

**The role of music therapy for an individual client having
undergone bilateral prophylactic mastectomy and breast
reconstruction surgery: a single case study**

by

**Susanna Sophia Hitge
(Student No: 15314571)**

**A dissertation submitted in partial fulfilment of the
requirements for the degree**

MMuz (Music Therapy)

in the Department of Music at the

UNIVERSITY OF PRETORIA

FACULTY OF HUMANITIES

SUPERVISOR: Dr CB Lotter

August 2017

Table of Contents

Abstract	vi
1 Chapter One: Introduction	1
1.1 Introduction	1
1.2 Background and Context	1
1.3 Aim and Research Questions.....	3
1.3.1 Aim	3
1.3.2 Research questions	3
1.4 Conclusion.....	3
2 Chapter Two: Literature review	5
2.1 Introduction	5
2.2 Definition of Body Image	5
2.3 Challenges faced by Women Who Have Undergone a Bilateral Prophylactic Mastectomy and Breast Reconstruction	5
2.4 Definitions of Intrapersonal and Interpersonal Connectedness	10
2.5 The Social Isolation of BRCA Positive Women	11
2.6 The Role of Music Therapy for Mastectomy Patients	12
2.7 The Role of music therapy for a sense of connectedness	14
2.8 Conclusion.....	16
3 Chapter Three: Methodology	17
3.1 Introduction	17
3.2 Research Paradigm.....	17
3.3 Mixed methods	17
3.4 Sample	19
3.5 Data Collection	20
3.5.1 Music therapy intervention	20
3.6 Qualitative data	21
3.6.1 Qualitative data source A:	21
3.6.2 Qualitative data source B:	22
3.7 Quantitative data	22
3.7.1 Quantitative data source A:	22
3.8 Data Selection	23
3.8.1 Qualitative Data	23

3.8.2	Quantitative Data	24
3.9	Data Preparation.....	24
3.9.1	Qualitative data.....	24
3.9.2	Quantitative data.....	25
3.10	Data Analysis.....	25
3.10.1	Qualitative data.....	25
3.10.2	Quantitative data.....	26
3.11	Research Quality and Study Limitations	26
3.12	Ethical Considerations.....	28
3.13	Conclusion.....	29
4	Chapter Four: Data Collection and Analysis Methods.....	30
4.1	Introduction	30
4.2	Self-Disclosure	30
4.3	The Participant	31
4.4	Data sources.....	31
4.5	Data Preparation.....	32
4.5.1	Qualitative Data Source A.....	32
4.5.2	Qualitative Data Source B.....	36
4.6	Thematic Analysis Qualitative Data	37
4.7	Coding.....	37
4.8	Development of Higher Order Codes	40
4.9	Identifying Sub-themes.....	46
4.10	Development of Themes	49
4.11	Analysis of the Quantitative Data.....	53
4.12	Conclusion.....	54
5	Chapter Five: Discussion	55
5.1	Introduction	55
5.2	Research Questions.....	55
5.3	Synopsis of the main themes, sub themes and quantitative data ..	55
5.4	Theme 1: Personal Experience of Therapy.....	57
5.4.1	Introduction.....	57
5.4.2	The need for therapy	57
5.4.3	Music therapy techniques	58
5.4.4	Journey of therapy	63
5.4.5	Conclusion.....	65

5.5	Theme 2: Body image	65
5.5.1	Introduction.....	65
5.5.2	Perceptions Related to her Body	65
5.5.3	Breasts	70
5.5.4	The BRCA2 gene.....	72
5.5.5	Health	74
5.5.6	Eating Disorder	75
5.5.7	Conclusion.....	76
5.6	Theme 3: Sense of interpersonal connectedness.....	76
5.6.1	Introduction.....	76
5.6.2	Connectedness with Her Family of Origin	77
5.6.3	Sense of connectedness with her mother	80
5.6.4	Sense of connectedness with her husband and children.....	81
5.6.5	Mourning the loss of her deceased aunt	83
5.6.6	Sense of disconnection from community.....	87
5.6.7	Conclusion.....	89
5.7	Theme 4: Existential Authenticity	90
5.7.1	Intrapersonal connectedness	91
5.7.2	Emotional pain.....	93
5.7.3	Trauma	95
5.7.4	Existential impact.....	99
5.8	Integration of Qualitative and Quantitative results	107
5.9	Conclusion.....	108
6	Chapter Six: Conclusion	109
6.1	Introduction	109
6.2	Concluding Remarks	109
6.3	Study Limitations	110
6.4	Recommendations	110
6.5	Summary.....	111
7	References.....	112
8	Appendices.....	125
8.1	Appendix A: Breast-Q© Questionnaire.....	125
8.2	Appendix B: Music Therapy Questionnaire.....	139
8.3	Appendix C: Colleague Information.....	142
8.4	Appendix D: Letter from Doctor to Patient	144

8.5	Appendix E: Letter of Informed Consent.....	146
8.6	Appendix F: Qualitative Data Set A.....	148
8.7	Appendix G: Qualitative Data Set B	149
8.9	Appendix H: English Transcript with First Order Codes	152
8.10	Appendix I: Higher Order with First Order Codes	153
8.11	Appendix J: Quantitative Data Set A1.....	154
8.12	Appendix K: Quantitative Data Set A2	164
8.13	Appendix L: Breast-Q® Post Operation Template	174
8.14	Appendix M: Q-Score® Summary Scores.....	175
8.15	Appendix N: Session Plans	176
8.16	Appendix O: Playlists.....	179

List of Figures

Figure 5-1: Drawing before surgery after BRCA2 diagnosis.....	59
Figure 5-2: Drawing post-surgery.	60
Figure 5-3: Poem about relationship with body	67
Figure 5-4: Translation of the poem:.....	67
Figure 5-5: Drawing symbolising connectedness and disconnectedness.....	78
Figure 5-6: Poem inspired by music	86
Figure 5-7: Translation of Poem about godmother.....	87
Figure 5-8: Clay work from session 6	98
Figure 5-9: Drawing of the first circle	104
Figure 5-10: Drawing of the second circle.....	104
Figure 5-11: Drawing of the third circle	105

List of Tables

Table 4-1: Excerpt of original transcript	33
Table 4-2: Translation of the Excerpt.....	34
Table 4-3: Numbered excerpts with English Translation	35
Table 4-4: Qualitative Data Source B	36
Table 4-5: Qualitative Data Source A: Codes of Qualitative Data set A examples	38
Table 4-6: Data set B with first order codes	39

Table 4-7: Higher order codes and examples of first order codes	41
Table 4-8: Summary of sub-themes and higher order codes	46
Table 4-9: Themes and sub-themes	49
Table 4-10: Hierarchy of themes and subthemes and higher-order codes	50
Table 4-11: Q-score summary	53
Table 5-1: Summary of themes and sub-themes	56
Table 5-2: Summary of quantitative data	56
Table 5-3: Session 3 playlist.....	66

Abstract

A mixed method case study was conducted to ascertain whether music therapy could play a role in addressing the body image, interpersonal and intrapersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction. Quantitative data were used to enrich and inform qualitative data. The participant was diagnosed with the mutated BRCA2 gene, which increases her risk to develop breast cancer by up to 80%. It also increases her risk to develop ovarian cancer by up to 30%.

The participant attended six music therapy sessions over three weeks. Data were collected in three ways: video recordings of the sessions; completion of a qualitative music therapy questionnaire after the six sessions (the intervention), as well as the completion of Breast-Q© at the first session and a week after the final session. This produced four data sets. Qualitative data source A was composed of a thick description of excerpts of the video footage. The answers of the qualitative music therapy questionnaire comprised qualitative data source B. Both these qualitative data sources were thematically analysed by doing open coding, resulting in the development of first order codes, higher order codes, sub-themes and main themes. The two quantitative data sets, A1 and A2 were the pre-intervention and post-intervention quantitative Breast-Q© questionnaires. The questionnaires were converted to data by the Q-Score program and the data was interpreted according to the Breast-Q© user manual to produce the findings.

The qualitative thematic analysis yielded rich results, describing the struggles of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction. The quantitative data did not show statistically significant differences in the pre-, and post-intervention scores. The study period was too short to address emotional discomfort and concerns brought to the fore by the music therapy adequately. The sample size was also small, as only one woman was recruited from a few suitable candidates, due to the low incidence of the diagnosis of BRCA1/2 mutated genes and the small number of women opting for risk reduction surgery.

Further research could include BRCA1/2 positive women who had breast cancer, and who have undergone a prophylactic mastectomy of the healthy breast. This could significantly increase the number of candidates for a larger study.

1 Chapter One: Introduction

1.1 Introduction

The role of music therapy as a supportive measure for cancer patients, with varying forms of cancer, is a field that has been researched (Ahmadi, 2013; Ahmadi 2011). Studies utilising different aspects of music therapy have also been conducted, more specifically, with patients with breast cancer (Bonde, 2015; Burns, 2009; Conradi, 2012). However, there are no published music therapy studies concerning the role of music therapy with women who have undergone preventative surgery for hereditary breast cancer. This study attempts to explore this topic. The background and context situating the study and the aims of the study are discussed in this chapter. Each chapter will also be briefly described.

1.2 Background and Context

According to the World Health Organisation [WHO] (2014) breast cancer is the most prevalent cancer diagnosis among women in the developed world, as well as in certain developing countries, including South Africa. There has been a 20% increase in new breast cancer cases in South Africa over the past decade and it has now surpassed cervical cancer as the most common malignancy found in the female population of South Africa (WHO, 2014).

A number of genetic syndromes are associated with an increased lifetime risk of developing breast cancer, but the most common are the BRCA1 and BRCA2 (BRCA for “breast cancer”) gene mutations (Lalloo & Evans, 2012). They can increase a woman’s lifetime risk of developing breast cancer, as well as ovarian cancer, by up to 85% (Shiovitz & Korde, 2015). Globally, between 5% and 10% of women with breast cancer have BRCA1 or BRCA2 gene mutations (Olopade, Grushko, Nanda, & Huo, 2008). It is estimated that this figure is 2.6% for South African women (Schoeman, Apffelstaedt, Baatjes, & Urban, 2013), with most of these patients being of Afrikaans speaking European descent (Van der Merwe, Bouwens, Pienaar, Van der Merwe, Yako, Geiger, & Kotze, 2012)

Patients with a proven genetic susceptibility to the development of breast cancer are given the options of intensified screening, chemoprophylaxis with agents such as Tamoxifen, or risk reduction surgery, usually involving a bilateral subcutaneous mastectomy (removal of both breasts, but sparing the skin) with the option of immediate reconstruction and bilateral salpingo-oophorectomy (the removal of both ovaries)

(Armstrong & Evans, 2014). The majority of patients select the latter as it is the most effective prevention strategy and reduces the risk of developing breast cancer by 90% (Den Heijer et al., 2012; Patenaude et al., 2008).

One effect of risk reduction surgery (prophylactic mastectomy) is a decrease in cancer related anxiety levels (Brandberg et al., 2008; Den Heijer et al., 2012). Unfortunately, patients often feel dissatisfied with the resulting change in appearance and develop a distorted body image, particular in relation to the appearance of their breasts. They also may have a decreased sense of sexual attractiveness (Den Heijer et al., 2012; McGaughey, 2006). Several studies (Den Heijer et al., 2011; Gopie et al., 2013; Lloyd, Watson, Oaker, Sacks, Querci Della Rovere, & Gui, 2000; Patenaude et al., 2008) have advised the use of supportive modalities to reduce the negative impact of the surgery on the psyche of a woman. Den Heijer (2012) found that women often feel lonely and isolated after they have the risk reduction bilateral prophylactic mastectomy and reconstruction. Women who seek social support have a better breast related body image.

In a different study, Lodder et al. (2002) and Hatcher and Fallowfield (2003) found that although women feel a sense of relief after the surgery is done, they have body image difficulties and also experience a sense of grief and loss of femininity. Many women in this study would have appreciated peer support before and after the operation.

No published studies were found regarding the role of music therapy interventions in improving body image and intrapersonal and interpersonal connectedness of women who had undergone prophylactic mastectomy. This research is a mixed method pilot study that may begin to address the existing gap by examining the role music therapy can play in improving the body image, and addressing intrapersonal and interpersonal connectedness of women who have undergone a bilateral prophylactic mastectomy and breast reconstruction. Body image and intrapersonal and interpersonal connectedness will be operationally defined based on relevant literature as discussed in the literature review.

This study entailed a music therapy process of six sessions over three weeks with one woman. A standardised peer reviewed patient reported outcome quantitative questionnaire, Breast-Q© (see Appendix A: Breast-Q© Questionnaire, p. 32) was used to collect quantitative data related to body image before and after the intervention. Qualitative data related to both body image and intrapersonal and interpersonal connectedness was collected through video excerpts of the music therapy sessions and an open ended qualitative questionnaire (see Appendix B: Music Therapy Questionnaire, p. 46).

1.3 Aim and Research Questions

1.3.1 Aim

This study aims to explore the role of music therapy in improving body image and addressing intrapersonal and interpersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction.

1.3.2 Research questions

This study aims to address the following questions with regard to a woman who underwent a bilateral prophylactic mastectomy and breast reconstruction within a year before enrolling in the study:

1. What role can music therapy play in improving body image of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

2. What role can music therapy play in addressing intrapersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

3. What role can music therapy play in addressing interpersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

1.4 Conclusion

A brief summary of the chapters following is given. The second chapter presents and reviews literature about the effects of bilateral prophylactic mastectomies on body image, the sense of interpersonal connectedness and interpersonal connectedness for women who have undergone risk reduction surgery. Definitions for body image and a sense of connectedness applicable to this study will be described. The role of music therapy in cancer management and fostering a sense of connectedness will be discussed last.

Chapter three is concerned with the methodology and design of the research. Sample selection, data collection methods, the data preparation process and the thematic analysis of the data will be presented.

Chapter four provides detailed descriptions of the process of the qualitative data analysis utilizing thematic analysis and the quantitative data processing. The results of both data sets will be presented.

Chapter five discusses the relevant findings, and integration of the quantitative and qualitative data will be outlined. The presented themes will be substantiated with appropriate quotes from the data sets. This chapter will be guided by literature linked to the findings of this study.

The final chapter provides a summary of the research process and the findings of the study. The limitations of this study and recommendations for possible further research will be considered.

2 Chapter Two: Literature review

2.1 Introduction

The literature review includes a discussion of the challenges faced by women who undergo a bilateral prophylactic mastectomy. Definitions will be given for body image and intrapersonal and interpersonal connectedness. The role of music therapy as a supportive intervention for breast cancer patients is then described.

2.2 Definition of Body Image

For the purposes of the study Grogan's (2007) definition of body image will be used, where body image is defined as "a person's perceptions, thoughts and feelings about his or her body" (p. 3). This definition can be interpreted to include experiences of embodiment (where bodily experiences alter cognition) and psychological constructs such as attitudes to and perception of the body. Body image is subjective and has no direct link to other people's attitude towards a person's body, though it is influenced by social factors such as culture and the media (Grogan, 2008).

2.3 Challenges faced by Women Who Have Undergone a Bilateral Prophylactic Mastectomy and Breast Reconstruction

In 2000, Lloyd et al. published the results of a study performed on ten BRCA 1/BRCA2 carriers who were interviewed after undergoing risk reduction mastectomy. Most of the women reported a sense of relief and a reduction in cancer related anxiety after the operation. The researchers found that, although most of the women did not regret the decision to have their breasts removed, they did have body image related difficulties after the surgery, linked to the unnatural appearance of their breasts. Even those women who were satisfied with the cosmetic results of their breast reconstructions were affected negatively in terms of body image. Relevant issues mentioned included a lack of sensation in their breasts and prolonged recovery time after surgery. Another important finding of the study was that the participants lacked information and support surrounding the operation and what to expect afterwards. The women felt isolated and found it difficult to find other women who had had the procedure to talk to (Lloyd et al., 2000).

Lodder et al. (2002) and Hatcher and Fallowfield (2003) reported findings in line with that of Lloyd et al. (2000), where women needed more information and peer support and had lasting body image difficulties. The researchers also found that participants had unaddressed emotional difficulties including feelings of grief, a perceived loss of femininity, and difficulties in intimate relationships. They advised that greater psychosocial support and more information regarding the physical and emotional difficulties that may be experienced after a risk reduction mastectomy should be given prior to surgery.

Rolnick et al. (2007) also found that some women suffered from negative emotions such as feeling less feminine, loss of their sexual attractiveness and that they did not feel “whole” anymore. The study also found that there was a need for more information about the surgical procedure and the emotional impact thereof. An interesting aspect was that women articulated the need that their family and friends should have counselling to better understand the emotional and social impact of the procedure to be able to offer emotional support after the operation. Some of the participants also voiced a need for support groups for women undergoing the operation.

The FORCE (Facing Our Risk of Cancer Empowered) website is dedicated to offer online information and support to women who have a high risk genetic burden to develop hereditary breast and ovarian cancer. Kenen, Shapiro, Hantsoo, Friedman and Coyne (2007) analysed the conversations between 21 members that appeared over a period of four years on the archived electronic message board. They accomplished this by using an inductive qualitative research process. The material was read, coded and themes were developed. It was found that the needs of the women posting on the message board included emotional support, information and reports of the other members' experiences of being BRCA1/2 positive and undergoing bilateral or unilateral prophylactic mastectomies and reconstructions. Of the 21 women seventeen had not had cancer previously, also referred to as “previvors”. The other four women had cancer before they had the prophylactic mastectomies. The topics mostly discussed by these women were the decision-making process to have the prophylactic mastectomy or not; the psychosocial, emotional and physical consequences of the surgery and the reconstruction and recuperation process. They revealed that they found disclosing the prophylactic mastectomy difficult due to possible negative reactions to the information. They tended to adopt strategies of self-protection by evading and concealing the fact that they had undergone the risk reduction surgery. The researchers found that women reported a sense of loss and the need to develop and renegotiate their relationships with others and their sense of self.

The results of the study revealed six themes. Women found that they suffered an effect on their self-image and their interpersonal relationships. The positive gene test result is often the catalyst for these changes and can continue years after the prophylactic mastectomy was completed. They also reported feelings of loss of their natural breasts and feeling differently from others. This often impacted their intimate relationships, as they experienced lack of nipple sensations that hindered their sexuality. Their perception of self also suffered as they perceived the changes in their bodies as stigmatised by others and they endeavoured to hide their bodies and not to disclose the history of the prophylactic mastectomies with reconstructions. The other great impact of their decision to have the surgery done was on friendship and workplace relationships. Family members were often afraid of being stigmatized and refused to discuss the inherited BRCA1/2 genes in their family and the significance it has in relation to their health and longevity. Women also found they struggled to trust their friends with the knowledge of their prophylactic mastectomies, as friends did not always respect the need for secrecy and informed other people. This enhanced their experience of being stigmatized. Lastly, women experienced disruptions in the mother to child relationships, often not knowing how much to disclose to their children about the genes and the operation. This was most significant when dealing with the feelings of pubescent daughters who developed breasts as their mothers lost theirs. The authors came to the conclusion that BRCA1/2 positive women who opted for prophylactic mastectomies paid a dear price in terms of mental discomfort, changes in social and familial relationships, physical pain and their perception of themselves as feminine whole and healthy. They offered their breasts and some sexual satisfaction for the possibility of freedom of the fear of developing breast or ovarian cancer. Their identities had to be redefined. The need for addressing these neglected psychosocial concerns was highlighted. The study method of analysing the conversational strings on the message board was both beneficial and detrimental. Women could voice their feelings and concerns without restraint, but the opportunity to focus questions on certain topics of interest was lost in the process.

Patenaude et al. (2008) also advised that consultation with a psychologist should be included in the peri-operative care of women who undergo risk reduction breast surgery. Furthermore, they state that most women in their study who had peer support found it very helpful because they could discuss issues like body image, nipple sensation, sexual intimacy, chronic pain, and clothing freely with the peer consultant. A peer in this instance refers to a woman who had also undergone risk reduction breast surgery.

Two more recent studies, by Den Heijer et al. (2012), and Gopie et al. (2013) differ from their precursors in that they both included baseline body image measurements taken before the risk reduction surgery and a follow-up of patients after surgery. All the participants of both these studies were BRCA1 or BRCA2 carriers, or had other genetic predispositions to developing breast cancer. The two studies revealed very similar results. Almost all the women involved reported experiencing a dramatic decline in cancer related anxiety and depression symptoms post-surgery and very few of them regretted their decision to undergo risk reduction surgery in light of the fact that it reduces the lifetime risk of developing breast cancer by about 90%. Despite these positive outcomes, many of the participants reported suffering long-term consequences regarding their body image and psychosexual identity, such as feeling uncomfortable when naked and shielding their reconstructed breasts from their intimate partners.

Gopie et al. (2013) followed up their subjects for up to 35 months after surgery. Participants completed a questionnaire before surgery, six months after surgery, and once again when breast reconstruction was completed (median 21 months). The questionnaires were aimed at investigating the body image and sexual satisfaction within a partner-relationship. The body image of most participants had deteriorated significantly when they were retested at six months after the operation (pp. 484-485). At the end of the study period, when the last measurements were taken, body image and sexual relationship satisfaction were both lower than before the surgery was performed. Body image difficulties included a dislike of how their reconstructed breasts looked and felt, and an aversion to their naked bodies. High levels of distress and anxiety pre-operatively were found to heighten the negative impact on body image caused by the surgery. The researchers warned that the impact of risk reduction breast surgery on women who never had cancer should not be underestimated, and recommended that psychological support should be made available before and after surgery.

The limitations of the study by Gopie et al. (2013) include the fact that not all the questionnaires were peer reviewed before the research was done. The researchers strongly advised that further investigations be performed using a validated breast reconstruction related measuring scale such as the Breast-Q®.

Den Heijer et al. (2012, pp. 1263-1268) assessed participants for up to nine years after they underwent risk reduction surgery due to a genetic risk for developing breast cancer – the longest follow-up period to date for this kind of study. Their findings highlighted that surgery had a negative impact on body image even years later. This

included dissatisfaction with the appearance of the scars, the unnatural look of the reconstructed breasts and lack of sensation in their breasts after surgery. Although the body image of most subjects improved slightly between six months and seven to nine years after surgery, they did not always reach the same level of satisfaction with their bodies that they experienced before surgery. Women who had body image difficulties prior to surgery had a much higher risk of developing a negative body image postoperatively. Breast-specific body image prior to surgery, in contrast, did not predict the outcome of breast specific body image afterwards (p. 1266). The researchers hypothesised that unsatisfactory cosmetic results, scars, and a lack of sensation in the breasts influenced this measurement. It was found that women who were dissatisfied with their breasts before the procedure accepted their reconstructed breasts with greater ease. This was ascribed to satisfaction with what they perceived as a better proportion of their breasts in relation to the rest of their bodies after surgery. Participants who suffered complications (from either the mastectomy or the breast reconstruction) experienced more body image and breast image related distress than those who did not have any complications. Women who possessed constructive coping strategies experienced a positive general and breast specific body image years after the surgery. Social support and an accepting and loving partner proved to be of great value. Women with supporting partners, who reassured them about their appearance, experienced a greater sense of femininity and fewer adverse effects on their sexual relationships than those without loving support. Women who were single and opted for risk reduction surgery were apprehensive about forming a new intimate relationship. They feared rejection and negative reactions from their new partner based on the appearance of their reconstructed breasts. Women who actively sought and received counselling for emotional and body image related distress also had a better long-term outcome, as did those who pro-actively gathered information about the procedure and possible complications prior to surgery (p 1267).

Despite the limitation of having a small sample size, Den Heijer et al. (2012) demonstrated that significant correlations exist between pre- and post-surgery body image. The researchers stressed that women should be clearly informed of possible negative outcomes before they have the operation. A consultation with a psychologist or social worker to explore existing body image difficulties was highly recommended and it was advised that vulnerable women should be offered more sessions with a counsellor before and after the surgery was performed.

2.4 Definitions of Intrapersonal and Interpersonal Connectedness

Leidy and Haase (1999) used the term sense of connectedness as a sense of meaningful and shared relationship with aspects of the inner self, a higher being, other people and nature. Townsend and McWhirter (2005) describe connectedness as both an interpersonal intersubjective state of being and an intrapersonal process that promotes psychosocial health and well-being. They further describe the dimensions of connectedness and refer to intrapersonal connectedness as an “internally focused self-component” (Townsend & McWhirter, 2005) and interpersonal connectedness as a “self-in-relation-to-others” construct (Townsend & McWhirter, 2005). For the purposes of this study, intrapersonal connectedness is defined as a sense of a meaningful and internally focused relationship with the inner self that promotes psychosocial health and well-being; interpersonal connectedness is defined as a sense of meaningful and shared relationships with others that promote psychosocial health and well-being. “Others” in this study include family, friends and members of the community that she interacts with socially.

Lee and Robbins (1995) refer to the connectedness to the “community *in toto*” as social connectedness. They stated that it is linked to “one’s opinion of the self in relation to other people.” Low levels of social connectedness are associated with depression, lower self-esteem and a feeling of loneliness and dissatisfaction with relationships (Lee, Draper and Lee, 2001). Aspects of social connectedness will be elaborated on in Chapter five of this document.

The term connectedness has been used in many different contexts. Hagerty, Lynch-Sauer, Patusky and Bouwsema (1993) described that the state of connectedness is present “when a person is actively involved with another person, object, group, or environment and that involvement promotes a sense of comfort, well-being, and anxiety reduction”. It is necessary to define disconnectedness as well, as it is pertinent to the present study and they define disconnectedness “as an experience when a person is not actively involved with another person, object, group or environment, and that the lack of involvement is associated with discomfort, anxiety and a lack of a sense of well-being. Hagerty et al. further view disconnectedness as an affective state.

Connecting and disconnecting are also important concepts related to the above mentioned. Miller and Stiver (1997) have a parsimonious definition of connection and see it as a mutually emphatic and empowering interaction between two or more people.

Disconnection on the other hand is defined by them as an interaction that hinders mutual empathy and empowerment. According to them, relationships are typically a mixture of both states, and a growing relationship needs the two-directional link between two or more persons of “being in connection” and “being emotionally accessible”. Robarts (1998) refers to the use of the word “connecting” in relation to shared meaning, communication and relationship. It has a broader meaning than to meet, to see, to empathise or to relate. Its very meaning implies a shared physical, mental and emotional journey and a dynamic search to “fit” with another person.

2.5 The Social Isolation of BRCA Positive Women

A few qualitative studies researched the impact social and family support has on the psychological distress of women with the positive diagnosis of the mutant BRCA1/2 genes. Some of the studies have been considered earlier in this chapter (Hatcher & Fallowfield, 2003; Lloyd et al. 2000; Lodder et al 2002). Den Heijer, Seynave, Vanheusden, Duinenvoorden, Bartels, Menke-Pluymers, and Tibben (2010) conducted a longitudinal study, following 222 participants up between four and nine years after they were informed of their BRCA1/2 status. They state that individual family members and their mutual interaction and communication experience a profound impact with the diagnosis of hereditary cancer. The family characteristics have an influence on the long-term emotional distress of women with a BRCA1/2 diagnosis. They found that good family communication has a positive effect on the psychological outcome of women. They included both the nuclear family and the family of origin of a woman in this assessment. Women who could communicate freely about their emotions and concerns had less cancer related anxiety and adjusted better to living with an increased breast or ovarian cancer risk. Women whose feelings are not validated are often lonely, afraid and isolated. Free communication within a family about the breast cancer risk and the associated decisions enabled women to seek other social support. The question was asked whether encouragement in the family circle to share emotional difficulties in this regard facilitated the sharing of information in a greater social milieu. The reverse was also noted. Women who had sufficient social support experienced communication with their family members easier than women who did not have social support. The main limitation of this study was the exclusion of women who did not have a partner.

Kenen, Arden-Jones and Eeles (2006) enrolled sixteen women under the age of 40, who had breast cancer and were carriers of the BRCA1 or BRCA2 mutated genes in a qualitative explorative study. “Social separation” was the specific phenomenon they

examined. Their findings included that women felt “isolated, separate, and alone”. All of the sixteen women of the study had one family member who was supportive, but found that this was not enough to counteract their feelings of isolation and loneliness. Some women used verbal discretion and silence in their interactions with family members, because they felt responsible for the emotional distress of others. Children often elicited this response. This was the precursor to social isolation in many cases. Participants also found that some family members terminated contact and communication with them. In these cases, it was most often the brother who ceased contact with their sisters. Women reported that the BRCA1/2 diagnosis was as devastating as their breast cancer diagnosis and it caused social isolation, due to the implied difficult decisions about risk management and the possibility of an early cancer death. Their peers being concerned with other life choices at stage of life contributed to loneliness. Feelings of guilt about transferring the gene to children also caused separation and break down of communication between family members.

2.6 The Role of Music Therapy for Mastectomy Patients

The effects of music therapy in the context of oncology have been well documented, including results for patients with breast cancer and those who had undergone mastectomies (Bonde, 2015; O’Callaghan, 2009). According to a review article by O’Callaghan (2009) music therapy resulted in an improved quality of life and increased feelings of hope and vitality for patients. Ahmadi (2011) found lyrics to be a powerful metaphor for expressing cancer related frustration and anger. Patients with nausea, pain, anxiety and depression have been found to respond positively to music therapy interventions (Ahmadi, 2013).

According to Conradi (2012), attending music therapy groups for a short period after the completion of cancer therapy enhanced the mood, psychological well-being, and quality of life of the breast cancer survivors in her study. Three participants attended six 90-minute music therapy sessions that consisted of active and receptive music therapy techniques. The receptive music therapy interventions included music listening, guided imagery while listening to music and relaxation exercises assisted by music. The active music therapy techniques were singing or playing an instrument, improvisation and improvisatory song writing. The study employed a mixed method design. Quantitative data was collected by means of three questionnaires: The Profile of Mood States-Short Form, the Quality of Life Cancer Survivor Scale, and the Coping Resources Inventory. These questionnaires were completed before the music therapy intervention, immediately after

the conclusion of intervention and two weeks later. Qualitative data consisted of transcripts of the video excerpts and a qualitative Music Therapy Questionnaire. Even though the sample was very small and the focus was on the qualitative data, the positive trend in the results from the quantitative data, though not statistically significant, supported the themes that emerged from the qualitative data. The participants found the group music therapy effective in enhancing their quality of life, it afforded them new ways of self-expression and it was a source of support for them after their cancer treatment was completed.

In a recent mixed method study, Bonde (2015) investigated the effect of the Bonny Method of Guided Imagery and Music (BMGIM) on breast cancer survivors. BMGIM is a music and image-based psychotherapeutic method where clients are verbally guided by a therapist while listening to carefully chosen music in a relaxed state. The researcher evaluated the mood and quality of life of six participants during ten therapeutic sessions. The qualitative leg of the study focused on grounded theory analysis of interviews and of images evoked during the therapy sessions. For the quantitative phase of the study a pre-and post-follow-up design was used, with the completion of structured questionnaires after each session in the study. The quantitative data was embedded into the qualitative analysis in order to expand on the latter. This study design afforded participants the opportunity to relate their personal experiences as part of the study. The interviews and questionnaires served as complementary information sources. Valuable evidence-based data was gained in the field of music therapy. Bonde concluded that BMGIM had a positive effect on the mood and quality of life of the breast cancer survivors who participated in the study.

Burns (2009) investigated the effects and the experience of group improvisation music therapy (GIMT) amongst 15 breast cancer patients in a mixed methods study. The researcher focused on whether the women experienced better psychosocial outcomes, lower levels of stress and improved mood states. The quantitative data collection was accomplished by the use of several standardised psychosocial, psychological and quality of life questionnaires. Physiological parameters such as the cortisol and antibody levels in the saliva of the subjects were also evaluated. Focus groups, semi-structured interviews and reflective experience work were used to gather the qualitative data. Weekly 90 minute GIMT sessions were held for eight consecutive weeks with two different groups. The quantitative data were collected at set points for the duration of the study and the qualitative data were collected two weeks after the completion of the music therapy sessions for the two groups. The qualitative data were subjected to thematic qualitative analysis and three main themes emerged: the difference in experience between

conventional medical care and music therapy, music therapy as a safe place of refuge, and music therapy as an empowering gift, because it afforded the women choices and an opportunity to build confidence. Although no statistically significant improvement was found between the pre- and post-test results as measured through standardised psychological questionnaires, there were positive trends in several of the sub-scales. Significant improvement between the pre- and post-cortisol measurements was found indicating a decrease in the stress levels of the participants.

Allen (2010) researched the effects of group music psychotherapy versus cognitive behavioural therapy on the self-concept of eleven randomly assigned breast cancer survivors. A Guided Imagery and Music model was used during the music psychotherapy sessions. The outcome of the music therapy group was statistically significantly better than the cognitive behavioural group.

In a mixed method study for a Doctoral Thesis, Bhana (2016) researched the role that BMGIM could play in palliative care. The qualitative leg of the study found that BMGIM was successful as a supportive measure for patients receiving chemo- and radiotherapy for cancer. Participants reported a number of improvements in the spiritual, physical and psychological dimensions of their wellbeing. Specific mention was made that the patients in palliative care found the music therapists kind, insightful and able to guide them towards finding meaning and their real-life experience. The limitations of the study were that the attrition rate was significant as only eight of the original 24 candidates completed the final survey of the study.

2.7 The Role of music therapy for a sense of connectedness

Gembris (2012) views music as a contributor to quality of life for all ages. He writes that making music, regardless of the skill of the participants, appears to have the ability to foster contact between people, answering to the human need to experience happiness, vitality and connectedness with others. Based on their observations of mother and infant interactions, Malloch and Trevarthen (2009) came to the conclusion that music is therapy, not only because it speaks to non-verbal and pre-verbal areas in our brain, but also because co-creating expressive sound and music is an inborn trait of humans that fosters empathy and relationships. Nordoff (in Ansdell, 2000, p.8) said the following of music and music therapy during his final illness, illustrating that music connects on different levels:

“‘You know, the greatest mystery of all is that we’re made of music.’ He has also often begun talking about music therapy to people by remarking that we ourselves are fundamentally rhythmic and tonal We make and experience music with our bodies which have pulses and tone, tensions and resolutions, phrasing and of actions, bursts of intensity, repetitions and developments. Music in short gives us access to a whole world of experience: bodily, emotionally intellectually and socially” (Ansdell, 2000, p. 8).

Bruscia (2014) describes music therapy as a reflexive process wherein the music therapist assists a client to achieve a state of optimum health. Bruscia states that music therapy is a unique form of therapy that is different from other therapies due to the combination of four important aspects: sound, creativity, beauty and relationship. Various forms of music are used and the intersubjective relationship between the therapist and the client, along with the music itself, are the driving forces for positive change. He further states that health can be conceptualised as wholeness and that music therapy is an ideal medium to help a client to integrate and create harmony between different aspects of self, life, and the world. Music therapy affords a client the opportunity to foster multifaceted relationships, referring to interpersonal relationships as well as intrapsychic relationships between different aspects of the self, including the body and its different parts. Bruscia also believes that music therapy can give a person a voice to express difficult emotions, while the therapist creates a safe and contained environment through music (Bruscia, 2014).

Most of the research on the role of music therapy for sense of connectedness and body image was conducted in a group setting, while the limited number of few studies with individuals typically dealt with eating disorders and child sexual abuse. Since the participant in this case study also suffers from an eating disorder, this literature is also relevant. Robarts (2006) said the following about clinical improvisation relating to her work with a young sexually abused girl: music can function as an interpersonal framework and provides an experience of interpersonal connectedness. Trondalen & Skåderud (2007) described the experience of connectedness during improvisation in the recovery process a young man had from anorexia nervosa. The experience of affect attunement between him and the therapist, and of being recognised on a non-verbal level promoted coherence and connectedness. This created opportunities to regulate his emotions and a greater sense of connectedness between his body and mind.

2.8 Conclusion

Several studies show that women often have lasting body image difficulties and feelings of isolation after bilateral prophylactic mastectomy and breast reconstruction. The benefits of additional support before and after the surgery were emphasised. The social isolation of women living with the BRCA1 and BRCA2 mutant genes was recounted. The literature shows that group music therapy can function as a supportive measure for women who have breast cancer. The fact that no published literature could be found on whether individual music therapy could play a role in improving body image and addressing intrapersonal and interpersonal connectedness of a woman who have undergone bilateral prophylactic mastectomy and reconstruction indicates the value of the proposed pilot study.

3 Chapter Three: Methodology

3.1 Introduction

A mixed methodology was selected for this pilot study because it allows for corroboration of the qualitative data by the quantitative data, while still reflecting the personal nature of the participant's experience through the qualitative data. Onwuegbuzie and Leech (2004) refer to five key advantages of mixed methodology namely: triangulation (studying the same phenomenon from different methods, seeking convergence); complementarity (enhancement and clarification of findings from one method with findings from another); initiation (uncovering paradoxes that can help to rephrase the question); development (informing the results from one method with the results from the other) and, finally, expansion (enhancing the range of the enquiry by using different methods) (Onwuegbuzie & Leech, 2004). In the following paragraphs, the research paradigm and the specific design for data acquisition used in this study will be discussed. The music therapy interventions and the method of data processing will also be highlighted.

3.2 Research Paradigm

Pragmatism is well suited to a mixed methodology study such as the one discussed here. Pragmatism mainly concerns itself with unifying the insight gained through both qualitative and quantitative research into a workable solution, and does not align itself with specific positions regarding ontology and epistemology (Morgan, 2007). This addresses the challenge of the incompatibility thesis where purists from qualitative and quantitative methodologies argue that the two different paradigms are mutually exclusive and cannot be utilised together in one study (Johnson & Onwuegbuzie, 2004). Pragmatism holds that the epistemology should not dictate the methodology but rather that the methodology should be chosen to answer the research question (Johnson & Onwuegbuzie, 2004). Pragmatism allows for the best opportunity to answer the research questions of this study.

3.3 Mixed methods

The study used a mixed method exploratory design (Hanson, Creswell, Clark, Petska, & Creswell, 2005). This method requires that a single study be conducted, mixing qualitative and quantitative research within one or more of four domains: the type of data collected, the research objective, the type of analysis, and the final conclusions (Creswell,

2003). In this study, the quantitative data were collected by means of the Breast-Q© (see Appendix A: Breast-Q© Questionnaire, p. 32) before the course of six music therapy sessions started. This quantitative measure was repeated one week after the conclusion of the sixth music therapy session. Two different modalities were used to collect the qualitative data: excerpts of video recordings of the sessions and a qualitative questionnaire (see Appendix B: Music Therapy Questionnaire, p. 46). The data were initially analysed separately. The quantitative data are used to enrich the qualitative findings, and interpretation and discussion of overall findings will involve combined quantitative and qualitative data sources (Hanson et al., 2005). Despite the fact that only one participant was recruited for the study, the quantitative data still had meaning in this single case study, as the measuring instrument was developed to be used in single cases or in studies with a bigger sample of participants (Pusic, Klassen, Scott, Klok, Cordeiro & Canot, 2000).

The challenges faced when attempting to integrate music therapy into mainstream health sciences and using it as a valuable adjunct can be addressed by conducting more quantitative and randomised controlled studies. Bonde (2015) states that quantitative research and randomised controlled trials specifically are needed in music therapy in order to expand collaboration with colleagues in the medical profession, and to elicit coverage for music therapy interventions through medical aids.

Qualitative research rests on the philosophy that there are multiple realities that are socially constructed and that interpretivism is an appropriate epistemological stance to better understand how a person relates to a specific experience. Traditionally this model has been in direct opposition to positivism, because it denies the idea of absolute truth (Bradt, Creswell, & Burns, 2013). Mixed methods studies are ideally suited to combine positivist and postpositivist paradigms. It allows for combining the results of both qualitative and quantitative data to enrich and inform each other (Johnson, Onwuegbusie, & Turner, 2007).

The research project was conducted during a process of six music therapy sessions with one woman instead of a group of between six and eight participants as was stated in the proposal. The reason for this was that the recruiting process failed to yield enough participants to realise this objective. The design took the form of an exploratory single case study and mixed method endpoint reporting with the emphasis placed on the qualitative data (Hanson et al., 2005).

As the researcher, I am aware that the study was conducted over a short period of time and that there were only six music therapy sessions. Short-term music therapy interventions have been studied previously and it was found that six sessions could be beneficial in improving the quality of life in a population of women who had breast cancer (Conradi, 2015). The sample size of this study was too small to yield statistically significant results that could answer to all the criteria for producing valid quantitative research discussed under 3.6. This study is, however, conceived as a pilot study for possible further research of this area and the quantitative data is reviewed to get an indication whether music therapy could improve the body image of a woman who had undergone a bilateral prophylactic mastectomy and breast reconstruction.

3.4 Sample

The participant was recruited from a surgical private practice in Cape Town. Medical practitioners, including breast cancer surgeons, oncologists, genetic counsellors, gynaecologists and general practitioners were contacted and requested to identify patients who might be suitable candidates. A total of ten relevant practices were contacted via email, telephonic discussions and meetings in person. They were requested to supply patients with information about the proposed study (see Appendix C: Colleague Information, p. 49). Three patients initially expressed willingness to participate; practitioners were asked to obtain their consent and to request them to contact the researcher (see Appendix D: Letter from Doctor to Patient, p. 51). Two participants agreed to meet with the researcher and both of them were recruited into the study. One of the prospective participants indicated that she could not continue with the study after the first session, citing personal circumstances as reason. The data pertaining to this participant, apart from the video excerpts, were destroyed. A second recruitment drive failed to find suitable candidates within the allowed time frame. The study was converted to a single case study focusing on the qualitative data collected, as the quantitative data is meant only to inform and enrich the qualitative data.

The researcher contacted prospective study participants telephonically and an appointment was made during which the purpose and methods of the study were explained verbally and in writing, after which the candidate had an opportunity to consider participation. Upon signing an informed consent form (see Appendix E: Letter of Informed Consent, p. 53), the participant was enrolled into the study and requested to attend the scheduled music therapy sessions.

This sampling method can be described as non-random purposive sampling and its aim is to gather information to study a specific case (critical case) in depth. Specific case or critical case sampling makes it possible to use small sample sizes, while still doing valid research (Onwuegbuzie & Collins, 2007). The aim is to collect rich data that expands the breadth and depth of the case. The participant was chosen because she complied with specific criteria necessary to answer the research question (Onwuegbuzie & Collins, 2007; Teddlie & Yu, 2007).

A participant had to meet the following criteria: a genetic predisposition for developing breast cancer; history of bilateral prophylactic mastectomy and breast reconstruction within the past three years; and no prior personal history of breast cancer.

3.5 Data Collection

3.5.1 Music therapy intervention

Six music therapy sessions of approximately 90 to 120 minutes were conducted. A variety of music therapy interventions were used during the sessions, including free improvisation on drums and other instruments, listening to music and imagery experiences, relaxation to music, movement to music, writing of poetry, and drawing and clay work to music. Each session was video recorded. The participant was required to sign informed consent for video recording prior to enrolment in the study (see Appendix E: Letter of Informed Consent, p. 53).

Summary of the six sessions:

Session one: this session was 98 minutes long. The prepared plan changed during the session, because the initial discussion to ascertain basic relevant history from the client flowed into the sharing of her whole experience of her mother's cancer and her own BRCA2 diagnoses. Relaxation, listening to music, drawing and reflection on the musically evoked images comprised the music therapy aspects of this session. The first Breast-Q© was completed during this session. Four excerpts of the verbal discussion were selected on basis of their relevance to the research topic.

The duration of session two was 80 minutes. The theme for the session was "nurturing and self-care". The session started with movement to music where the therapist led the movements. This was followed by two instrument improvisations. The first

improvisation was a structured call-and-response drumming session that flowed into free play on the drums. The second improvisation was a free metallophone and drum improvisation. The participant played on the melodic instrument and the researcher on the djembe drum. Poetry writing to music followed the improvisation and the poetry was reflected on to conclude the session. The thick description of this whole excerpt of about fifteen minutes was selected for thematic analysis.

Session three was begun with stretching exercises lead by the participant and free movement to music. The instrument improvisation started with free play on the djembe drums. The remainder of the session consisted of a music listening experience and writing about her ideal body. Two excerpts from this session were added to the data set. The session was two hours long.

Session four, which lasted 82 minutes started with drumming improvisation, followed by a vocal improvisation. Mirror movement where the participant lead, preceded a relaxation and music listening experience after which she was requested to draw an image of how she sees her body. The excerpt chosen from this session included the whole verbal reflection on her images.

Session five started with verbal reflection on the previous week. The total duration of the session was 128 minutes and consisted of stretching, a vocal improvisation, a music listening experience and drawing of the music inspired images. Verbal reflection on this concluded the session and the transcript of the whole session was submitted to the data set.

The final session, session six, was initiated with a verbal reflection on the theme for the session, a vocal improvisation. Clay work with music about the most salient theme of the previous sessions and reflection on that followed and the session was concluded with a final instrument improvisation. Four excerpts from this session, which lasted 110 minutes, were selected for analysis.

3.6 Qualitative data

3.6.1 Qualitative data source A:

The researcher collected the qualitative data source A in the form of video footage of the sessions. Video data is useful because it has the advantages of permanence and

density (Bottorf, 1994). Permanence refers to the fact that the data can be reviewed repeatedly and that different aspects of the data can be examined through a variety of lenses. Video recordings yield rich data, because facial expressions, and verbal and nonverbal communication, such as gestures and silences can be recorded. There are, however, limitations to the use of video recordings including: the historical context of the participants and their behaviours cannot always be recorded; there are mechanical constraints when using cameras and microphones, because participants cannot be recorded from all possible visual angles and some sounds are not audible on recordings; and the participants can be influenced by the fact they are being recorded and can change their behaviour accordingly (Bottorf, 1994).

3.6.2 Qualitative data source B:

The participant was asked to complete a qualitative music therapy questionnaire compiled by the researcher (see Appendix B: Music Therapy Questionnaire, p. 46) a week after the sixth music therapy session. The music therapy questionnaire was developed in order to gather information relating to body image, intrapersonal and interpersonal connectedness and therefore asked questions such as how the music therapy process influenced the participant's perceptions and feelings about her body, her relationship with different parts of her psyche, and her sense of interpersonal connectedness. It also has a final section in which the participant was free to write general comments in her own words.

3.7 Quantitative data

3.7.1 Quantitative data source A:

Several questionnaires have been developed in answer to the challenge of developing a valid comprehensive patient reported outcome measurement (PROM) for use after breast cancer surgery or treatment. All of these are aimed at measuring and understanding the impact of various breast cancer treatments on a woman's psyche. One of these questionnaires, the Breast-Q® (see Appendix A: Breast-Q® Questionnaire, p. 32), was found to be very comprehensive and reliable. Breast-Q® was validated through analysis using the Rasch statistical method as well as traditional psychometric tests, rendering it suitable for application to both large study groups and individual patients in clinical practices (Pusic et al., 2009). It has been peer reviewed and used in clinical trials. The questionnaire addresses the first research question of this study, which is concerned with body image after bilateral prophylactic mastectomy and breast

reconstruction. The subdomains in the questionnaire, designed to examine body image from different angles, namely psychosocial well-being, sexual well-being, and satisfaction with breasts were used to examine body image. Permission to use the questionnaire is readily obtainable from the developers and it can be utilised without any financial implications if used for academic and research purposes (see Appendix A: Breast-Q© Questionnaire, p. 32). Computer software for interpretation of the results is also easily accessible (Cano et al., 2013).

Breast-Q© (see Appendix A, p. 32) was used to collect the quantitative data with regard to body image in this mixed method study. The Breast-Q© subdomains to measure body image were used as prescribed by the developers. This included the separate sections measuring “psychosocial well-being”, sexual well-being, and satisfaction with reconstructed breasts (Cano, Klassen, Scott, & Pusic, 2013). In terms of the study’s operational definition of body image (perceptions, feelings and thoughts about the body), the subdomains fall within the parameters of the operational definition, as they include perceptions, feelings and thoughts relating to the body. Perspectives around body image will thus be further defined based on both quantitative and qualitative findings.

The participant was requested to complete the Breast-Q© postoperative reconstruction module containing the subdomains mentioned under paragraph 3.5.2.1 (see Appendix A, p. 32), prior to the start of the first music therapy intervention and a week after the sixth music therapy session. Completion of the second Breast-Q© questionnaire coincided with the completion of the qualitative music therapy questionnaire (see Appendix B: Music Therapy Questionnaire).

3.8 Data Selection

3.8.1 Qualitative Data

The transcripts of the video data generated rich data. Certain excerpts of the transcripts were purposely selected because it was closely related to the study questions. Polkinghorne (2005) states that since the aim of qualitative research is to enrich the insight into an experience, it is important to purposely select data sources that are saturated with information. The corpus of the data (Braun & Clarke, 2006) was examined repeatedly to make the selection of the sections to be analysed through thematic analysis. Two different sets of data (Braun & Clarke, 2006) were generated: Qualitative data set A (see Appendix F: Qualitative Data Set A) comprising selected excerpts of the transcripts of the video

footage; and Qualitative data set B (see Appendix G: Qualitative Data Set B) in the form of the answers to the qualitative music therapy questionnaire.

3.8.2 Quantitative Data

Only modules of the Breast-Q ® questionnaire that related to research questions were used as described in section 3.5.2.1 (see Appendix A: Breast-Q® Questionnaire). Two separate sets of data were generated: quantitative data set A1, see Appendix J: Quantitative Data Set A1, which comprised the answers to the pre-intervention test, and quantitative data set A2 (see Appendix K: Quantitative Data Set A2), which represents the post-intervention Breast-Q® answer sheet.

3.9 Data Preparation

3.9.1 Qualitative data

3.9.1.1 Qualitative data source A:

Excerpts were drawn from the thick descriptions of the video recordings of the sessions. Thick descriptions are accounts of social settings where detailed descriptions are given about the verbal, nonverbal and contextual behaviour of the participants (Bryman, 2012). The thick descriptions include gestures and facial expressions. The data were reviewed repeatedly under supervision to identify clusters of behaviour that could be seen as relevant to body image and intrapersonal and interpersonal connectedness. The selected excerpts were transcribed. The texts were transferred to data analysis templates, leaving enough space to write down comments and numbers (Gibbs, 2007). The lines were numbered continuously. The descriptions of different sessions are demarcated by the number of the session in the text.

3.9.1.2 Qualitative data source B:

The response to the questionnaire was transferred to data analysis templates which have enough space to add comments and numbers. All the lines were numbered. See example under section 4.5.2.

3.9.2 Quantitative data

3.9.2.1 Quantitative data source A:

Data from the Breast-Q© (see Appendix A: Breast-Q© Questionnaire, p. 32) questionnaires (Quantitative data sources A1 and A2, (see Appendix J: Quantitative Data Set A1 and Appendix K: Quantitative Data Set A2) were entered into relevant Microsoft Excel templates that accompany each Breast-Q© module. Data were next exported to Q-Score©, the Breast-Q© scoring software, to transform the raw data into summary scores (Sugrue, M., MacGregor, Sugrue, R., Curran & Murphy, 2013).

3.10 Data Analysis

3.10.1 Qualitative data

Data driven qualitative thematic analysis (Braun & Clarke, 2014) was used to analyse the thick descriptions of the video excerpts and the answers to the open-ended questions in the music therapy questionnaire. Thematic analysis provides rich accounts of the data gathered (Braun & Clarke, 2014). Data driven analysis implies that the researcher brackets previous theoretical knowledge and perceptions about the topic, allowing for themes to emerge from the data. This is of particular importance, because I had a dual role as a participant-researcher. Bracketing does not imply that knowledge and concepts embedded in the researcher will be ignored or excluded, but rather that they will be recognised and acknowledged. In contrast to data driven qualitative analysis, concept driven coding would involve the researcher using a set of preconceived codes and themes under which the data would be classified (Gibbs, 2007).

I immersed myself in the text of the video excerpts' thick descriptions and the answers to the open-ended questions from the music therapy questionnaire by reading and rereading these reflexively to familiarize myself with the depth and breadth of the text and to identify patterns, also called themes, in the data (Braun & Clarke, 2014). Braun and Clarke write (2014) that a theme reports important information about the data in relation to the research question. It represents some form of patterned response or meaning within the set of data. It is important to decide what constitutes a theme when the data is coded (Braun & Clarke, 2014). An inductive approach was followed in identifying themes, meaning that the themes are tightly bound to the data. This involves a process of coding where the codes are not clustered under a preconceived coding frame. The researcher also bracketed prior knowledge of, and interest in the research topic (Braun & Clarke,

2014). The analysis focused on the semantic meaning of the data, as it is a pilot study of an under-researched area (Braun & Clarke, 2014). However, coding is not only a way of marking and describing similar ideas, it is ultimately a way of analytic evaluation of the text. Examining the text continually in order to make comparisons between the data accomplished this analysis. This process is referred to as 'open coding'. Further order codes and higher order codes were added as themes emerged from the data (Gibbs, 2007).

Findings of both the quantitative and qualitative analyses will be integrated in order to address the research aims and the questions. This will be done in the discussion section to ascertain whether the qualitative analysis enriched and explained the quantitative data.

3.10.2 Quantitative data

The outcome analysed is body image. Subsets of Breast-Q© (see Appendix A: Breast-Q© Questionnaire, p. 32) scales were selected according to the outcome being analysed. The data on the Q-Score® Excel templates (see Appendix L: Breast-Q© Post Operation Template) were exported the Q-Score® scoring system. Q-Score© analyses data based on RUMM 2030 algorithms. This data analysing system was developed by Rasch Unidimensional Measurement Models Laboratory and it transforms raw data automatically into summary scores where the two endpoints are zero (very dissatisfied) to 100 (very satisfied). Each scale has a unique scoring algorithm and the program has the ability to read the raw data of the patients' response, score the data and to provide a complete set of transformed scores for each scale completed (Cano et al., 2013). The summary scores of the pre-intervention test and the post-intervention tests were interpreted according to the guidelines in the BREAST-Q© User Manual (Breast-Q, 2012). According to this document a change from five to ten signifies very little change on the multi-item scales. A difference in the scores ranging between ten and twenty indicates 'a moderate' change and an alteration of greater than twenty between the scores of the two tests can be interpreted as 'very much' change.

3.11 Research Quality and Study Limitations

Quality assurance procedures for quantitative research involve ensuring internal and external validity, reliability and the statistical significance of the results, whereas qualitative procedures involve ensuring trustworthiness and authenticity (Bryman, 2012). The current study poses the following salient limitations and quality risks that will be

addressed in different ways: Firstly, the small sample size and lack of control group do not allow claims in terms of external and internal validity. In addition, the participant had the bilateral prophylactic mastectomies and breast reconstructions prior to the study, thus baseline pre-surgical body image scores are not available. Secondly, I had the dual role of researcher and participant, as I facilitated the music therapy sessions. In terms of the participant, the Hawthorne effect (McCambridge, Witton, & Elbourne, 2014) thus needs to be considered, as the participant knew and interacted with me as researcher and facilitator, and was aware of the purpose of the study, both of which may have altered her responses/behaviour in order to align to the purpose of the study, to please or to be seen in a more positive light (Shaughnessy, Zechmeister, & Zechmeister, 2012). The participant might also have enrolled in the study because she had specific needs that she hoped to have addressed during the music therapy process, which might have led to further biased responses, whether or not needs were met. In terms of addressing the first concern, it follows that no claims will be made in terms of internal and external validity. Reproducibility with larger samples will be possible for measuring body image through Breast-Q©. In terms of both the first and second concern, note that the study is both an exploratory case study and a pilot study that will aim to offer rich data in terms of the personal nature of the participants lived experience, as well as valuable information regarding feasibility, design, questionnaires, relevant variables and their operational definitions. In order to improve research quality and address the Hawthorne effect, triangulation was employed in a mixed method design with both quantitative and qualitative methods and three different data sources (quantitative Breast-Q© data pre- and post-intervention, qualitative analysis of both session excerpts and the qualitative music therapy questionnaire). All aspects of the research will be accurately described and documented.

Thirdly, in terms of my dual role as researcher and participant, experimenter bias has been considered, referring to a situation where the researcher unconsciously and subtly influences the participants to adjust their responses/behaviour, and collects and codes data in a manner that produces more positive results (Dunbar, 2005). I am, however, aware that meaning was constructed in the intersubjective interaction between the participant and the researcher (Finlay, 2009). Bias will thus always be present and can lead to valuable insight into the intersubjective relationships between the participant and me, and how it influences the research process and the data. Finlay (2009) writes about other sources of bias and states that a researcher must bring previous knowledge, and preconceived ideas and expectations about the field of research and the participants, into conscious awareness through rigorous reflexive practices. I have done this by keeping a reflexive research journal and field notes and memo's written during the research process.

Awareness of bias can assist the process of bracketing, where the researcher acknowledges and accurately describes prior knowledge and perceptions of the research subject, rather than attempting to ignore this subjectivity. I endeavoured to do a continual critical literature review as a way of interrogating my preconceived ideas and prior knowledge of the phenomenon I studied (Hays & Singh, 2012).

The halo effect may also be relevant, where my professional history as a medical doctor as well as my personal and familial medical history may create bias (Onwuegbuzie & Daniel, 2003). In order to address this, I have taken on a continuously critical and reflexive attitude during the research process, I have identified and accurately described bias (Ansdell & Pavlicevic, 2001) and engaged in regular peer supervision. Selection of session excerpts as well as thick descriptions and analysis of quantitative data were peer reviewed throughout the process. An inductive approach is followed in identifying themes, where the themes are tightly bound to the data. This involves a process of coding where codes are not clustered under a preconceived coding frame. I am bracketing prior knowledge of, and interest in the research topic (Braun & Clarke, 2014).

3.12 Ethical Considerations

In 3.7 above I have discussed various measures taken to address study limitations and research quality, contributing to ethically responsible research practice. In addition, the following measures were employed to ensure participant's anonymity and confidentiality, and obtain her informed consent.

The participant's confidentiality and privacy are protected by changing her name – no actual name or other identifying information appears on documentation and in the dissertation, except for the completed consent form, where her actual name appears. The latter is not included in the dissertation.

The participant's informed consent has been obtained both in terms of her contact details being accessed via the referring specialist (see Appendix D, p. 51), Letter from Doctor to Patient, Appendix E, p. 53, Colleague Information) and in terms of enrolling in the study (see Appendix D, p. 51, Letter of Informed Consent). The letter of informed consent states that enrolment is voluntary and includes the participant's permission for sessions to be video recorded. It is stated that video recordings will only be used for the purposes of the study. It will be stored securely at the Music Therapy Unit of the University of Pretoria, and will be destroyed 15 years after the commencement of the study, thus

ensuring confidentiality. The letter of informed consent further states that the participant may withdraw at any stage upon which her data will be destroyed, except for music therapy video footage, and that she will have access to the results of the study.

3.13 Conclusion

This chapter discussed the mixed methodology of the study. The study was situated within pragmatism and the benefits of doing mixed method studies were given. The purposive sampling method and reasons for the single case study were outlined. The six individual music therapy sessions as well as the process of selecting meaningful excerpts from the videos were detailed. A brief description of the transcription of the data was given. The qualitative and quantitative data collection methods via questionnaires were described. Data preparation and data analysis for both the qualitative and quantitative data sets were discussed. Indication of how I aimed to ensure that this study adheres to ethical and research validity standards was given. Chapter four deals with the data preparation and analysis in greater detail.

4 Chapter Four: Data Collection and Analysis Methods

4.1 Introduction

This chapter describes the process of data collection, preparation of the transcripts and qualitative thematic analysis. The phases of inductive open coding and the development of higher order codes, sub-themes and themes will be illustrated with examples from the text relevant to the research. Considerations regarding self-disclosure, and the back-ground of the participant are briefly outlined. Bias and bracketing were discussed in chapter three (see section 3.11). Analysis of the quantitative data will be described and illustrations of the results will be given. The coding process from the first order codes to the final themes was conducted under supervision to decrease bias and to ensure that the themes reflected the essence of the codes.

4.2 Self-Disclosure

At this juncture, I will reflect on my own experience with a familial breast cancer syndrome, although unrelated to the BRCA1 or 2 genes. I have a maternal family history of breast cancer affecting women, spanning several generations. My mother succumbed to breast cancer in 2011. I had the bilateral prophylactic mastectomy in 2011 and the oophorectomy in 2013. My own experience of isolation and loneliness, adaption to an altered perception of my body and my personal journey of healing sparked my interest in the subject matter.

My medical background and seven years as the theatre assistant of a cancer surgeon specialising in breast cancer also had a bearing on my approach to the subject. However, I had no previous doctor-patient relationship with the participant and I was not involved in the management of her genetic risks, which assisted with focusing on my role as music therapist and participant researcher. I refrained from giving medical advice during the research period. I did however explain certain concepts to the client to help her to clarify questions she had about the medical and surgical process. The participant was aware of the basic information of my background. The therapeutic relationship was however structured in such a way that my personal history and experiences with breast cancer was not introduced and discussed before, during or after the sessions. Having said that I am aware that according to Lather (1986) that meaning is constructed and negotiated between the researcher and the research participant and my history would affect the research process and the significance I ascribe to the results and interpretation

thereof. I also endeavoured to bracket my prior knowledge on and personal interest in the subject during the data collection and data analysis processes. This was discussed in the previous chapter, section 3.11. I rigorously self-examined and evaluated my behaviour and verbal responses during the sessions, as it was captured on the video footage. I kept a personal diary (Frost & Kinmond, 2014) during the process and attended weekly supervision sessions to assist in bringing into consciousness my subjective interpretation and understanding of the subject. A continued review of new literature kept me informed of new research and theories about the different aspects of this study.

4.3 The Participant

Michelle is a 44 year old woman and was diagnosed with the BRCA2 gene in December of 2015. The research participant underwent a bilateral prophylactic mastectomy and reconstruction in June of 2016, due to testing positive for the BRCA2 breast cancer gene. This diagnosis increases her risk to develop breast- and ovarian cancer significantly. The genetic tests for the gene was prompted when her mother was diagnosed with bilateral breast cancer. The circumstances of the testing were not ideal as Michelle received no pre-test genetic counselling. The test results were relayed telephonically from a general practitioner with whom she did not have a professional patient/doctor relationship. She sought genetic counselling after she received the positive test results. The genetic counsellor referred her to a specialist breast cancer surgeon. He advised her on the possibility of undergoing risk reduction surgery in the form of bilateral subcutaneous prophylactic mastectomies and bilateral oophorectomies. She opted to have the surgery done in July 2016. Testing positive for the BRCA2 gene had a significant impact on Michelle's emotional well-being, because her mother was the first person in her family to be diagnosed with breast cancer. She thus had not anticipated that the test might be positive, especially since both her sisters tested negative for the gene prior to her diagnosis. Her only brother refused to be tested.

4.4 Data sources

There were three data sources: qualitative data source A (Thick descriptions of video excerpts), (see Appendix F: Qualitative Data Set A); qualitative data source B (answers to the qualitative music therapy questionnaire), (see Appendix G: Qualitative Data Set B); quantitative data source A1 and A2, (tests and scores of the Breast-Q© questionnaire (see Appendix J: Quantitative Data Set A1 and Appendix K: Quantitative Data Set A2)).

Thick descriptions and verbatim transcriptions and translations into English of video excerpts of the six music therapy sessions were made. This process demanded the video data to be examined in detail. Sections of the narrative captured by the videos were viewed repeatedly to ensure that the transcripts were as accurate as possible. Some contextual comments and descriptive comments were added to the transcript. Pauses and accents were indicated in the text. Excerpts relevant to the focus of the research were selected and these constituted qualitative data source A. The qualitative questionnaire and the answers of the open-ended questions were used as the qualitative data source B. This questionnaire was administered a week after the music therapy intervention drew to a close. The quantitative data were collected via the postoperative breast reconstruction module of the international standardised patient outcome questionnaire Breast-Q®. The client completed the test for the first time during the initial music therapy session and a second time a week after the music therapy intervention terminated, coinciding with the completion of the qualitative questionnaire. These two sets constituted quantitative data source A1 (see Appendix J: Quantitative Data Set A1) and quantitative data source A2 (see Appendix K: Quantitative Data Set A2).

4.5 Data Preparation

This section is used to describe Qualitative Data Sets A and B, while Quantitative Data Sets A1 and A2 are discussed in section 3.10.1.

4.5.1 Qualitative Data Source A

Transcripts of data are representations where one modality is translated into another modality. As with any translation it not only “transports” information, but also transforms the meaning (Ansdell & Pavlicevic, 2001). Bryman (2012) quotes Heritage and lists the importance of transcribing interviews: it compensates for the natural limitations of memory; it provides an opportunity for a more thorough and repeated examination of the dialogue between people; it allows for scrutiny by other researchers and serves as proof against accusations of bias by the original researcher; and it allows for re-examination of the data for purposes other than initially intended as new theories and scientific knowledge comes to the fore. Transcribing data can be seen as the first step of familiarising oneself with the data and should be viewed as an interpretive and meaning assignment act (Braun & Clarke, 2004). The six music therapy sessions, each lasting 80 to 128 minutes were video recorded. Thick descriptions were compiled by transcribing the verbal exchange verbatim mainly in Afrikaans, and adding contextual information such as pauses, facial

expression and gestures. Some of the dialogue was in English and was transcribed as such. Excerpts of the transcription were selected according to their relevance to the research questions (see **Table 4-1**, and **Table 4-2** for the translation). Michelle is represented in the transcript with a capital “M” and the to the researcher with a “R”.

Table 4-1: Excerpt of original transcript

5	M: Nee, BRCA2 positief. Ma ook BRCA2
6	En sy het die jaar voor laas jaar die operasie gehad.
7	M: Sy het mos kanker gekry, dit was eers net in die een bors. Wel eers
8	de een bors gedoen, om een of ander rede, en ek kan nie verstaan
9	hoekom die dr dit nie gedoen het nie. Ek neem hom verkeerdelik seker
10	daarvoor kwalik. Sy het eers die knop in die een bors gehad, en toe
11	het hulle die biopsie gedoen, en toe het hulle die een bors afgesit en
12	haar anders bors kleiner gemaak. En ek onthou ek het daardie tyd
13	gevra, moet hulle nie eers seker maak die ander bors is ook skoon
14	nie, toe se hulle “nee, hulle maak eers die bors kleiner en dan stuur
15	hulle dit in elk geval weg. Toe was daar ook kanker gewees in daai
16	weefsel, maar interessant genoeg, hy het nog gevra of hy dit kan vat
17	vir ‘n studie, dit was toe twee ‘n verskillende tipe kankers. Toe is sy
18	nou weer terug teater toe om die ander een ook af te sit.
19	My tannie is mos nou verlede jaar oorlede.
20	R: Ook borskanker?
21	M: Ja dit was vir my baie swaar. Sy was my godmother, peetma.
22	R: Sy was nie lank siek nie. Ek het onthou jy het vir my gesê dit was so
23	skielik. (Michelle se oë word vol trane)
24	R: Ek is so jammer.
25	M: ‘Skuus, ek is fine, ja nee dit is mos maar hoe dit werk.

Table 4-2: Translation of the Excerpt

5	No, BRCA2 Positive. My mother is also BRCA2
6	And she had the operation the year before last.
7	She developed cancer, at first it was only in one breast, well they've only done
8	the first breast, and for a certain reason, I do not understand why the doctor
9	didn't do it. I blame him, probably wrongly, for that.
10	She had the lump in only one breast, and after that they did the biopsy
11	and then they amputated one breast and made the other breast smaller
12	I remember I asked at that time whether they should not confirm that
13	the other breast is clear.
14	They said no, they make the one breast smaller first and send it
15	away in any case [for pathology]. There was cancer in that breast
16	as well, and interestingly enough, he asked if he could use it
17	for a study: there were two different types of cancer [in each breast]
18	She then went back to theatre to have the other breast amputated.
19	My aunt, as you know, died last year.
20	Also breast cancer?
21	Yes, I took it very hard. She was my godmother.
22	She was not ill for long. I remember you told me it was so
23	sudden. [Michelle's eyes fill with tears.]
24	I am so sorry.
25	Sorry, I am fine, yes, no, that is how it works.

That text was transferred to a Microsoft Excel spreadsheet, and each line was numbered. Prepared text was translated into English in an adjacent column, matching the line numbers as close as possible to the original (see **Table 4-3**).

Table 4-3: Numbered excerpts with English Translation

5	M: Nee, BRCA2 positief. Ma ook BRCA2	No, BRCA2 Positive. My mother is also BRCA2
6	En sy het die jaar voor laas jaar die operasie gehad.	And she had the operation the year before last.
7	M: Sy het mos kanker gekry, dit was eers net in die een bors. Wel eers	She developed cancer, at first it was only in one breast, well they've only done
8	de een bors gedoen, om een of ander rede, en ek kan nie verstaan	the first breast, and for a certain reason, I do not understand why the doctor
9	hoekom die dr dit nie gedoen het nie. Ek neem hom verkeerdelik seker	didn't do it. I blame him, probably wrongly, for that.
10	daarvoor kwalik. Sy het eers die knop in die een bors gehad, en toe	She had the lump in only one breast, and after that they did the biopsy
11	het hulle die biopsie gedoen, en toe het hulle die een bors afgesit en	and then they amputated one breast and made the other breast smaller
12	haar anders bors kleiner gemaak. En ek onthou ek het daardie tyd	I remember I asked at that time whether they should not confirm that
13	gevra, moet hulle nie eers seker maak die ander bors is ook skoon	the other breast is clear.
14	nie, toe se hulle "nee, hulle maak eers die bors kleiner en dan stuur	They said no, they make the one breast smaller first and send it
15	hulle dit in elk geval weg. Toe was daar ook kanker gewees in daai	away in any case [for pathology]. There was cancer in that breast
16	weefsel, maar interessant genoeg, hy het nog gevra of hy dit kan vat	as well, and interestingly enough, he asked if he could use it
17	vir 'n studie, dit was toe twee 'n verskillende tipe kankers. Toe is sy	for a study: there were two different types of cancer [in each breast]
18	nou weer terug teater toe om die ander een ook af te sit.	She then went back to theatre to have the other breast amputated.
19	My tannie is mos nou verlede jaar oorlede.	My aunt, as you know, died last year.
20	R: Ook borskanker?	Also breast cancer?

4.5.2 Qualitative Data Source B

The open-ended qualitative questionnaire was completed a week after the conclusion of therapy. I transferred the questions and answers to a Microsoft® Excel template where the lines were numbered. The participant answered the questions in English (see **Table 4-4**).

Table 4-4: Qualitative Data Source B

	Questionnaire:	Answers:
1	Did the music therapy process change the way you perceive, feel or think	Yes, I felt more of a mind and body connection.
2	about your body. If so, please discuss.	My mind (thoughts) felt more in sync with my body.
3		Before therapy I had a strong sense of betrayal by my body
4		
5	Did the music therapy process change aspects of relationships with intimate or	Yes, Because I felt calmer, I was less agitated with others.
6	close family members?	
7	Did the music therapy process provide you with a sense of social support/or	A definite yes. I felt understood, empathy, warmth.
8	social connection?	Every session felt like a very rewarding social connection.
9		
10	Did the music therapy process change the way you perceive, feel or think about	Yes. It gave me the tool to explore mediums like singing and writing
11	yourself in ways not mentioned above?	in a safe environment.
12		these acts in turn taught me more about myself as a person.
13		The music therapy made me feel empowered.
14		This counterbalanced the scale.
15		results opened a dark side of my being.
16		the music therapy opened a light positive side to my being.
17		
18	Would you recommend music therapy to other women who have undergone	Absolutely! Fear is a big part of the mastectomy journey.
19	bilateral prophylactic mastectomy and breast reconstruction? If so, please	Music Therapy was a safe environment where one was able to look

	Questionnaire:	Answers:
20	discuss why you would recommend music therapy.	the fear in the eyes and stop fighting it,
21		but accept it as part of the "New journey".
22		I was given a wonderful tool to help with the overwhelming fear at times.
23		
24	Please add any comments you wish to share.	For me the music therapy process was a wonderful blessing
25		that enriched me.
26		For sure, I am more able to cope with my "New journey" after my six sessions.

4.6 Thematic Analysis Qualitative Data

Analysis of the qualitative data was accomplished by using thematic analysis (Braun & Clarke, 2015). The process unfolded as follows: thick descriptions and the verbatim account of the relevant video excerpts; copying of the answers to the qualitative questionnaire into a data template; identification of the first order codes by familiarising myself with the data by the iterative rereading of the material; higher order codes were formulated; similar higher order codes were organised into sub-themes, and themes were drawn from the sub-themes related to the focus of the research. Data analysis began with the first transcriptions of the data in a recursive rather than linear mode (Braun & Clarke, 2004).

4.7 Coding

Braun and Clarke (2006) defines thematic analysis as a “method for identifying, analysis and reporting pattern (themes) within data”. It is not only a way to organise data allowing for describing rich detail of the data, but also assists with the interpretation thereof. Thematic analysis where the themes identified are closely linked to the data is referred to as inductive coding. Codes are data driven and not organised in a pre-conceived coding-frame (Braun & Clarke, 2006). The process of coding involves breaking the data down into component parts and giving them labels (Bryman, 2012). Formulating initial codes are the first step in data analysis as the data is organised in meaningful units (Braun & Clarke, 2004). This was done by actively reading the data, searching for patterns and meanings. Some codes were single words while others were short phrases. The units

of coding were the dialogue of the participant. Not every line was coded, but short sentences or phrases (Marks & Yardley, 2004). Care was taken not to decontextualize the data by relating it to the research questions and the nature of the phenomenon studied (Bryman, 2012). First order codes were written into an adjacent column (see Appendix H: English Transcript with First Order Codes). The data were coded at four separate occasions to ensure consistency in the coding process. (Joffe & Yardley, 2004).

Table 4-5: Qualitative Data Source A: Codes of Qualitative Data set A examples

	Translation of transcript	First order codes
100	For them it was not as bad as it was for me.	was not as bad as for them as for me
101	Coping with this every day, my world collapsed. For them it was like a blip	world collapsed, blip on their radar
102	on their radar. One sister lives far away and couldn't be there for my mother.	
103	My other sister is a nurse at Cape Gate and she has a	
104	different personality to me. And I ...I was the one	I was the one who supported my mother
105	who supported my mother at doctors' appointments. I was the one who waited	at doctors' appointments
106	when she went into theatre, I was the one who stood outside	waited when she went to theatre, I was the one who stood outside
107	waiting for her to come out. All these things were very, very real.	very real
108	And then I got... I also got the thing. I was then one who emptied her drains.	thing [gene], emptied her drains
109	I cleaned her wounds. I did all those things	I cleaned her wounds. I did all those things
110	and they, in the medical profession did not come to do these things.	They in medical field did not come out to do this
111	It was thus very difficult for me to the there for her,	very difficult for me to the there for her,
112	but to be hit repetitively! They simply continued with their lives	Hit repetitively, others simply continued with their lives
113	or that was the feeling I had.	Feeling I had
114	Yes, that was how it felt for me.	
115	That is definitely how it is on our family. It is more difficult for someone who is caring, because you...You are emotionally connected to the other person	It is more difficult for someone who is caring
116	and because you experience things on an emotional level, it is more difficult.	emotionally connected to that person
117	More difficult.	experience things on a more emotional level
118		

	Translation of transcript	First order codes
119	And your husband? What did he say about everything?	
120	He was actually very supportive. It was difficult for me because	husband was actually very supportive, he comes and goes

Table 4-6: Data set B with first order codes

	Answers:	First Order Codes:
1	Yes, I felt more of a mind and body connection.	Mind body connection
2	My mind (thoughts) felt more in sync with my body.	Mind more in sync with body
3	Before therapy I had a strong sense of betrayal by my body	betrayal before therapy
4		
5	Yes, Because I felt calmer, I was less agitated with others.	Felt calmer, less agitated
6		
7	A definite yes. I felt understood, empathy, warmth.	understanding, warmth, empathy
8	Every session felt like a very rewarding social connection.	social connection
9		
10	Yes. It gave me the tool to explore mediums like singing and writing	explore mediums like singing and writing
11	in a safe environment.	safe environment
12	these acts in turn taught me more about myself as a person.	self-knowledge
13	The music therapy made me feel empowered.	empowered
14	This counterbalanced the scale.	Counter-balanced the scale
15	results opened a dark side of my being.	opened a dark side of being
16	the music therapy opened a light positive side to my being.	music therapy opened light side of being
17		
18	Absolutely! Fear is a big part of the mastectomy journey.	Fear
19	Music Therapy was a safe environment where one was able to look	Safe environment
20	the fear in the eyes and stop fighting it,	confront fear
21	but accept it as part of the "New journey".	new journey
22	I was given a wonderful tool to help with the overwhelming fear at times.	tool to help with overwhelming fear
23		

	Answers:	First Order Codes:
24	For me the music therapy process was a wonderful blessing	Music therapy was wonderful blessing
25	that enriched me.	enriched
26	For sure, I am more able to cope with my "New journey" after my six sessions.	more able to cope, "New Journey"

4.8 Development of Higher Order Codes

The codes were studied to note patterns of distinctions and similarities. Different higher order codes were developed and the codes were further analysed by grouping similar codes under the higher order **Table 4-7**). The higher order codes were transferred to a new Excel spreadsheet as they became evident during the repetitive coding process. The first order codes were transferred to reflect the original line number in columns headed by the higher order codes. I reflected in this process as I reread and re-analysed the original codes. The whole document is available on request. A summary of the higher order codes and examples of the first order codes are displayed in **Table 4-7**.

Table 4-7: Higher order codes and examples of first order codes

Higher order codes	Examples of first order codes
Genetic connection with mother	I received a package from my mother (635)
Supporting her mother	I was the one who supported my mother (104)
Lack of support from her mother	We do not have that (emotional) communication (1016) My mother is not an emotionally warm person (379)
Aunt as emotional mother	She was the hug, phone you, "I love you", that type of person (386, 387)
Abandonment through death	You left me (354)
Relationship with siblings	I am angry with my siblings for this (449)
Separation from family of origin	I took myself away from them (985)
Connection to husband	They are part of me, my husband as well (1037)
Genetic connection to children	They (children) carry my genes (600)
Emotional connection with children	I have two children who are very emotional. They are very aware whether their mother is OK (123)
Connection with husband and children as unit (nuclear family)	I have my husband and children (1135)
Lack of support from community	That is what the community wants, they want to drop off the flowers or the lasagne, and then you must be OK (411)
Being visible	I actually do not want to be too visible (699, 670) They ask direct questions (564)
Being separate from community	Took me away from my community (842)
What is wrong with her?	Community of women see it as "what is wrong with her"? (852)
Detail of body	If I look at the detail there are things I do not like (643)

Higher order codes	Examples of first order codes
	It is too much detail (629)
Body as whole	I try to see the whole and not the detail (652)
Breasts	It would have been a lot worse if I did not have breasts (740) I enjoy my breasts, yes that I look “normal” (745) My body and my breasts are stripped (618)
Ageing	The body has also aged slightly (154)
Expectation of cancer	Suddenly go from having no expectation to having an expectation to develop cancer (786)
BRCA2 Gene	My mother is also BRCA2 positive (5) BRCA2 positive (participant) (5) Suddenly heard about the gene I felt differently (837)
Knowledge	I wanted knowledge (199)
Anticipation anxiety	It is something that fills me with fear and anxiety (400) The build up to the operation is a lot worse (221)
Validation received	It is the wonderful thing of sitting here, it is validated (444) My family did not validate it (444)
Lack of validation	
Shifting barriers	I have shifted a lot of barriers in here (582)
Coping	You have to cope with those (grey areas) (579) “it [Ritalin] makes that I can cope” (1310)
Love	“I try to replace the hurt with the love I experienced” (430) “I searched for that love” (970) Small pictures of love (360)
Music	It is the amazing thing about music, it opens

Higher order codes	Examples of first order codes
	doors 592
Mastectomy	They amputated one breast (12)
Not good enough	I think I fail, grey areas are not really good enough (557, 558)
Perfect pictures and lists	"I have such perfect pictures in my head about how it should be" (487) "I have this perfect list in my head" (275)
Package/package	I received a package from my mother (635) What kind of package do I give to my children (637)
Self-reproach	"I tend to second guess myself" (1139)
Self-doubt	I am not always convinced it was the right decision (573, 574)
Safety	It let me feel safe to continue (586)
Hope	Here hope is back (656) Hope vanished, hope was taken away by fear (655) Butterfly is a symbol of hope (654)
Life	"I want life to carry on" (670) "growth and life is what I choose" (677)
Death	"is death ever going to leave me?" (392) "I have an unfounded irrational fear of death" (398) "The reality of the meaning of it all was close to me: breast cancer, the gene, death" (389)
Mortality	"I was confronted with her mortality" (427)
Protection of self	"you pull the ring around you tighter to protect yourself" (352) I think it is about survival (314)
Being OK/not being OK	It is not OK that I am not OK (1224).

Higher order codes	Examples of first order codes
Survival	I survived (657)
Journey	"I think my journey is an inner journey" (670)
Becoming aware of self	"I become aware of who I am" (884)
Fear	Hope was taken away by fear (655)
Identity	"you redefine yourself with people who had cancer" (216)
Gratitude	"I am once again thankful for the opportunity here" (433) "It made me realise how much I had to be thankful for" (744) "I am thankful that happened to me" (832)
Depth	"you cannot go through these things and not develop a new dimension of depth" (684)
Change	"everything has changed" (622)
Doubt	"Now I have fear and I have doubt" (782)
Distrust	"I think I am a bit 'mistrusting' of people" (277) "I do not trust doctors" (928)
Disappointment	"It was a disappointment for me that there is not a support group" (197) My sisters were absent (407)
Hostility	"I think people experience me as hostile" (847)
Complicated	"it's too much detail, it gets complicated" (630)
Emotional difficulty	it is an emotional thing, as you say, suffer in silence (141)
Inner struggle	The struggle is in your head (647)
Shame	"I do not know why it bothers me so, 'you have no reason to be ashamed'" (1158-1159)
Withdrawal	"I withdraw a little bit" (848)

Higher order codes	Examples of first order codes
Loss	"it is a loss" (340) "loss of loved ones" (370)
Anger	"I am especially angry with my two sisters in the medical field" (450)
Exhaustion	"it is incredibly exhausting" (1298) "People exhaust me" (260)
Cancer as reality	"the reality of the meaning of all was close to me, breast cancer, the gene death" (389-390)
Disruption	"a year and a half my house fell down and I cannot rebuild it" (1132-1133)
Betrayal	In regards with my body, it is a betrayal (615)
Fragile	We are all a bit fragile (624)
Rejection	"it made me feel incredibly lonely, rejection, on my own..." (351) I almost felt that I never belonged (989)
Abandonment	"you have left me" (354) My sisters were absent (407)
Breast cancer	There was cancer in that breast as well (15)
Unexpectedness	[cancer] was not on radar (32)
Personality type	I have this type of personality, I like to get a thing done (60)
Control	I like to control (251) It is difficult for me not to be in control (436)
Growth	In this pain, there is growth (263)
Disconnection	I think I did disconnect (311, 312)
Someone that understands/ listens	Wonderful to hear that someone understands (322)
Loneliness	I always felt lonely (342)

Higher order codes	Examples of first order codes
Shock	It is a shock every time I see her (422)
Anorexia Nervosa	I was a little chubby and started to lose weight (467)
Bulimia Nervosa	It then changed to Bulimia (468)

4.9 Identifying Sub-themes

Further patterns in the data were recognised and were labelled by grouping the higher order codes into sub-themes. The higher order codes were transferred to separate paper clippings and were arranged and re-arranged to develop the separate sub-themes by continuous reflection on the data (see **Table 4-8**).

Table 4-8: Summary of sub-themes and higher order codes

Sub Themes	Higher order codes
Relationship with mother	Genetic connection Support to mother Lack of support from mother
Mourning the loss of her aunt	Emotional mother Abandonment by aunt Relationship with aunt Death of her aunt
Relationship with family of origin	Relationship with siblings Relationship with her family of origin Separation from family of origin
Relationship with nuclear family circle	Connection to husband Genetic connection with children Emotional connection with Children Connection with husband and children
Disconnection from community	Lack of support Being visible

Sub Themes	Higher order codes
	Being separate What is wrong with her Disconnection
Perceptions of body	Detail of body Body as a whole Breasts Ageing Mastectomy
Eating disorder	Anorexia nervosa Bulimia nervosa
Health	Longevity Death sentence Expectation of cancer BRCA2 gene Breast cancer
Need for support	Knowledge Anticipation anxiety
Support received	Validation Shifting barriers Coping Love Therapy
Sense of belonging	Someone that understands Someone that listens
Music	Music can be silence Music makes me quiet
Control	Not good enough Losing control Perfect pictures/lists Package/package Self-reproach

Sub Themes	Higher order codes
	Self-doubt Anxiety Unexpectedness of cancer Personality type Coping
Existential impact	Safety Hope Life Death Mortality Protection of self Being OK/not being OK Survival Journey Becoming aware of self Fear Identity Gratitude Depth Change Growth Betrayal Love
Emotional pain	Doubt Distrust Disappointment Hostility Complicated Emotional difficulty Inner struggle Shame Blame Loneliness

Sub Themes	Higher order codes
Trauma	Withdrawal Loss Anger Pain Exhaustion Cancer as reality Disruption Fragile Rejection Abandonment Shock

4.10 Development of Themes

Candidate themes were developed by further interpretation of the data and searching for connected meanings, while still recognising the differences between aspects of the data. The collated coded data were studied continually to see if there are coherent patterns linking them with the themes. A mind map was created with the possible themes and sub-themes. The data sets were reread to see if the candidate themes were coherent with the data. Attention was paid to recognising latent and manifest themes in the data. Latent themes refer to themes that are implied in the data and manifest themes are evident from the data without the need to make inferences (Joffe & Yardley, 2004). New codes were added as they were recognised during this process and were added to the sub-themes and finally the themes. The themes were finally named by formulating a descriptive term reflecting the essence of the themes and encompassing the sub-themes as they were organised under the themes (see **Table 4-9**). A synopsis of the hierarchy of the themes, sub-themes and higher order codes is shown in **Table 4-10**.

Table 4-9: Themes and sub-themes

Themes	Sub-themes
Sense of connectedness	Relationship with mother Mourning the loss of her aunt Relationship with nuclear family circle

	Relationship with family or origin Disconnection from community
Body image	Perceptions of body Eating disorder Health BRCA2 gene
Personal experience of therapy	Music Sense of belonging Support received Need for support
Existential authenticity	Control Existential impact Trauma Emotional pain

Table 4-10: Hierarchy of themes and subthemes and higher-order codes

Themes	Sub-themes	Higher-order codes
Sense of connectedness	Relationship with mother	Genetic connection
		Support to mother
		Lack of support from mother
	Mourning the loss of her aunt	Emotional mother
		Abandonment by aunt
		Relationship with aunt
		Death of her aunt
	Relationship with nuclear family circle	Connection to husband
		Genetic connection with children
		Emotional connection with children
		Children
	Relationship with family or origin	Connection with husband and children
		Relationship with siblings

Themes	Sub-themes	Higher-order codes
		Relationship with her family of origin
		Separation from family of origin
	Disconnection from community	Lack of support
		Being visible
		Being separate
		What is wrong with her
		Disconnection
Body image	Perceptions of body	Detail of body
		Body as a whole
		Breasts
		Ageing
		Mastectomy
		Body too unique
	Eating disorder	Anorexia nervosa
		Bulimia nervosa
	Health	Longevity
		Death sentence
		Expectation of cancer
		BRCA 2 gene
		Breast cancer
Personal experience of therapy	Sense of belonging	Someone that understands
		Someone that listens
	Support received	Validation
		Shifting barriers
		Coping
		Love
		Therapy
	Need for support	Knowledge
		Anticipation anxiety
	Music	Music can be silence
		Music makes me quiet
Existential authenticity	Control	Not good enough
		Losing control
		Perfect pictures/lists
		Package/package
		Self-reproach
		Self-doubt
		Anxiety
		Unexpectedness of cancer
		Personality type
		Coping
	Existential impact	Safety

Themes	Sub-themes	Higher-order codes
		Hope
		Life
		Death
		Mortality
		Protection of self
		Being OK/ not being OK
		Survival
		Journey
		Becoming aware of self
		Fear
		Identity
		Gratitude
		Depth
		Change
		Growth
		Betrayal
		Love
	Emotional pain	Doubt
		Distrust
		Disappointment
		Hostility
		Complicated
		Emotional difficulty
		Inner struggle
		Shame
		Blame
		Loneliness
	Trauma	Withdrawal
		Loss
		Anger
		Pain
		Exhaustion
		Cancer as reality
		Disruption
		Fragile
		Rejection
		Abandonment
		Shock
		Rejection

4.11 Analysis of the Quantitative Data

The quantitative data were analysed as described in chapter three under section 3.10.1. **Table 4-11** is a summary of the results of the pre- and post- tests with a brief interpretation.

Table 4-11: Q-score summary

Item	Pre-intervention Score	Post-intervention Score	Numeric Difference and Interpretation
Satisfaction with breasts	53	59	Plus 6 Small positive change
Satisfaction with Outcome	67	67	Zero No change
Psycho-social Well-being	92	57	Minus 35 Large negative change
Sexual Well-being	67	63	Minus 4 Small negative change
Physical Well-being: Chest	74	85	Plus 11 Moderate positive change

4.12 Conclusion

This section presented a description of the processes followed for data analysis and a summary of the results. The participant was introduced in context to the study. A few comments about self-disclosure and the reflective practices followed during the research were made. Further elaboration on the data sources was provided. The thematic coding process, and the development of higher order codes, sub-themes and main themes were discussed with relevant examples from the data. The quantitative data analysis and results were presented in the last section of this chapter.

Chapter five will present the main themes and the research questions and will discuss the main themes and the relevant subthemes, with references to the data. The qualitative and quantitative results are integrated at the end of the next chapter.

5 Chapter Five: Discussion

5.1 Introduction

This chapter presents a summary of the research questions and discusses the themes which emerged from the qualitative data analysis. Reference is made to sub-themes and relevant codes and each theme is illustrated and supported with quotations from the translated transcript from each qualitative data set. The quantitative data is integrated in the discussion where the findings pertain to a certain theme. The discussion is anchored on the following four themes: personal experience with therapy; body image; sense of connectedness; and existential authenticity. The variety of music therapy techniques used, helped the client find the freedom to tell her story. This discussion focuses on the client's narrative as it emerged during the sessions, as well as her own and the therapist's reflections on the subconscious negotiation of meaning during the music therapy process.

5.2 Research Questions

This research was guided by the following questions:

1. What role can music therapy play in improving the body image of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

2. What role can music therapy play in addressing interpersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

3. What role can music therapy play in addressing intrapersonal connectedness of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction?

5.3 Synopsis of the main themes, sub themes and quantitative data

Table 5-1: gives a synopsis of the main themes and sub-themes that evolved during the thematic analysis of the data as described in the previous chapter. **Error! Reference source not found.** shows the summary of the study's quantitative results.

Table 5-1: Summary of themes and sub-themes

Themes	Sub-themes
Personal experience of therapy	Music Sense of belonging Support received Need for support Growth
Body image	Perceptions of body Eating disorder Health BRCA2 gene
Sense of connectedness	Relationship with mother Relationship with aunt Relationship with close family circle Relationship with family of origin Disconnection from community
Existential authenticity	Intrapersonal connectedness Control Existential impact Trauma Emotional pain

Table 5-2: Summary of quantitative data

Item	Pre-intervention Score	Post-intervention Score	Numeric Difference and Interpretation
Satisfaction with breasts	53	59	Plus 6 Little positive change
Satisfaction with Outcome	67	67	Zero No change
Psycho-social Well-being	92	57	Minus 35 Large negative change

Sexual Well-being	67	63	Minus 4 Little negative change
Physical Well-being: Chest	74	85	Plus 11 Moderate positive change

5.4 Theme 1: Personal Experience of Therapy

5.4.1 Introduction

This section consists of two outlines: firstly, a summary of the participant's own therapeutic journey which started with trying to better understand herself as an anorexic teenager, followed by her experience of her mother's diagnosis with cancer and her subsequent discovery of her own acute vulnerability through the BRCA2 gene which she inherited.

Secondly, an outline is given of the unique way in which music therapy complements developmental and neurological processes in a person. The description of the techniques used and brief examples of its utilization are discussed. The themes and sub-themes identified during the qualitative analysis are situated within the music therapy context and are weaved into the narrative of the following sections.

5.4.2 The need for therapy

Michelle experienced a need for emotional support as soon as she was informed of her BRCA2 status. She wanted to empower herself with the knowledge to make the right decisions and to prepare herself emotionally for the procedure. She was disappointed to learn that a group specifically for women with a high hereditary risk for developing breast or ovarian cancer did not exist in the Western Cape. In retrospect, she said, the time leading up to the operation was the most anxiety provoking and a significant deal of the anticipatory fear she felt, could have been relieved by a discussion with an informed peer.

To take responsibility for her own well-being is congruent with her character. As a young woman, when she had a life-threatening relapse of anorexia nervosa, Michelle went for treatment of her own accord. She described herself as somebody who always

searched for the right solutions (line 475-478). She never accepted that she had to be the way she was and always strived to grow in self-awareness and self-knowledge. In terms of existentialism the quest to see the positive and the negative in all situations and to use it to facilitate growth is the hallmark of authentic living (Thompson 2007).

5.4.3 Music therapy techniques

A receptive music therapy technique was used during the first session. Bruscia (2014) defines receptive methods in music therapy as leading to experiences where the client is requested to listen to music (both pre-recorded and live performances of pre-composed, self-composed or improvised music) and to respond in an appropriate manner. The listening experience can focus on different aspects of the music provided: emotional; spiritual; intellectual, and aesthetic. The client can respond verbally to the music or through another creative modality such as art, dance, creative writing, painting, clay sculpturing or movement (Bruscia, 2014, location 2981).

The planned structure of session one (see Appendix N: Session Plans) was adapted as the session developed. What transpired early was that Michelle had the desire to talk about her history related to breast cancer. The therapist sensed the importance of keeping the narrative flowing, as this was deemed as the first step in building trust and rapport with the participant.

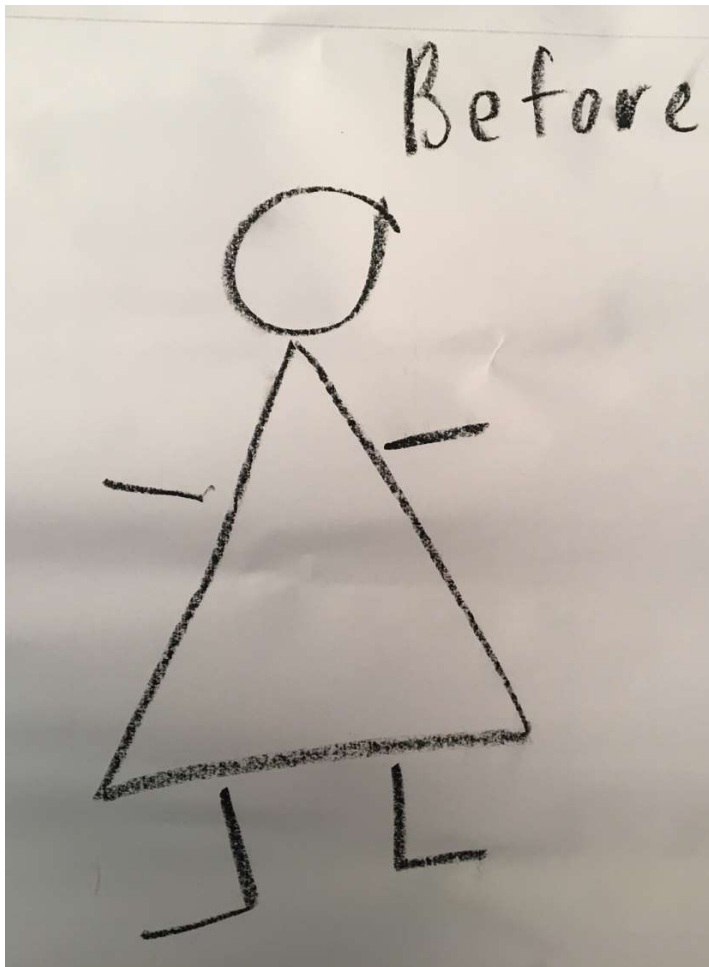
Michelle was emotionally upset when she related her experiences with familial breast cancer, the BRCA2 gene, and the bilateral prophylactic mastectomy with breast reconstruction. She spoke about disruption, loneliness, disappointment, loss and fear she experienced. These codes are discussed under section 5.8.4 dealing with existential trauma.

In the week leading up to the session, the therapist invited Michelle to supply her with the titles of music she found supportive during the crisis. She chose the Mozart piano concerto number 9 K 271, "Jeunnehomme" (Shiff et al, 1995, Tracks 1, 2 & 3). This composition was then used as part of the receptive music therapy technique, aimed at reminding her of the supportive role it has played during the breast cancer trauma. She was requested to create, while the music played, images of herself before and after the operation. She was free to use an art modality of her choice. As previously, the music induced feelings of comfort and safety, and she said that during times of anxiety, the concerto created a sense of inner quiet and calm. According to her, this music helped her

to overcome exhaustion and curb negative rumination. She was able to verbalise that there was growth in the pain and that she gained self-knowledge (line 263). This is further highlighted under section 5.8.4.

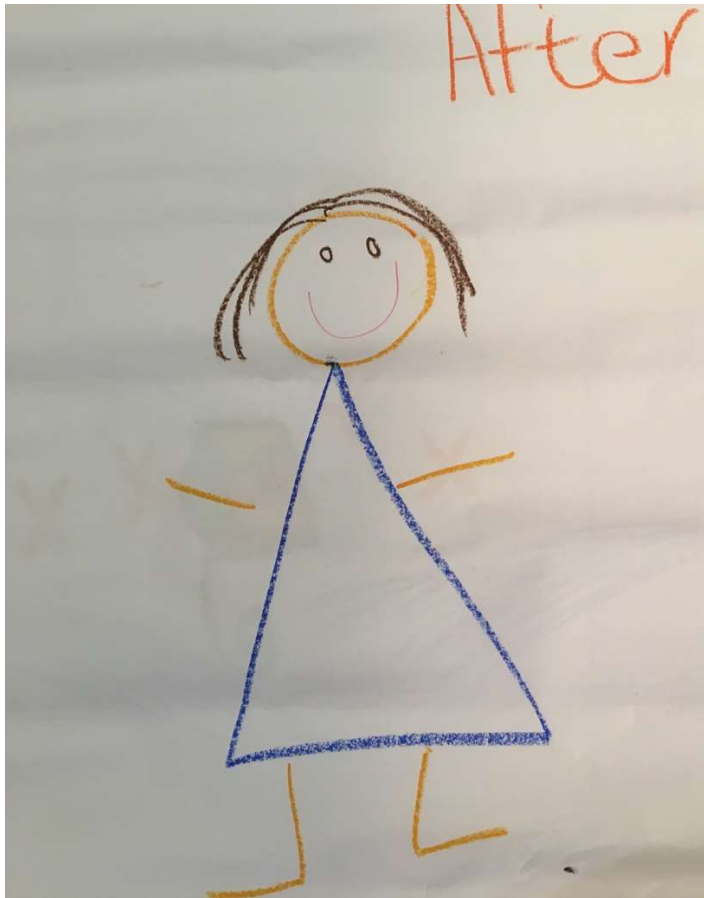
The following images (**Figure 5-1** and **Figure 5-2**) were conjured by the music:

Figure 5-1: Drawing before surgery after BRCA2 diagnosis



Michelle explained this drawing as an illustration of how she felt after her diagnosis with the gene. Everything seemed black and she felt betrayed by her body and feared it (line 270). This is highlighted further under section 5.5.2.

Figure 5-2: Drawing post-surgery.



She explained the post-surgery image as a picture of a lighter self; yet she still perceived herself as changed by the whole crisis and had a measure of residual fear about developing breast cancer (lines 272-273).

Free instrumental improvisation was introduced as part of the second and all subsequent sessions. This is an important part of the therapeutic process, because it has the potential to create an intersubjective relationship. The importance of this becomes clear once you understand the primal function this had early on in our life when as infant we communicated nonverbally with our mother. Stern (1985) noted that since verbal communication between a mother and her infant is not possible, they rely on a different mode of communication. This is enabled by the mirror neuron system in the forebrain. The transitional space between mother and infant described by Winnicott (as cited by Trevarthen, 1979) can also be called an intersubjective relationship. With “intersubjectivity” Trevarthen alluded to the ability of the mother and the infant to communicate and understand one another’s internal states (Trevarthen, 1979).

Malloch and Trevarthen (2000, 2009) described how mother-infant dyads relate using elements of music. They came up with the concept of “communicative musicality” as they found that the narratives between a mother and infant consist of rhythmic patterns of pitch, timbre and melody. Mothers and infants do not only use sound in this way, but also their movements, gestures and facial expressions (Birnbaum, 2014; Pavlicevic, 1997; Trevartin & Malloch, 2000). A mother would attempt to comprehend her infant’s internal state by reading his voice, facial expressions and movements as a musical phrase, and would communicate to the baby that she understood by adapting her own voice, facial expressions and movements. Stern referred to this reciprocal process as “affect attunement” (Pavlicevic, 1997). The origin of this empathic process lies in the mirror neuron system that allows the brain of an observer to activate the mirror neuron system in the brain of the person observed. The receptive and motor neurons involved in the process are linked to the centres in the brain that regulate affect. It is therefore possible to experience another person’s inner state by “reading” his movement (and sound), and also to influence another’s affective state through own movements and sounds (Behrends, Müller, & Dziobek, 2012; Gratier, 2003; Valdesolo & De Steno, 2011). Stern (2010) referred to these cross-modal emotion-movement complexes as “vitality affects”, coupling kinetic forms to affect. The quality of a person’s movements reveals the nature of the emotion experienced. Pavlicevic (1997) describes the fluid exchange of emotion in different modalities like movement, facial expressions or vocalizations as “dynamic forms”. These are abstract representations and humans can respond to one another using different modes of expression (Birnbaum, 2014).

The ability to respond to music is an inborn human trait (Ansdell, 2000). Trevarthen and Malloch (2000) draw our attention to the fact that music is more than “non-verbal” or “pre-verbal”. Music is therapeutic, not only because it speaks to pre-verbal or non-verbal areas in our brain. Musicality is an inborn trait of humans that fosters relationship and empathy (the experience of another’s emotional state) by co-creating expressive sound and movement in time.

The therapeutic stance in creative music therapy is the humanistic principle that the therapist and the client are equals in a relationship where the client is held in absolute positive regard (Spinelli, 1994). In the therapeutic situation, play is a joint creation of the client and the therapist. A safe environment for the client in which to play, must be created. Pavlicevic (1997) stated, in music therapy terms, that the music therapist must create the safety for the client to express herself musically through improvisation. The therapist must be able to understand the dynamic form of the client’s playing and respond to it in a

meaningful way, so that the client comprehends that she is understood and is able to reciprocate through music. This is the basis for the development of a safe intersubjective relationship between client and therapist. The dynamic form of music and its ability to establish emotional attunement, makes it ideal for offering safety on a subconscious and non-verbal level. Michelle initially found improvisation intimidating and daunting, as she believed she had a limited aptitude for making music: "I am not very musical" (Video 2B 13 min) and "making music with instruments is out of my comfort zone" (Video 3A 10 min 29 sec).

However, she displayed willingness to take risks and felt freer in active music making with each progressive session. She approached the first drumming improvisation in session two with reserved openness. Her drum playing, initially, was timid and she preferred rubbing the skin of the drum to hitting it. The sound of this action reminded her of the sounds of the sea and of rain and she said that it made her feel calm. She was willing to take risks during call and response drumming techniques and introduced new rhythmic material and even her voice during a drumming and vocal dialogue. In due course, she became more confident and played a bigger variety of tempo's, rhythms and dynamic levels. During session three she said that she felt less inhibited in playing.

Her sound preferences in general were gentle, clear, sparse sounds. This was evident from her comments and her style of playing in session two during a drum and alto metallophone improvisation. She used the whole range of the metallophone while the therapist provided sparse rhythmic support on a djembe drum at a piano dynamic level. She improvised a flowing, wistful melody, listening intently to the sound of the instrument, commenting that the clear sounds were beautiful (Video 2B 12 minutes). Her confidence increased during the improvisation and she and the therapist engaged in a two-way humorous musical interplay towards the end of the improvisation.

The reciprocal sharing of an affective state during mirror movement, as negotiated between Michelle and the therapist, allowed her to exercise control on the one hand, and experience the therapist's empathy on the other hand, as the therapist carefully moved with her to the music. Her movements became more confident as the sessions progressed. She imitated a tree during a storm in session four, starting with small swinging movements, increasing the amplitude of movement to encompass the full range of her arms and ending with a relaxed stance after slowing down gradually. Her comment was that the trees survived the storm and that she enjoyed relating a story with her body.

The area in which Michelle showed the most growth was with the use of her voice. In session four, she claimed that she sang out of tune when, in fact, she had a pure, rich voice and controlled the pitch of her singing well. She was very reluctant to sing and the therapist decided to provide more safety by using a recording of native American vocalisations by a female singer to facilitate the vocal experience as they both sang with the pre-recorded music. At first her posture was very rigid with her arms crossed against her chest and she sat motionless as she and the researcher sang. Her confidence increased rapidly and she was soon moving her body in time with the music and later joined the therapist playing the drum while they sang. She smiled after the recording ended and said that she really enjoyed it and that music therapy was a gift to herself. The therapist repeated this technique with each session and Michelle sang with increasing abandonment, accompanied by relaxed movement. In session five she and the therapist sang together and she mentioned that she really enjoyed it and that she felt freer and unguarded. It is significant that she requested a recording of the piece. She wanted to sing with it at home during the time between the sessions. The mirror movement techniques used in these sessions, facilitated increasing trust and emotional intimacy.

5.4.4 Journey of therapy

“My genetic results opened a dark side of my being. The music therapy opened a light positive side to my being” (lines 14-16 Qualitative data source B) With these words Michelle summarised the journey on which six sessions of music therapy took her. She herself must also be given credit for the fact that she embraced the therapy with dedication, sincerity and honesty. From her side, she did everything possible to make this an intersubjective success. Her resilience and her decision to make this journey a positive experience, in which her pain supports personal growth and gives new depth, is the most significant factor in the outcome of her narrative. She said the following in session two: “There is still hope, I think I can grow past cancer” (line 824).

Increased openness in Michelle to engage in the music therapy techniques was facilitated by a reciprocal relation between music therapy processes and verbal reflection about what transpired in them. This was due to the fact that quite early in the therapy process Michelle started to experience a feeling of safety, and a trust in the music and the researcher developed. This was true for the whole process. She later on commented that she felt safe and understood and experienced empathy throughout the study period. She referred to Music Therapy as a safe space where she could confront her “overwhelming” fear and make it part of her journey to healing, rather than fighting it.

As the process continued, her barriers shifted and she exhibited a growing willingness to listen to more confrontational music. The root of this new openness can be found in an often-stated wonderment that she felt her feelings validated during the research period. She expressed that she experienced safety, that it was easy to communicate with the researcher, and that she felt supported. The researcher, being a medical practitioner too, could answer some of Michelle's medical questions. This gave her some comfort as she felt she could trust the researcher despite the fact that she came from the medical fraternity (see under heading 5.5.5). The progression in trust and her increased sense of confidence was noticeable on different levels: she became more confident in sharing hopelessness, despair and feelings of loss on an emotional and intellectual level. She also became more tolerant of unknown music and allowed herself to express the evoked images and emotions creatively through art and experimentation with different ways of being in the music space. This was especially evident during free improvisation. She became able to add nuances to her playing by altering dynamic levels and by experimenting with different musical instruments, in contrast to her initial timid and rigid playing.

Where she initially only experienced the calming of her anxiety in the Mozart piano concerto number nine, K 271 "Jeunnehomme" (Shiff et al, 1995, Tracks 1, 2 & 3) she had the same experience in session four with a drumming improvisation. And she talked about the way in which the music helped her to shift barriers. In her own words:

I have shifted a lot of barriers in here; for me to write was, if you asked before I would have said 'no, nothing will come, nothing will flow'. I really felt I could let go today [during the drumming improvisation]. It is that wonderful thing of 'it is fine' [her playing], and that being fine let me feel safe to continue, because I did not sit there and nothing came. It is great, thank you. (lines 582-587)

She also said: "It is the amazing thing about music - it opens door to things that were locked away" (lines 592-593).

The music really opened doors to things that were locked away in her subconscious. Some of the themes tabulated under heading 5.3 easily came to the fore, but others emerged with more difficulty. Themes like growth and hope readily made themselves known. Others, like her unhappiness with her body image struggled to emerge.

5.4.5 Conclusion

The different music therapy techniques used each contributed to the overall opening up of Michelle's deep-seated struggle to find herself and to live with what has happened in her life. They created the platform from which she and the therapist could work together in letting the music play a revealing role in her life. The following sections discuss the themes that presented themselves in Michelle's narration and will further explore this therapeutic process. The first research question, what role music therapy can play in improving the body image of a woman who has undergone a bilateral prophylactic mastectomy and breast reconstruction, is the focus of the next session.

5.5 Theme 2: Body image

5.5.1 Introduction

Body image is defined as "a person's perceptions, thought and feeling about his or her body" (Grogan, 2007). This definition is further described under section 2.2 of the literature review. This section seeks to answer the first research question by describing the second theme and its subthemes, namely: Michelle's perceptions of and her relationship with her body; the BRCA2 gene; and her journey with an eating disorder. This is supported with relevant quotations from the thick descriptions of the video footage.

5.5.2 Perceptions Related to her Body

During session three Michelle was asked to choose how she wanted to represent her relationship with her body. A receptive music therapy technique was used to anchor her in the present. She listened to the pieces shown in **Error! Reference source not found.:**

Table 5-3: Session 3 playlist

Name and Composer	Album	Artist
Piano Concerto No 1 In E Minor. Op. 11. 2 nd movement, Romance F. Chopin:	Chopin: Piano Concertos No 1 & 2	Pavel Kowalski, Chopin Academia Orchestra
Carmina Burana: "In trutina" Carl Orff	Pure	Hayley Westenra, Royal Philharmonic Orchestra.
Lakmé, Act 1 Flower Duet: Leo Delibes	40 Most Beautiful Arias	Hei-Kyung Hong, Jennifer Larmore, Bayerisches Staatsorchester
Beautiful	7th Symphony	Apocalyptica
The Eagle Watches	Peacemaker's Journey	Joanne Shenandoah

Michelle's artistic reaction was a poignant poem about her relationship with her body (see **Figure 5-3** and **Figure 5-4** for translation) as a lifelong journey. She stated that the perfect body was "the body you are at home in". In the poem, she asked whether such a journey ever ends. The Poem:

Figure 5-3: Poem about relationship with body

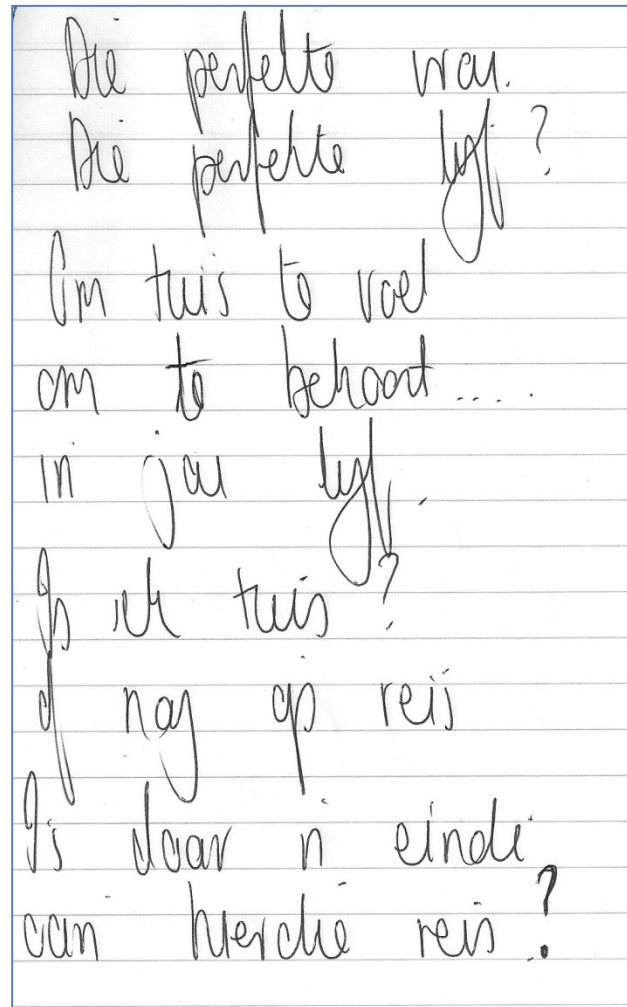


Figure 5-4: Translation of the poem:

The perfect body?
The perfect woman
To feel at home
To belong
In your body
Am I home?
Or still on the journey
Is there an end
To this journey?

She adds:

The operation did not start this journey, it started long ago. To a certain extent, it made it easier for me that this journey started long ago. It wasn't there, no searching, then suddenly... it was nothing new. This journey started long ago and maybe it turned a bit from west to east, so for me that was not an incredibly difficult thing. (lines 501-506)

Discontent with her body started with her discovery as a young prepubescent girl that she was different from her friends in the sense that she was slightly overweight (lines 451-459). This discovery culminated in a serious eating disorder, which will be discussed later in this section. Now, as an adult woman, she looks at her body with ambivalence.

It is important how I feel in my body. So if I feel good in my body and I feel in control then so is everything else. If I lose control over my body then everything becomes ugly. Then I become...when I was OK with my body, I was OK with my breasts. When I put on extra weight and have an extra roll here, then I begin to feel uncomfortable and I don't like it then everything is ugly for me. Suddenly I see the wrinkling of the prosthesis and I do not like it. But when I succeed in losing a little weight then I am more comfortable and it has nothing to do with what I think or others think I look. Then I am more comfortable in my body and suddenly it is fine, OK. Everything is in my head. When I was on holiday I lost weight...after the holiday I gained weight and I used Lexamil that definitely made me gain weight. I threw it away quickly. I lost weight well over the holiday but now that the anxiety and stress is here I am gaining it again. Now that is an evil cycle: you eat for anxiety and I told you I suffered for years from bulimia, and it comes back, now suddenly my world falls apart. (lines 1248-1264)

On the one hand, the overall appearance of her body was acceptable to her, and had been for a long time. On the other hand, she was upset by the changes to her body that was brought about by the bilateral prophylactic mastectomy and the subsequent prophylactic oophorectomy that caused sudden menopause and necessitated hormone replacement (lines 145-154; 575-578). She tried to balance out this ambivalence by focusing on the positive aspects of her body: she is healthy, her chest is not flat as she

still has breasts, and her body can still move and exercise, which is something she enjoyed immensely (line 725). However, even these sentiments were tinged with contradiction:

Yes, my body is healthy enough and I can move, I can move and I enjoy a jog on the farms. That is important to me. I enjoy it: If my body did not feel healthy, I would not have been able to that. I try to not only focus on my body as being only my breasts, but the fact that I am *more flabby is less enjoyable to me*. It is less comfortable, but I must simply accept it. (lines 732-736)

Her attempts to convince herself to be thankful that she did not have cancer and needed not to worry about her looks, even though she did not look the same as before, was sometimes expressed as self-reproach – something she wanted to “punish” herself for (lines 538-544).

Her postoperative body image, as evaluated by the first instalment of the Breast-Q© questionnaire, was marginally better than the score of the test completed after the six music therapy sessions. As therapy progressed, she became progressively able to express her concerns about her body. In session four she expressed the wish for her body to look the way it did before the operation, she did not want to look visibly different (line 699). The accelerated ageing and subsequent wrinkling of her stomach bothered her. She also struggled to maintain her weight. This coloured her view of her body significantly. Her sense of connectedness with her body depended on how it looked:

It depends on how my body is physically. So, for me, if I put on weight – after the operation I had the paunch and the wrinkling...so I do not look at the wrinkling. I try to keep my weight constant so that here... [touches her stomach] and when I feel it, I feel disconnected, loathesome, disgusting but if I don't feel it, then it is ...I gained weight after the operation and that was tough for me. Because every time I looked in the mirror and dressed that is what I saw, not necessarily the breasts. I saw the weight and did not like myself with the extra weight not how I felt in my clothes. I managed to lose a little of the weight, but I realized I am an emotional eater now that school pressure started I can feel I am losing control and it makes me feel negative about my body. (lines 508-520)

After a vigorous drumming improvisation, she used strong emotive language when she spoke about weight gain, using words such as “disconnection”, “loathing”, “disgust”, and “ugly”. Later, she also mentioned that she found it difficult to make peace with the fact that her body was different and that this might have been visible to other people (lines 685-903). She wished that her body were invisible and she did not want to see the detail of her body, because it was too difficult to deal with (lines 641-643). This sentiment was strongly linked to avoidance of thoughts about the detail of the genetic connection between her and her children and the fact that they could have inherited the mutant BRCA2 gene (lines 634-641).

5.5.3 Breasts

At the outset of therapy, Michelle was positive about her breasts, albeit with the acknowledgement during the first session that she was not somebody who consciously looked at her breasts:

I must say, now that it is not painful anymore, it is easier for me to accept it. Or not to accept it [pause], but it does not feel quite so external; it does not feel something odd to my body. I got used to my body, and when I sit like this [she sits with her arms folded at the elbows, forearms parallel to each other, flat on the surface of the table], it does not feel foreign. It is only when I press against it [she touches both breast with the flat palms of her hands] that I feel that it does not feel like my breasts, it feels foreign. But when I sit like this [hands flat on table as earlier described], then it is not, then it does not bother me They do not look the same, there is an oddness. It is not that I do not look consciously, I am fortunately just not someone who looks too much [she points to her breasts]. (lines 172-182)

Michelle was thankful that she was not flat-chested like her mother, whose appearance without her prostheses was a stark reminder of how she could have looked:

It would have been a lot worse if I did not have breasts, so yes ... I see it every day with my mother, because she does not wear her breasts. I see it and I realize, yes, if I look at my prostheses. It would have been terrible not to have breasts, then everything would have been black. It makes me realize how much I have to be thankful for. So

thankfulness ... I enjoy my breasts. Yes, in *that I look normal*. (lines 740-745)

She was also thankful that she was able to retain her own nipples. The viability of preserving her nipples was in question before the surgery, as the blood flow to her nipples could have been compromised by a mamma reduction (reducing the size of her breasts) she had had many years ago, but fortunately this proved not to be the case (lines 183-187). Different layers of her perception of her breasts were uncovered as the music therapy progressed. Initially she said that, since she does not have pain anymore, her breasts do not feel foreign (lines 172-176). She commented that her two reconstructed breasts looked different from one another and that the right one was more beautiful and looked more natural than the other. She had a complication after the reconstruction of the one breast and underwent a second procedure which compromised the natural shape of the breast. Later, she iterated that her breasts did not feel foreign anymore and that she had accepted them, and that she was thankful for what she had, even though there was an indentation above the one breast. She mentioned that a person is not defined by her breasts alone (lines 943-951). Just prior to this, she wanted to know if the researcher thought people could see that she did not have real breasts. Michelle could not see the difference, but was perplexed because she did not know if other people could see that the breasts were reconstructed (lines 939-942). As the sessions progressed, more ambivalence, concerns, and negative feelings towards her breasts emerged. In contrast to earlier statements, she said that her breasts did not look natural but artificial, and that they did not move and that they felt foreign to her body (lines 485-486; 757-759). Her surgeon offered her the option of further surgical procedures to address these concerns. However, she did not know whether it was worth the trauma and another period of convalescence since she had fully recovered after the prophylactic mastectomy. Michelle's feelings about her body and breasts could be the embodiment of the feeling of betrayal she experienced after the BRCA2 diagnosis (**Table 4-4**).

According to MacLachlan (as cited in Piot –Ziegler, Sassi, Raffoul & Delaloye, 2010, p. 481):

...embodiment is the identification of an abstract idea with a physical identity. The abstract idea could be the self, a nation, love, god the devil or whatever. When such ideas are identified in the flesh, we say they are incarnate....

Therapeutic opportunities such as mirror movement, improvisation and vocalization to experience her body differently through music were provided after this discussion. This enabled her to more eloquently express her feelings of ambivalence towards her body and breasts, and the betrayal she experienced.

Her perception of her body as unique (different) and conspicuous extended to her breasts and she once again exhibited ambivalence about appearing in public with her breasts not well covered. She joined a swimming class after the operation. She did not feel unduly exposed in her bathing suit and surmised that the other women might want to see what her breasts looked like, whether they looked “normal”, yet she was not very concerned about this (lines 716-719). However, her first visit to a gymnasium caused her much distress. She was anxious about the possibility that her breasts might behave unnaturally (abnormal movement or wrinkling of the prostheses) and that people might be able to see this (lines 1144-1146).

Her level of comfort with her body in her intimate relationship with her husband did not change significantly. He did not make any comment and did not indicate that he was uncomfortable with the way she looked. She never felt the need to cover her breasts when she was naked in his company. This can be viewed as a testament to his support and acceptance and the strength of their relationship (van Oostrom, Meijers-Heijboer, Duivenvoorden, Bocker-Vriends, van Asperen, Sijmons, Seynave, Van Gool, Klijn, and Tibben, 2007). Michelle commented as follows on this aspect: “Perfect body to me is the one you feel at home in” (line 490). She further said:

So, in a space of my choice I am comfortable. I made the choice and I do not know how comfortable my husband is, but he does not appear uncomfortable, but I am comfortable in front of him. I do not feel I must cover up or hide or ... no, if I want to camouflage myself – I do not think so. (lines 718-722)

5.5.4 The BRCA2 gene

When she was diagnosed with the BRCA2 mutated gene, it heralded a new milestone in Michelle’s lifelong struggle with accepting her body. The mutated gene carries the following significance: an up to 85% increased risk of developing breast cancer and a 10-30% increased risk of developing ovarian cancer (Armstrong & Evans, 2014); breast cancers that are often bilateral (as was the case with Michelle’s mother); and earlier onset

of breast cancer. Later generations affected by the mutated gene tend to develop breast and ovarian cancer at a younger age than their ancestors. Although breast cancer under the age of 25 is unusual, it does occur in individuals with the mutated gene (Hamilton, Inella & Bounds, 2015). Michelle referred to this diagnosis as a “bomb shell” (line 74) and a “tsunami” (line 75) that crashed on her after her mother’s illness. Her body, the vessel that holds the genetic future of her children and herself, was handed a “death sentence” (line 81) within a moment. Her expectation of longevity was replaced by the expectation to develop cancer:

I went from believing myself healthy and having a life of longevity and suddenly ... the only thing that changed was the verdict. Now I have fear and doubt. What impact that has on my body just that. It worries me. (lines 780-781)

... Where you suddenly change from having no expectation to having an expectation of developing cancer. I really had not expectation of that before. It played no role in my life. (lines 786-788)

Michelle unfortunately disregarded advice in favour of genetic counselling prior to being tested (lines 65-67). The benefits of genetic counselling include preparing a person for the limitations of the tests, but also for the possible implications of the result. A person would be taken through the possible post-test decision-making steps, should she test positive, which makes the aftermath of receiving positive results easier to process (MacBayer, 2007). Lacking this preparation, Michelle was engulfed by the test result as if by a tsunami.

Despite the fact that her risk of developing breast cancer has been reduced by 90% to 95% after the operation (Armstrong & Evans, 2014), there are other health conditions associated with the gene that concerns Michelle (lines 814-816). After the test, before the operation, Michelle went for genetic counselling. There she learned about other possible complications for her family and herself because of the gene mutation. Cavanagh and Rogers (2015) conducted a meta-analysis and found some evidence that, apart from the increased risk of breast- and ovarian cancer, the BRCA2 gene can be linked to prostate, pancreatic and colorectal cancer. The fact that Michelle could have transmitted the gene to her children caused her much fear and guilt (lines 600-605; 634-637). The surgeon reassured her that, by the time her now six-year old daughter turns 25, and becomes old enough to be tested, the management of the cancer risk might only involve

the administering of oral medication. However, this did not completely alleviate her fear and feelings of guilt.

5.5.5 Health

Michelle perceived herself as healthy before the diagnosis of the BRCA2 gene. She also saw her children's health as strongly connected to her own:

Regarding my body, before the operation, my perception and idea of myself was that I was healthy. My grandmother got to three months short of 100. I always thought my mother would be around forever and I am going to be around forever. Forever, because I look the most like you. You just have...life is good regarding my health and I am healthy. There is a butterfly on... My children are part of me, in other words, they carry my genes. Their health and my health are one. Then the bombshell came, and I feel rather naked, and where do I stand, where do my children stand? The health that is in my body, what role does it play in terms of my children? It is the genetic factors with different components. Suddenly I almost want to separate them from me ... (lines 594-606)

She exercises regularly, does not smoke or use alcohol excessively and follows a healthy diet, but the discovery of the BRCA2 mutated gene has thrown a shadow over her perception of being healthy. Now she is concerned about what to eat, how much to exercise (lines 551-553), and whether or not it was wise to undergo the preventative bilateral prophylactic mastectomy, reconstruction and bilateral oophorectomy (lines 797-804). This inner confusion was brought about by conflicting opinions reported in the popular media and on the internet. Some groups advocated the importance of preventative surgery, while other groups were set against it and cautioned against the use of silicon prosthesis and hormone replacement therapy. She had read it, and in session four mentioned that the mere fact that someone proclaimed the judgement of a possible future cancer diagnosis, could be a contributing factor in developing cancer, due to the stress and the belief in the verdict (line 782). Her distrust of doctors (lines 927-931) and people in general (277; 799) compromised her ability to make decisions about the right path to follow and left her in doubt with regard to whether or not she was doing enough to preserve her health and prevent cancer.

5.5.6 Eating Disorder

Body image concerns are often, though not always, associated with anorexia nervosa, defined by Kaplan and Sadock (2015, p.509) as follows:

Anorexia nervosa is a syndrome characterized by three essential criteria. The first is a self-induced starvation to a significant degree — a behavior. The second is a relentless drive for thinness or a morbid fear of fatness — a psychopathology. The third criterion is the presence of medical signs and symptoms resulting from starvation—a physiological symptomatology. Anorexia nervosa is often, but not always, associated with disturbances of body image, the perception that one is distressingly large despite obvious medical starvation. The distortion of body image *is disturbing when present ... (p.509).*

Disorders such as bulimia nervosa have a stronger association with body image difficulties. Again Kaplan and Sadock (2015, p.518):

Most patients with bulimia nervosa are within their normal weight range, but some may be underweight or overweight. These patients are concerned about their body image and their appearance, worried about how others see them, and concerned about *their sexual attractiveness*.

Both these conditions disturbed Michelle's life for a long time. Anorexia nervosa became a problem from the age of nine until her early twenties. She gained the necessary weight after treatment, but was never free of the disease during this period. The symptoms shifted to that of a predominantly bulimia nervosa picture characterised by overeating followed by purging through self-induced vomiting and excessive exercise (Kaplan & Sadock, 2015).

Michelle showed great courage in overcoming the disease when she had herself admitted to the eating disorder treatment programme at a tertiary provincial hospital (line 476). This proved to be an intervention that literally saved her life (line 1177). She was able to stay well for a long period of time, and it is only during the past few months, with the general unhappiness about her body and her weight gain, that bulimic behaviour resurfaced (lines 162). This was information that she shared in the last session and she confessed that nobody, apart from her other therapist and the researcher knew about it. There is a strong link between the re-emergence of the eating disorder and Michelle's

sense of losing control or being out of control (1266-1272). This is discussed in more detail in section 5.8.1.1.

5.5.7 Conclusion

Did music therapy help Michelle with body image difficulties? In her case the question is even more intriguing because the way she perceives her body always tended to be negative, as her struggle with anorexia nervosa and bulimia nervosa both indicated. To this inclination the prophylactic surgery, resultant hormonal changes, and the dark mistrust in her genetic make-up, added more impetus.

What the music therapy accomplished was firstly, to take away the mask of satisfaction with how she looked after the operation, opening her eyes to her hidden, subconscious, troubling body image. This is a decisive and important first step on the road to making peace with her body. Continued music therapy undoubtedly could assist her with this difficult task.

The second result of the music therapy in this regard was to create a safe environment in which she could be free to explore her feelings and trustingly share her current struggle with bulimia nervosa with the researcher.

This relates to the question whether music therapy could address intrapersonal connectedness. The uncovering of the different layers of Michelle's relationship with her body partly answers that question. This aspect is further explored under section 5.7.1.

The quantitative data concerned with body image illustrated minimal to moderate changes. The score for the satisfaction with her breasts increased minimally from 53 to 59. The test-score for the overall satisfaction with the outcome of the procedure did not change from 67. Her general physical well-being recorded moderate change from 74 to 85, reflecting her enjoyment of the opportunity to exercise regularly.

5.6 Theme 3: Sense of interpersonal connectedness

5.6.1 Introduction

This section deals with aspects of the sense of connectedness as identified from the data analysis. The lived experience of fracture (lines 74-81; 101) in the life of the participant cut her off from important dimensions of connectedness in her life: connection

with the self and her own body (intrapersonal connectedness), (Qualitative data source B lines 1-3, **Table 4-4**); with a living community (interpersonal connectedness), (lines 841-842); connection with life itself (line 780); and connection to a possible future (line 81). Attention is partly given to the last comment in the section on existential authenticity. In contrast with this, her sense of connection with nature (lines 1209-1210) and her nuclear family (husband and children) (lines 1355-1366) were the sustenance for her survival.

5.6.2 Connectedness with Her Family of Origin

Michelle's connection with her family of origin had been complex in the past and she never felt secure and understood as a member of that circle. For example:

I have cut myself from them [family of origin] (line 952) ...I felt a bit like this about my family [of origin], searched for that love, that understanding 'it was terrible what happened to you', but I did not receive it. It is great for me, because I do not search for it from them anymore. It brought about a big change. It is great. (line 970)

She experienced a lack of empathy from her mother (lines 383-385), her siblings (line 92), and her brother-in-law (who is a British specialist breast cancer surgeon), (lines 213-215) when she was diagnosed with the BRCA2 mutated gene (lines 89-93). This deteriorated even more after the after the risk reduction surgery was done (lines 349-352). Her sense of separation from the important people in her life started when she was a small child. This she illustrated poignantly with a drawing made in the fifth session, after a receptive music therapy technique where she listened to the Rachmaninov piano concerto no 3 (Argerich, 1995, Tracks 1, 2 & 3) while drawing the picture shown in **Figure 5-5**. This composition was chosen for its richness, strong melodic and harmonic structure, and the contrasting elements of the music. It evoked deep emotions in Michelle and she was able to express the pain of rejection she was unable to voice up to that point in the therapy process. She was requested to produce an image or symbol that signified disconnectedness and connectedness for her. The green figure on the left represents her nuclear family. The six disconnected circles on the right is a representation of her father and mother, her three siblings, and herself.

Figure 5-5: Drawing symbolising connectedness and disconnectedness.



She drew herself as a colourless circle, in contrast to the brightly coloured spheres representing the rest of her family of origin. She explained the drawing as indicating that she never felt as if she belonged or had a voice. She said the following in session five:

I thought I never really knew who I was in relation to my family. When I found myself, I realized, that I always felt that I never belonged. I did not have my own colour, I did not have my own voice. Once I found my own colour, I realized there was a lot of common ground, but there is also a lot of me that is different. It is OK. I'm happier where I am. It is better for me to be here. For a long time, I felt uncomfortable in relation to my family of origin. I did not know where I belonged. Now I have found my own place. I realized I was a lot different, but that it is OK. (lines 988-996)

Lee and Robbins (2000) postulate that humans are driven by a “powerful need for connectedness”. Bauman and Leary (1995) list the results of being disconnected from others as: a decreased sense of belonging; isolation from the social environment, and a lack of purpose and meaning in life. According to them, a sense of connectedness functions as a buffer against the ill effects of stress (Bauman and Leary, 1995). Kärcher (2002) elaborates on this, stating that a sense of connectedness can serve as protection in the prevention of stress-related difficulties and help to resolve intra- and interpersonal dilemmas.

The story of the participant's childhood and young adulthood presents clues to the origin of this sense of disconnectedness. Michelle experienced severe anxiety that her parents would die when she was a young child (lines 371-276), to such an extent that she did not want to go to school. Baumaster and Tice (1990) view anxiety about death of the self or another as partially originating from a threat to the sense of belonging. In their research with teenage girls in Minnesota, Harris, Blum and Resnick (1991) found that a secure sense of connectedness to the family is a strong protective factor against the development of "quietly disturbed behaviour", such as eating disorders and self-mutilation (p119). The participant was diagnosed with severe anorexia nervosa as a nine-year old child. She found the subsequent treatment, during which she was isolated in a hospital room, more than a thousand kilometres from her family, traumatic. Treatment required that she had to earn privileges such as the use of a toothbrush or a blanket (lines 458-465). She struggled to recover and recalled the following conversation with her father: "My dad then told me: 'If you do not pick yourself up, I am going to send you to the asylum for the insane. You are becoming a losing horse and nobody will back a losing horse'" (lines 466-468; 1192-1193). This triggered the conversion of anorexia nervosa to bulimia nervosa (line 466), an affliction that resurfaced after her bilateral prophylactic mastectomy (line 1263). Her eating disorder has been discussed in the section on body image in this chapter (See paragraph 5.5.6). This treatment from her family created the perception that the people who should help her and search for answers with her abandoned her (lines 478-480). She mentioned that she felt very vulnerable and lonely, once again in a crisis and seeking answers, without the people who should have supported her (lines 344-347). She has feelings of anger, specifically towards her sisters (lines 449- 450), especially the elder one who is a medical doctor (lines 142-148) and a woman she expected to be understanding and supportive, but who did not reach out during this difficult time. She first identified her feelings as those of loneliness and vulnerability (lines 471-474).

These emotions changed to disappointment when her female siblings who tested negative for the defective gene simply continued with their lives, seemingly oblivious to Michelle's severe distress (lines 91-96; 98-101). Her siblings had little empathy for the fear and uncertainty that clouded Michelle's future, and the difficult decision she had to make in terms of undergoing a bilateral prophylactic mastectomy. The sister who lives in Cape Town, did not visit Michelle in hospital after her operation. This intensified her feelings of rejection and vulnerability (lines 349-351).

Den Heijer et al. (2010) states that familial breast cancer has a severe impact on the individual family members and their interactions and communication. The long-term

adaption of affected women depended on how they perceived the level of social support and family communication about this difficult topic. Supportive interaction from family members alleviates the fears and distress about the diagnosis up to six months after positive testing for the gene. Apart from the interpersonal benefits of open communication about emotions, there is also an intrapsychic mechanism at play: voicing cancer related fears can lead to increased insight and a different perspective on genetic testing.

5.6.3 Sense of connectedness with her mother

The unexpected diagnosis of breast cancer in her mother, awakened the fear in Michelle that her mother might die (lines 377-378). The subsequent diagnosis of the BRCA2 mutated gene in both Michelle and her mother reminded her of their mortality: “I always thought my mother was going to be around forever, and I am going to be around forever” (lines 596).

These feelings were voiced after stretching, mirror movement to music, and a djembe drum improvisation. Michelle was able to access stronger emotions expressed in bursts of vigorous drum playing and changes in dynamic level and tempo. She ended this improvisation by rubbing the skin of the drum, changing to a reflective mood. This was followed by a particularly pensive instrumental improvisation with chime bars, tubular bells and a djembe drum. She commented that the music reminded her of quiet and stillness and that she found that she felt safe and restful (lines 257-258).

She relives the shock of her mother’s mortality every time she sees her mother (line 427), especially since her mother does not wear the special bra and prosthesis she was fitted with. It is not because of aesthetic considerations that she finds this upsetting, but being reminded of breast cancer (lines 419-427). Another aspect to consider when contemplating Michelle’s intense reaction to her mother’s “breastlessness”, is the meaning an infant assigns to a mother’s breasts and the role it plays in the unconscious intrapsychic processes of the woman who lost her breasts. In this case, it is not only the mother but also the daughter who has to work through the loss of the good breast while her own loss is looming. Lin (2016), borrowing from psychoanalytical theories, also considers the significance of the need to reconstruct the lost breast, stating that this urge lies in primal fears around perceived traumatic absences and losses. According to her, Klein (as cited in Lin, 2016) viewed the “good” breast as the first creative expression of the infant which also serves the function of gratifying her needs and keeping her alive. The Kleinian baby has an internal representation of a breast that feeds, connecting creativity with survival.

Winnicott (1971, p.47) expanded on this view, stating that there is an association between creativity and the mother's breast: "The breast is created by the infant over and over again out of the infant's capacity to love". According to Winnicott (in Lin, 2016), the breast is similar to a transitional object, helping the baby to distinguish "not me" from "me". Winnicott's object relations theory states that a mother's breast is a baby's representation of the "good enough mother". This is the mother who is able to satisfy the child's needs. As the process of individualisation starts and the mother does not always fulfil all the needs of the baby immediately, the breast becomes a transitional object while the child's ego develops and she becomes aware of "me" and "not me" objects (Clair & Wigren, 2004).

In Michelle's and her mother's case, the mother and child roles were reversed during the treatment and recuperation phase of her mother's recovery (lines 104-108). She supported her mother after the operation and during the subsequent treatment, in the same way that she would have wanted to be supported (lines 1013-1016). This caring behaviour was, however, not reciprocated when Michelle underwent her operation. The participant views her journey as different from her mother's cancer and mastectomy experience. However, she is of the opinion that her journey and the decisions involved were more difficult than those of her mother (lines 416-419). This view is supported by research conducted by Espen et al. (2004) in which some BRCA1/2 positive women who had breast cancer in the one breast and underwent a prophylactic mastectomy on the contralateral side, admitted that it was more difficult to decide to have a healthy breast removed than a diseased one.

5.6.4 Sense of connectedness with her husband and children

Michelle's perception of her connectedness with her husband and children encompassed several dimensions: the emotional connections between them; the physical and genetic link with her children; the need for balance in her family; and the support to find more specific psychological interventions from third persons.

5.6.4.1 Connection to her husband

Michelle's husband was very supportive during the whole process even though he was sometimes absent due to his work and could therefore not fulfil all her needs. He demonstrated his insight by encouraging her to find therapeutic support. She appreciated and respected him for it. She said the following in session one: "He was actually very

supportive. It is difficult for me because he comes and goes and I was on my own, but he was very supportive" (lines 120-121). She further stated:

He was wonderful by enabling me to see somebody. I found Dr. B and I still see her once a week. It is thus not so necessary to depend too much on him [my husband] emotionally. I could ...discuss those things with her. You know a man is different from a woman and, he cannot be there for you the way you need him to be there for you. Without criticising him. So, the things he was not able to be there for, I was able to find somewhere else. (lines 126-134)

She further described her communication with her husband and her need for further assistance in the following terms during session two: "...my mom is not a talker; nor my husband. He is away a lot and I married someone who is not a very emotional person..." (lines 405-407). She later stated that they are very different, but that he gives her the space to be herself, and that he is very good to her (lines 1041-1043).

Her husband's support in finding extra therapy had two opposing effects on Michelle: on the one hand, she was able to fulfil the emotional needs he could not meet in a professional therapeutic relationship which helped and nurtured her; on the other hand, she kept important information away from him because she did not feel she was able to tell him about all her concerns and her loneliness (lines 1239-1240). However, she is cognisant to stay connected to her husband:

... I want to tell myself that I must be careful that I do not become so selfish or to journey as such that I journey away from my husband. Do you understand that a big thing happened in my life, but it was also a big thing that happened in his life, but I do not think it is completely the *same*? I do not want to move away from him in my journey. It may be difficult to understand. One can go on such a tangent of your own, then it later becomes like this [she indicates two splitting pathways with her hands]. No, I am only aware that I want to make sure there is always a connection between us. That there is always the need [for each other], that I do not become too independent and so sorted out on my own. Yes, that the connection is always there, because it is also important for my emotional well-being, because my husband and children are important to me. Even though I want a good relationship with myself, I

do not want it at the expense of other relationships that are also important to me. (lines 889-903)

5.6.4.2 Connection with children

She is very aware of the need to maintain a balance in her family. She is adamant that her children must not be negatively affected by her predicament (lines 447-448). According to her, they are very emotionally sensitive and sense when she is psychologically unwell, finding it very upsetting: “I have two children who are very emotional. They are very aware whether their mother is OK. It is very important to me to have an outlet [therapy]. I keep the balance in our family” (line 122-125).

However, she was very open with them about her operation and the fact that it was done to keep her physically well, but she was also very careful not to show them her fear and uncertainty about her and their genetic future (lines 136-140). She expressed the wish to separate them from her genetically, to protect them from a future in which cancer and disease lurked due to the possible inheritance of cancer-causing genes (lines 600-617). In a longitudinal study spanning 8 years, Hamilton, Innella and Bounds (2015) found that women, especially those in their fifth decade, were mostly concerned about the concept of linked lives and experienced guilt about the possibility of passing on a mutated gene to their children. They were also concerned about when and how to have their daughters tested.

It is clear that Michelle feels very connected to her husband and children and that they serve as an emotional safe haven where she can express and receive love. She said: “This [nuclear family] is where I get my love and caring” (line 1326). She later iterated: “This is where I get my love and caring. From my family, my home family” (line 1338).

5.6.5 Mourning the loss of her deceased aunt

The death of Michelle’s aunt had a profound effect on her emotional well-being, as it made the fear of losing someone to death a reality (lines 368-370). She perceived 2016 as “a very bad year” (line 28). Not only did she have to deal with discovering her own and her mother’s mortality, and with decisions that affected her appearance and her sense of self, but she also had to come to terms with the unexpected breast cancer related death of her mother’s sister (lines 19; 21). This aunt was her godmother and they were very close (line 27). Their relationship was important to Michelle and she described it as emotionally nurturing (lines 379-386). This was why this death distressed her so much

(line 21). The other members in her family of origin did not react to the aunt's death with the same intensity (lines 412-414; 438-444).

The researcher addressed these intense feelings with a technique that made use of movement-to-music, improvisation and a receptive music therapy experience. The improvisation leading up to the receptive technique and writing was composed of a structured drum improvisation that evolved into a playful drum and vocal exchange, and a free metallophone and drum improvisation. Michelle was afforded the opportunity to explore sounds while the researcher provided musical holding by employing music therapy techniques such as mirroring and matching and reflecting (Pavlicevic, 1997, pp 125-126). The therapeutic stance of the researcher was to provide a safe musical space before the receptive technique was introduced; she therefore assured Michelle that the music would provide emotional safety and that she had conscious and subconscious control over the process and could move back from dark emotions with the facilitation of music.

Michelle listened to music (see

Appendix O: Playlists) and then wrote a musically inspired poem (**Figure 5-6** shows the original, and **Figure 5-7** the translation) about her godmother. In it she expressed the feelings of intense betrayal, loss, longing, and pain caused by her aunt's death. The poem reproduced the ambience of the music, and was full of longing. Reflecting on the writing experience, Michelle said that she wrote much more than she expected to be able to. She also commented that the music "leads you to places in your head where you cannot necessarily go without it" (Video 2D, 20 seconds). She noted that the different tempos of the individual pieces were the triggers for the different memories she revisited:

I like the music and the different tempos, I realised it makes a difference to where you go to in your head. It was actually very interesting when you played the last piece, it was more upbeat and the words that emerged from it were lighter. One should not listen to dark music during dark times. (lines 303-307)

Figure 5-6: Poem inspired by music

Jy het my verloot.
 en my met nees gerief
 sal die donkerte my verloot?
 gaan jy my vermoed?
 Vir jou het ek 'n boom geplant.
 My kameis gerief met klankie... die mooiste melodie
 Pretzies van liefde
 Bly by my
 Lief my
 omkeer my
 In die skadu van jou boom wil ek rui.
 om te by my
 Dins soam met my
 my my voete

Figure 5-7: Translation of Poem about godmother

You left me
 and you filled me with fear
 will darkness ever leave me?
 are you going to betray me?
 For you I planted a tree
 I filled my rooms with sound, the most beautiful melodies
 Small pictures of love
 Stay with me
 Lift me
 Embrace me
 I want to rest in the shade of your tree
 Come lie with me
 Dance with me
 Guide my feet

Although the music evoked the poem, Michelle was unable to talk about the poem and chose to speak about aspects of the disconnectedness from her community mentioned in the next section, paragraph 5.7.6. She only reflected on the poem in the next session when invited to do so after the improvisation in session three discussed in paragraph 5.7.3 where she also spoke about the relationship with her mother. But the poem itself clearly expresses Michelle's feelings. In it she begs her aunt to stay with her, guide her, and to enfold her in warmth and love. It speaks of memories about care and support.

5.6.6 Sense of disconnection from community

Michelle perceives herself to be under scrutiny in the small farming community where she lives (line 673). She voiced it in the following way:

In the community where I live and operate due to my children
 and things, I am a bit too unique in the sense of ... things spread like
 wildfire and I live under the magnifying glass. I do not know what the
 community expects, and I am in my body the way I was always in my
 body. I have always been a jeans-and-t-shirt type of person. But I think
 people look and want to see something and I do not know what they see
 ... (lines 687-689)

When I go to S [local supermarket], I feel like I am under the magnifying glass. Not only regarding my body, [pause] people want to see, it intrigues them, because nobody had it before. It is in the media, but does it look normal? How does she look in a [swimming] costume? And, how does it behave when she runs? People are intrigued. (lines 763-768)

She found acquaintances and friends to be inquisitive rather than supportive. She saw herself in her community as one living under a magnifying glass or in a fish bowl, on display for everybody to see and discuss. She felt that everyone wanted to know what her reconstructed breasts looked like. She felt that, when her friends supported her by bringing food and flowers after the operation and during the period of convalescence, they wanted information in return and that they expected her to carry on like before the operation (lines 410-412). She suspected that nobody understood her need to mourn her losses. She experienced a strong desire to “turn inward” in order to protect herself and to survive (lines 865-878). Through the music therapy she discovered that her disconnection was a way of protecting herself (lines 311-327). She did not feel safe enough to share her journey, feelings, fears, and her “new” body with them.

MacBrayer (2007) describes how invaluable the support of family and friends are. During her own journey as a BRCA1 positive woman she found that people with whom she did not need to maintain a social façade or pretensions and with whom she could be open and honest regarding her fears and pain, to be a healing and protective factor. Michelle feels that certain friends and community members perceive her as hostile, which, to her, signifies their lack of understanding for the magnitude of the insult to her safety and sense of hope (lines 333-334; 868-877). She experienced this when a female friend, who is a medical doctor and knew about the genetic results, was offended because Michelle did not reach out to her. Her friend warned her that she might need people in the future and that there might not be anybody left who would be willing to support her. Michelle, who had expected a doctor to have more understanding of her emotional plight, was disturbed by her friend’s comment (lines 1113-1139). She was anxious about people’s judgment of whether or not she looked normal (lines 765-768; 1142-1146). Initially, she seemed very unconcerned about the way her appearance might be judged by others, but as the therapy progressed and her sense of safety and trust increased, her fear and ambivalence about social relationships presented itself. She had embarked on an inner journey which she wanted to protect from other people because, as she put it, “they walk with dirty feet through your heart and leave footprints”. She summarised it as follows:

It is like that; I want to look the way I looked before. It is not a public... This is not a public journey, and it was like that for me. I did not want to look different physically. I do not want that people could look at me and it looks physically different from ... because they are not in my heart, even though I think they would like to be in my heart. They'd love to probe and it is unbelievable how people are and they are not in my heart and I do not want to give them the right, because people walk with muddy [dirty] feet through your heart and soul, and yes, I do not want to give them that right. (lines 699-707)

5.6.7 Conclusion

As with the discussion of body image, which was a long-standing challenge exacerbated by the surgery, difficulties with interpersonal connectedness started long before the prophylactic procedure. It is clear that she never really felt part of her family of origin or society in general. Six sessions of music therapy are possibly too small an intervention to bring about big changes in this regard.

That said, her creative responses to the music therapy helped her visualise the extent of the disconnectedness. It is also significant that the music therapy enabled her to build a trusting and playful connection with the therapist who is also a medical doctor – a profession towards which she voiced deep feelings of mistrust.

The question whether music therapy helped with intrapersonal connectedness was addressed. On the intrapersonal connectedness issue, the results are clearer than for interpersonal connectedness. The evidence that she grew in insight about her own negative feelings towards her changed body, is one sign of this. The music therapy also helped her to connect with her deep sense of loss about her aunt's death and enabled her to express her reflections which she could not voice, in a written poetic form.

In relation to interpersonal connectedness she could also formulate her feelings of distrust towards the community and their efforts to reach out to her. Unfortunately, the six sessions of therapy were not enough to address her lack of trust in the good intentions of friends and acquaintances. It is however of value to note that she found her music therapy sessions to be an important and enjoyable experience in social connectedness (see **Table 4-4**).

The quantitative data supports the notion that the music therapy assisted in uncovering the ambivalence she has in relation to social connectedness. Her score on her perception of social support was significantly lower from the pre- to the post-test scores.

5.7 Theme 4: Existential Authenticity

In an article about the psychology of suffering Diamond (2010) sees severe illness such as cancer as akin to natural disasters, or as he calls it “natural evil”. He describes the initial state of emotional shock people experience at such times with a term borrowed from psychiatrist Lifton: “psychic numbing”. Then he says:

They have been precipitously exposed to either natural or human evil, or both, and unable to psychologically process the experience. Denial is no longer a viable defence. They feel out of control, victimized, helpless, powerless, frightened, and disillusioned. Often, they also feel angry and bitter about what has happened. Angry at god, or with fate or life itself. They have abruptly been stripped of their innocent belief in life's inherent fairness. Their *Weltanschauung* (worldview) has been shattered. Many will never be the same. Like Humpty Dumpty, the bits and pieces cannot be put back together exactly as they were. Rather, victims of evil must somehow rebuild themselves anew, psychologically assimilating this devastating experience and its implications into a more mature, realistic, meaningful *Weltanschauung*, a reconstructed, sturdier, more flexible platform or foundation upon which to stand in life—one which can withstand, accept, and even embrace the existential facts of anxiety, loss, suffering, disease, death and, at times, seeming meaninglessness. A revised philosophy or worldview which recognizes and honours what philosopher Watts called the “wisdom of insecurity”.

This part of the discussion examines how Michelle experienced this stripping of her beliefs and started to rebuild herself anew, psychologically assimilating the devastating experience and its implications into a more mature realistic meaningful platform upon which to stand in life. The points discussed here presented themselves as she reacted to the music therapy. It will in part answer one of the research questions, namely the intra-personal connectedness. But it is also a reminder of the fact that the importance of often are overlooked factors in the event of a positive BRCA1/2 test. This

was the conclusion reached when research was done concerning aspects beyond the psychosocial support women needed in the event of a positive test (Vos, van Aperen, Oosterwijk, Menko, Collee, Gomez Garcia & Tibben, 2012).

This section comprises the following sub-themes: Intrapersonal connectedness; control; existential impact; trauma, and emotional pain. The discussion draws from the thick descriptions of the video recorded sessions and literature pertaining to the different aspects mentioned.

5.7.1 Intrapersonal connectedness

The separation relevant to this study started with her mother's breast cancer diagnosis (lines 34; 38; 76). This was compounded by a positive test for the mutated BRCA2 gene in her DNA (lines 79-81). Shortly after this, her aunt, with whom she had the closest emotional family bond (lines 27; 379-387), passed away unexpectedly due to breast cancer. A few months later she herself underwent the bilateral prophylactic mastectomy. Her world was shattered (lines 91; 101; 837-839) and she felt disconnected from a body she no longer believed she could trust to be well into old age (line 270; 392; 594; 778-782), from a possible future with her children (line 399), and from a world that was supposed to be a safe and predictable place (837-839). It exposed her to the possibility of a dreaded future with the chance of early death, in stark contrast to her maternal grandmother who passed away three months prior to her hundredth birthday (line 340). It was all the more sinister because it was so unexpected – there was no recent family history of breast cancer (lines 30-33).

5.7.1.1 Control

One of the strongest indicators of Michelle's intrapersonal disconnectedness was the feeling that she had lost control. Michelle describes the need to be in control of her life/emotions as part of her personality: "I like to control" (line 251), and "I like to be in control and it is difficult for me not to be in control" (line 436). She finds it distressing that she is unable to control her emotions and cries a lot: "It is difficult for me to be in a place where I cannot control my tears" (lines 437), and "I just want to be more in control of myself" (line 1088). She is goal orientated and would complete any task if she knew how to do it. She is willing to work very hard to accomplish goals: "Just tell me what to do and I will do it" (line 1132).

Her diagnosis with the BRCA2 mutated gene threw her controlled, ordered world in disarray. In her mind, she has an image of this diagnosis as an unexpected “package” that has been opened, but not yet sorted or packed away again (lines 282-285). She had no control over when she received the package from her mother and has no control over whether or not she passed it on to her children (lines 634-637).

What to do now is also not clear to her. She is plagued by doubts regarding whether or not she is doing enough to keep herself and her family healthy. She also worries about the pesticides she comes in contact with, the silicon in her prosthesis, and the effects of the hormone replacement therapy (line 555). MacBrayer (2007), in writing about her own experience living with the BRCA1 mutated gene, mentions that she has been beset by anxiety about the pesticides she ingests and the pollutants and chemicals surrounding her ever since her diagnosis. MacBrayer (2007) feels that agents that would not affect people without the gene mutation might cause her to develop cancer, due to her genetic vulnerability.

In Michelle’s present world, there are too many grey areas (lines 546-549; 557-559), whereas she prefers black and white guidelines, as they are easier to follow and, to her, imply a guarantee that she will stave off cancer, despite how unrealistic that may be. She is troubled with self-doubt about things such as nutrition and her choice to have the operation done (lines 793-795), and about how much she should exercise (lines 551-553). Her distrust of doctors and people in general aggravates her doubts about her choice to have the surgery (lines 276-280). She explains that she has these perfect pictures and lists in her head of how she should be and what she should do, but poignantly admits that she does not know what is written on the lists (lines 275-276). She can never live up to the perfect pictures in her head. This applies to her breasts as well: they are not perfect to her but she does not even know what constitutes perfect. In her opinion, they were not perfect before the procedure either and they actually appear more beautiful in certain aspects now than before:

I have such perfect pictures in my head about how it should be
and it is not often that my perfect picture is realized. So, it is far from the
perfect picture, but before it was also far from the perfect picture. (lines
487-489)

Self-reproach is another facet of her doubts. She chastises herself for not doing enough to stay involved with her friends and community (lines 843-846), or for not doing

all the correct things under all circumstances. As mentioned in paragraph 1.4.6, the most disturbing presentation of her perception of being out of control is the continual struggle with bulimia. She used to be better able to keep her appetite and her weight under strict control (1263-1273), but now struggles to do so due to constant worry and stress. She admits with guilt that she is resorting to desperate measures, such as taking Methylphenidate, to stay in control, but these measures are also “very out of control things” (line 1101-1102). Methylphenidate is a stimulant reserved for the treatment of attention deficit and hyperactive disorder (Kaplan & Sadock, 2015), a condition her son suffers from. The Methylphenidate helps her to control her appetite and gives her a feeling of having enough energy to maintain her grip on life and on a world which appears to have shifted on its axis (lines 1097-1102; 1263-1266; 1293-1298). It also enables her to deal with the anxiety she suffers from (line 1308) and to “cope” (line 1310). She admits that she is emotionally very tired from hiding and trying to keep all the balls in the air, but she hides it even from her nuclear family. Out of desperation, she resorts to taking a pill (1239-1244; 1293-1298). The anxiety is part of the “evil cycle” that drives her feelings of being out of control and afraid – so are the measures she resorts to in order to counteract her fear and lack of inner safety (1258-1266). She realises that she is treading on dangerous ground, but does not know how to respond to her own concerns. This present dilemma is different to what she has faced before:

I think: there is something seriously wrong with you, Michelle. This is where the downwards trajectory begins to the danger zone. I simply continued [in the past]. I did not have children, I did not have an ADHD child, I did not have school, I did not have any of that. In the past it was just me, I the past could book myself into Hospital X. I did not have two children to raise, I did not have a husband who works away [from home]. I have to do these things. What helped in the past is not necessarily going to help now. I try to make time for myself, I try to get back to nature, I go to Dr. B [therapist] and I come here. I try to do the things that are right, the things that should help. This is new territory. In the past, I had breasts. (lines 1281-1292)

5.7.2 Emotional pain

The predominant place of Michelle’s struggle to come to terms with her altered health circumstances was inside and private (lines 609; 638-639; 646-647; 649-652). She was fiercely protective of her inner world, while she felt lonely and abandoned (669-674;

865-870). She spoke in no uncertain terms of her family's expectation that she should carry on as usual after the operation, and of her pain and her need to protect herself:

Now it is past, Michelle must be OK, but in your privacy, that you don't show the world – you do not show to your family – you are not okay. It is a process and, as you say, it is a loss. Life is never going to be the same without it. If I think of my childhood, I always felt lonely, I never felt as if I belonged or as if I was understood, even as a child. That is okay, but when you live through a crisis and you feel alone once again, then you distance yourself. It is too painful, I experienced it as very severe, it was incredibly bad, when I was diagnosed, or when I got the results. Yes, and the others just carry on. (lines 338-347)

Her need for protection from the eyes and ears of others stemmed from a lack of trust in others. She states that she does not trust people (line 797-799) and later qualifies this even further by saying that she does not trust the members of the medical profession, as mentioned in paragraphs 5.5.5 and 5.8.1.1. She expresses this as follows: "I realised after our conversation last week, I think a big thing for me [pause] ... I do not trust doctors [medical fraternity]" (lines 927-928). This view could be rooted in her previous experiences of abandonment and rejection by people she should have been able to count on as a child. Three of her family members are in the medical profession and she harbours anger towards them (line 450), making it difficult for her to trust doctors and their advice (930-931). Her disappointment in and the perceived lack of empathy from family members, along with their expectation that she should carry on as if nothing happened, cemented this distrust deep into her psyche (lines 954-967). She expressed anger towards her two sisters in particular, because of their indifference to her wellbeing (lines 344-347; 349-352). She felt that she could not trust other people with her emotional difficulties, since her family members and friends generally did not respect the sanctity of her inner world and, as she put it, walked with dirty feet through her heart (lines 700-707; 1241-1242). Her reaction was to "turn towards herself", sometimes isolating from friends and community members she used to interact with often. She suspected they perceived it as hostility, but felt it was a necessary step for her in order to feel safe and protected (lines 329-334). It continues to be an inner struggle and she had to remind herself that she had no reason to feel ashamed, as she did nothing wrong and that it should not bother her that people discuss her:

... but people are not kind and I know in town I am ...dinner talk? Understand? And it must not disturb me that people talk about me, that is the thing. It mustn't disturb me that people talk about me because it is not something I can...I have not been sent to prison. Why does it bother me? I don't know why it bothers me. I can say the following in my head: you do not have an issue. What are you ashamed about? You have no reason to be ashamed. (lines 1153-1159)

Michelle did not perceive herself as depressed, but felt she did have emotional difficulties which she was only able to reveal to her other therapist and the researcher. She felt she had to “box it” when she left the therapy space (lines 660-662). She expressed her own wounded state and her children's vulnerability in session four by saying the following: “We are all a bit fragile” (line 624).

These feelings were revealed after a receptive music therapy that is discussed under section 5.8.4 (p. 97), where she had to respond through art to three different pieces of music. She was given the opportunity to embody the fragility by leading a mirror movement exercise to an instrumental rendition of the song “Fragile” by Sting (Sting, 1994, Track 10).

5.7.3 Trauma

Michelle experienced her mother's cancer diagnosis, the process of caring for her mother, their shared BRCA2 diagnosis which put her at high genetic risk of developing breast cancer, and the death of her godmother as traumatic events. Chalmers and Thomson (1996) found that daughters responsible for providing physical and emotional support to a mother with breast cancer often suffer from vicarious trauma, living through the experience with their loved one. Michelle describes it in terms of a catastrophe: “my world collapsed” (line 101); “a bomb shell went off” (line 74); “tsunami's” (line 74), and “tragedy has struck me” (line 838). She describes the disruption of her life and her inability to hold everything together poignantly:

...it lies in your heart, it carries on in your head in overtime and overdrive. I think that is where it comes from: pull yourself together, face the world and continue with life. I can't do it the same way as...as it was a year and a half ago. This is what people expect and now I say to myself this is what must be done. Understand, it does not all come tumbling down and they continue and I must carry on and now I must try rebuild

*again. A year and a half ago the walls caved in and I just can't get them
built again. (lines 1124-1133)*

She experiences intrusive thoughts about breast cancer and especially about passing the mutated gene to her children. These thoughts hamper her daily life and cause avoidance behaviour, because she consciously tries not to think about it (lines 629-623; 638-644). High levels of psychological distress, including intrusive thoughts and concerns about developing breast cancer and dying, which impaired their daily functioning, was also noted by Metcalfe, Esplen, Goel, and Narod (2004 p. 23). When they researched the psychosocial functioning of women who have undergone bilateral prophylactic mastectomies, they found that some women experienced bilateral prophylactic mastectomy as very disruptive, leaving them traumatised. These women developed high levels of psychological distress, including intrusive thoughts and concerns about developing breast cancer and dying, which impaired their daily functioning. The severity and frequency of their symptoms were on par with that of study populations who experienced a traumatic event. Factors that influenced perceptions and increased distress were: a mother diagnosed with breast cancer; being BRCA1/2 or 2 mutation carriers; and a family history of breast cancer. They found that this led to persistent high levels of distress after the bilateral prophylactic mastectomy. The researchers advised further psychological consultation to assist such women with adapting to life after a prophylactic mastectomy and living with the high genetic risk (p.23).

In examining the prognostic factors for hereditary cancer distress six months after genetic tests for breast, ovarian, and colon cancer susceptibility, Van Oostrom et al. (2007) found that high pre-test levels of distress, a higher number of first-degree relatives affected, strong emotional illness representations, and complicated grief were important predictive factors for identifying people who needed additional counselling. Emotional illness representations are a reflection of a person's perceptions of the emotional outcome of an illness (Rozema, Völlink & Lechner, 2008). Van Oostrom et al. (2007) found the following to have an impact as well: illness coherence, or how clear and comprehensive an individual feels her condition to be (Rees, Fry, Cull & Sutton, 2004); passive coping; being younger than thirteen years of age when a parent was diagnosed with cancer; and family communication. They stated that, although most patients functioned well with the knowledge of their risk status, a relatively large proportion of participants (10% to 20%) experienced lasting levels of high distress. Michelle's involvement in her mother's care after her diagnosis (lines 104-108), her grief after the death of her aunt (lines 368-370), her feelings of losing control (line 436), and the communication style in her family of origin

(lines 990; 1000; 1003) leaves her, in line with the findings of Van Oostrom et al. (2007), vulnerable to have clinically high distress levels for at least six months after her BRCA2 diagnosis. In Michelle's case, there was one positive point. A supportive partner was found to be a positive mediating factor that protected against stress (p. 76). Her husband fulfils that role to some degree.

Clemens, as quoted by Kraft (2014) states that losing a part or a function of the body is cause for great distress that has to be resolved. This is especially important if such a body part is emotionally significant, like a breast which is associated with motherhood and femininity. Michelle responded to the trauma with feelings of loss (lines 340-341), anger, and pain (line 263). Grieving the loss of a woman's own breasts, even though immediate reconstruction followed the mastectomy is still a need according to Lin (2016). Piot-Ziegler et al. (2010) reported the same finding, stressing that even immediate reconstruction after the mastectomy, women still grieved the loss of their own breasts and integrating a new corporality can lead to an emotionally painful identity crisis.

During the period after her surgery, Michelle found that people exhausted her (line 262) and she used music (lines 258-259), nature (line 268), and the love of her close family circle (line 1236) to sustain and nurture her in her process of reconstructing the meaning of life and her identity:

Growth and life, this is what I choose. I choose to grow. I choose
to make this journey a positive one, to grow through it and to get to know
myself better. I want to become a better me, a better version of myself.
(lines 677-678)

This sentiment was also strikingly imaged in session six. While the researcher used a receptive technique to unlock subconscious thoughts. Michelle, in a relaxed state, listened to several contrasting pieces of music. Afterwards she worked with clay to recreate the most salient aspect of her experience of the music therapy process. She formed three faces, representing her husband and two children. She explained that she wanted her therapy process to benefit her loved ones. The researcher drew Michelle's attention to the fact that she herself was absent from the picture and asked where she would place herself in relation to the others. She then fashioned a tree from the clay (see **Figure 5-8**) and placed it in a supportive position beneath her family. She described herself as a tree living in the desert, possessing a deep, strong root system that enabled it to survive a storm. Her branches were sheared off, but she was not uprooted and still

had the impetus to grow (lines 1069-1071). The most positive end result of existential trauma is the decision to focus on growth.

Figure 5-8: Clay work from session 6



5.7.4 Existential impact

Writing about the existential plight of daughters whose mothers had breast cancer, Raveis and Pretter (2005) focuses their discussion on the following themes: the emotional responses of the daughters to their mothers' illness; the changes in perceptions of the mother-daughter relationship; and the perceived risk of also developing breast cancer. The emotions most frequently experienced by the participants in their study were shock, grief, fear, denial, panic, distress, and sadness. The initial shock was of the shortest duration of these experiences and included themes such as the suddenness of the diagnosis and the unexpectedness of it in families without a history of breast cancer. The shock was often followed by denial and disbelief, fear, and panic. Preconceived ideas about safety and their families' invulnerability against cancer were shattered. They were made aware of their mothers' mortality, and by implication, of their own mortality too. They felt emotionally overwhelmed and traumatized by the diagnosis their mother has received and small reminders often re-awakened the emotional memories. The longer lasting effects were sadness and fear.

In Michelle's case, it was the death of her aunt and the subsequent grief she experienced that made sadness her constant companion over the previous year. It still brings tears to her eyes (line 368, also see poem under section 5.7.5). Michelle experienced the full range of emotions described by Raveis and Pretter (2005). In her case, the most pervasive and debilitating emotional response, was fear. She describes it as the single most important motivational factor in making decisions about her children's and her own health.

In the study by Raveis & Pretter (2005), women described that their perception of their mother as immortal and strong changed after breast cancer diagnosis, and subsequently the bond and conducts of interaction between mothers and daughters changed too. Michelle described her realisation as follows: "My perceptions of my mother changed ... I was confronted with her mortality" (lines 425;427).

Her expectation that her mother would get old altered instantaneously. This evoked heightened supportive and protective behaviour, leading to role reversal where Michelle became the caregiver. However, this did not seem to help Michelle develop a stronger bond with her mother, as was the case with many of the women in the study (lines 384-385). This might be due to the perceived lack of support from her mother when Michelle had to deal with her own increased cancer risk and the subsequent surgical procedure.

Michelle's perception of her own risk for developing breast cancer was not only changed by the diagnoses of her mother and her godmother, but also by her own BRCA2 positive status. Similar to the women described in the study (Raveis and Pretter, 2005), she was confronted with existential concerns that mirrored in her what her mother presumably experienced:

He [her general practitioner] then told me I was positive [BRCA2 gene] and I did not ... [pause] really know what it actually [meant] ... and I thought, OK, this is now like my death sentence. (lines 79-81)

Thompson (2007) defines Existentialism as a philosophical school of thought which concerns itself with purpose and meaning. The concept of meaning in existentialism is paradoxical: on the one hand, it declares human existence as meaningless, discarding the belief that there is an essential grand and meaningful design behind existence; on the other hand, humans are seen as meaning-creating individuals, continually weaving the golden thread of meaning into their existence. Grief and loss can cast a shadow over previously created constellations of meaning, necessitating the reconstruction of new meaning (p.127), as was the case with Michelle.

Added to this, is the task of formulating a new identity which is both personal and social. The trauma Michelle experienced caused a whole cascade of existential dilemmas to unfold. Trauma, according to Thompson and Walsh (2010), is not only a physical injury, but more often also a psychological insult. That is why distressing life events not only leave a psychological wound (p.377), but also a "psychosocial injury". They refer to a psychosocial phenomenon as an entity that has both psychological and sociological aspects incorporated. The authors stress that there is a subjective component in the process of narrative and meaning creating after trauma. They further state that psychosocial trauma could be a serious wound, even more so than physical injury, because it can be seen as an existential injury, or an "injury of the self" (p. 378). It can distort, damage, or even demolish our sense of who we are and how we fit in or belong to the wider society. It challenges the groundwork of our existence, altering how we see the world and how meaning is given to the world, "... in effect, destabilising or even shattering our frameworks of meaning, our spiritual and existential dimensions. In this sense, trauma can be seen as is a psychosocial phenomenon" (p. 379) because it is caused by and resolved in a social context and altered by meanings and insights related to the events (p. 378). For existentialism, human existence is simultaneously social and personal. No person can be isolated from the context of their society and no society is possible without

people. The suffering of loss and subsequent grief are closely related to trauma and can be viewed as an existential injury, as it affects the spiritual dimensions of a person significantly (Thompson & Walsh, 2010). From an existential point of view, identity is a journey but we are likened much more to the road being travelled than to the traveller. Identity is perceived as fluid and is shaped both by our choices and by the way people respond to them. We need a sense of continuity while changing because identity is negotiated, without a “fixed self” or “essence”. The past, present and future, can only be connected in meaningful ways if there are a sense of linking threads. These links can be destroyed by grief and trauma, and together with it, a person’s sense of identity. And so, ontological security is negatively affected. Ontological security refers to a person’s ability to cope with and be secure in a world where the only certainty is that change will occur. It is the ability to respond confidently to insecurity and with the self-belief that a person is able to rise to the challenges of life and its losses (p. 380). Being secure implies that a person is free from fear, doubt, apprehension and alarm. Thompson and Walsh (2010, p. 379) quotes Attig in summarising the above concepts as follows:

Attig (2002) writes of two types of pain that people experience when they are grieving: soul pain, which refers to the pain of losing our sense of rootedness in our everyday normality; and spiritual pain, which refers to the suffering involved in losing our sense of transcendence, leaving us dispirited, joyless and hopeless. Trauma, as a grief- inducing experience, produces the same reactions — soul pain and spiritual pain. Both can be related to the existentialist concept of ‘ontological security’. ‘Ontology’ is the study of being, and thus of reality. Ontological security therefore refers not simply to physical security (Am I safe?), but rather to how secure we feel with our identity. As noted above, trauma challenges our very sense of who we are and where we fit into the world. It undermines our identity. Ontological security is a psychosocial phenomenon, insofar as it incorporates both psychological and sociological dimensions.

In Michelle’s case, the single most recurrent code in the data is fear. The excerpt from the data is a poem written during a creative writing experience with music and the subsequent verbal reflection on it. It illustrates the extent of the shift in her ontological security, set in motion by pain, loss and grief. See **Figure 5-3**. “This is my godmother who died from breast cancer [cries]. Look, I think the whole process is a thing of much fear and the loss of loved ones...” (line 368-370)

I always had this terrible fear that...something was going to happen to my mother. I always wrote letters to my Mom. I always, once again for ungrounded reasons, did not want to go to school, because I was afraid that when I came back, my mother would not be there. So, it was very bad when my mother got cancer, because it was very unexpected, because it awakened that fear again. (line 374-378)

Regarding the poem, Michelle said the following:

That, this was the reality, the reality that means everything, the breast cancer and then nothing, then the gene...Death. The question then is, is death ever to leave me? Everybody says life changes within seconds and I never had this fear before my mother [her cancer]. Even with my mother everybody said, you know: "it is part of getting older" It was a long journey for me, but when I got the genetic results, the fear became immediate. It is that thing, you go for the operation and you go for therapy, but it is always there. I have an unfounded irrational fear of death, and I do not know why [pause]...I have small children; one wants to be there for them. It is something that fills me with fear and anxiety, you know, when you feel something is compressing your chest. (lines 389-401)

It is the thing, you go for the operation and you go for therapy, but it is always there. I have an unfounded irrational fear of dying, and I do not know why. Maybe it is because I have small children, you want to be there for them. It is something that fills me with fear and anxiety. (lines 398-403)

The insecurity caused by grief was a significant part of Michelle's journey to rediscovering herself and her place in a world filled with uncertainty and unknown threats. Attig (2011) sees the relearning of the self and different ways of being as one of the active tasks that form part of grieving. For Michelle, it led her to re-evaluate her goals, hopes, dreams, and her view of herself as immortal. She had to confront the "fundamental human difficulty in comprehending and acknowledging our own vulnerability" (Solomon, Z. 1995).

Attig (2011) states that bereavement causes a loss of wholeness in three connected ways. The patterns of our lives are shattered, the narratives and flow of a person's biography are disrupted, and a person is left feeling disconnected from larger

entities she was previously connected to. A person may feel that her losses are irretrievable, and that she is subjected to a plight beyond her control with endless anguish and distress and without any hope for the future. The tasks of grieving assist in making new connections and re-establishing coherence in the narratives of a life lived.

Michelle spoke about the moment when hope vanished (lines 655-656), and then the moment when hope came back. Lotter's "three circles receptive music therapy technique" (personal communication, August 2016) was utilised in session five and it elicited three drawings depicting her journey from a woman who was well, to one who became hopeless, and then finally willing to face the future. Three contrasting pieces of music were played, one piece of music per circle. Michelle was requested to draw a separate image in a separate circle for each piece of music. The theme for the circles was the mapping out of her sense of self as she transitioned from a woman who was free of the possibility of disease, to a woman living with the risk of cancer, to a woman with a different body after risk reduction surgery. She drew herself as a daisy with her two children attached to her, with a butterfly on one of the flowers (see **Figure 5-9**). The second circle (**Figure 5-10**) shows three separate images of tulips without leaves, signifying her attempt to separate her and her children genetically and to try to separate herself from a future without hope. The last circle (**Figure 5-11**) contains three tulips with a butterfly hovering above the flowers. She explained the images as her change in perception about herself after the discovery of the BRCA2 gene, when hope vanished, to discovering new and unique dimensions in her relationships with herself, her children and life itself. The butterfly is a symbol of hope for Michelle. Kübler-Ross (1998), describing her experience visiting the Nazi "death factory", Maidanek, mentions the ubiquity of butterfly images created by the Jewish prisoners. She later came to realise these poignant drawings depicted hope, in this case of life after death. Michelle strives for a life where cancer does not play such a big role (lines 819-821). She has the will to write a new biography as time continues, healing some wounds (line 791).

Figure 5-9: Drawing of the first circle

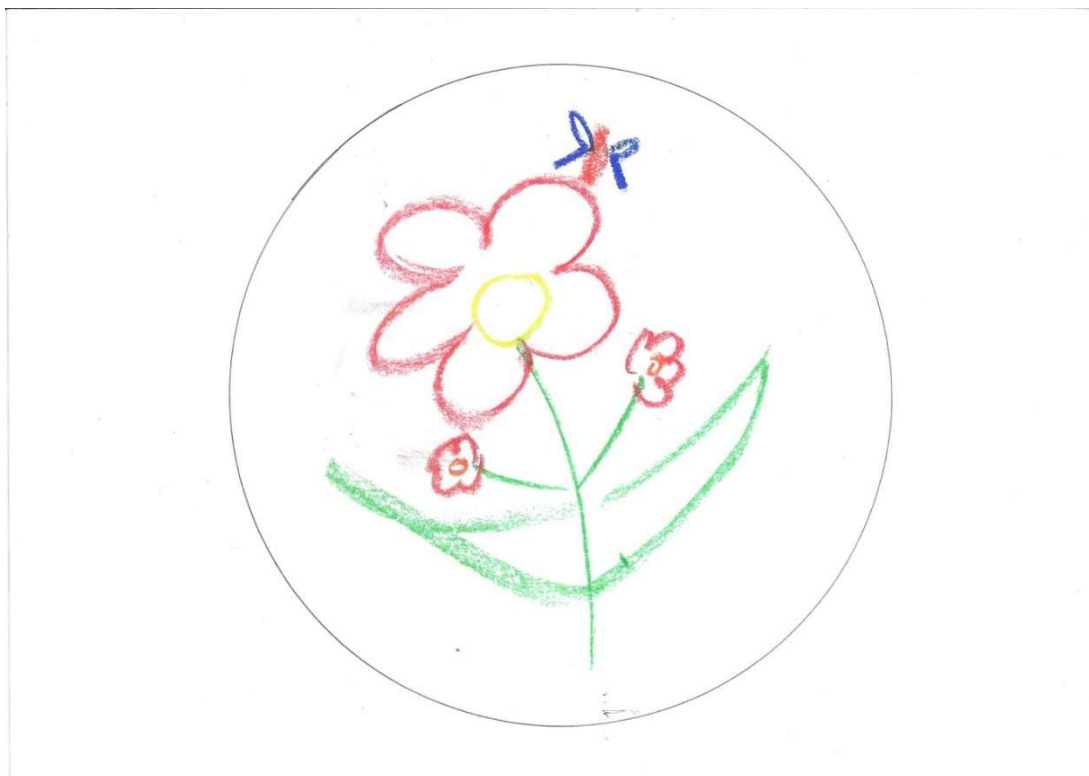


Figure 5-10: Drawing of the second circle

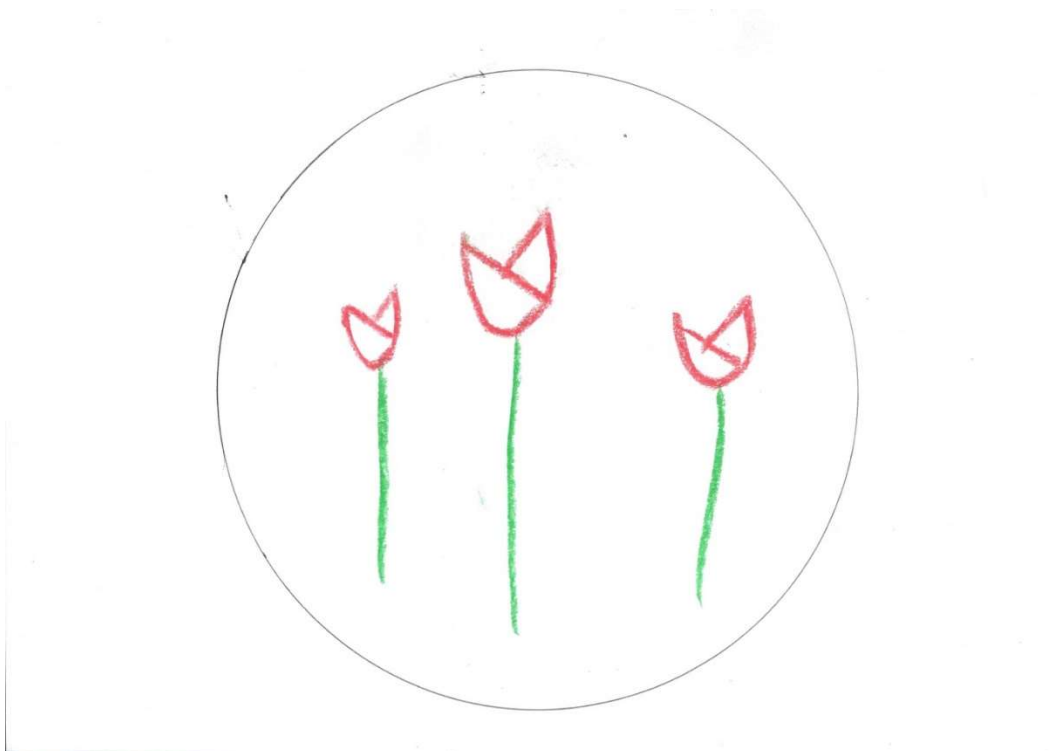
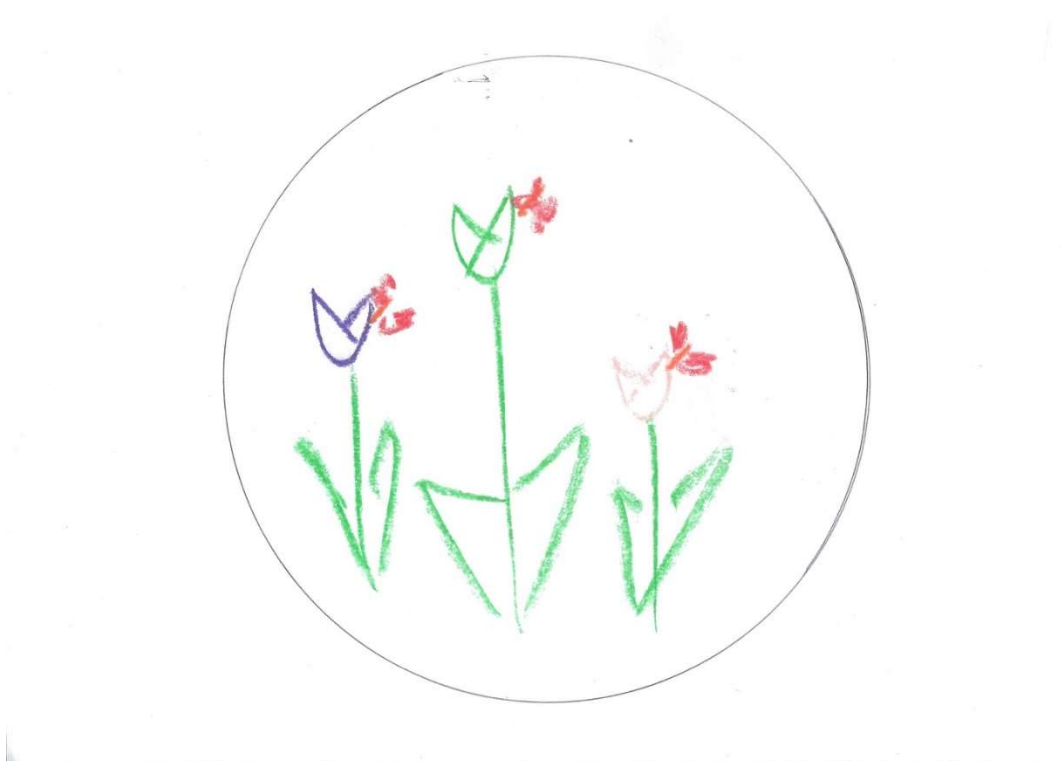


Figure 5-11: Drawing of the third circle



As part of the process of recovering her ontological security, Michelle relearned her place in the world and defined who she is in this new world:

Michelle, it is going to be OK. You are going to find yourself, you have always found the path. And ... maybe come back [to music therapy], maybe this is what you need, but you are going to find the balance again. (lines 1369-1371).

How long? I think a lifetime, because it was a lifetime of searching and becoming who I am and processes and, working through things. This has been the journey since birth. (lines 1373-1375)

One must probably have patience with the process. (line 1392)

In her struggle to let go of her anxiety and fear (lines 839-840) and the distinct experience of her world as being out of control (line 118), Michelle was confronted with the inevitability of change (lines 332-333; 621). It puzzled her that she was the only one in her family who reacted the way she did (lines 439-440). She was the only one who fell apart and she despaired that she would never be whole again, but expressed the distinct wish to discover a new dimension of depth to her inner self (lines 684). The disruption of her life that left her feeling disoriented, extended to her personal, family and social life (Attig 145). She found forging a new identity troublesome, as she did not know who to model it on. She had her mother as an example of how to handle the events, but that example did not resonate with her. Her relationship with her aunt was unique and different from the emotional bond between her and her mother, partly explaining her intense reaction to this loss. Attig (2011) relates the importance of this process as follows:

As we grieve, we struggle to give new sense and direction to the continuing stories of our lives. We seek new direction, purpose, and meaning as we live our autobiographies. The death of someone close is a pivotal turning point for us and changes forever the narratives of our lives. As we cope, we reconnect with the past, present, and future in senseful ways. We develop new perspectives on, or reinterpret, our past relationship with those who died and the life we built around that relationship; we pursue new meaning and purpose in our present daily living; and we redefine our expectations, hopes, and dreams for the future. As we again find or establish coherence in our lives, we regain our bearings in our own life histories and secure new self-identities. We

experience our lives as “making sense” to us again and again “know who we are.” In short, we pursue viable ways of going on with our lives (p.149).

She searched for a new community because she had lost her own (lines 841-842). The suggestion of orientating herself towards survivors of breast cancer evoked the comment that she did not have cancer and should not identify with people with cancer (lines 210-216). Finding a new place in the world was difficult, but she accepted the challenge of relearning how to be herself by focusing inside and gaining self-knowledge (lines 684). She gained the insight that she had to be kinder to herself (line 442), and conceded that she was also impatient when telling herself that she had to overcome her difficulties and continue with her life: “I am very good at reprimanding myself, now I reprimand myself: this life is now...You have life, you must enjoy every day” (line 1090-1092).

5.8 Integration of Qualitative and Quantitative results

It must be stated that the quantitative data is used to enrich the findings of the qualitative data. The Breast Q© test was designed and has statistical validity to be used for one client or groups of clients. However, in the case of this study, the aim was to ascertain whether quantitative data refute or corroborate the qualitative data. It was also used as a means for triangulation. The scores for the relevant sub-tests for the pre- and post-tests were average, lying between 53 and 74 on the zero-to-100-scale. The only exception to this was the score for the sub-test “psychosocial well-being”, which was 92 prior to the study. This was also the only score that changed dramatically, lowering by 35 points to 57 after the study concluded. The other values differed insignificantly or only moderately. “Satisfaction with breasts” changed with six positive points, the “satisfaction with outcome” sub-scale did not differ and remained at 67. Her score of the “sexual well-being” sub-scale decreased with only four points, indicating insignificant change and the “physical well-being related to her chest” increased moderately with 11 points, probably due to the progression of physical recovery after the surgery, resulting in less pain and more mobility. The reason for the decline in the score for “social well-being” from 92 to 57 could be the short duration of the study (with only six sessions) and the fact that the participant confronted and acknowledged her feelings of isolation in the latter part of the study. This might have influenced her test-scores.

The quantitative data corroborate the qualitative data in the domain of psycho-social well-being. The client's need for support in this area was evident from the qualitative data. Confronting feelings of social isolation, mistrust, and abandonment were prominent sub-themes of the therapy and concurs with a decrease in her sense of connectedness with her family of origin and her community. In terms of connectedness to her body, she said that she felt more connected to her body, although she admitted to increased negative feelings towards the appearance of her body, not necessarily connected with the risk reduction surgery. The insignificant change in the quantitative test-scores relating to the physical aspects of her body image confirms slight ambivalence.

5.9 Conclusion

The main themes that arose as salient from the qualitative and quantitative data discussed in this chapter, were: sense of connectedness; body image; existential challenges; and the personal experiences of therapy, and music therapy specifically. The qualitative aspects of the study underlined the need for support in terms of sense of connectedness and body image after prophylactic bilateral mastectomy with reconstruction. The existential challenges of a BRCA2 positive woman before and after such an operation, is evident in the narrative. The participant found music therapy helpful as a supporting measure during the time of the study. The quantitative data supports these findings. Limitations of the study and recommendations for further study are discussed in Chapter 6, along with a few concluding remarks.

6 Chapter Six: Conclusion

6.1 Introduction

These are concluding remarks about this study. It also describes the limitations of this research and offers recommendations for future research.

6.2 Concluding Remarks

The study was a mixed method pilot study of an under-researched topic. The aims of the study were to ascertain what role music therapy could play in addressing body image and intra- and interpersonal sense of connectedness for a woman who had undergone a bilateral prophylactic mastectomy. It was presented as a case study of one woman who attended six music therapy sessions. Qualitative data were collected via thick descriptions of video recordings made during the therapy process and a qualitative music therapy questionnaire. Quantitative data were collected pre- and post-intervention through a standardised peer reviewed questionnaire, Breast Q©, to measure body image of women after they had bilateral prophylactic mastectomies to reduce their risk for developing breast cancer.

Thematic qualitative data analysis was used to analyse the two qualitative data sets and the Q Score© automatic scoring system was used to tally the quantitative results. The qualitative analysis indicated that music therapy could play a role in addressing body image, and sense of intrapersonal and interpersonal connectedness for a woman who has undergone a bilateral prophylactic mastectomy. The quantitative data did not refute this thesis, but neither did it offer statistically valid results apart from illustrating a decrease in the sub-scale for psychosocial well-being. It is hypothesised that the therapy period of six sessions over three weeks was not sufficient to deal with all the emotional needs of the participant.

Her ambivalence about certain aspects of her reconstructed breasts and body in general was revealed as the study progressed. She was provided with the opportunity to express her feelings about her body through music. Music therapy techniques that were particularly beneficial in this regard were improvisation, singing and movement to music.

Music therapy facilitated the expression of difficult and painful emotional processes that were previously suppressed. An important part of this was to acknowledge her

disappointment in her family and community for their lack of empathy with her circumstances. As the study progressed she became more aware of her social isolation. However, she not only found the music therapy to be beneficial as a therapeutic modality, but also as a satisfying and enjoyable social support structure.

In terms of intrapersonal connectedness the participant became aware of certain existential challenges and the anxiety it provoked in her psyche. The ability and the opportunity to experience and discuss it in an environment where the music provided safety were beneficial according to her. The validation for her feelings enabled her to acknowledge it. While the value of the therapy during the study lies in the increased insight that she developed, there was not enough time to fully address all these concerns.

6.3 Study Limitations

The limited number of prospective participants due to the rarity of the condition made recruitment of participants cumbersome. Despite interest from a number of qualifying candidates, only one woman was recruited. The results can thus not be generalised to bigger populations and is only valid for this case study. The study period was also limited and a longer study might yield more conclusive answers to the question of whether music therapy can benefit a woman in terms of body image, and sense of connectedness after prophylactic bilateral mastectomy. A bigger sample size would also give more credence to the quantitative results.

6.4 Recommendations

Further music therapy studies using mixed methods are recommended to explore whether music therapy can offer support for BRCA1/2 positive women who opt for risk reduction surgery in the peri-operative period. The field of study can also be widened to include BRCA1/2 women who had had breast cancer before they underwent prophylactic surgery on their other breasts, and to BRCA1/2 positive women who choose intensified breast cancer surveillance. The recruitment of greater numbers of participants are recommended.

The Breast Q© quantitative patient outcome satisfaction measuring instrument was useful because it is designed to be valid whether it is administered to any number of participants. The qualitative questionnaire needs further development to better serve future research.

6.5 Summary

Thematic analysis of the qualitative data illustrated that music therapy did benefit the participant, although all the emotional aspects involved in the therapy were not resolved due to time constraints. The results of the quantitative data did not yield statistically significant proof of this, but neither were the qualitative findings refuted. The value of the study was to unmask suppressed emotions and ambivalence about body image and sense of inter-personal connectedness, and increased awareness of intra-personal connectedness in this participant.

7 References

Ahmadi, F. (2011). Song lyrics and the alteration of self-image. *Nordic Journal of Music Therapy*, 20(3), 225–241. doi:10.1080/08098131.2010.522718

Ahmadi, F. (2013). Music as a method of coping with cancer: A qualitative study among cancer patients in Sweden. *Arts & Health*, 5(2), 152–165. doi:10.1080/17533015.2013.780087

Allen, J. L. (2010). *The effectiveness of group music therapy in improving the self-concept of breast cancer survivors* (Doctoral dissertation). Available from ProQuest Dissertations and Thesis database. (UMI No. 3423187)

Ansdell, G. (2000). *Music for life. Aspects of creative music therapy with adults*. London, UK: Jessica Kingsley.

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

Apocalyptica (2010). Beautiful. On 7th *Symphony* [CD]. Germany: Sony Music. (2010)

Armstrong, A. C., & Evans, G. D. (2014). Management of women at high risk of breast cancer. *BMJ*, 348, 1-9. doi.org/10.1136/bmj.g2756

Attig, T. (2011). *How we Grieve: Relearning the world*. Retrieved from <https://www.books.google.co.za/books>

Baumaster, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117 (3), 497-529.

Baumaster, R.F. & Tice, D.M. (1990). Point-counterpoints: Anxiety and social exclusion. *Journal of Social and Clinical Psychology*, 9(2), 165-195.

Behrends, A., Müller, S., & Dziobek, I. (2012). Moving in and out of synchrony: A concept for a new intervention fostering empathy through interactional movement and dance. *Arts in Psychotherapy*, 39(2), 107-116. doi:10.1016/j.aip.2012.02.003

Bhana, V., M. (2016). *Implementation of Bonny Method of Guided Imagery and Music (BMGIM) to complement care provided in the selected cancer interim homes in Gauteng Province* (Doctoral Thesis). Retrieved from <http://www.repository.up.ac.za/discover?query=Varishka+manilal+bhana&submit2.x=12&submit2.y=6>

Birnbaum, J. C. (2014). Intersubjectivity and Nordoff-Robbins Music Therapy. *Music Therapy Perspectives*, 32(1), 30–37. doi:10.1093/mtp/miu004

Bonde, L. O. (2015). Using Mixed Methods in Music Therapy Health Care Research: Reflections on the Relationship Between the Research Question, Design and Methods in the Research Project Receptive Music Therapy with Female Cancer Patients in Rehabilitation. *Voices: A World Forum for Music Therapy*, 15(2). doi:10.15845/Voices.v152.738

Bottomorf, J. L. (1994). Using videotaped recordings in qualitative research. In J. M. Morse (Ed.), *Critical issues in qualitative research method*. London, UK: Sage.

Bradt, J., Creswell, J. W., & Burns, D. S. (2013). Mixed methods research in music therapy research. *Journal of Music Therapy*, 50(2), 123–148.

Brandberg, Y., Sandelin, K., Erikson, S., Jurell, G., Liljegren, A., Lindblom, A., Arver, B. (2008). Psychological reactions, quality of life, and body image after bilateral prophylactic mastectomy in women at high risk for breast cancer: A prospective 1-year follow-up study. *Journal of Clinical Oncology*, 26(24), 3943–3949. doi.org/10.1200/JCO.2007.13.9568

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

Memorial Sloan-Kettering Cancer Center (2012), *BREAST-Q Users' Manual, Version 1.0*. Retrieved from <http://webcore.mskcc.org/breastq/scoreBQ.html>

Bruscia, K. E. (2014). *Defining Music Therapy-Third Edition* (3rd ed.). Retrieved from <http://www.barcelona.com>

Bryman, A. (2012). *Social research methods* (4th ed.). New York: Oxford University Press.

Burns, S. J. I. (2009). *The Experience and Effects of Group Improvisational Music Therapy amongst Women Recently Diagnosed with Breast Cancer: a mixed methods study.*(Doctoral dissertation) Retrieved from <http://nova.newcastle.edu.au/vital/access/manager/Repository/uon:6890>

Cano, S. J., Klassen, A. F., Scott, A. M., & Pusic, A. L. (2013). A closer look at the BREAST-Q©. *Clinical Plastic Surgery*, 40(2), 287–296. doi:/10.1016/j.cps.2012.12.002

Clair, M., Wigren, J. (2004). *Object Relations and Self Psychology. An Introduction* (4th ed.). Belmont, CA: Brooks/Cole.

Cavanagh, H., & Rogers, M., A. (2015) The role of BRCA1 and BRCA2 mutations in prostate, pancreatic and stomach cancers. *Hereditary Cancer in Clinical Practice*, 13(16) 1-7. doi: 10.1186/s13053-015-0038-x

Chalmers, K., & Thomson, K. (1996). Coming to terms with the risk of breast cancer: Perceptions of women with primary relatives with breast cancer. *Qualitative Health Research*. 6(2) 256-282. Doi: 10.1177/104973239600600207

Chopin, F. (Unknown). Piano concerto no. 1 in E minor, opus 11, 2nd movement, romance. [Recorded by Chopin Academia Orchestra, P. Kowalski] On *Chopin: piano concertos no 1 & 2*. <https://itunes.apple.com/us/album/chopin-piano-concertos-nos-1-2/id699921370>

Conradi, J. (2012). *Perceived benefits of group music therapy for breast cancer survivors: mood, psychosocial well-being, and quality of life.* (Doctoral dissertation) Retrieved from <http://etd.lib.msu.edu/islandora/object/etd:1242/datastream/OBJ/view>

Creswell, J. W. (2003). Research design Qualitative quantitative and mixed methods approaches. *Research Design Qualitative Quantitative and Mixed Methods Approaches*, 3, 26. doi:/10.3109/08941939.2012.723954

Delibes, L. (Unknown). Lakmé act 1: Flower duet. [Recorded by Bayerisches Staatsorchester, H-K Hong, J. Larmore] On *40 Most beautiful areas* [CD]. United Kingdom: Warner Classics. (2006)

Den Heijer, M., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Bartels, C. C. M., Menke-Pluymers, M. B. E., & Tibben, A. (2010). Psychological distress in women at risk for hereditary breast cancer: The role of family communication and perceived social support. *Psycho-Oncology*, 20(12), 1317–1323. Advance online publication. doi:/10.1002/pon.1850

Den Heijer, M., Seynaeve, C., Timman, R., Duivenvoorden, H. J., Vanheusden, K., Tilanus-Linthorst, M., ... Tibben, A. (2012). Body image and psychological distress after prophylactic mastectomy and breast reconstruction in genetically predisposed women: A prospective long-term follow-up study. *European Journal of Cancer*, 48(9), 1263–1268. doi:/10.1016/j.ejca.2011.10.020

SA Diamond. (2010, January 15). The psychology of suffering: how we cope with cosmic evil [Web log post]. Retrieved from <http://psychologytoday.com/print/37091>

Dunbar, G. (2005). *Evaluating research methods in psychology: a case study approach*. Oxford, UK: Blackwell.

Esplen, J. E., Hunter, J., Leszcz, M., Warner, G., Narod, S., Metcalfe, K., ... Wong, J. (2004). A multicentre study of supportive-expressive group therapy for women with BRCA1/BRCA2 mutations. *American Cancer Society*. Advance online publication. doi: 10.1002/cncr.20661

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology & Practice*, 3(1), pp. 6-25.

Frost, N. & Kinmond, K. (2014). Evaluating qualitative research. In Sullivan, C., Gibson, S. & Riley, S. (Eds). *Doing your qualitative psychology project*, p. 8. doi: 10.4135/9781473914209

Gembris, H. (2012). Music-making as a lifelong development and resource for health. In MacDonald, R.A.R., Kreutz, G. & Mitchell, L (Eds.), *Music, health, and wellbeing* (p. 391). Retrieved from <http://www.play.google.com/books/reader>

Gibbs, G. R. (2007). *Analysing qualitative data*. London, UK: Sage.

Gopie, J. P., Mureau, M. a M., Seynaeve, C., Ter Kuile, M. M., Menke-Pluymers, M. B. E., Timman, R., & Tibben, A. (2013). Body image issues after bilateral prophylactic mastectomy with breast reconstruction in healthy women at risk for hereditary breast cancer. *Familial Cancer*, 12(3), 479–87. doi:/10.1007/s10689-012-9588-5

Gratier, M. (2003). Expressive timing and interactional synchrony between mothers and infants: cultural similarities, cultural differences, and the immigration experience. *Cognitive Development*, 18(4), 533–554. doi:/10.1016/j.cogdev.2003.09.009

Grogan, S. (2007). *Body image: Understanding Body dissatisfaction in men, women and children* (2nd ed.). East Sussex, UK: Routledge. Retrieved from <https://books.google.com/books?hl=en&lr=&id=oAZ9e31O2sIC&pgis=1>

Hagerty, M.K., Lynch-Sauer, J., Patusky, K.L., & Bouwsema, M. (1993). An emerging theory of human relatedness. *Journal of Nursing Scholarship*, 15 (3), 291-296.

Hamilton, R. J., Innella, N. A., & Bounds, D. T. (2015). Living with genetic vulnerability: a life course perspective. *Journal of Genetic Counselling*. doi:/10.1007/s10897-015-9877-x,

Hamilton, R. J., Innella, N. A., & Bounds, D. T. (2016). The life course perspective: a guide for genetic counsellors. *Journal of Genetic Counselling*, 25, 44-48. doi: 10.1007/s10897-015-9878-9

Hanson, W., Creswell, J. D. D., Clark, V., Petska, K., & Creswell, J. D. D. (2005). Mixed methods research designs in counselling psychology. *Journal of Counselling*, 52(2), 224–235. doi:/DOI: 10.1037/0022-0167.52.2.224

Harris, L., Blum, R.W., & Resnick, M. (1991) Teen females in Minnesota: A portrait of quiet disturbance. *Women & Therapy*, 11 (3 & 4), 119-135.

Hatcher, M. B., & Fallowfield, L. (2003). A qualitative study looking at the psychosocial implications of bilateral prophylactic mastectomy. *The Breast*, 12(1), 1–9. doi:/10.1016/S0960-9776(02)00135-2

Hays, D. G., & Singh, A. A. (2012). *Qualitative enquiry in clinical and educational settings*. New York, NY: The Guilford Press.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112–133. doi:/10.1177/1558689806298224

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14–26. doi:/10.2307/3700093

Joppe, H., & Yardley, L. (2004). Content and thematic analysis. In M.F. Marks & L. Yardley (Eds.), *Research methods for clinical and health psychology* (pp. 56-68). London, UK: Sage.

Karcher, M., J. (2002). The cycle of violence and disconnection among rural middle school students. *Journal of School Violence*, 1(1), 35-51. doi: 10.1300/J202v01n01_03

Kenen, R., Ardern-Jones, A., & Eeles, R. (2006). “Social separation” among women under 40 years of age diagnosed with breast cancer and carrying the BRCA1 or BRCA2 mutation. *Journal of Genetic Counselling*, 15 (3), 149-162. http://doi:/10.1007/s10897-005-9015-2

Kenen, R.H., Shapiro, P.J., Hantsoo, L., Friedman, S., Coyne, J.C. (2007). Women with BRCA1 and BRCA2 mutations renegotiating a post prophylactic mastectomy identity: Self-image and self-disclosure. *Journal of Genetic Counselling*, 16(6), (789-798). doi:/10.1007/s10897-007-9112-5

Kraft Goin, M. (2014) The importance of understanding the psychological meaning of Angelina Jolie’s story. *Journal of Psychiatric Practice*, 20(1), 61-62. doi: 10.1097/01.pra.0000442939.0c

Kübler-Ross, E. (1998). *The wheel of life: A memoir of living and dying*. New York, NY: Touchstone.

Laloo, F., & Evans, D. G. (2012). Familial Breast Cancer. *Clinical Genetics*, 82(2), 105–114. doi:/10.1111/j.1399-0004.2012.01859.x

Lather, P. (1986). Research as praxis. *Harvard Educational Review*, 56 (3), 257-277.

Lee, R. M. & Robbins, S. B. (1995). Measuring belongingness: The social connectedness and the social assurance scales. *Journal of Counselling Psychology*, 45(2), 232-241.

Lee, R. M., & Robbins, S. B. (1998). The relationship between social connectedness and anxiety, self-esteem, and social identity. *Journal of Counselling Psychology*, 45, 338-345.

Lee, R. M., & Robbins, S. B. (2000). Understanding social connectedness in college women and men. *Journal of Counselling and Development*, 78, 484-491.

Lee, R. M., Draper, M., & Lee, S. (2001). Social connectedness, dysfunctional interpersonal behaviors, and psychological distress: Testing a mediator model. *Journal of Counselling Psychology*, 48 (3), 310-318. □

Leidy, N. K., & Haase, J. E. (1999). Functional status from the patient's perspective: The challenge of preserving personal integrity. *Research in Nursing and Health*, 22(1), 67–77. doi:/10.1002/(SICI)1098-240X(199902)22:1<67::AID-NUR8>3.0.CO;2-D

Lin, L. (2016) Something and nothing: On the psychopolitics of breasts and breastlessness. *Studies in Gender and Sexuality*, 17(1), 45-56. doi: 10.1080/15240657.2016.1135682

Lloyd, S. M., Watson, M., Oaker, G., Sacks, N., Querci Della Rovere, U., & Gui, G. (2000). Understanding the experience of prophylactic bilateral mastectomy: A qualitative study of ten women. *Psycho-Oncology*, 9(6), 473–485. doi:/10.1002/1099-1611(200011/12)9:6<473::AID-PON490>3.0.CO;2-T

Lodder, L. N., Frets, P. G., Trijsburg, R. W., Meijers-Heijboer, E. J., Klijn, J. G. M., Seynaeve, C., ... Niermeijer, M. F. (2002). One year follow-up of women opting for presymptomatic testing for BRCA1 and BRCA2: emotional impact of the test outcome and decisions on risk management (surveillance or prophylactic surgery). *Breast Cancer*

Research and Treatment, 73(2), 97–112.
doi:/10.1023/A:1015269620265

MacBrayer, E., K. (2007). My life as a mutant: the BRCA1 experience. *Professional Psychology: Research and Practice*. 38(6) 571-575. doi: 10.1037/0735-7028.38.6.571

Malloch, S., & Trevarthen, C. (2009). *Musicality: Communicating the vitality and interests of life. Communicative Musicality: Exploring the Basis of Human Companionship* (pp. 1–11). Oxford, UK: Oxford University Press.

McCambridge, J., Witton, J., & Elbourne, D. R. (2014). Systematic review of the Hawthorne effect: New concepts are needed to study research participation effects. *Journal of Clinical Epidemiology*, 67(3), 267–277. doi:/10.1016/j.jclinepi.2013.08.015

McGaughey, A. (2006). Body image after bilateral prophylactic mastectomy: An integrative literature review. *Journal of Midwifery and Women's Health*, 51(6). doi:/10.1016/j.jmwh.2006.07.002

Metcalfe, K. A., Esplen, M.J., Goel, V., & Narod, S. A. (2004). Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. *Psycho-Oncology* 13, 14-25. Advanced online publication. doi: 10.1002/pon.726.

Memorial Sloan Kettering Cancer Centre. (2012) *Breast-Q® User Manual* (1) [Software and instruction manual]. Retrieved from <http://webcore.mskcc.org.breastq/scoreBQ.html>

Miller, J.B., & Stiver, I.P. (1997). *The healing connection: How women form relationships and therapy and in life* (pp. 26, 45). Boston, MA: Beacon.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained: methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, 1(1), 48–76. doi:/10.1177/2345678906292462

Mozart, W. (Unknown) Mozart piano concerto No. 9 in E-flat, K 271 “Jeunehomme”: Allegro, Andantino, Rondeau. [Camerata des Mozarteums Salzburg, A. Schiff, S Vegh]. On *Mozart: the piano concertos* [CD]. London. UK: Decca. (1995)

Native American Music (Unknown). The eagle watchers [Recorded by J. Shenandoah]. On *The peacemaker's journey* [CD]. Boulder, CO: Silver wave records. (2000)

O'Callaghan, C. (2009). Objectivist and constructionist music therapy research in oncology and palliative care: An overview and reflection. *Music and Medicine*, 1(1), 41-60. doi:/10.1177/1943862109337135

Olopade, O. I., Grushko, T. a., Nanda, R., & Huo, D. (2008). Advances in breast cancer: pathways to personalized medicine. *Clinical Cancer Research*, 14(24), 7988–7999. doi:/10.1158/1078-0432.CCR-08-1211

Onwuegbuzie, A. J., & Collins, K. (2007). A typology of mixed methods sampling designs in social science research. *The Qualitative Report*, 12(2), 36. doi:/10.1016/j.bbi.2003.12.001

Onwuegbuzie, A. J., & Daniel, L. G. (2003). Typology of analytical and interpretational errors. *Quantitative and Qualitative Educational Research*, 6(2), 1–53.

Onwuegbuzie, A. J., & Leech, N. L. (2004). Enhancing the interpretation of “significant” findings : the role of mixed methods research. *The Qualitative Report*, 9(4), 770–792.

Orff, C.(Unknown). In trutina [Recorded by H. Westerna, Royal philharmonic orchestra]. on *Pure* [CD]. London, UK: Decca. (2004)

Patenaude, A. F., Orozco, S., Xiaochun, L., Kaelin, C. M., Gadd, M., Matory, Y., ... Garber, J. E. (2008). Support needs and acceptability of psychological consultation: attitudes of 108 women who had undergone or were considering prophylactic mastectomy. *Psycho-Oncology*, 7(8), 832–843. doi:/10. 1002/pon.1279

Pavlicevic, M. (1997). *Music therapy in context. music, meaning and relationship*. London, UK: Jessica Kingsley.

Piot-Ziegler, C., Sassi, M. L., Raffoul, W. & Delaloye, J.F. (2010). Mastectomy, body deconstruction, and impact: a qualitative study. *British Journal of Health Psychology*, 15, 479-510. doi: 10.1348/135910709X472174

Polkinghorne, D. E. (2007) Validity issues in narrative research. *Qualitative Inquiry*, 13(4), 471-486. doi: 10.1177/1077800406297670

Pusic, A. L., Klassen, A. F., Scott, A. M., Klok, J. A., Cordeiro, P. G., & Cano, S. J. (2009). Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q®. *Plastic and Reconstructive Surgery*, 124(2), 345–353. doi:/10.1097/PRS.0b013e3181aee807

Rachmaninoff, S (Unknown). Piano concerto no. 3 in D minor. Opus 30. [Recorded by M. Argerich, R. Chailly & RSO]. On *Rachmaninoff piano concerto no. 3 in D minor. Opus 30*. London, UK: Decca. (1995)

Raveis, V., H., & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology*, 14, 49-60. Advanced online publication. doi: 10.1002/pon.819

Rees, G., Fry, A., Cull, A., & Sutton, S. (2004) Illness perceptions and distress in women at increased risk of breast cancer. *Psychology and Health* 19(6), 749-765. doi: 10.1080/08870440412331279764

Robarts, J. (1998). Connecting. *British Journal of Music Therapy*, 12(1), 2.

Robarts, J. (2006). Music therapy with a sexually abused child. *Clinical Child Psychology and Psychiatry* 11(2) 249-269. Doi: 10.1177/1359104506061418

Rolnick, S. J., Altschuler, A., Nekhlyudov, L., Elmore, J.G., Greene, S.M., Harris. E.L., Herrinton, L.J., Barton, M. B., Geiger, A.M., & Fletcher, S. W. (2007) What women wish they knew before prophylactic mastectomy. *Cancer Nursing*, 30(4), 285-291. doi: 10.1097/01.NCC.0000281739.22930.4c

Rozema, H., Völlink, T., & Lechner, L. (2009). The role of illness representations in coping and health of patients treated for breast cancer. *Psycho-Oncology*. Advanced online publication. doi: 10.1002/pon.1488

Sadock, B. J., Sadock, V. À., & Ruiz, P. (2015). *Kaplan & Sadock's synopsis of psychiatry: behavioral sciences/clinical psychiatry* (11th ed.). Philadelphia, PA: Wolters Kluwer.

Schoeman, M., Apffelstaedt, J. P., Baatjes, K., & Urban, M. (2013). Implementation of a breast cancer genetic service in South Africa - lessons learned. *South African Medical Journal / Suid-Afrikaanse Tydskrif Vir Geneeskunde*, 103(8), 529–533. doi:/10.7196/SAMJ.6814

Shaughnessy, J. J., Zechmeister, E. B., & Zechmeister Jeanne S. (2012). *Research methods in psychology* (9th ed.). New York, NY: McGraw-Hill.

Shiovitz, S., & Korde, L. A. (2015). Genetics of breast cancer: a topic in evolution. *Annals of Oncology*. doi: 10. 1093/annonc/mdv022

Solomon, Z. (1995). Oscillating between denial and recognition of PTSD: why are lessons learned forgotten? *Journal of Traumatic Stress*, 8, 271-282.

Spinelli, E. (1994). *Demystifying therapy*. London, UK: Constable and Company Ltd.

Stern, D.N. (1985). *The interpersonal world of the infant. A view from psychoanalysis & developmental psychology*. New York, NY: Basic Books.

Stern, D. (2010). The issue of vitality. *Nordic Journal of Music Therapy*, 19(2), 88–102. doi:/10.1080/08098131.2010.497634

Sting (1994). Fragile. On *Fields of Gold – The best of Sting 1984 -1994* [CD] Japan, Universal Records

Sugrue, R., MacGregor, G., Sugrue, m., Curran, S.& Murphy, L. (2013). An evaluation of patient reported outcomes following breast cancer reconstruction utilizing Breast-Q®. *The Breast*, 22, 158-161. <http://dx.doi.org/10.1016/j.breast.2012.12.001>

Teddlie, C., & Yu, F. (2007). Mixed methods sampling: a typology with examples. *Journal of Mixed Methods Research*, 1(1), 77–100. doi:/10.1177/2345678906292430

Thompson, N. (2016), Spirituality: an existentialist perspective. *Illness, Crisis & Loss* 15(2), 125-136.

Thompson, N., & Walsh, M. (2010). The existential basis of trauma. *Journal of Social Work in Practice*, 24 (4), 377-389. doi: 10.1080/02650531003638163

Townsend, K. C., & McWhirter, B. T. (2005). Connectedness: A Review of the Literature with Implications for Counselling, Assessment, and Research. *Journal of Counselling & Development*, 83, 191–201

Trevartin, C., & Malloch, S. N. (2000). The dance of wellbeing: defining the musical therapeutic effect. *Nordic Journal of Music Therapy*, 9(2), 3–17.

Trondalen, G., & Skåderud, F. (2007). Playing with affects and the importance of “affect attunement”. *Nordic Journal of Music Therapy*. 16 (2) 100-111.

Trevarthen, C. (1979). Communication and cooperation in early infancy: a description of primary intersubjectivity. In *Before speech: The beginning of interpersonal communication* (pp. 321–347). London, UK: Cambridge University Press.

Valdesolo, P., & DeSteno, D. (2011). Synchrony and the social tuning of compassion. *Emotion*, 11(2), 262–266. doi:/10.1037/a0021302

Van der Merwe, N., Bouwens, C. S. H., Pienaar, R., Van der Merwe, L., Yako, Y. Y., Geiger, D. H., & Kotze, M. J. (2012). CYP2D6 genotyping and use of antidepressants in breast cancer patients: test development for clinical application. *Metabolic Brain Disease*, 27(3), 319–326. doi:/10.1007/s11011-012-9312-z

Van Oostrom, I., Meijers-Heijboer, H., Duinenvoorden, H.J., Bröcker-Vriends, A.H.J.T., van Aspern, C. J., Sijmons, R.H., ... Tibben, A. (2007). Prognostic factors for hereditary cancer distress six months after BRCA1/2 or HNPCC genetic susceptibility testing. *European Journal of Cancer*, 43, 71-77. http://doi: 10. 1016/j.ejca.2006.08.023

Vos, J., van Aperen, C. J., Oosterwijk, J.C., Menko F. H., Collee, M.J., Garcia, E.G., & Tibben, A. (2012). The counselees' self-reported request for psychological help in genetic counselling for hereditary breast/ovarian cancer: not only psychopathology matters. *Psycho-Onchology*, 22. Advanced online publication. doi: 10.1057/palgrave.kmrp.8500141

WHO. (2014). World Health Organization. (2014). *Non-communicable diseases (Country Cancer Profile: South Africa)*. Retrieved from http://www.who.int/cancer/country-profiles/zaf_en.pdf?ua=1

Winnicott, D. W. (1971). *Playing and reality*. London, UK: Tavistock.

8 Appendices

8.1 Appendix A: Breast-Q® Questionnaire

The following questions are about your breasts and breast reconstruction surgery. After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

1. With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
How you look in the mirror clothed?	1	2	3	4
The shape of your reconstructed breast(s) when you are wearing a bra?	1	2	3	4
How normal you feel in your clothes?	1	2	3	4
The size of your reconstructed breast(s)?	1	2	3	4
Being able to wear clothing that is more fitted?	1	2	3	4
How your breasts are lined up in relation to each other?	1	2	3	4
How comfortably your bras fit?	1	2	3	4
The softness of your reconstructed breast(s)?	1	2	3	4
How equal in size your breasts are to each other?	1	2	3	4
How natural your reconstructed breast(s) looks?	1	2	3	4

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
How naturally your reconstructed breast(s) sits/hangs?	1	2	3	4
How your reconstructed breast(s) feels to touch?	1	2	3	4
How much your reconstructed breast(s) feels like a natural part of your body?	1	2	3	4
How closely matched your breasts are to each other?	1	2	3	4
How your reconstructed breast(s) look now compared to before you had any breast surgery?	1	2	3	4
How you look in the mirror unclothed?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

This question is about breast reconstruction using IMPLANTS. If you do not have an implant(s) please skip to question 3. If you do have an implant(s), please answer question 2 below.

2. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The amount of rippling (wrinkling) of your implant(s) that you can see?	1	2	3	4
The amount of rippling (wrinkling) of your implant(s) that you can feel?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

3. We would like to know how you feel about the outcome of your breast reconstruction surgery. Please indicate how much you agree or disagree with each statement:

	Disagree	Somewhat Agree	Definitely Agree
Having reconstruction is much better than the alternative of having no breast(s).	1	2	3
I would encourage other women in my situation to have breast reconstruction surgery.	1	2	3
I would do it again.	1	2	3
I have no regrets about having the surgery.	1	2	3
Having this surgery changed my life for the better.	1	2	3
The outcome perfectly matched my expectations.	1	2	3
It turned out exactly as I had planned.	1	2	3

Please check that you have answered all the questions before going on to the next page

4. With your breasts in mind, in the past 2 weeks, how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Confident in a social setting?	1	2	3	4	5
Emotionally able to do the things that you want to do?	1	2	3	4	5
Emotionally healthy?	1	2	3	4	5
Of equal worth to other women?	1	2	3	4	5
Self-confident?	1	2	3	4	5
Feminine in your clothes?	1	2	3	4	5
Accepting of your body?	1	2	3	4	5
Normal?	1	2	3	4	5
Like other women?	1	2	3	4	5
Attractive?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

5. Thinking of your sexuality, since your breast reconstruction, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
Sexually attractive in your clothes?	1	2	3	4	5	N/A
Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
Confident sexually?	1	2	3	4	5	N/A
Satisfied with your sex- life?	1	2	3	4	5	N/A
Confident sexually about how your breast(s) look when unclothed?	1	2	3	4	5	N/A
Sexually attractive when unclothed?	1	2	3	4	5	N/A

Please check that you have answered all the questions before going on to the next page

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Neck pain?	1	2	3	4	5
Upper back pain?	1	2	3	4	5
Shoulder pain?	1	2	3	4	5
Arm pain?	1	2	3	4	5
Rib pain?	1	2	3	4	5
Pain in the muscles of your chest?	1	2	3	4	5
Difficulty lifting or moving your arms?	1	2	3	4	5
Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
Tightness in your breast area?	1	2	3	4	5
Pulling in your breast area?	1	2	3	4	5
Nagging feeling in your breast area?	1	2	3	4	5
Tenderness in your breast area?	1	2	3	4	5
Sharp pains in your breast area?	1	2	3	4	5
Shooting pains in your breast area?	1	2	3	4	5
Aching feeling in your breast area?	1	2	3	4	5
Throbbing feeling in your breast area?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

The following questions are about reconstruction using a TRAM or DIEP flap (i.e., reconstruction using skin and fat from you abdomen/tummy area). If you do not have a TRAM or DIEP flap, please skip to question 10. If you do have a TRAM or DIEP flap, please answer the following questions:

7. In the past 2 weeks, with your abdomen (tummy area) in mind, how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Difficulty sitting up because of abdominal muscle weakness (e.g. getting out of bed)?	1	2	3	4	5
Difficulty doing everyday activities because of abdominal muscle weakness (e.g. making your bed)?	1	2	3	4	5
Abdominal discomfort?	1	2	3	4	5
Abdominal bloating?	1	2	3	4	5
Abdominal bulging?	1	2	3	4	5
Tightness in your abdomen?	1	2	3	4	5
Pulling in your abdomen?	1	2	3	4	5
Lower back pain?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

8. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
How your abdomen looks?	1	2	3	4
The position of your navel (belly button)?	1	2	3	4
How your abdominal scars look?	1	2	3	4

Please check that you have answered all the questions before going on to the next
page

9. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
How your abdomen feels now compared to before your surgery?	1	2	3	4
How your abdomen looks now compared to before your surgery?	1	2	3	4

This question is about NIPPLE reconstruction. If you did not have nipple reconstruction, please skip to question 11. If you did have nipple reconstruction, please answer question 10 below.

10. In the past 2 weeks, how satisfied or dissatisfied are you with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The shape of your reconstructed nipple(s)?	1	2	3	4
How your reconstructed nipple(s) and areola(s) look?	1	2	3	4
How natural your reconstructed nipple(s) look?	1	2	3	4
The colour of your reconstructed nipple/areolar complex?	1	2	3	4
The height (projection) of your reconstructed nipple(s)?	1	2	3	4



User agreement

Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 463 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "Mapi" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
Information Support Unit
27 rue de la Villette
69003 Lyon
France
Telephone: +33 (0)472 13 66 75
Fax: +33 (0)472 13 66 82
Email: PRQinformation@mapi-trust.org

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by Mapi for use only in accordance with the terms and conditions defined herein. Mapi reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

Section 1.01 Identification of the User

User name	Dr Susan Hitge
Legal Form	Master's student
Address	PO Box 2072 Durbanville 7551
Country	South Africa
Name of the contact in charge of the Agreement	Dr SS Hitge
Telephone number	+27834170886
Fax number	
Email address	susan.hitge@gmail.com
If different:	
Legal Form	
Address	
Country	

Section 1.02 Identification of the Questionnaire

Title	BREAST-Q™ (BREAST-Q™)
Author(s)	Pusic Andrea L; Cano Stefan; Klassen Anne F
Owner	Memorial Sloan-Kettering Cancer Center and The University of British Columbia

Copyright	Memorial Sloan-Kettering Cancer Center and The University of British Columbia © 2007. All rights reserved
Original bibliographic references	Klassen AF, Pusio AL, Scott A, Klok J, Cano SJ. Satisfaction and quality of life in women who undergo breast surgery: a qualitative study. <i>BMC Womens Health</i>. 2009 May 1;9:11 Pusio AL, Klassen AF, Scott AM, Klok JA, Cordeiro PG, Cano SJ. Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q. <i>Plast Reconstr Surg</i>. 2009 Aug;124(2):345-53 Pusio AL, Chen CM, Cano S, Klassen A, McCarthy C, Collins ED, Cordeiro PG. Measuring quality of life in cosmetic and reconstructive breast surgery: a systematic review of patient-reported outcomes instruments. <i>Plast Reconstr Surg</i>. 2007 Sep 15;120(4):823-37 (Abstract) Pusio AL et al. Measuring Quality of Life in Breast Surgery: Content Development of a New Modular System to Capture Patient-Reported Outcomes (The MSKCC Breast Q). <i>ISOQOL Annual Meeting</i>, October 2006, Lisbon, Portugal Pusio AL, Reavey PL, Klassen AF, Scott A, McCarthy C, Cano SJ. Measuring patient outcomes in breast augmentation: introducing the BREAST-Q Augmentation module. <i>Clin Plast Surg</i>. 2009 Jan;36(1):23-32

Article 2. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter:

Context of use	Clinical project or study
Title	Dr
Disease or condition	Hereditary breast cancer
Type of research	Other
Number of patient expected	10
Number of submission to the Questionnaire for each patient	2
Term of clinical follow-up for each patient	6 months
Mode of administration	Paper

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter:

(a) Rights transferred

Acting in the Author's name, Mapi transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")

(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, free of charge, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, medical publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing Mapi of the same beforehand by the signature of a Translation Agreement and to providing a copy of the translation thus obtained as soon as possible to Mapi.

The User acknowledges and accepts that it is not entitled to amend, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without Mapi's prior specific written consent

(b) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.



► Use in a publication or on a website with unrestricted access:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a protected version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PRQinformation@mapi-trust.org – Internet: www.proqolid.org
- to provide Mapi, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes.

► Use for dissemination:

- On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a clean version of the Questionnaire, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.

The User undertakes to also respect the following special obligations:

- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PRQinformation@mapi-trust.org – Internet: www.proqolid.org

- On promotional / marketing documents

In the case of publication on promotional/marketing documents, the User undertakes to respect the following special obligations:

- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PRQinformation@mapi-trust.org – Internet: www.proqolid.org
- to provide Mapi, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes

For any other use not defined herein, please contact Mapi for the specific conditions of use and access fees (if applicable).

Article 3. Term

Mapi transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. Territories and Languages

Mapi transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Language
English for the USA

Versions/Modules
BREAST-Q™ Expectations module BREAST-Q™ Mastectomy module BREAST-Q™ Reconstruction module

Article 6. Price and Payment Terms

The User undertakes in relation to Mapi to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

ROYALTY FEES *	Commercial users	Cost per study	Please contact Dr Andrea Pusio at PusioA@mskcc.org
		Cost per language	Please contact Dr Andrea Pusio at PusioA@mskcc.org
	Funded academic research	Cost per study	Free
		Cost per language	Free
	Not funded academic users	Cost per study	Free
		Cost per language	Free
DISTRIBUTION FEES *	Commercial users	Cost per study	700 € per module
		Cost per language	300 €
	Funded academic research	Cost per study	Free
		Cost per language	Free
	Not funded academic users	Cost per study	Free
		Cost per language	Free

* Excluding VAT

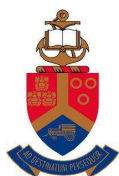
- *Commercial users: Industry, GPO, any for-profit companies*
- *Funded Academic research: Projects receiving funding from commerce, government, EU or registered charity. Funded academic research—sponsored by industry fits the "commercial users" category.*
- *Not funded academic users, individual medical practice: Projects are not explicitly funded, but funding comes from overall departmental funds or from the University or individual funds*

Agreed and acknowledged by

User's name: Dr Susan Hittge

Date:
02/08/2015

8.2 Appendix B: Music Therapy Questionnaire



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Please complete the following questionnaire. Do not write your name on the questionnaire, in order to ensure anonymity. Your participation and time are valued – thank you!

Pseudonym:

Age:

Time since surgery:

Did the music therapy process change the way you perceive, feel or think about your body? If so, please discuss.

.....

.....

.....

.....

.....

.....

.....

Did the music therapy process change aspects of relationships with intimate or close family members? If so, please discuss.

.....

.....

.....

.....

.....

.....

.....

.....

Did the music therapy process provide you with a sense of social support and/or social connection? If so, please discuss.

.....

.....

.....

.....

.....

.....

.....

Did the music therapy process change the way you perceive, feel or think about yourself in ways not mentioned above? If so, please discuss.

.....

.....

.....

.....

.....

.....

Would you recommend music therapy to other women who have undergone bilateral prophylactic mastectomy with breast reconstruction? If so, please discuss why you would recommend music therapy.

.....

.....

.....

.....

.....

.....

.....

.....

Please add any comments you wish to share:

.....

.....

.....

.....

.....

.....

8.3 Appendix C: Colleague Information



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Dr Susan Hitge (MB.,ChB.)
susan.hitge@gmail.com
083 417 0668

Request for permission to contact patients

Dear Colleague,

STUDY TITLE: The role of music therapy in improving body image and addressing intrapersonal and interpersonal connectedness of women who have undergone bilateral prophylactic mastectomy and breast reconstruction.

I am researching the role of music therapy in improving body image and addressing intrapersonal and interpersonal connectedness of women who have undergone bilateral prophylactic mastectomy and breast reconstruction.

In order to pursue this goal I will conduct six group music therapy sessions with between six and eight study participants who meet the following criteria: a genetic predisposition for developing breast cancer; history of bilateral prophylactic mastectomy and breast reconstruction within the past three years; no prior history of breast cancer.

Breast-Q©, a standardised questionnaire that evaluates patient satisfaction after risk reduction surgery and reconstruction for patients with a genetic vulnerability to developing breast cancer, will be completed by each participant before the first session and after the sixth session. The sessions will be video recorded (please see ethical considerations below) and a music therapy questionnaire will be conducted at the conclusion of the study.

I would appreciate your cooperation in identifying potential candidates from your patient base and obtaining their permission to be contacted by me in regard to the proposed research.

I will personally meet with each candidate who indicates her possible willingness to participate in order to explain the study and the methods that will be used. Participation in the study is voluntary. Ethical measures such as confidentiality, safety and informed consent will be employed. The names of the participants will be changed and the data will be stored securely at the University of Pretoria for 15 years after the commencement of the study, after which it will be destroyed. The data will only be used for teaching and research purposes.

Patients who are interested in participating in the study can contact me directly at susan.hitge@gmail.com or they can inform your surgery of their interest. Please would you email me the details of any patients interested in participating.

Thank you for your attention.

Best regards

Dr. S.S. Hitge

Date

8.4 Appendix D: Letter from Doctor to Patient

Dear _____

This surgery has been contacted by Dr Susan Hitge, who is conducting a research study through the University of Pretoria. She is exploring the role that group music therapy could play in improving body image and addressing a sense of connectedness to self and others of women who have undergone bilateral prophylactic mastectomy and breast reconstruction. She would like to invite women who have been through this experience to participate.

Participation in the study would involve being part of six group music therapy sessions. These will each be approximately 90 minutes in duration, spread over a period of six weeks. They will include activities such as group drumming, music listening and imaging, movement to music and art work to music. Participants will be asked to complete a relatively short questionnaire before the music therapy process and two questionnaires after the process. The music therapy sessions will be video recorded. Confidentiality will be ensured by storing the documentation and video footage securely for the duration of the study. Participants' anonymity will be ensured by not using names or any identifying information on any documentation related to the study. The data obtained from the research will be stored securely for a further 15 years after the commencement of the study at the Music Department of the University of Pretoria after which it will be destroyed. The participants will have access to the results of the study.

Dr Hitge asked me to forward this letter to patients who meet the criteria for inclusion in the study. She would be grateful if you would consider being part of this research. Enrolment in the study is entirely voluntary and participants may withdraw at any stage in which case data concerning the person will be destroyed.

Dr. Hitge can be contacted directly at susan.hitge@gmail.com or you can inform the surgery of your interest in participating in the study. We will inform Dr. Hitge of your interest and she will make an appointment with you to discuss the study protocol and to obtain informed consent for the video recordings.

Best regards

Date

8.5 Appendix E: Letter of Informed Consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Informed consent form: Participant

STUDY TITLE: The role of group music therapy in improving body image and addressing intrapersonal and interpersonal connectedness of women who have undergone bilateral prophylactic mastectomy and breast reconstruction

I,

___ (full name and surname), hereby declare myself willing to participate in this research study by attending six group music therapy sessions. I am willing to complete the Breast-Q© questionnaire before and again after the music therapy process, as well as completing a music therapy questionnaire, also after the process have ended. I hereby give my consent for the music therapy sessions to be video-recorded, understanding that these recordings will only be used for the purposes of the study and that my confidentiality and anonymity are assured. These recordings will be stored securely at the University of Pretoria and will only be used for research and training purposes. The data will be destroyed 15 years after the commencement of the study. I understand that if any other researchers would like to do a secondary analysis of this data in that time period that my consent will be required. My anonymity will be assured through not using my name or any other identifying information on any of the data or documentation, apart from this consent form.

I understand that I may withdraw from the study at any time and that all data related to me, except the group video footage will then be destroyed.

Participant details:

Name: _____ Signature: _____

Contact No: _____ Date: _____

Researcher:

Name: _____

Signature: _____

Date: _____

Supervisor

Name: _____

Signature: _____

Date: _____

8.6 Appendix F: Qualitative Data Set A

8.7 Appendix G: Qualitative Data Set B

46

6.2 Appendix B: Music Therapy Questionnaire



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Please complete the following questionnaire. Do not write your name on the questionnaire, in order to ensure anonymity. Your participation and time are valued – thank you!

Pseudonym: MICHELLE

Age: 44

Time since surgery: 7 MONTHS

Did the music therapy process change the way you perceive, feel or think about your body? If so, please discuss.

YES, I FELT MORE OF A MIND AND BODY
CONNECTION. MY MIND (THOUGHTS) FELT MORE
IN SYNC WITH MY BODY.

BEFORE THERAPY I HAD A STRONG
SENSE OF BETRAYAL BY MY BODY.

Did the music therapy process change aspects of relationships with intimate or close family members? If so, please discuss.

YES, BECAUSE I FELT CALMER I WAS
LESS AGITATED WITH OTHERS.

Did the music therapy process provide you with a sense of social support and/or social connection? If so, please discuss.

A DEFINATE YES!

I FELT UNDERSTOOD, EMPATHY, WARMTH.
EVERY SESSION FELT LIKE A VERY REWARDING
SOCIAL CONNECTION.

Did the music therapy process change the way you perceive, feel or think about yourself in ways not mentioned above? If so, please discuss.

YES, IT GAVE ME THE TOOL TO EXPLORE
MEDIUMS, LIKE SINGING AND WRITING,
IN A SAFE ENVIRONMENT. THESE ACTS IN TURN
THOUGHT ME MORE ABOUT MYSELF AS A PERSON.
THE MUSIC THERAPY MADE ME FEEL
EMPOWERED. THIS COUNTER BALANCES THE SCALE. MY
GENETIC RESULT CREATES A DARK SIDE OF MY BEING.
THE MUSIC THERAPY CREATES A LIGHT POSITIVE SIDE
TO MY BEING.

48

Would you recommend music therapy to other women who have undergone bilateral prophylactic mastectomy with breast reconstruction? If so, please discuss why you would recommend music therapy.

ABSOLUTELY! FEAR IS A BIG PART OF THE MASTECTOMY JOURNEY. MUSIC THERAPY WAS A SAFE ENVIRONMENT TO WHERE ONE WAS ABLE TO LOOK THE FEAR IN THE EYE AND STOP FIGHTING IT BUT ACCEPT IT AS PART OF THE "NEW JOURNEY" I WAS GIVEN WONDERFUL TOOLS TO HELP WITH THE OVERWHELMING FEAR AT TIMES.

Please add any comments you wish to share:

FOR ME THE MUSIC THERAPY PROCESS WAS A WONDERFUL BLESSING THAT ENRICHED ME. FOR SURE, I AM ~~AM~~ MORE ABLE TO COPE WITH MY "NEW JOURNEY" AFTER MY 6 SESSIONS.

8.9 Appendix H: English Transcript with First Order Codes

8.10 Appendix I: Higher Order with First Order Codes

8.11 Appendix J: Quantitative Data Set A1

MICHELLE
PRE-TEST

32

6 Appendices

6.1 Appendix A: Breast-Q® Questionnaire

The following questions are about your breasts and breast reconstruction surgery. After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

1. With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a) How you look in the mirror clothed?	1	2	3	4
b) The shape of your reconstructed breast(s) when you are wearing a bra?	1	2	3	4
c) How normal you feel in your clothes?	1	2	3	4
d) The size of your reconstructed breast(s)?	1	2	3	4
e) Being able to wear clothing that is more fitted?	1	2	3	4
f) How your breasts are lined up in relation to each other?	1	2	3	4
g) How comfortably your bras fit?	1	2	3	4
h) The softness of your reconstructed breast(s)?	1	2	3	4
i) How equal in size your breasts are to each other?	1	2	3	4
j) How natural your reconstructed breast(s) looks?	1	2	3	4
k) How naturally your reconstructed breast(s)	1	2	3	4

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
sits/hangs?				
l) How your reconstructed breast(s) feels to touch?	1	2	3	4
m) How much your reconstructed breast(s) feels like a natural part of your body?	1	2	3	4
n) How closely matched your breasts are to each other?	1	2	3	4
o) How your reconstructed breast(s) look now compared to before you had any breast surgery?	1	2	3	4
p) How you look in the mirror unclothed?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

This question is about breast reconstruction using IMPLANTS. If you do not have an implant(s) please skip to question 3. If you do have an implant(s), please answer question 2 below.

2. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a) The amount of rippling (wrinkling) of your implant(s) that you can see?	1	2	3	4
b) The amount of rippling (wrinkling) of your implant(s) that you can feel?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

3. We would like to know how you feel about the outcome of your breast reconstruction surgery. Please indicate how much you agree or disagree with each statement:

	Disagree	Somewhat Agree	Definitely Agree
c) Having reconstruction is much better than the alternative of having no breast(s).	1	2	3
d) I would encourage other women in my situation to have breast reconstruction surgery.	1	2	3
e) I would do it again.	1	2	3
f) I have no regrets about having the surgery.	1	2	3
g) Having this surgery changed my life for the better.	1	2	3
h) The outcome perfectly matched my expectations.	1	2	3
i) It turned out exactly as I had planned.	1	2	3

Please check that you have answered all the questions before going on to the next page

4. With your breasts in mind, in the past 2 weeks, how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
j) Confident in a social setting?	1	2	3	4	5
k) Emotionally able to do the things that you want to do?	1	2	3	4	5
l) Emotionally healthy?	1	2	3	4	5
m) Of equal worth to other women?	1	2	3	4	5
n) Self-confident?	1	2	3	4	5
o) Feminine in your clothes?	1	2	3	4	5
p) Accepting of your body?	1	2	3	4	5
q) Normal?	1	2	3	4	5
r) Like other women?	1	2	3	4	5
s) Attractive?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page.

5. Thinking of your sexuality, since your breast reconstruction, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
t) Sexually attractive in your clothes?	1	2	3	4	5	N/A
u) Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
v) Confident sexually?	1	2	3	4	5	N/A
w) Satisfied with your sex-life?	1	2	3	4	5	N/A
x) Confident sexually about how your breast(s) look when unclothed?	1	2	3	4	5	N/A
y) Sexually attractive when unclothed?	1	2	3	4	5	N/A

Please check that you have answered all the questions before going on to the next page

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a) Neck pain?	1	2	3	4	5
b) Upper back pain?	1	2	3	4	5
c) Shoulder pain?	1	2	3	4	5
d) Arm pain?	1	2	3	4	5
e) Rib pain?	1	2	3	4	5
f) Pain in the muscles of your chest?	1	2	3	4	5
g) Difficulty lifting or moving your arms?	1	2	3	4	5
h) Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
i) Tightness in your breast area?	1	2	3	4	5
j) Pulling in your breast area?	1	2	3	4	5
k) Nagging feeling in your breast area?	1	2	3	4	5
l) Tenderness in your breast area?	1	2	3	4	5
m) Sharp pains in your breast area?	1	2	3	4	5
n) Shooting pains in your breast area?	1	2	3	4	5
o) Aching feeling in your breast area?	1	2	3	4	5
p) Throbbing feeling in your breast area?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

The following questions are about reconstruction using a TRAM or DIEP flap (i.e., reconstruction using skin and fat from your abdomen/tummy area). If you do not have a TRAM or DIEP flap, please skip to question 10. If you do have a TRAM or DIEP flap, please answer the following questions:

7. In the past 2 weeks, with your abdomen (tummy area) in mind, how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
z) Difficulty sitting up because of abdominal muscle weakness (e.g. getting out of bed)?	1	2	3	4	5
aa) Difficulty doing everyday activities because of abdominal muscle weakness (e.g. making your bed)?	1	2	3	4	5
bb) Abdominal discomfort?	1	2	3	4	5
cc) Abdominal bloating?	1	2	3	4	5
dd) Abdominal bulging?	1	2	3	4	5
ee) Tightness in your abdomen?	1	2	3	4	5
ff) Pulling in your abdomen?	1	2	3	4	5
gg) Lower back pain?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

8. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
hh) How your abdomen looks?	1	2	3	4
ii) The position of your navel (belly button)?	1	2	3	4
jj) How your abdominal scars look?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

9. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
kk) How your abdomen feels now compared to before your surgery?	1	2	3	4
ll) How your abdomen looks now compared to before your surgery?	1	2	3	4

This question is about NIPPLE reconstruction. If you did not have nipple reconstruction, please skip to question 11. If you did have nipple reconstruction, please answer question 10 below.

10. In the past 2 weeks, how satisfied or dissatisfied are you with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
mm) The shape of your reconstructed nipple(s)?	1	2	3	4
nn) How your reconstructed nipple(s) and areola(s) look?	1	2	3	4
oo) How natural your reconstructed nipple(s) look?	1	2	3	4
pp) The colour of your reconstructed nipple/areolar complex?	1	2	3	4
qq) The height (projection) of your reconstructed nipple(s)?	1	2	3	4

8.12 Appendix K: Quantitative Data Set A2

MICHELLE
POST-TEST

32

6 Appendices

6.1 Appendix A: Breast-Q® Questionnaire

The following questions are about your breasts and breast reconstruction surgery. After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

1. With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a) How you look in the mirror clothed?	1	2	3	4
b) The shape of your reconstructed breast(s) when you are wearing a bra?	1	2	3	4
c) How normal you feel in your clothes?	1	2	3	4
d) The size of your reconstructed breast(s)?	1	2	3	4
e) Being able to wear clothing that is more fitted?	1	2	3	4
f) How your breasts are lined up in relation to each other?	1	2	3	4
g) How comfortably your bras fit?	1	2	3	4
h) The softness of your reconstructed breast(s)?	1	2	3	4
i) How equal in size your breasts are to each other?	1	2	3	4
j) How natural your reconstructed breast(s) looks?	1	2	3	4
k) How naturally your reconstructed breast(s)	1	2	3	4

33

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
sits/hangs?				
l) How your reconstructed breast(s) feels to touch?	1	2	3	4
m) How much your reconstructed breast(s) feels like a natural part of your body?	1	2	3	4
n) How closely matched your breasts are to each other?	1	2	3	4
o) How your reconstructed breast(s) look now compared to before you had any breast surgery?	1	2	3	4
p) How you look in the mirror unclothed?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

34

This question is about breast reconstruction using IMPLANTS. If you do not have an implant(s) please skip to question 3. If you do have an implant(s), please answer question 2 below.

2. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a) The amount of rippling (wrinkling) of your implant(s) that you can see?	1	2	3	4
b) The amount of rippling (wrinkling) of your implant(s) that you can feel?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

3. We would like to know how you feel about the outcome of your breast reconstruction surgery. Please indicate how much you agree or disagree with each statement:

	Disagree	Somewhat Agree	Definitely Agree
c) Having reconstruction is much better than the alternative of having no breast(s).	1	2	3
d) I would encourage other women in my situation to have breast reconstruction surgery.	1	2	3
e) I would do it again.	1	2	3
f) I have no regrets about having the surgery.	1	2	3
g) Having this surgery changed my life for the better.	1	2	3
h) The outcome perfectly matched my expectations.	1	2	3
i) It turned out exactly as I had planned.	1	2	3

Please check that you have answered all the questions before going on to the next page

4. With your breasts in mind, in the past 2 weeks, how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
j) Confident in a social setting?	1	2	3	4	5
k) Emotionally able to do the things that you want to do?	1	2	3	4	5
l) Emotionally healthy?	1	2	3	4	5
m) Of equal worth to other women?	1	2	3	4	5
n) Self-confident?	1	2	3	4	5
o) Feminine in your clothes?	1	2	3	4	5
p) Accepting of your body?	1	2	3	4	5
q) Normal?	1	2	3	4	5
r) Like other women?	1	2	3	4	5
s) Attractive?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

5. Thinking of your sexuality, since your breast reconstruction, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
t) Sexually attractive in your clothes?	1	2	3	4	5	N/A
u) Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
v) Confident sexually?	1	2	3	4	5	N/A
w) Satisfied with your sex-life?	1	2	3	4	5	N/A
x) Confident sexually about how your breast(s) look when unclothed?	1	2	3	4	5	N/A
y) Sexually attractive when unclothed?	1	2	3	4	5	N/A

Please check that you have answered all the questions before going on to the next page

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a) Neck pain?	1	2	3	4	5
b) Upper back pain?	1	2	3	4	5
c) Shoulder pain?	1	2	3	4	5
d) Arm pain?	1	2	3	4	5
e) Rib pain?	1	2	3	4	5
f) Pain in the muscles of your chest?	1	2	3	4	5
g) Difficulty lifting or moving your arms?	1	2	3	4	5
h) Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
i) Tightness in your breast area?	1	2	3	4	5
j) Pulling in your breast area?	1	2	3	4	5
k) Nagging feeling in your breast area?	1	2	3	4	5
l) Tenderness in your breast area?	1	2	3	4	5
m) Sharp pains in your breast area?	1	2	3	4	5
n) Shooting pains in your breast area?	1	2	3	4	5
o) Aching feeling in your breast area?	1	2	3	4	5
p) Throbbing feeling in your breast area?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

The following questions are about reconstruction using a TRAM or DIEP flap (i.e., reconstruction using skin and fat from your abdomen/tummy area). If you do not have a TRAM or DIEP flap, please skip to question 10. If you do have a TRAM or DIEP flap, please answer the following questions:

7. In the past 2 weeks, with your abdomen (tummy area) in mind, how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
z) Difficulty sitting up because of abdominal muscle weakness (e.g. getting out of bed)?	1	2	3	4	5
aa) Difficulty doing everyday activities because of abdominal muscle weakness (e.g. making your bed)?	1	2	3	4	5
bb) Abdominal discomfort?	1	2	3	4	5
cc) Abdominal bloating?	1	2	3	4	5
dd) Abdominal bulging?	1	2	3	4	5
ee) Tightness in your abdomen?	1	2	3	4	5
ff) Pulling in your abdomen?	1	2	3	4	5
gg) Lower back pain?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

40

8. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
hh) How your abdomen looks?	1	2	3	4
ii) The position of your navel (belly button)?	1	2	3	4
jj) How your abdominal scars look?	1	2	3	4

Please check that you have answered all the questions before going on to the next page

41

9. In the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
kk) How your abdomen feels now compared to before your surgery?	1	2	3	4
ll) How your abdomen looks now compared to before your surgery?	1	2	3	4

This question is about NIPPLE reconstruction. If you did not have nipple reconstruction, please skip to question 11. If you did have nipple reconstruction, please answer question 10 below.

10. In the past 2 weeks, how satisfied or dissatisfied are you with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
mm) The shape of your reconstructed nipple(s)?	1	2	3	4
nn) How your reconstructed nipple(s) and areola(s) look?	1	2	3	4
oo) How natural your reconstructed nipple(s) look?	1	2	3	4
pp) The colour of your reconstructed nipple/areolar complex?	1	2	3	4
qq) The height (projection) of your reconstructed nipple(s)?	1	2	3	4

8.13 Appendix L: Breast-Q® Post Operation Template

	Satisfaction with Breast															
	Values 1-4, 88, 99 are valid															
ID	1 a	1 b	1 c	1 d	1 e	1 f	1 g	1 h	1 i	1 j	1 k	1 l	1 m	1 n	1 o	1 p
Michelle pre-test	3	3	3	3	3	2	2	2	2	3	3	3	3	3	4	3
Michelle post-test	3	2	4	3	4	3	3	3	3	3	3	3	3	3	3	3

	Satisfaction with Breast (Implant only)		Satisfaction with Outcome						
	Values 1-4, 88, 99 are valid		Values 1-3, 88, 99 are valid						
ID	2a	2b	3a	3b	3c	3d	3e	3f	3g
Michelle pre-test	3	3	3	3	3	3	2	2	2
Michelle post-test	3	3	3	3	3	2	3	2	2

	Psychosocial Well-Being										Sexual Well-Being					
	Values 1-5, 88, 99 are valid										Values 1-5, 66, 88, 99 are valid					
ID	4 a	4 b	4 c	4 d	4 e	4 f	4 g	4 h	4 i	4 j	5 a	5 b	5 c	5 d	5 e	5 f
Michelle pre-test	5	5	4	5	5	5	5	5	5	5	5	4	4	4	4	4
Michelle post-test	4	4	3	4	4	4	4	3	4	3	4	4	4	4	4	4

	Physical Well-Being															
	Values 1-5, 88, 99 are valid															
ID	6 a	6 b	6 c	6 d	6 e	6 f	6 g	6 h	6 i	6 j	6 k	6 l	6 m	6 n	6 o	6 p
Michelle pre-test	1	1	3	4	1	1	4	2	2	2	1	2	1	1	1	1
Michelle post-test	1	1	3	1	1	1	2	1	2	2	1	1	1	1	1	1

8.14 Appendix M: Q-Score© Summary Scores

Raw data – Q Score results

	1	2	3	4	5	6	7
8	9	10	11				
ID	2. Satisfaction with Breasts				3. Satisfaction with		
Outcome	4. PsychoSocial Well-being				5. Sexual Well-being		
6. Physical Well-being: Chest					7. Physical Well-being: Abdomen		
10. Satisfaction with Nipples					11. Satisfaction with Information		
12. Surgeon	13. Medical Staff				14. Office Staff		
Michelle 1	53	67	92	67	74	N/A	
N/A	N/A	N/A	N/A	N/A			
Michelle 2	59	67	57	63	85	N/A	
N/A	N/A	N/A	N/A	N/A			

8.15 Appendix N: Session Plans

Session 1

1. Welcoming and introduction
2. History taking
3. Drumming circle, call and response introduction as ice breaker
4. Movement to music modelled by the therapist
5. Listening to preferred music (participants to inform me in advance of titles)
6. Drawing of images: pre-surgery body image and a post-surgery body image
7. Verbal reflection
8. Ending of session relaxation to music
9. Music used: Mozart piano concerto no 9 K....
10. Completion of Breast-Q© questionnaire

Session 2

1. Verbal check-in
2. Breathing and stretching to music, therapist leads
3. Drumming: Call-and-response taking turns to lead on drums
4. Drumming: Call-and-response adding vocal sounds
5. Drumming: Building a melody, taking turns
6. Instrumental improvisation: metallophone, chime bars, djembe's, bells, rain stick, small percussion instruments available
7. Song writing to music Playlist:
8. Verbal reflection

Session 3

1. Verbal check-in
2. Stretching and movement to music: participant leads, therapist follows
3. Free movement to music
4. Drumming: participant and therapist dyad playing: Therapist to mirror and match flowing into free drumming.
5. Drumming with vocalisation

6. Instrumental improvisation: metallophone, chime bars, djembe's, small percussion instruments
7. Poetry writing to music, theme to be reflections on your body
8. Verbal reflection

Session 4

1. Verbal check-in
2. Drumming: Free improvisation, therapist to match and intervene
3. Vocal improvisation with guitar. Play chords related to the tone A, singing only the one note. If she struggles to sing with CD
4. Mirror movement
5. Relaxation to music
6. Drawing-theme "connectedness to your husband and children"
7. Verbal reflection

Session 5

1. Verbal check-in
2. Singing/vocalization (with pre-recorded music if she struggles to relax)
3. Music listening and drawing/writing/poetry writing on theme: Connection to my family of origin.
4. Verbal reflection on art
5. Mirror movement and relaxation

Session 6

1. Verbal check-in
2. Vocal exercise/singing
3. Music listening and relaxation
4. Clay work on theme: reflection on the past five weeks.
5. Verbal reflection on work
6. Mirror-movement flowing into free movement
7. Final improvisation on instruments of choice

8.16 Appendix O: Playlists

Retrieved from <http://www.itunes.apple.com>



Research Session 1

4 songs, 36 minutes, 70,1 MB

Name	Time	Album	Artist
1 Piano Concerto No.9 in E flat, K....	10:25	Mozart: The Piano Concertos	András Schiff, Sándor Végh & Ca...
2 Piano Concerto No.9 in E flat, K....	10:57	Mozart: The Piano Concertos	András Schiff, Sándor Végh & Ca...
3 Piano Concerto No.9 in E flat, K....	10:07	Mozart: The Piano Concertos	Sándor Végh, András Schiff & Ca...
4 Story of My Life	4:35	Wonders (Deluxe Edition)	The Piano Guys

Page 1 of 1



Research Session 2

5 songs, 16,9 minutes, 30,3 MB

Name	Time	Album	Artist
1 Flute (Reprise) [Closing Credits V...	2:21	Trois couleurs: Bleu, Blanc, Roug...	Zbigniew Preisner
2 Brahms: Lerchengesang, Op. 70/2	4:30	Brahms: Songs Without Words	Mischa Maisky, Pavel Gililov
3 Jan's Notebook	2:39	Memoryhouse	Max Richter
4 In Perfect Silence	4:42	Stories in the Sky	David Tolk
5 Fantasy	2:43	Songs from the Labyrinth	Edin Karamazov

Page 1 of 1



Research Session 3

6 songs, 25,2 minutes, 51,2 MB

Name	Time	Album	Artist
1 Blank Space / Style (feat. Devin...	2:53	Blank Space / Style (feat. Devin...	Louisa Wendorff
2 Chopin: Piano Concerto #1 In E...	9:05	Chopin: Piano Concertos #1 & 2	Pavel Kowalski: Chopin Academi...
3 Carmina Burana: "In trutina"	2:19	Pure	Hayley Westenra, Royal Philhar...
4 Lakmé, Act 1 Flower Duet: "Dôm...	4:39	40 Most Beautiful Arias	Hei-Kyung Hong, Jennifer Larmo...
5 Beautiful	2:18	7th Symphony	Apocalyptica
6 The Eagle Watches	4:01	Peacemaker's Journey	Joanne Shenandoah



Research session 4

6 songs, 25,6 minutes, 52,9 MB

Name	Time	Album	Artist
1 In Love	3:17	Orenda	Joanne Shenandoah
2 Silence	5:06	The Thin Red Line (Original Moti...	Gavin Greenaway
3 Conquest of Paradise	4:38	1492 - Conquest of Paradise	Vangelis
4 Messenger	4:58	Her Song - Exotic Voices of Wom...	Joanne Shenandoah
5 Hooghan	4:07	A Train Tracks: Vocal Chords (Ve...	Sharon Burch
6 Críollita Santiagueña	3:36	Mercedes Sosa Interpreta a Atah...	Mercedes Sosa

Page 1 of 1



Research Session 5

2 songs, 18,8 minutes, 39,2 MB

Name	Time	Album	Artist
1 In Love	3:17	Orenda	Joanne Shenandoah
2 Piano Concerto No. 3 in D Minor,...	15:31	Rachmaninov: Piano Concerto N...	Martha Argerich, Radio-Symphon...

Page 1 of 1



Research Session 6

15 songs, 55,6 minutes, 93,5 MB

Name	Time	Album	Artist
1 In Love	3:17	Orenda	Joanne Shenandoah
2 Unaccompanied Cello Suite No....	2:21	Inspired By Bach: The Cello Suites	Yo-Yo Ma
3 Schubert: Du Bist Die Ruh, Op....	5:01	Schubert: Arpeggione Sonata, S...	Mischa Maisky, Daria Hovora
4 Bassoon Concerto in F, Op. 75: I...	4:05	Weber: Clarinet & Bassoon Conc...	Milan Turkovic, Bamberg Symph...
5 Anthem	3:05	Jonathan Livingston Seagull (Ori...	Lee Holdridge & Neil Diamond
6 Kyrie (Vidala-Baguala)	5:00	Misa Criolla	Mercedes Sosa
7 Gloria (Carnavalito Yaravi)	8:21	Misa Criolla	Mercedes Sosa
8 Credo (Chacarera Trunca)	3:24	Misa Criolla	Mercedes Sosa
9 Sanctus (Carnaval Cochabambino)	3:06	Misa Criolla	Mercedes Sosa
10 Agnus Dei (Estilo Pampeano)	3:24	Misa Criolla	Mercedes Sosa
11 La Anunciación (chamamé)	2:09	Misa Criolla	Mercedes Sosa
12 El Nacimiento (vidala catamarqu...	3:15	Misa Criolla	Mercedes Sosa
13 Los Pastores (chaya riojana)	3:05	Misa Criolla	Mercedes Sosa
14 Los Reyes Magos (takirari)	2:17	Misa Criolla	Mercedes Sosa
15 La Huida (vidala tucumana)	3:55	Misa Criolla	Mercedes Sosa