a musician is hard work	<i>A lot of practising works, but if you don't prepare then it won't go well.</i> <i>It becomes a whole process of planning beforehand.</i>
	I love everything about music	<i>I always love music – even more than that. I love every aspect of music.</i>
	Music my future	<i>I am passionate about music. I will keep on practising music so that I can master the skill.</i> <i>Then I can, in future, play in a band and make myself more applicable to the music.</i>
Music regulates my emotions	Calms me down	<i>... it calms you down a lot. To listen to music, like I said, it calms you down.</i>
	Pitch directly relates to emotion	<i>When the guy sings with a deep voice, then you sort of laugh at him because you know he is getting depressed from his voice.</i>
	Helps me cope with medical issues	<i>So even when you get those days when you don't feel well and you are sort of... not well, then music helps to calm you.</i>
	Lifts my mood	<i>It always makes me better because I don't feel crushed by anything.</i>
	Music makes me feel overcome with emotion	<i>As soon as you listen to music, then you sort of feel – WOW - you know, you get an overwhelming feeling.</i>

		<i>Sometimes you get so overwhelmed by your performance that you think, whoa, I have to focus on playing now.</i>
Anxiety brought on by musical experience	Performing makes me anxious	<i>Frustration and nerves always bother me. I am nervous when I play drums in church. I then sometimes don't want to play, but it only happens sometimes. Other times there are no problems.</i>
	The effect of medical issues on musical experience is worrisome	<i>It influences me when I make music, because I cannot practise comfortably and I cannot play comfortably. Sometimes, I will struggle with it and try to get it right before anything happens, so...</i>
I am passionate about performing	Performing is fun	<i>I practise at home so that I can perform again and to have fun performances.</i>
	I am proud of my performing skills	<i>People see it as a normal performance. They say that I perform well and that it is fun to listen to me performing. I am a master at playing the drums.</i>
I make friends through music	Performing sprouts friendships	<i>Performing often has an impact on the relationships between people.</i>
	Everyone loves music	<i>But if you don't like music, it will become fun.</i>
	Music is fun	<i>Sometimes, you make jokes in between and then you have a good time and laugh. It is fun making jokes before you carry on rehearsing. You interact with people and chat with them.</i>
Music builds positive self-esteem	I would be frustrated and lost without music	<i>It doesn't affect me [upset]. It has nothing to do with me. It gets frustrating without music.</i>
	Makes me a better person	<i>The music I listen to has always made my life better. Every performance that you give makes you a better person and enhances your personality.</i>
	Performing proves that I am good at something too	<i>You give a little of yourself to prove that you can perform.</i>
	I am a proud musician	<i>Well, I am actually more of a master on drums than on any other instrument. People enjoy when I perform and tell me that it was a good performance afterwards.</i>

Peter's interview revealed that music is his life and his future. This became clear when he said "I always love music" (65:46)³ and that he must "practise

hard” in order to be a good musician “in future” (65:144). Music further regulates his emotions without him necessarily having control over the emotions that he feels. He explains this by saying “you feel like – WOW” (65:67). What was interesting was to find that Peter is also aware that he experiences anxiety related to musical performance when he says “I get nervous” (65:5). Peter is clearly passionate about performing music and he is able to make friends in this way. In the end, music contributes to Peter’s life in a way that allows him to build positive self-esteem.

4.2. Matthew

I met Matthew just after he had finished a day’s volunteering at a penguin rehabilitation centre. That specific day was full of excitement as the centre had released rehabilitated penguins back into sea. When I first saw Matthew he was all smiles and told me about his morning paying a lot of attention to detail. At our first meeting all he also spoke about was his adventures with the D6 Cape Minstrels. He also showed me a Youtube video of him performing with the minstrel group. Matthew is a proud member of the D6 band as a tambourine player and in December 2013 he took to the streets of Cape Town with all the troops for the annual Cape Minstrel Carnival. This dream of walking with the Cape Minstrels was made a reality when Matthew decided, while camping, to dress up in his D6 gear and collect money from every camper that he could find near their camp site in order to pay the expenses of going to Cape Town. Seeing that he already had all the money he needed, his parents had no choice but to drive him to Cape Town for the New Year’s festivities. He especially loves the face painting that completes their D6 gear and showed me many pictures of his different face paint art works. It would thus almost seem natural that Matthew also loves the circus. We spent a whole afternoon

³ The numbers in brackets refer to the quote in the interview transcripts. The first number refers to the number of the document (interview transcript) in the ATLAS.ti 7 hermeneutic unit and the second number to the quote that was coded. This is thus quote number 46 in Peter’s transcript, which is document number 65 in the ATLAS.ti 7 hermeneutic unit.

watching Cirque du Soleil with Matthew almost polishing off a box of chocolates just before lunch – not that it spoiled his appetite in the least.

Matthew is a typical, energetic teenage boy who always has a smile on his face and loves spending time and making jokes with his family. He also loves camping with his cousins and enjoys evenings spent dancing with them, making new friends along the way. As a baby Matthew had lifesaving heart surgery to repair a narrowed aorta. The surgery was a huge success and to date the only medical issue that he has to deal with is taking his heart medication every day. Matthew had the opportunity to attend a local main stream high school at which both his parents teach. Although he could not follow the set school curriculum, he participated in some of the practical classes, not focusing on subjects such as Mathematics and Science. When spending time with Matthew one almost forgets at times that he too is a child living with Williams syndrome.

4.2.1. Emerging themes for Matthew

Matthew's interview revealed four emergent themes and nine categories regarding his musical experiences. Table 4 shows the emergent themes and related categories identified in Matthew's interview, together with raw data supporting each theme.

Table 4: Emerging themes for Matthew

Emergent themes	Categories	Raw data
Music is a positive experience	I always like music – everything about music	<i>[Big smile] I like it a whole lot. I like hearing the music and the drums and everything. And, uhm... I think the drums and the piano, the band and everything.</i>
	Music makes me feel better	<i>A lot better.</i>
I love performing	I love performing in Cape Town	<i>Yes! When I rehearsed with the D6 band one evening. Not during the day, but at night when we arrived.</i>

	I love performing with my family in church	<i>My mother kind of forced me, well not quite forced, but told me I should go sing with my father and so I went. It was a lot of fun! [Giggles]</i>
	I love to dance	<i>When I go to dances [giggles]</i>
Music helps me to connect with others	I make new friends through music	<i>There where we camped over Christmas. They always have dances and then me, my sister, my other sister and my cousins go. It was a lot of fun. I did, immediately when I had to perform there, they first painted my face and gave me my gear and then we had to go and walk in the Bo-Kaap. There were many, there were 77 troops that participated.</i>
	Performing allows me to be accepted by others	<i>They think it's very nice.</i>
Everybody depends on music	It would be impossible for anyone to believe that music is a waste of time	<i>There aren't any. Because it's music. It isn't a waste of time. [Tone of voice suggests that this should be obvious to me].</i>
	Everyone would be mad without music	<i>They would have been mad all the time.</i>

During the interview, while speaking about musical experience, Matthew said “I like it a whole lot” (66:1) and that he always likes music emphasising that, to him, a musical experience is a positive one. When speaking about music listening and performing, Matthew said “it’s fun!” (66:2), highlighting his love of musical performance. Music also helps Matthew to connect with others, which is a very important factor in his life. This became clear when Matthew said that the D6 Cape Minstrel band is “my band” (66:19). When I spoke to Matthew about not having music and that some people might prefer not having music, I realised that in his mind, everybody is and should be dependent on music by reacting with “whoa...” (66:13). Matthew was in fact almost shocked by the idea that some people might not like music the same way he does.

4.3. Jonathan

I met Jonathan in his soon-to-be pizza restaurant built for him as a gift from his parents. Jonathan told me that, as soon as the restaurant opens, he will be the boss and will have the responsibility of making sure that the business runs

smoothly – which will be no small feat for anyone. Jonathan not only loves eating pizza, but making it too. One of his dreams is for his pizzeria to also have a karaoke bar at which he can entertain his guests and they can join him for evenings filled not only with delicious food, but wonderful music too.

During our first conversation, I initially found it hard to believe that he is a 17-year-old boy who had only just learnt how to write his own name, still struggling to write his surname. He had the opportunity to receive one-on-one education using music as primary teaching method, thus learning through songs. In my experience this method is one of the most effective ways of teaching Williams syndrome individuals, as music is one of the ways through which they make sense of the world. When it comes to music, Jonathan plays the drums and loves karaoke. He also knows more about the current song charts than I could ever dream of knowing, every so often playing me some of his favourite songs from his cell phone. When not helping his parents to prepare the restaurant for the opening, he likes to spend time searching for newly released music and downloading music from the radio.

4.3.1. Emerging themes for Jonathan

Jonathan's interview revealed ten emergent themes and eleven categories regarding his musical experiences. Table 5 shows the unique emergent themes identified in Jonathan's interview, together with raw data supporting each theme.

Table 5: Emerging themes for Jonathan

Emergent themes	Categories	Raw data
I love to perform	I enjoy playing drums	<i>I like playing drums. I do not play anymore, but I would like to play again.</i>
	I love to sing	<i>I would do very well if I could join a band. I've wanted to become a singer since I was little.</i>

Key to sensory learning	Musical experience is a sensory one	<i>When I play the drums, I feel the drum stick in my hand. I feel how I have to play and hold the sticks. This guides me while I play. I also see how I play. I see what drums I have to hit and what drums not to play on.</i> <i>Well, when I want to learn a new song I will listen to it 10 or even 20 times in order to hear how the beat goes and to hear what the singer does where.</i>
	Music is my key to learning	<i>When I use music that says "A" or "B" it helps me to learn better. It makes it a lot better, I can already write a few words. I can also write my name, but I am still learning to write my surname.</i>
	Music is in my nature	<i>It is in my nature to hear music.</i>
Music helps me to make friends	I love sharing music with others	<i>There are so many songs that I like, I have a song on my phone that I want to play for you. [Reaches into his pocket] Oh no! I left my phone at the restaurant... [upset]</i>
	The crowd love me when I perform	<i>You see, I know all the people in town. I know every single person in this town. When they hear that I can sing they ask me to sing for them. When I perform for them they clap and cheer and go crazy.</i>
	Music adds fun to my life	<i>If people would ask me why I do music I would tell them that it is fun! People like participating in musical activities.</i> <i>It feels good. Every type of music has its own nature and that's what I like about music.</i>
People depend on music	You're missing out if you don't like music	<i>I would also tell them that they are missing out.</i>
	Not having music would hurt	<i>It would be very difficult if I cannot listen to music because I really want music with me. That's how I feel about it. If music was taken away from me it would be very hard.</i> <i>It actually hurts a lot.</i>
	Life wouldn't be fun without music	<i>I think it would be terrible. It is fun to listen to music.</i>

By analysing the interview transcripts from Jonathan's interview, I found that he has a great love of performing, which was made clear when Jonathan said playing drums and singing is "a lot of fun" (67:12). During the interview, Jonathan said that it "feels good" (67:3) when listening to or making music, drawing attention to the fact that he is aware of sensory input when experiencing music. As with most Williams syndrome children, Jonathan loves

making new friends and music helps him to do just that. Musical performance allows Jonathan the opportunity to bond with others, as shown when he says “they ask me to sing for them” (67:18). Jonathan said that music is “human nature” (67:8) and he thus believes that people are dependent on music, not only for their wellbeing, but also for survival. According to Jonathan, we need music in order to live a happy life.

4.4. Cross-case analysis: Superordinate themes

After my initial case-by-case analysis, I searched for connections between the participants’ interviews. When comparing the results from the interviews with Peter, Matthew and Jonathan, several similarities and differences came to light. By highlighting these aspects, I reach the final steps of the data analysis process for my IPA study. Table 6 shows the similarities (superordinate themes) that emerged from the three participants’ interviews.

Table 6: Superordinate themes

Corresponding emergent themes	Superordinate theme	Raw data
I am passionate about performing I love performing I love to perform	A passion for performing	Peter: <i>I performed for a school once and it was a lot of fun.</i> Matthew: <i>It [singing in church] was a lot of fun.</i> Jonathan: <i>Wow, then I see the crowd going mad. It makes me even feel more passionate about singing then.</i>
I make friends through music Music helps me to connect to others Music helps me to make friends	Fostering friendships	Peter: <i>Every time that you do a performance you make some jokes because you kind of become a joker-like person. You remember this, it may be old things, but you remember it and then you laugh at it.</i>

		Matthew: <i>When I rehearsed with the D6 band one evening. Not during the day, but at night when we arrived.</i> Jonathan: <i>Whenever we want to have a good time, we listen to music.</i>
Music helps me to control my emotions Music is a positive experience Key to sensory learning	Lightens the load	Peter: <i>It always makes me feel calm and relaxed.</i> Matthew: <i>A lot better. Sometimes when I'm very upset about something, then I go and listen to music and it makes me feel a lot better afterwards.</i> Jonathan: <i>Say for instance my parents want to teach me. I am busy learning to read and write. When I use music that says "A" or "B" it helps me to learn better. It makes it a lot better, I can already write a few words.</i>
Music is my life Music builds positive self-esteem Everybody depends on music People depend on music	Dependent on music	Peter: <i>It lets you feel comfortable much easier.</i> Matthew: <i>There aren't any. Because it's music. It isn't a waste of time.</i> Jonathan: <i>Not having music will take away peoples good times and happiness.</i>

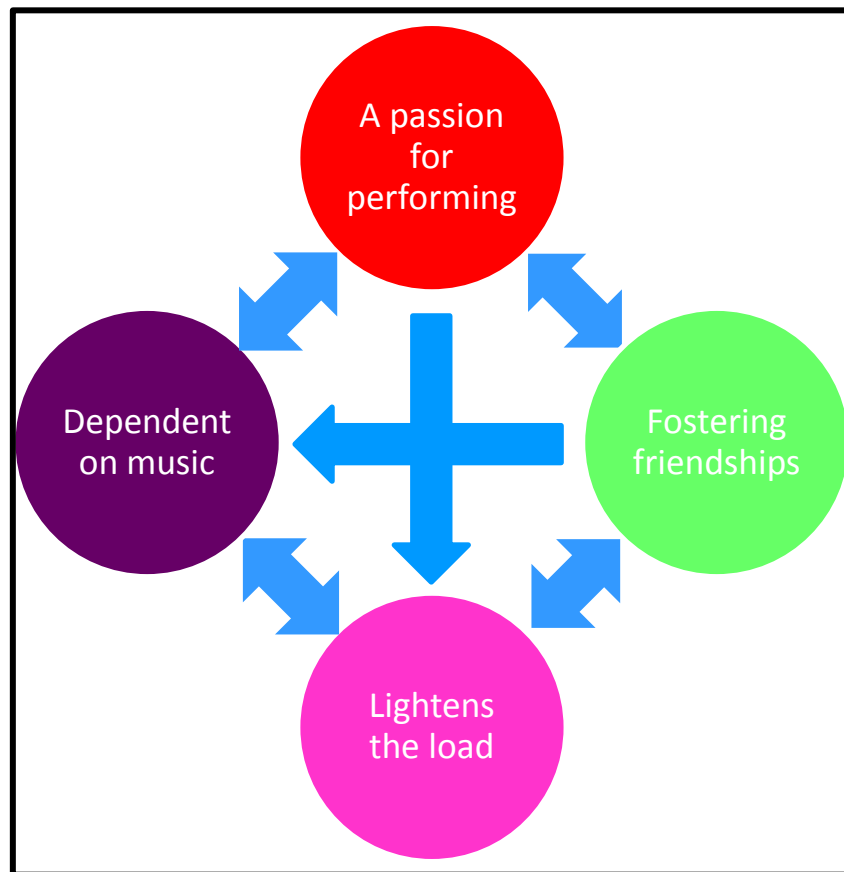


Figure 12: Patterns between superordinate themes

Figure 12 shows the patterns that emerged from the identified superordinate themes of this study. During the final stages of analysis it became clear that for Peter, Matthew and Jonathan their passion for performing is what allows them to foster friendships within a social music environment. The fact that they make friendships through performing in turn fuels their passion. Peter's, Matthew's and Jonathan's passion for performing also helps lighten the load as it enhances their emotional wellbeing. Through the friendships they cultivate, Peter, Matthew and Jonathan are able to feel accepted by others, which in turn lightens their load and helps them cope with some of their everyday struggles. It thus became clear that none of the three participants would be able to cope without music and they are therefore dependent on music for their wellbeing. By lightening the load that Peter, Matthew and Jonathan have to bear, music enables them to function better within a social environment and make new

friends. Because Peter, Matthew and Jonathan are hyper-social, they depend on music for creating new friends.

Superordinate theme 1: A passion for performing

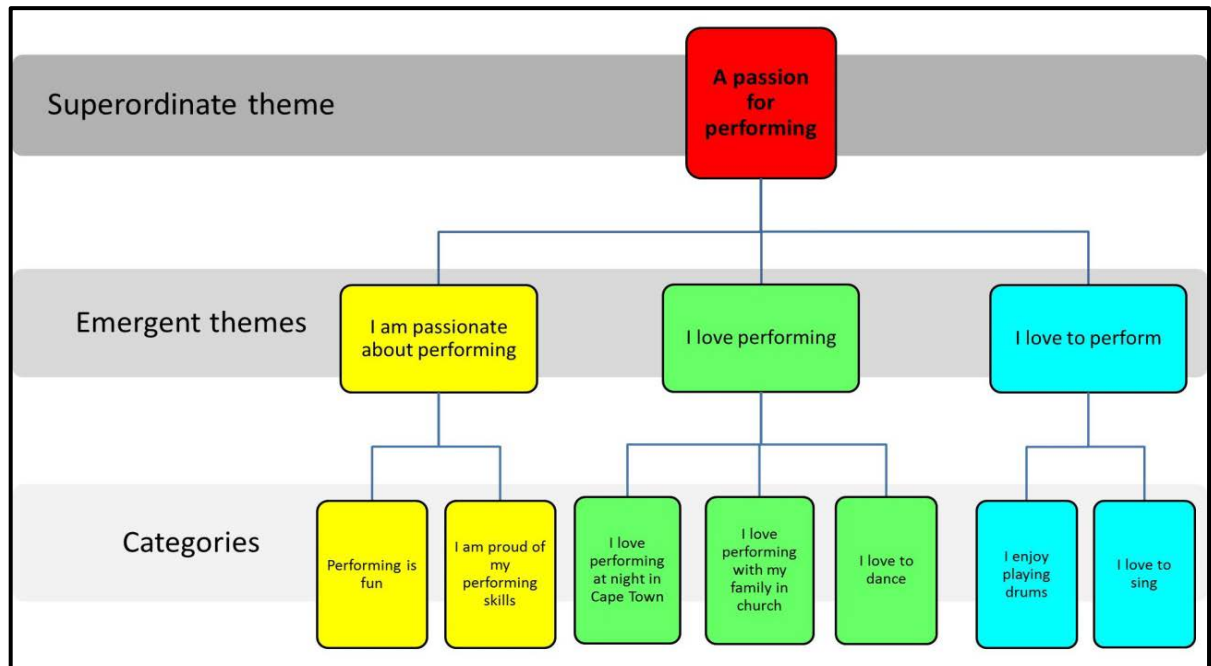


Figure 13: The emerging themes and categories associated with superordinate theme 1

Musical performance is an essential part of the lives and musical experiences of Peter, Matthew and Jonathan. Not only do these performances provide them with fun and excitement, but it also contributes to their self-confidence, thus promoting a healthy self-image for all three participants. During his interview Peter said “I performed for a school once and even got a certificate for the music that I made” (65:97), clearly indicating how proud he feels about his performance. Peter also regards musical performance as a means through which he can grow as a person and said the following:

Peter: *Every performance that you perform makes you a better person and contributes to a better personality [hands on the table show seriousness] (65:133).*

Matthew and Jonathan also love performing and they both also focus on what their crowd thinks of their performances.

Matthew: *I have sung in church as well. It was a lot of fun! [giggles] (66:16).*

Jonathan: *I played the drums and it was quite fun (67:4).*

I feel great. I am very glad about that (67:19).

The cross-case analysis revealed that music is a source of fun in the lives of all three Williams syndrome participants' lives, whether it be listening to music, sharing it with others or performing. Music allows Peter, Matthew and Jonathan to have a good time and their lives would seemingly have a lot less happiness if music were to be removed from it, as the following discussion and excerpts will show.

Jonathan: *If people would ask me why I do music, I would tell them that it is fun! People like participating in musical activities (67:9).*

Peter, Matthew and Jonathan love the attention they get from performing in front of a crowd. Matthew loves attending dances with his sisters and cousins, highlighting his love of socialisation.

Matthew: *They always have dances and then me, my sister, my other sister and my cousins go (66:7).*

Musical performance is a way through which all three participants are able to share their love of music and their talents with others within a social environment, providing them with opportunities to interact with others.

Superordinate theme 2: Fostering friendships

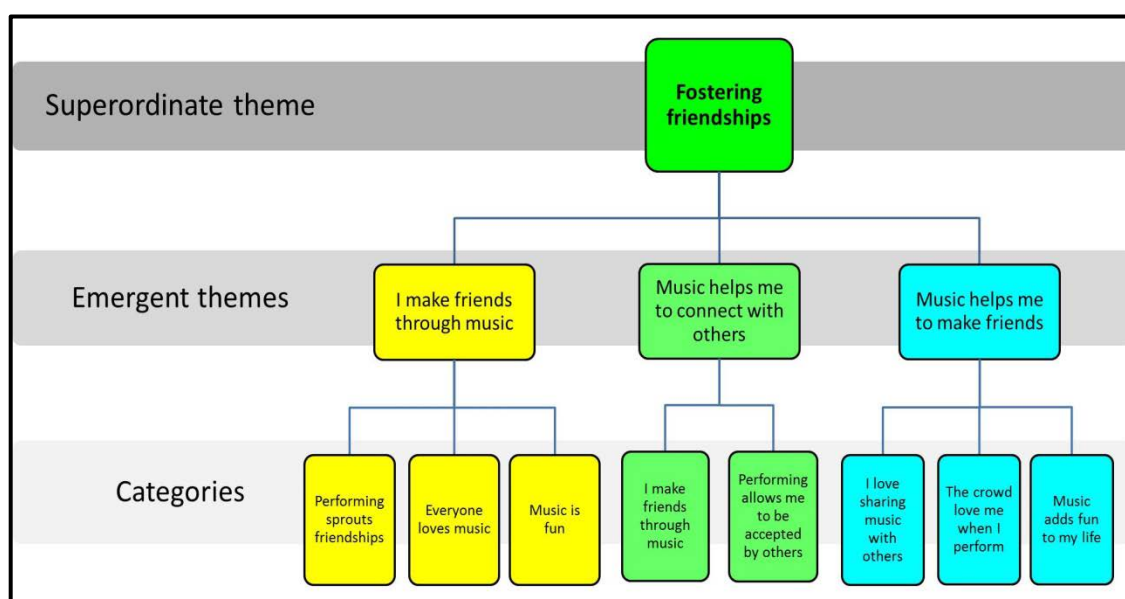


Figure 14: The emerging themes and categories associated with superordinate theme 2

As with most Williams syndrome individuals, Peter, Matthew and Jonathan are hyper-social, seeking out any and all opportunities to make new friends and interact with others. Music provides them with a means through which they can connect with others within a social setting. For Peter, musical performance allows him to make jokes with friends, but even more than that, he tends to experience making music on his own to be depressing.

Peter: *I don't always have someone to play with me. I often play drums on my own and then I get upset. If I don't have someone to play with, then I cannot play comfortably. When someone does play with me I enjoy it a lot (65:100).*

One of the most effective ways in which music helps Peter to make friends is through musical performance, as it allows him to make new friends within a social environment. Jonathan's need for socialisation is reflected in his love of sharing music with others. Jonathan not only shares his favourite musical pieces with others, but also loves people joining him in performing.

Jonathan: *I have a few CDs that I am going to take with me to the restaurant. I also love having karaoke nights where I can perform and people can sing with me (67:17).*

While analysing the interview transcripts, I realised that Peter, Matthew and Jonathan not only interact with people on a social level and create new friendships through musical performance, but it also adds meaning to their lives in a context of social acceptance. Music seems to be one aspect through which Peter, Matthew and Jonathan can relate to a normal society. Their musical skills allow them to prove to others that they also have skills for which they can be accepted within the music as well as the general community. For Peter, performing with others allows him to be acknowledged as a worthwhile musician, colleague and friend.

Peter: *Sometimes you make jokes and laugh when playing together [smiles]. And it is nice sometimes to make jokes in between before you go on. ... You remember this, it may be old things, but you remember it and then you laugh at it (65:135).*

[Big smile] They think it was a very good performance. They see it as a normal performance (65:93-94).

Matthew's dream of performing with the Cape Minstrels provides him the opportunity to be completely accepted as a true D6 member and gives him ample happy musical memories and stories to tell while fostering life-long friendships. This seems to be one of the things in Matthew's life of which he is most proud. He also feels honoured to be able to participate in their rehearsal late into the night, like a true band member would.

Matthew: *Yes! When I rehearsed with the D6 band one evening. Not during the day, but at night. They gave me their gear to put on and then the band began playing. I had to play with them (66:21).*

For Jonathan, making music is a way in which he can show the world what he is capable of, allowing them to admire his musical skills. Music provides Jonathan with the opportunity to be accepted into the community as a worthy musician and valued friend. In Jonathan's life, music and friendship go hand in hand and the one cannot exist without the other.

Jonathan: *I know every single person in this town. When they hear that I can sing, they ask me to sing for them. When I perform for them, they clap and cheer and go crazy (67:18).*

Music contributes to Peter's, Matthew's and Jonathan's lives in a way that enables them to make friends, to be accepted within their communities and to feel valued. Music and friendship help Peter, Matthew and Jonathan to cope with their everyday struggles, all the while lifting their mood.

Superordinate theme 3: Lightens the load

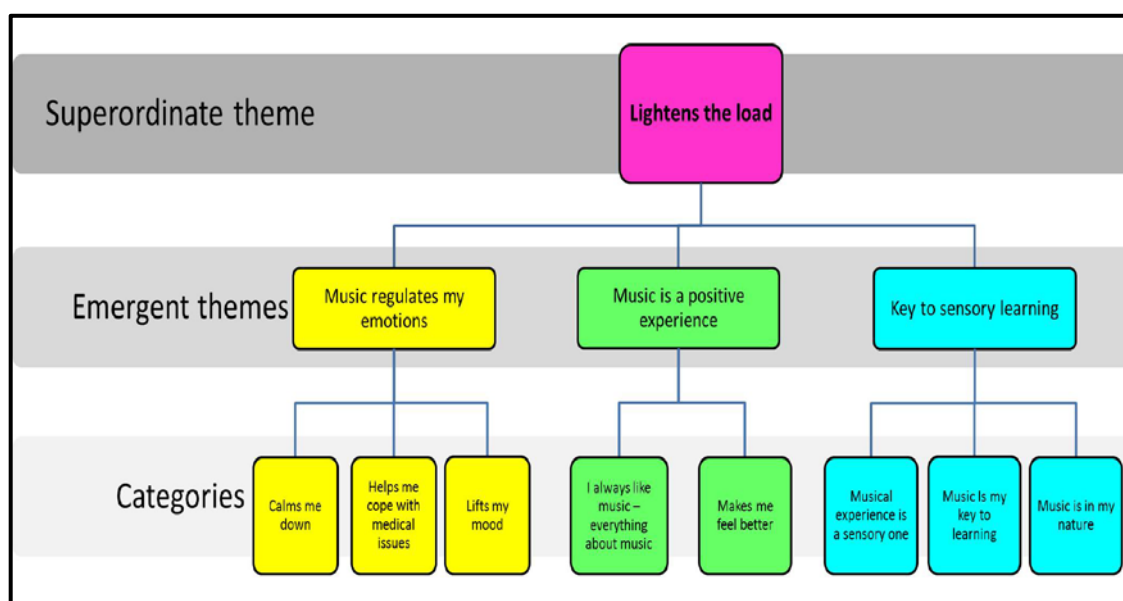


Figure 15: The emerging themes and categories associated with superordinate theme 3

The cross-case analysis for this study shows that music helps all three participants cope with difficult situations and negative emotions. One of the

main themes in Peter's interview is that music helps him to stay calm, while also helping him to cope with anxiety (65:102, 103, 130), medical issues (65:57, 64) and mood (65:79). Below are excerpts emphasising the ways in which musical experience helps Peter in his everyday life.

Peter: *Music helps me to not feel crushed by anything (65:90).*

Music plays a big role in my life because, uhm, with the music that we listen when travelling, it helps me to relax (65:102).

Listening to music plays an important role in Peter's life. To him, listening to music is calming and fun, and thus makes a positive contribution to his life. This in turn could lessen the experience of anxiety and its effects in Peter's everyday life and, unlike making music, Peter does not associate listening to music with anxiety or stress. Music thus clearly helps lighten Peter's load in terms of the struggles in his everyday life as shown by the following extracts.

Peter: *I listen to music when I feel up for it because it calms you down a lot. It lets you feel comfortable much easier. So even if you get days when you don't feel well and you are sort of, not good, then music makes you calm and relaxed (65:74).*

It is important to keep in mind that music has more importance in Peter's life than purely calming him down. Music is something that brings fun to Peter's life and he often stated during the interview that he enjoys listening to music during the day or when travelling. Despite his intense love of music and the evidence that music has the ability to help him feel calm and lighten his load, Peter surprisingly has days that he does not want to listen to music.

Peter: *It depends on what your feelings are. So if you feel that you don't want to listen to music today, then you don't have to. But sometimes I listen to music even when I don't want to (65:79).*

During the interview it seemed that Peter experiences days where his mood leads to him not wanting to listen to any music. At first glance it would thus appear that he does not want to listen to music when he is feeling down, in effect contradicting the fact that music has the ability to ease his suffering. But when one listens to his story, it is clear that even when he thinks he is not in the mood for music, he tends to listen to it anyway. This indicates that music plays a key role in keeping Peter calm and altering his mood for the better.

While in conversation with Matthew, he emphasised that he needs music to help him in many parts of his life. When asked where he needs music, he moved back in his chair before giving me his answer.

Matthew: *Uhm, when I... When things at work, where you were, are not working right or I did something wrong, then I get mad. Then I need to listen to music in order to not feel so mad anymore (66:14).*

Music seems to fulfil a therapeutic role in Matthew's life, keeping him calm when things do not necessarily go according to plan. When analysing the transcripts from Matthew's interview, I realised that Matthew not only needs music to help him calm down when he is angry. Music also helps him to feel better when he is upset or having a bad day physically, ensuring his positive wellbeing. In Jonathan's life, music not only provides him with fun and lifts his mood, it also helps him to learn.

Jonathan: *Say, for instance, my parents want to teach me. I am busy learning to read and write. When I use music that says "A" or "B" it helps me to learn better. It makes it a lot better, I can already write a few words. I can also write my name, but I am still learning to write my surname (67:28).*

Because of this important role that music plays in their lives, it also became clear that none of the three participants could fathom that music might, for

some, be a waste of time. Music fulfils a therapeutic role in all three participants' lives, aiding them in dealing with bad feelings and coping with tough situations, undoubtedly helping them cope with everyday hardships.

Superordinate theme 4: Dependent on music

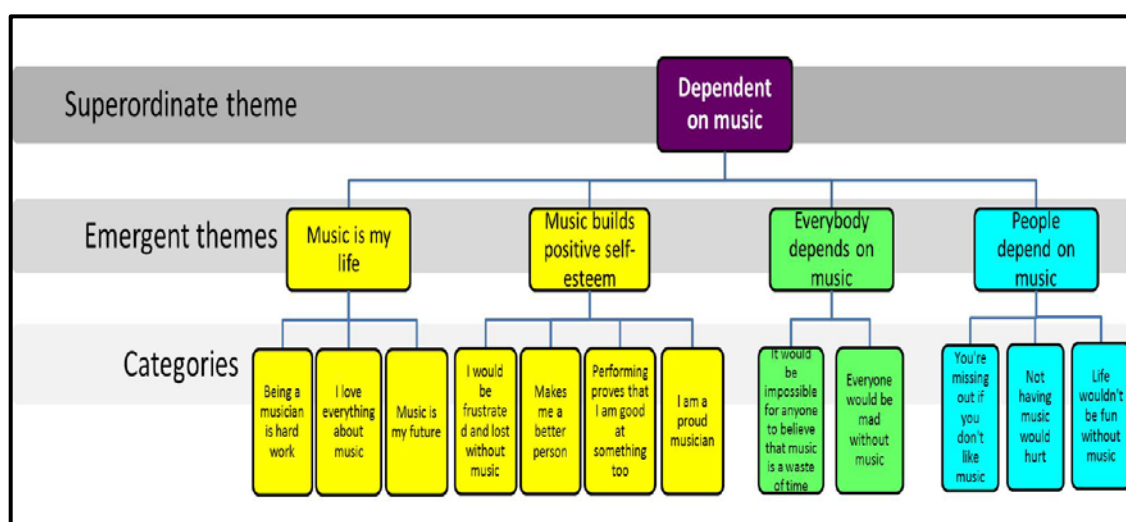


Figure 16: The emerging themes and categories associated with superordinate theme 4

One of the most prominent themes that emerged in the cross-case analysis was that neither Peter nor Matthew nor Jonathan could fathom the idea that music could, for some people, be a waste of time. In their mind, we are all dependent on music and the world would not be able to exist without it. Matthew stated this very clearly during his interview by saying that “there aren’t any” people who would think this. In my opinion, this emphasises the importance of music in Matthew’s everyday life. It is such an inseparable part of his life that he cannot conceive that it would be different for others. The idea that Peter cannot think of music as a waste of time for anyone became clear when he said:

Peter: [Very seriously] It does not affect me. It does not affect me (65:122).

It seems that this scenario is so unreal to Peter that he truly cannot think it to be true for anyone or that he prefers to not speak about this subject. This is a clear indication of music being an intricate part of Peter's life and that he believes that this should hold true for everyone. When Jonathan was asked what he would say to people who think music is a waste of time and money, it was clear that he could not really believe that this could even be possible, as shown in the following excerpt.

Jonathan: *I will tell them that music is part of our nature. I would also tell them that they are missing out (67:8).*

The superordinate theme of being dependent on music is highlighted when Jonathan says that music is part of our human nature. It would thus seem that he deems music to be an inseparable part of our everyday lives, giving meaning to all that we do. Peter, Matthew and Jonathan seem to transfer their love of music to others, regarding it as impossible for people not to share their love of, passion for, and dependence on music.

Peter's, Matthew's and Jonathan's worlds, as they know them, depend on their musical experiences. In Peter's mind, the world would be a very boring place without music. He believes that music is what makes life interesting and that without it nothing interesting would happen in our lives or in the world. Peter also stated that not having music would be frustrating and that he even feels frustrated when there are days when he cannot listen to music because he has to go to town with his family.

Peter: *The world would have been totally different. There would not be anything interesting that happens (65:82).*

Not being able to listen to music can be frustrating (65:78).

Listening to music also plays an important role in Peter's life. To him, listening to music is calming and fun, and thus has a positive influence on his life. The following extract confirms the idea that Peter is dependent on music, as he needs music to cope with everyday struggles.

Peter: *So even if you get days when you don't feel well and you are sort of, not good, then music makes you calm and relaxed (65:64).*

When I asked Matthew what would happen if he had to go a day without music, he could not immediately answer my question. It seemed as if he initially was taken aback by the question before he answered:

Matthew: *Whoa... I don't know... Uhm... I would be very upset (66:12).*

We then spoke about a world without music and Matthew was almost shocked by the idea. After a few moments he then explained to me how he thinks the world would be different if music did not exist.

Matthew: *People wouldn't be very happy. They would be mad all the time. They would never, never... They would just be mad. Forever (66:13).*

This response was a key point in the interview. It proved to me that music might well be the most important thing in Matthew's life and that, without it, he would be a much less happy teenage boy without anything to feel passionate about. No smiles, no jokes. To me, this emphasises Matthew's dependence on music.

Jonathan's interview revealed that music truly is an important aspect of his wellbeing and that without it he would not be himself. The following excerpt reveals what would happen if Jonathan had to go without music.

Jonathan: *It would be very difficult if I cannot listen to music because I really want music with me. That's how I feel about it. If music was taken away from me, it would be very hard (67:25).*

From Jonathan's point of view, music is the element that brings fun to life and without it the world would have no fun or happiness.

Jonathan: *People would not be able to dance. I like to dance, I really love it. I think it would be terrible. It is fun to listen to music. Not having music will take away people's good times and happiness. You won't even be able to have a happy wedding without music (67:26).*

Jonathan also said that not being able to have music would literally hurt and that he would be lost without it.

Jonathan: *It actually hurts a lot. Uhm... Wow. I like music and it would feel that I don't belong with music then anymore (67:22-23).*

In my opinion, Jonathan depends on music in every aspect of his life and he would not know who he is without it. Without having music in their lives, Peter, Matthew and Jonathan would be unhappy and their lives would not have meaning. The transcripts of all three participants clearly show a clear affection for music. What I found interesting was the fact that Peter, Matthew and Jonathan cannot seem to grasp the idea that some people might not necessarily share their love of music, transferring their love of music to others. When I asked Matthew how he feels about music, he immediately answered "I like it a whole lot!" with a big smile on his face. For Jonathan music "feels good" and is part of his human nature. Peter's, Matthew's and Jonathan's love of music also influences and guides their perception of self, helping to shape their personalities and self-images.

4.5. Cross-case analysis: Unique emerging themes and categories

While searching for connections between the emergent themes of each participant, I also noticed some key emergent themes and categories that differed between the cases. These three themes will now be discussed as unique emergent themes and categories, and are important for the context of this study as an IPA study focuses on individual lived experiences. By highlighting the unique emergent themes, I thus stay true to my chosen method and provide a deeper insight into the lived musical experiences of the three identified Williams syndrome participants.

Table 7: Differences between the cases

Unique emergent themes and categories	Peter	Matthew	Jonathan
Anxiety related to musical experience	Yes	No	No
Pitches directly relate to emotion	Yes	No	No
Music makes me feel overcome with emotion	Yes	No	No
Key to sensory learning	No	No	Yes

Unique emerging category 1: Anxiety brought on by musical experience

The interview conducted with Peter revealed that musical performance contribute to the anxiety he experiences in his everyday life. While conducting the interview with Peter, he often referred to uncertainties while making music with or for others. This uncertainty could possibly stem from the inability to predict what and how the ensemble will play together and also uncertainty about exactly how the music will be executed. In my opinion, this could also indicate the need Peter has for social acceptance, especially when his musical skills come into play. The excerpts that follow will aid in highlighting aspects from the interview with Peter that indicate this.

Peter: *Oh well, frustration and, and nervousness. That always bothers me. I get on my nerves [nervously laughs at himself] when I begin*

to play drums in church or so. Then I don't really want to anymore but, but that happens sometimes and other times it's fine. Then there aren't any problems. So... (65:6)

So often the group will play together but they don't know what waits for them. So unexpectedly it could then be heavy music that is played or lighter music. Sometimes the music gets too fast and then you sort of have to move yourself forward, but you can't always do that because you don't know what the other people will do. You also don't always know whether to stay on a high or low note. As soon as you hear the other people going to a high pitch you have to go with them, otherwise the music won't work (65:76).

It would thus seem that a lot of the performance anxiety Peter experiences might not only be related to doubts in terms of musical execution, but also a need for the acceptance and approval of others. When analysing Peter's interview transcripts, it became clear that he thinks about the effects that his medical issues have on his musical performance and that these issues result in him not being able to make music comfortably and in a relaxed way. Peter is also not able to learn his drumming parts from scores and thus plays his parts by ear by means of improvisation. This too could contribute to his performance anxiety. The excerpts that follow reveal that Peter seemingly wants to ignore or deny this anxiety. This could be an attempt to avoid the experience of anxiety caused by medical issues, or it could be a coping mechanism to avoid admitting to the effects of anxiety on Peter's everyday musical experiences.

Peter: *Well, it influences me when I make music, because I cannot practise comfortably and I cannot play comfortably (65:56).*

It's not a problem at all. I normally have difficulty getting up, but I... I don't get stressed about it [plays with his fingers; rub hands together]. If I get stressed then I just say to myself that today is not

my day and then I just leave it there (65:58-59). But other times I struggle with it and try to get things right before anything happens, so... (65:60)

Even though the effect that medical issues have on Peter's musical experience contributes to the levels of anxiety he experiences, music in turn also helps him to cope with these medical issues. Despite this experience of anxiety, the emotions Peter experiences while listening to music are directly related to pitch.

Unique emerging category 2: Pitches imply emotion

Although Peter does not like speaking about sad feelings while experiencing music, he clearly also associates certain pitches with specific emotions. Peter experiences melodies with higher pitches as happy (65:31) and lower pitches as sad or depressing (65:30), describing this experience as upsetting (65:99) and making his ears more sensitive (65:77). The timbral sensitivity of people living with Williams syndrome could also contribute to the fact that Peter experiences male, or deep voices, as more depressing than higher pitched voices.

Peter: *When the guy sings with a deep voice, then you sort of laugh at him, because you know he is getting depressed from his voice. Then other times they won't get depressed and then they go into a higher voice (65:30-31).*

Peter's affective response to music is emphasised further when he speaks about the way in which music makes him feel overcome with emotion.

Unique emerging theme 3: Music makes me feel overcome with emotion

One of the most striking moments of Peter's interview, for me, was when he described music as overwhelming, referring to being completely overcome with emotion when engaging with musical activities.

Peter: *As soon as you listen to music, then you sort of feel – WOW – you know, you get an overwhelming feeling. This kind of lets you relax and, on the other hand, it overwhelms you when you listen to music. But it is the same feeling that I have with any music. When I listen to guitar music or drumming music then it kind of gets ... you know, you kind of feel funny (65:67).*

The fact that Peter describes these overwhelming feelings as “funny” could indicate that he does not always know how to describe certain feelings or might even not be able to identify all the feelings that are induced by musical experience. These feelings could thus range from happiness and awe to sadness. The fact that Peter uses the word “overwhelming” to describe these feelings might point to the fact that he probably experiences a whole range of emotions when listening to music.

During the interview with Peter and in my data analysis process I realised that Peter experiences music on a very intense level. This could be the reason why he does not associate musical experiences only with positive feelings but also with anxiety. Music is an intricate part of who Peter is and helped to shape his personality and self-esteem. Music then seems to truly be Peter's life and he is totally dependent on music for his wellbeing. For Jonathan, music contributes to his wellbeing in a unique way, seeing that music presents him with an opportunity to learn.

Unique emerging theme 4: Key to sensory learning

Although the emergent theme “key to sensory learning” is part of the superordinate theme “lightens the load”, it is unique in the sense that Jonathan was the only participant to mention that music helps him to learn. Because of this, I feel that it is necessary to discuss the emergent theme as unique as well, especially when considering the cognitive impairments associated with Williams syndrome. One of the most prominent roles that music plays in Jonathan’s life is that it helps him to learn more effectively. For Jonathan, learning to read and write fluently is important and no small feat. Music helps him to learn more successfully and in a fun way.

Jonathan: Say, for instance, my parents want to teach me. I am busy learning to read and write. When I use music that says “A” or “B” it helps me to learn better. It makes it a lot better, I can already write a few words. I can also write my name, but I am still learning to write my surname (67:28).

Learning through music is beneficial for Jonathan, seeing that he is comfortable with music and it is something that he understands. This makes it clear that music does contribute to Jonathan’s overall wellbeing, adding fun and excitement while helping him to feel accomplished while learning.

Conclusion

Through the data analysis I realised that Peter, Matthew and Jonathan share an intense love of, and need for, music in their everyday lives. Music allows them to build meaningful friendships through participation in musical activities, while also allowing them the opportunity to be accepted by others. Furthermore, music helps them deal with certain difficulties in their lives while providing them with memorable, fun musical experiences. Music proved to be a crucial part of all three participants’ lives and they cannot imagine having to live their lives without it. The three

interviews give an insight into each of the three participants' lives, providing evidence for the importance of musical experience in their everyday lives. The findings of this IPA study will now be linked to the existing literature in order to provide a context for each of the superordinate themes so as to draw out the implications of the study.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

Introduction

This final chapter of the study consists of six sections. In the first section (5.1 – 5.4) the four superordinate themes will be discussed in terms of existing literature. The second section (5.5) will address the limitations of the study. The third section (5.6) of this chapter will discuss the implications of the study for researchers, music educators, parents and therapists. In the fourth section (5.7) recommendations will be made for future research, while the fifth section (5.8) focuses on answering the research questions. The final section provides the conclusion based on the findings of this study. This chapter emphasises the importance of musical experience for the three participants by shedding light on the unique aspects of the musical experiences of these individuals living with Williams syndrome in order to answer the research questions:

How do individuals suffering from Williams syndrome understand their lived musical experiences?

What do individuals living with Williams syndrome experience when engaging in music?

How do individuals living with Williams syndrome experience music?

With this study, I aimed to give voice to three Williams syndrome participants. During my conversations with the participants and the data-analysis process I learned that music is more than a pastime for these individuals, but that it is their way of life. Conducting this study was a humbling experience and led me to again realise that we should be thankful for the privileges, the small things in life and music.

5.1. A passion for performing

Levitin and Bellugi (1998:379-380) conducted a study which found that Williams syndrome individuals have remarkable musical abilities. Although it is true that these abilities are not necessarily better than those of individuals in the wider society, they are extraordinary considering the cognitive impairments of individuals living with the syndrome. A research project conducted by Reis *et al.* (2000:10) also found average and above average musical abilities among most of the Williams syndrome participants taking part in that study. Reis *et al.* (2000:2) state that Williams syndrome was associated with high musicality from the first time it was defined, and argues that music has even been reported to be the “truest love” of individuals living with Williams syndrome. I also found this to be true of Peter, Matthew and Jonathan. All three participants clearly mention their love of music and their passion for performing. For them, performing music is one of the things in their lives that they are also good at. This is a key factor in the argument on the uniqueness of musical experiences for Williams syndrome individuals. Despite the impairment of their cognitive and visual-spatial development, Peter, Matthew and Jonathan are good at making music. Music seems to be something that allows them to conquer these impairments, thus further fuelling their love for music and musical performance.

According to Wills (2011:38), musical performance contributes to children’s wellbeing in that it encourages high-quality relationships with others. She also speaks about the idea that we can, through musical performance, escape our day-to-day lives in a way that transcends time and space (Wills, 2011:39). Making music provides Peter, Matthew and Jonathan an opportunity for self-expression on a level they possibly could not experience otherwise. This might well be one of the reasons that Peter, Matthew and Jonathan love to perform. Through musical performance Peter, Matthew and Jonathan build meaningful friendships and enhance their positive self-esteem and identity. Furthermore, through music, Peter, Matthew and Jonathan share their God-given talents with

the world. This is confirmed by the fact that Matthew loves to perform in church and Peter, who also plays the drums in his church, believes that it one of his responsibilities to share with the world what God gave him. Through musical performance they enhance their wellbeing, all the while also developing positive self-esteem.

Rice (2001: 28-29) conducted a study which found that musical performance is symbolic of cultural and personal progress, professionalism and a kind of musical hierarchy. Bernard (2005:15) argues that musicmaking is an essential part of understanding your identity. She builds this argument in her article "Making music, making selves", based on her study in which she found that music teachers form their professional identities around their experiences of making music. I believe that this also holds true for Peter, Matthew and Jonathan in the sense that their passion for performance helps them to shape their identities. Musical performance allows Peter, Matthew and Jonathan to be the great musicians they dream to be and to be seen as "normal" by others, even if it is only briefly. This enables them to bond with people from the wider society and to be accepted for who they are instead of only being labelled as a person diagnosed with Williams syndrome. I agree with Rice (2001: 31) when he states that "A good way of making music [...] is often also a good way of being socially in the world". In my opinion, this is a very important aspect of this dissertation, as it sheds light on the uniqueness and value of musical experiences in the lives of individuals living with Williams syndrome. Music provides them with the opportunity not only to live out their passion for performing, but it also aids their hyper-sociability by helping them to make friends and connect with others.

5.2. Fostering friendships

Huron (2001:47) wrote about the evolutionary adaptation of music and argues that music could possibly maintain social cohesion and teach people to be more observant and understanding. He also states that music has the ability to

let groups of people act in unison by synchronising the mood of the individuals in the group (Huron, 2001:54). Huron (2001:57) goes on to claim that music influences bonding and social identity as a result of the release of oxytocin (associated with human and animal bonding) during musical activities. According to North and Hargreaves (2006:85), when a person identifies with others within a group context, this could contribute to improved self-esteem. Shared musical experiences could thus enhance the positive self-esteem of Peter, Matthew and Jonathan.

Tsirir (2012:82) speaks about the role that music could possibly play in human life and how it can promote wellbeing. In his article “In times of crisis: music, love and human life” he argues that music and love are not mutually exclusive. I consider this to be relevant for the friendships that Peter, Matthew and Jonathan seek through music, as friendship and acceptance, in my view, cannot exist without love. This argument is confirmed by Cook and Silverman (2013:243) who, during their research on music and spirituality in cancer patients, found that their patients felt loved when engaging in music therapy sessions. I believe that the idea of feeling loved while engaging with music relates to Wills’s (2011:40) concept of connectedness which refers to children being able to share experiences through a sense of “being at one” with those who are taking part in the musical experience with them. This promotes a feeling of unity with others allowing children to connect with one another. In the light of this study, this connectedness is what Peter, Matthew and Jonathan ultimately search for when engaging in musical activities with others (whether it be performing or listening to music), again highlighting the value of musical experiences for these individuals living with Williams syndrome.

According to O’Callaghan (2014:1038) music can promote the resilience, coping skills, normalcy and social connection of children with cancer. Morinville *et al.* (2013:384, 388) conducted a study on music listening motivation and happiness and found that music is important for peer relatedness and social identity. Miranda and Gaudereau (2011:2) further argue for the importance of

music listening for social identity and forming relationships with peers. This also appears to be true for Peter, Matthew and Jonathan, for whom music is a means of connecting with others in order to create friendships and shape their identities. When considering the high level of sociability of Williams syndrome individuals, this is an invaluable aspect of the meaning that musical experience has in their lives. Wayman (2005:76, 84) conducted a study on “the meaning of the music education experience” from which the theme of belongingness emerged. This theme emphasises the need that students have to socialise in a music educational setting. Social interaction is something that neither Peter nor Matthew nor Jonathan can live without. Music allows them to interact with others on a social level and to be accepted as someone’s friend. The acceptance that Peter, Matthew and Jonathan gain and seek through their musical experiences also directly relate to the idea of belongingness as defined by Wayman (2005:84). It is my opinion that this is one of the reasons that all three participants stated that they would not be able to cope without having music in their lives.

There have been studies which show that ethnomusicologists, in viewing music as a metaphor, claim that music is social behaviour and that every musical performance is also a performance of social structure (Rice, 2001:23-24). The results of this study correlate with the arguments put forward by Rice (2001:26-28) and DeNora (2013:3) that music is a means of social bonding. Through musical performance Peter, Matthew and Jonathan find sanctuary within social and community structures. This enhances their wellbeing while also contributing to the wellbeing of the people with whom they share music. I found the term “co-occurrence” which Rice (2001:31) uses to describe the dynamics of musical performance within an ensemble, where behaviours and ideas come together to create something beautiful and meaningful, to be very powerful. In the case of Peter, Matthew and Jonathan I would like to use the word “co-existence” to emphasise that music allows them to co-exist with others in such a way that they do not feel they have special needs or need to be labelled as

having Williams syndrome. Through music they can co-exist as friends and equals.

There is an undeniable link between music and identity on a cultural and personal level; music thus plays an important role in the formation of self-image (Ahmadi, 2011:228; Morinville *et al.*, 2013:384; O'Callaghan *et al.*, 2014:1038). Huron (2001:58) emphasises that music is not only a central part of our social behaviour, but also that it plays an important role in mood regulation. This is an important point for the current study, as it indicates that music helps Peter, Matthew and Jonathan to deal with the struggles they have to face in their everyday lives.

5.3. Lightens the load

Huron (2001:58) and Morinville *et al.* (2013:384, 388) found that people tend to listen to music to lighten their mood. Huron (2001:58) also reports that many people use music to lower the intensity of feelings of nervousness, anxiety and tension. O'Callaghan *et al.* (2014:1038) and Ahmadi (2011:225) report that terminal cancer patients felt better when engaging with music in that it enhanced their mood, and encouraged reminiscence and social connection. The study conducted by O'Callaghan *et al.* (2014:1042) further revealed that music helped cancer patients sleep better, uplifted their mood, brought relaxation, helped them relax, and made them feel safe and at peace, happy and serene. For these terminally ill patients, music ensured maintaining healthy identities and made them feel understood – almost as if taking on a human role during their illness. DeNora (2013:112) also argues that music can play a vital role in managing people's chronic illness when they incorporate it in to their everyday activities.

Rice (2001:23) states that for some cultures music is a form of medicine and therapy, helping to heal the sick. Schnabl Schweitzer (2011:312) also mentions that her study on pastoral care and music revealed that participants tend to get

in touch with their feelings and cope with suffering through music, allowing them to get a new perspective on their lives and current circumstances. Peter, Matthew and Jonathan also reported that music helped them to feel better when they were having a bad day. Music helps lift their mood, keeps them calm and aids them in coping with the challenges they face in their everyday lives. This in turn makes a positive contribution to their emotional wellbeing. For these three individuals living with Williams syndrome music is a way in which they can make sense of their struggles and this in turn helps to bring relief to their suffering.

Ahmadi (2011:230) found that music helps individuals diagnosed with cancer to accept their diagnoses while fostering a new, healthy self-image and self-identity. For Peter, Matthew and Jonathan, although music helps them to cope with the struggles brought on by having Williams syndrome, it is also a way to escape their diagnoses by being able to be “normal” for the time that they take part in musical activities. Tsiris (2010:46) also speaks about music therapy being able to bring a feeling of normalcy to the lives of people who have had traumatic experiences. I believe that music also has this effect on Peter, Matthew and Jonathan, as it allows them this “feeling of normalcy” despite the fact that they have Williams syndrome. Music thus, in the words of DeNora (2013:47, 72), provides Peter, Matthew and Jonathan with an “asylum” from their everyday hardships. This correlates with the study conducted by Ahmadi (2011:238) in which he found that cancer patients use music to connect to the person they were before getting sick, and so denying or escaping their diagnoses for time being. DeNora (2013:45, 47) also argues that music allows one the opportunity of normalcy and belonging within certain settings, in a way breaking down barriers that would normally exist.

The superordinate theme “lightens the load” is supported by Morinville *et al.* (2013:385), who found that music is related to life satisfaction among adolescents, giving meaning to their lives by enhancing their emotional states and wellbeing. As in the case of Peter, Matthew and Jonathan, Morinville *et al.*

(2013:385) and DeNora (2013:66) also report that their participants tended to engage with music in order to feel happy (Rice, 2001:31), get rid of stress, seek solace and cope with problems. Music thus fulfils a motivational role in Peter, Matthew and Jonathan's lives. According to Morinville *et al.* (2013:388) and Rice (2001:31), this indicates that listening to music can prolong happiness over a longer period than the actual time spent listening to music, establishing that music has a high level of affective power. McFerran and Saarikallio (2014:89) conducted a study on "Depending on music to feel better" and state that music plays an important role in the lives of adolescents with mental impairments in terms of self-expression. When these young people are given the opportunity to express themselves through music, they experience improved moods. This is also true for Peter, Matthew and Jonathan, as music helps them to feel better during tough times by allowing them to express their feelings in order to experience emotional liberation.

Reis *et al.* (2000:13) and report that music helped Williams syndrome individuals perform better in areas where they show academic deficit. This correlates with Jonathan's experience in that music also helps him to learn more effectively. This allows him to experience feelings of accomplishment in an area where it would otherwise be almost impossible. Through my study, and in correlation with the research done by O'Callaghan *et al.* (2014:1038) and Ahmadi (2011:230), it became clear that music does more for Peter, Matthew and Jonathan than merely helping them to lighten their loads; it has a direct impact on their quality of life, strengthening the idea that they are dependent on music.

5.4. Dependent on music

According to Huron (2001:49), we have yet to discover a human culture that did not or does not engage in some form of musical activities. Music is even deemed to be heritable and some people believe that musical talent is inherited and innate rather than purely learnt (Huron, 2001:48). This is an important

notion for this study, because Jonathan specifically refers to music as being part of human nature. Matthew and Peter also cannot imagine having to live without music and are of the opinion that all people, without exception, must love music.

DeNora (2013:4) and Ahmadi (2011:226) found that music improves the quality of life for cancer patients. This is also true for Peter, Matthew and Jonathan as they depend on music for their overall well-being and happiness. Ruud (1998:47-48) argue that music is important for finding our place in the world and finding significance in life. Peter, Matthew and Jonathan feel that without music their lives would not have meaning and they would not know who they are or how to make sense of the world. Rice (2001:24) also found that music is a means through which we are able to understand the world on a deeper, personal level.

Cook and Silverman (2013:240) argue that music helped children who were diagnosed with cancer cope with their illness, lowered their stress and anxiety levels, and improved their quality of life. This also applies to Peter, Matthew and Jonathan, as they all said at some stage during the interview that music helps them to feel calm and/or relaxed. Music thus also helps them to cope with the stresses brought on by their diagnoses. Music does not only lighten the load for Peter, Matthew and Jonathan at times, but they depend on music to help them cope with the challenges brought on by having Williams syndrome on a daily basis.

Just as Peter, Matthew and Jonathan stated that they would not be able to cope without having music in their lives, the cancer patients in the study conducted by O'Callaghan *et al.* (2014:1044) stated that they would not be able to cope without music. One patient even said that music is the only thing that truly works transforming "dark and black cancer experiences into relaxed and enlightened states". Six of the participants in O'Callaghan *et al.*'s (2014:1044) study said that music is "essential for survival". This also applies for Peter,

Matthew and Jonathan seeing that music is the one thing that makes their lives bearable during tough times. My findings thus agree with DeNora's (2013:33) concept that music provides people with a safe place in which to flourish – an asylum.

5.5. Limitations

The limitations that I have identified in the research project are related to the data-collection process. While conducting the interviews with the three participants, I realised that possibly because of their well-developed language skills, they regarded the interview as a very formal occasion. It took me some time to ensure that the interview environment was relaxed and to assure the participants that I just wanted to have a relaxed conversation with them through which they could tell me their stories. In future, I will thus not tell the participants that I will be conducting an "interview" with them, but rather just refer to having a casual conversation from the start. Furthermore, while this study revealed that Peter, Matthew and Jonathan have a passion for performing, that music helps them to foster friendships, that music lightens their load and that they depend on music, this cannot be generalised to all individuals living with Williams syndrome. This study does, however, give a thick description which allows readers to decide whether the results are transferrable to their personal experiences and situations.

5.6. Implications for different audiences

This research on the lived musical experiences of three individuals living with Williams syndrome has implications for researchers in special needs music education, parents of individuals suffering from Williams syndrome, music therapists and music educators. This study gives insight into the importance of musical experiences in the lives of three individuals living with Williams syndrome and shows that music has a very important role to fulfil in the lives of these individuals. It is important for parents, teachers and therapists to be

aware of the calming effect that music has on people with Williams syndrome and that music is a means through which these individuals can make sense of the world and their own emotions.

Because of the medical issues associated with Williams syndrome, it is valuable to know how music can contribute to helping individuals diagnosed with Williams syndrome deal with these issues, while helping them to maintain positive self-esteem and overall wellbeing. This study also emphasises the need and love that people with Williams syndrome have for making friends and socialising, and shows that music can also contribute to the lives of individuals living with Williams syndrome in this regard. I also believe that this study is of value for the broader community, as it raises awareness of Williams syndrome by informing people about the syndrome by giving a voice to individuals so diagnosed.

5.7. Future research

When considering future research, I think it is important to focus on the effect that musical experience can have on the lives of those living with Williams syndrome in helping them deal with their medical issues and mood regulation. It would also be of value to conduct research on how music can be used in an educational setting to aid the learning process of Williams syndrome individuals, especially as music could possibly be a way in which the visual-spatial and cognitive impairments associated with the syndrome can be compensated for.

5.8. Research questions answered

As part of the conclusion of my study I would like to draw attention to the main research question and two sub-questions that guided my research project. I shall first discuss the two sub-questions before pointing out how the main research question has been answered in this study.

The first sub-question guiding my study is:

What did individuals living with Williams syndrome experience when engaging in music?

While engaging with music Peter, Matthew and Jonathan experience feelings of happiness, calmness, relaxation and acceptance. Musical experiences help all three participants to deal with the struggles in their lives, while also helping them to feel better and lift their mood. Musical experience further allows Peter, Matthew and Jonathan to feel accepted by the community for who they are and what they have to give. Through musical performance Peter, Matthew and Jonathan create friendships that contribute to their overall wellbeing. Musical performance also gives Peter, Matthew and Jonathan the opportunity to feel proud of their accomplishments, while showing the world that they also have skills at which they can excel.

The second sub-question guiding my study is:

How did individuals living with Williams syndrome experience music?

In order for me to answer this question, I have to emphasise that all three participants, when speaking about their musical experiences, focused on listening to and making music. These are obviously the most prominent ways of experiencing music in all three participants' lives. Only Matthew and Jonathan mentioned moving to music, with only Matthew emphasising that he loves to attend dances with family and friends. During the data-analysis process I realised that Peter, Matthew and Jonathan experience music with high intensity levels and often with extreme emotions.

The main research question guiding my study is:

How do individuals suffering from Williams syndrome understand their lived musical experiences?

This question can be answered by referring to the superordinate themes of a passion for performing, fostering friendships, lightening the load and dependence on music. For Peter, Matthew and Jonathan, their musical experiences allow them to connect to and understand the world. Because of their cognitive impairments, they cannot fully understand the world effectively in any other way. Music seems to be the main aspect of their lives that can truly make their struggles more bearable, while also giving them the opportunity to be accepted by the community as worthy musicians, thus disregarding their diagnosis of having Williams syndrome for that moment. All three participants agree that music makes them happy and that it gives meaning to their lives. For me, the most important aspect of how these three individuals living with Williams syndrome understand their musical experiences is that it allows them to feel normal. It allows them to be seen by others for who they are, not only as people suffering from Williams syndrome, but as individuals who have such an intense passion for music and much love to give to and share with the world.

Conclusion

Through this research I found that Peter, Matthew and Jonathan experience music on a very intense level. They need music in their everyday lives to function and maintain their wellbeing. Without music they would not know who they are and lose their feelings of happiness. Music provides Peter, Matthew and Jonathan with the opportunity to cope with having Williams syndrome and also to cope when having bad days physically or emotionally. What makes the musical experience of these Williams syndrome individuals unique is that it allows them to foster the friendships they long for.

Music is a way in which Peter, Matthew and Jonathan can escape the Williams syndrome label they will carry throughout their lives and they can just be normal people with normal friendships – even if just for a little while. Because of the cognitive impairments associated with Williams syndrome, Peter, Matthew and Jonathan struggle to make sense of the world in the way normal developing children do. Music is one of the few things in this world that Peter, Matthew and Jonathan truly understand and this helps them also to make sense of their world, their circumstances and their place in life. For these three individuals living with Williams syndrome, music is the love of their lives and a means of survival.

I would like to end with a quotation from O’Callaghan *et al.* (2014:1045):

“When no one understands, music can have an identity, express what’s needed and be dialogued with. It could also be a tool for accessing and enlightening “dark” intrapsychic worlds and “moulding” emotion. It can allow those experiencing devastating loss a “safe place” where emotions can dominate. Music can bring harmony from dissonance; order from chaos; resolution from tension; contain and release.”

I believe that music is the best friend that Peter, Matthew and Jonathan long for and, in a way, although they do not know each other, they are connected through music.

Annexure A: Peter



Mrs. E. Erasmus
083 604 8940
ewievdem@gmail.com

Privaatsak X6001
Potchefstroom
Suid-Afrika, 2520

Tel: (018) 299-1111/2222
Web: <http://www.nwu.ac.za>

Skool vir Musiek
018 299 1680
018 299 1707 (Faks)

Title of study: The lived musical experiences of Williams syndrome children: an interpretative phenomenological analysis.

Dear participant,

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to decide not to participate or to withdraw at any time without affecting your relationship with the researcher, the instructor or the North-West University.

The purpose of this study is to understand the musical experiences of Williams syndrome children. The qualitative research approach will be an interpretative phenomenological analysis. Data will be collected by conducting in-depth, semi-structured interviews with four Williams syndrome children. The interviews will be recorded and transcribed for analysis. Individuals involved in the study will be children with Williams syndrome who have had meaningful musical experiences.

Do not hesitate to ask any questions about the study either before participating or during the time that you are participating. I would be happy to share your findings with you after the research is completed. However, your name will not be associated with the research findings in any way, and only the researcher and study leader will know your identity as participant.

There are no known risks and/or discomforts associated with this study. The expected benefits associated with your participation include heightening the awareness of and giving insight to parents, teachers, therapists and researchers about the musical experiences of Williams syndrome children.

Please sign your consent with full knowledge of the nature and purpose of the procedures. A copy of this consent form will be given to you to keep.

Signature (parent/guardian)

Date: 10/04/2014

Signature (participant)

Date: 10/04/2014

Signature (researcher)

A handwritten signature in black ink, appearing to read 'Erasmus', is written over a faint, illegible printed name.

Date: 12/04/2014

Annexure B: Matthew



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Mrs. E. Erasmus
083 604 8940
ewievdem@gmail.com

Dr. L. van der Merwe
018 299 1689
083 467 9469
Liesl.VanDerMerwe@nwu.ac.za

Privaatsak X6001
Potchefstroom
Suid-Afrika, 2520

Tel: (018) 299-1111/2222
Web: <http://www.nwu.ac.za>

Skool vir Musiek
018 299 1680
018 299 1707 (Faks)

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There are no known risks and/or discomforts associated with this study. The expected benefits associated with your participation include heightening the awareness of and giving insight to parents, teachers, therapists and researchers about the musical experiences of Williams syndrome children.

Please sign your consent with full knowledge of the nature and purpose of the procedures. A copy of this consent form will be given to you to keep.

Signature (parent/guardian)

Date 18.2.2014

Signature (participant)

Date 18.2.2014

Signature (researcher)

Date 19.2.2014

Annexure C: Jonathan



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Mrs. E. Erasmus
083 604 8940
ewievdm@gmail.com

Dr. L. van der Merwe
018 299 1689
083 467 9469
Liesl.VanDerMerwe@nwu.ac.za

Privaatsak X6001
Potchefstroom
Suid-Afrika, 2520

Tel: (018) 299-1111/2222
Web: <http://www.nwu.ac.za>

Skool vir Musiek
018 299 1680
018 299 1707 (Faks)

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The purpose of this study is to understand the musical experiences of Williams syndrome children. The qualitative research approach will be an interpretative phenomenological analysis. Data will be collected by conducting in-depth, semi-structured interviews with four Williams syndrome children. The interviews will be recorded and transcribed for analysis. Individuals involved in the study will be children with Williams syndrome who have had meaningful musical experiences.

Do not hesitate to ask any questions about the study either before participating or during the time that you are participating. I would be happy to share your findings with you after the research is completed. However, your name will not be associated with the research findings in any way, and only the researcher and study leader will know your identity as participant.

There are no known risks and/or discomforts associated with this study. The expected benefits associated with your participation include heightening the awareness of and giving insight to parents, teachers, therapists and researchers about the musical experiences of Williams syndrome children.

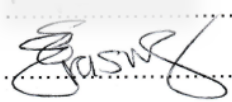
Please sign your consent with full knowledge of the nature and purpose of the procedures. A copy of this consent form will be given to you to keep.

Signature (parent/guardian)

Date 8/02/2014

Signature (participant)

Date

Signature (researcher) 

Date 8/2/2014

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