

**Body narrative interrupted: The relationship between  
body disfigurement, depression and self-concept**


by

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Dissertation

in partial fulfilment of the requirements for the degree

**MAGISTER ARTIUM (PSYCH)**



in the

**FACULTY OF ARTS**

at the

**RAND AFRIKAANS UNIVERSITY**

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October 2003

## Acknowledgements

- \* I would like to thank my dissertation supervisor, Professor G.P. de Bruin, for his willingness to undertake a project of this category, his unflagging faith in me, his patience, teachings and ongoing inspiration, encouragement and support, not only in the production of this dissertation but in the broader realms of training as a psychologist throughout the year. I would also like to thank Professor de Bruin for his purchasing of the Beck Depression-II Inventory and also the accompanying answer-sheet packages. It was only through such acts of generosity, and his belief in the purpose of the Inventory and study, that I was able to obtain a measure of the levels of depression as experienced by the participants and in so doing, make a more meaningful contribution.
- \* I would also like to thank Dr. A. Novello, for her faith in my abilities, words of encouragement and advice during the difficult moments, for her willingness to assist, wherever possible, and her belief in and commitment to the nature of this study and the reality of the trauma experienced by women who live with body disfigurement.
- \* Thank you to Dr. Herbert Marsh and Kate Johnson of the Research Centre, University of Western Sydney and Professor Jane Stake of the University of Missouri - St. Louis who, without question or hesitation, forwarded their self-concept scales to me without cost. Their kindness and generosity enabled for a measure of self-concept that might not otherwise have been possible.
- \* To Professor Bruce Bracken of The College of William and Mary, Williamsburg who took of his time to direct my research by providing invaluable information, guidance and support.
- \* A huge thank you to Riëtte Eiselen and Wilhelm Koster of the Department of Statistics at the Rand Afrikaans University for their effortless support, willingness to assist, guidance and sheer enthusiasm that far exceeded the scope of requirements.

- \* Thank you to Professor Elna McIntosh of the DISA Sexual Medicine Centre for the time taken to meet with me and share freely in her knowledge. The advice provided and insight gained from the meeting proved invaluable.
- \* Thank you to Professor Anthony Koller in the obtaining and forwarding of invaluable information and without whom, the richness of this study would not have been possible.
- \* Thank you to Beulah Jankelowitz of Reach for Recovery who, without hesitation, went out of her way to assist in areas of this study that far exceeded that which was asked of her. Her willingness, enthusiasm and belief in the underlying cause of this study contributed significantly to its completion. Additionally, Beulah's overriding support provided through the difficult times and at times when Beulah herself was busy, adds testimony to her remarkable assiduous and selfless character.
- \* Thanks too, must go to all of the participants of this study and who invited me into their lives in the sharing of their experiences. A study of this nature, most especially given the sensitive focus of this study, would not have been possible, at any level, without their willingness to give of themselves, their faith and their trust. It was both a pleasure and a privilege to work with these individuals and an incredibly humbling experience.
- \* Thank you to my parents, Rita and Raymond Watson, for their ceaseless encouragement, support and shared enthusiasm for my work and also for their continued faith in my abilities no matter how difficult the road ahead. I feel so incredibly blessed to be the daughter of two of the most remarkable people I know, of two people who would move heaven and earth to be there for me. I love you.
- \* Much thanks to my friend Tersia Oosthuizen who, despite the many difficult moments encountered during the course of this study, managed to keep me sane. Thank you too for the encouragement, endless support and the many sleepless nights sacrificed selflessly just to hear my recitals of the literature, or of my struggles and anxieties when things went awry.

# Table of Contents

## Page

<b>SUMMARY</b>	9
<b>OPSOMMING</b>	12

### **CHAPTER ONE: OVERVIEW OF STUDY**

1.1	Opening remarks	14
1.2	Motivation for the study	14
1.2.1	<i>Body perceptual disturbances following recovery of illness</i>	15
1.2.2	<i>Creating an awareness of the psychological &amp; psychosocial dilemmas</i>	15
1.2.3	<i>Psychopathology, common ailments &amp; visibility of the disfigured body parts</i>	16
1.3	Goals of the study	16
1.3.1	<i>Exploration of body self-concept and depression</i>	16
1.3.2	<i>To inform the follow-up study</i>	16
1.4	Implementation value of the study	17
1.4.1	<i>To inform the development of a measure of body self-concept</i>	17
1.4.2	<i>Orientation, pre-testing and fine-tuning</i>	17
1.4.3	<i>Contribution to current literature</i>	17
1.4.4	<i>To stimulate research interests and awareness of therapeutic needs</i>	17
1.5	Research design	18
1.6	Summary of chapters	18
1.7	Summary of chapter	19

### **CHAPTER TWO: SOCIETAL PRESCRIPTIONS OF THE FEMININE SELF-CONCEPT, PERCEPTIONS OF SELF AND DISCLOSURE AS A METHOD OF HEALING**

2.1	Introduction	21
2.2	Dictating the body beautiful	21
2.3	Body image disturbances in illness and health	22
2.4	Dividing the body into alienated body parts	23

2.5	To disclose or not to disclose	24
2.6	The therapeutic benefits of disclosure	24
2.6.1	<i>Recognising the inhibition phase</i>	25
2.7	Psychotherapy and the process of healing	25
2.8	Summary of chapter	26

### **CHAPTER THREE: THE MANY FACES OF MASTECTOMY**

3.1	Introduction	29
3.2	The Breast and the physical/sexual self	29
3.2.1	<i>Mourning the breast in mastectomy</i>	29
3.2.2	<i>Sexual dysfunction and breast cancer</i>	29
3.3	Breast cancer and methods of coping	30
3.3.1	<i>Emotional coping</i>	30
3.3.2	<i>Coping with social support</i>	31
3.3.3	<i>Coping through reconstructive surgery</i>	31
3.4	Psychopathology and breast cancer diagnosis	32
3.4.1	<i>Psychopathology and adjuvant treatment</i>	32
3.4.2	<i>Psychopathology and the need for psychotherapy</i>	33
3.5	Challenges of the psychologists	34
3.6	Summary of chapter	34

UNIVERSITY  
OF  
JOHANNESBURG

### **CHAPTER FOUR: PSYCHOLOGICAL, PHYSIOLOGICAL AND PSYCHOSEXUAL DIFFICULTIES FOLLOWING HYSTERECTOMY OR VULVECTOMY**

4.1	Introduction	36
4.2	The multifactorial implications of hysterectomy and vulvectomy	36
4.2.1	<i>The psychological effects of hysterectomy</i>	37
4.2.2	<i>The psychological effects of vulvectomy</i>	37
4.2.3	<i>The psychosexual ramifications of hysterectomy</i>	38
4.2.4	<i>Psychosexual morbidity and vulvectomy</i>	38
4.2.5	<i>Physiological effects of hysterectomy</i>	39
4.2.6	<i>The physiological effects of vulvectomy</i>	39
4.3	The effects of treatment in gynaecological malignancies	40
4.3.1	<i>Chemotherapy</i>	41
4.3.2	<i>Cytotoxic agents and radiation</i>	41
4.4	Psychopathology and myths in gynaecology malignancies	42

4.5	Challenges for medical professionals	42
4.6	Summary of chapter	44

## **CHAPTER FIVE: THE HIERARCHICAL AND MULTIDIMENSIONAL SELF-CONCEPT**

5.1	Introduction	46
5.2	Constructing the construct	46
5.3	The historical self-concept	47
5.4	The multidimensional and hierarchical nature of self-concept	47
5.4.1	<i>General self-concept as a higher order factor</i>	48
5.4.2	<i>The Self-Description Questionnaire III (SDQ-III)</i>	49
5.5	Self-concept defined	49
5.6	Relating self-concept to body disfigurement	50
5.7	Summary of chapter	50

## **CHAPTER SIX: RESEARCH METHODOLOGY**

6.1	Introduction	52
6.2	The research problem	52
6.3	Quantitative research	53
6.4	Phase one	54
6.5	Selection of participants	54
6.5.1	<i>Selection criteria</i>	55
6.5.1.1	<i>Racial group</i>	55
6.5.1.2	<i>Marital status</i>	55
6.5.1.3	<i>Age</i>	55
6.5.1.4	<i>Mental health</i>	55
6.5.1.5	<i>Length of time since illness/disease &amp; treatment</i>	55
6.5.1.6	<i>Reconstructive surgery</i>	56
6.5.2	<i>Descriptive data</i>	56
6.6	Instrumentation	57
6.6.1	<i>The Beck Depression Inventory II : BDHI</i>	58
6.6.2	<i>Self-Description Questionnaire III : SDQ-III</i>	59
6.6.3	<i>Six Factor Self-Concept Scale for Adults</i>	61
6.6.4	<i>Biographical Questionnaire</i>	61
6.7	Procedure	62
6.8	Data analysis	63



6.9	Ethical considerations	63
6.9.1	<i>Harm to participants</i>	63
6.9.2	<i>Informed consent</i>	63
6.9.3	<i>Confidentiality and anonymity</i>	64
6.9.4	<i>Competence</i>	64
6.10	Summary of chapter	64

## **CHAPTER SEVEN: RESULTS AND DISCUSSION**

7.1	Introduction	66
7.2	Comparison of mean scores for the BDI-II, SDQ-III, & SFSCS	66
7.2.1	<i>Comparison of importance &amp; accuracy for the SDQ-III</i>	67
7.3	Discussion	71
7.4	The self in a state of process	71
7.4.1	<i>Living with cancer in the absence of cancer</i>	72
7.4.2	<i>Levels of depression</i>	73
7.4.3	<i>The spiritual/religious self</i>	73
7.4.4	<i>General esteem</i>	74
7.4.5	<i>Opposite sex relations</i>	74
7.4.6	<i>The power factor</i>	75
7.4.7	<i>Importance versus accuracy</i>	75
7.5	Summary of chapter	76



## **CHAPTER EIGHT: CONCLUSION**

8.1	Evaluation of the study	79
8.2	Strengths of the study	81
8.2.1	<i>Orientation, pre-testing &amp; fine-tuning</i>	81
8.2.2	<i>The strengthening of future endeavours</i>	81
8.3	Limitations of the study	81
8.3.1	<i>The limitations of time</i>	82
8.3.2	<i>Participant dilemmas</i>	82
8.3.3	<i>Healthy matched sample comparison</i>	83
8.3.4	<i>The impact of life experiences</i>	83
8.3.5	<i>Self-concept scales</i>	84
8.4	Recommendations for future research	84
8.5	Final comment	85

**REFERENCE LIST** 88

**TABLES**

6.1	Descriptives of the Biographical Questionnaire	62
7.1	Differences between scores for the BDI-II, SDQ-III & SFSCS (Kruskal-Wallis test)	67
7.2	Comparison of importance & accuracy for the SDQ-III (Wilcoxon Signed Rank test)	69

**FIGURES**

<b>Figure 1.</b>	<i>Spider Graph: Comparison of Importance &amp; Accuracy for the SDQ-III (Wilcoxon Signed Ranks Test)</i>	70
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**APPENDICES**

Appendix A	Biographical Questionnaire	96
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## Summary

Many women who live with body disfigurement as a consequence of illness, continue to suffer from body perceptual disturbances many years following their recovery. Problematic however, is the tendency of disease-specific studies investigating body perceptual disturbances to focus on illness associated body changes. Consequently, this silences the experiences of many women who live with body disfigurement in the absence of illness and more specifically, in instances where body disfigurement is the result of having suffered a common ailment (Francis, 2002; Newell, 2000).

Impeding the concerns raised are inferences of earlier studies such as that by Patterson and Craig (1963) who reason that, by virtue of the body's integrity being dependent upon external appearances, hysterectomy, as something internal to the body, fails to feature as a psychological difficulty experienced in women who have this.

Recent studies by Newell (2000) and Francis (2002) identify a need for research on body disfigurement following a common ailment and in the absence of illness. In an attempt to address some of the concerns raised, and in keeping with body disfigurement resulting from a common ailment (e.g. cancer, dysmenorrhoea and uterine fibroids, etc), this study compares levels of depression and self-concept in women who have undergone either mastectomy, hysterectomy or vulvectomy. Additionally, this study challenged the inferences by Patterson and Craig (1963) in that the onset of psychopathology in these women is here thought to develop irrespective of the levels of disfigurement visibility (whether disfigurement is internal to the body as in hysterectomy or external to the body as in mastectomy and vulvectomy).

In terms of the three areas of participation, of the hysterectomy group (n = 16), of the mastectomy group (n = 8), and of the vulvectomy group (n = 4). Additionally, only participants who had not undergone reconstructive surgery were selected.

To investigate for self-concept and body perceptual disturbances, data was collected using the Beck Depression Inventory II, the Self-Description Questionnaire III, the Six Factor Self-Concept Scale and also from open-ended questions posited in a Biographical

Questionnaire. The Mann-Whitney, Kruskal-Wallis and Wilcoxon Signed Ranks tests were utilised as nonparametric statistics of choice in the data analyses.

The results showed seven areas of significant group differences as this pertains to: levels of depression, physical appearance, spiritual/religious values, general esteem, opposite sex peer relations, parent relations and power.

Most striking was the participant responses made in respect to the Importance versus Accuracy subsection of the SDQ-III. Of the 12 statements contained under this section, all were considered to be more important to the participants than the statement was thought accurate of them. Significant differences on this subsection were observed in terms of: parent relations, spiritual/religious values, emotional stability and physical appearance.

Although investigating depression and self-concept in women with body disfigurement in South Africa proved to be a complex and difficult research undertaking, the results of this study clearly strengthen its implementation value and demonstrate the need for future research in this area. This pilot study enabled for invaluable insight to be gleaned in terms of the thoughts, feelings and struggles of these women. Similarly the study provided for a method of pre-testing and fine-tuning prior to Phase Two. Additionally, the results of this study contribute to the sparse volume of literature on body disfigurement in the absence of illness. This complex, yet emotionally charged and dynamic terrain is fraught with a magnitude of possibilities for future research and of which can take an infinite number of directions.

Altered body appearance and function can invariably result in highly complex psychological and psychosocial disturbances. Francis (2002) echoes what this study commits to when she says: "... when the process of knowing is fractured in a sudden catastrophe, when knowing of the external surfaces of the familiar body is interrupted, the sense of being at home in ones body becomes problematic" (p. 108). As such, this study embraces the possibility that many women in South Africa, who live with body disfigurement in the absence of illness, continue to suffer disturbances in body perception years later and that this is so despite being illness free and irrespective of visibility levels. The study's demonstration of this in real-life intervention serves to highlight this.

Similarly, in that 92.3% of participants felt the need to join group therapy or formulate support groups for disfigured individuals as a means by which to voice and better come to terms with past and current traumatic experiences encountered as a result of living with altered body appearance and function, the need for future research in body disfigurement in the absence of illness, is strengthened.

It is hoped that, albeit in some small way, this study adds volume to the silenced experience of these women. Similarly, this study hopes to provide a foundation from which many silenced experiences can be voiced.



## Opsomming

Vroue wat as gevolg van ongesteldheid of siekte met liggaamlike skending moet saamleef, ly dikwels aan verwronge persepsies rakende hulle liggame vir jare nadat hulle van die siekte genees is. Navorsers neig egter om te fokus op perseptuele verwringing by persone wat nog siek is. Die gevolg hiervan is dat die ervarings van vroue wat in die afwesigheid van siekte met liggaamskending saamleef, dikwels nie gehoor word nie (Francis, 2002; Newell, 2000).

'n Verdere kompliserende faktor is dat vorige studies argumenteer dat die sigbaarheid van die liggaamskending 'n belangrike rol speel in die ervaring daarvan (Patterson & Craig, 1963). Hiervolgens sal 'n histerektomie, as voorbeeld, in 'n mindere mate sielkundige problematiek tot gevolg hê, aangesien die skending intern is en die liggaam se uiterlike integriteit nie geraak word nie.

Resente studies deur Francis (2002) en Newell (2000) het die noodsaaklikheid van navorsing oor liggaamskending as gevolg van 'n algemene siekte (byvoorbeeld kanker), maar waar die siekte nie meer teenwoordig is nie, beklemtoon. Ten einde meer lig op hierdie saak te werp word daar in hierdie studie 'n vergelyking getref tussen die vlakke van depressie en self-konsep by vroue wat of 'n histerektomie, of 'n vulvektomie, of 'n mastektomie ondergaan het. Die studie werp ook lig op Patterson en Craig (1963) se aanname dat die sigbaarheid van die skending 'n belangrike rol by die ontwikkeling van psigopatologie speel.

Daar was drie groepe deelnemers, naamlik 'n histerektomoe groep ( $n = 16$ ), 'n mastektomie groep ( $n = 8$ ), en 'n vulvektomie groep ( $n = 4$ ). Slegs individue wat geen rekonstruktiewe sjirurgie ondergaan het nie, is as deelnemers ingesluit.

Data ten opsigte van depressie en selfkonsep is aan die hand van die Beck Depression Inventory II, die Self-Description Questionnaire III, die Six Factor Self-Concept Scale en oop vrae in die biografiese vraelys verkry. Die Mann-Whitney, Kruskal Wallis en Wilcoxon rangorde toetse is gebruik as nie-parametriese data-ontledingstegnieke.

Die resultate het sewe areas van groepsverskille aangedui: vlakke van derpressie, fisieke voorkoms, spirituele/religieuse waardes, algemene eiewaarde, teenoorgestelde geslag verhoudings, ouerverhoudings, en mag.

'n Opvallende aspek van die resultate het betrekking op die Belangrikheid teenoor Akkuraatheid subafdeling van die SDQ-III. Die respondente het vir al twaalf stellings in die afdeling aangedui dat dit meer belangrik was as wat die akkurate beskrywings van hulle gegee het. Betekenisvolle verskille in hierdie afdeling is waargeneem ten opsigte van: ouerverhoudings, spirituele/religieuse waardes, emosionele stabiliteit, en fisieke voorkoms.

Alhoewel die ondersoek na depressie en self-konsep by vroue met liggaamskending 'n komplekse navorsingsterrein is, onderstreep die resultate van hierdie studie die belangrikheid daarvan sowel as die behoefte aan verdere navorsing. Hierdie loodsstudie bied waardevolle insig ten opsigte van die denke, gevoelens en probleme van hierdie vroue en dra hopelik by om die navorsingsliteratuur in die terrein te verbreed. Die studie dra ook daartoe by om die navorsingsontwerp vir 'n opvolgstudie te verfyn.

'n Verandering in liggaamsvoorkoms en funksionering lei dikwels tot hoogs komplekse sielkundige en psigo-sosiale versteurings. Francis (2002) beaam die onderhawige studie waneer sy stel dat: "... when the process of knowing is fractured in a sudden catastrophe, when knowing of the external surfaces of the body is interrupted, the sense of being at home in ones body becomes problematic" (p. 108). Hierdie studie beklemtoon die moontlikheid dat vroue vir baie jare na 'n liggaamskending die slagoffers is van verwronge liggaamsbeelde. Dit ten spyte daarvan dat hulle vry is van siekte en ongeag die sigbaarheid van die skending.

'n Totaal van 92,3% van die deelnemers het aangedui dat hulle 'n behoefte aan groepterapie of 'n ondersteuningsgroep het waarin hulle die geleentheid het om hulle ervarings aan te spreek. Hierdie bevinding beklemtoon die belangrikheid van verder navorsing ten opsigte van liggaamskending in die afwesigheid van siekte.

Ingelyks word daar gehoop dat die studie 'n stewege grondslag daarstel vanwaar 'n stem aan baie van die verswe? ervarings gegee kan word.

## Chapter One

### Overview of Study

*The process of knowing involves:*

*Knowing the body and the self as subjectively lived in and the role of the body in this process. When this process of knowing is fractured in a sudden catastrophe, when knowing of the external surfaces of the familiar body is interrupted, the sense of being at home in one's body becomes problematic (Francis, 2002 p. 108)*

#### 1.1 Opening Remarks

Universally, and in the majority of instances, certain body appearances, whether congenital, the result of trauma, disease, or directly linked to the aging process, are unwanted by those who receive them. Although these changes in bodily appearance and function are richly ascribed to in nursing and medical literature, few studies detail the experiences and difficulties of individuals who have undergone these changes to physical appearance (Newell, 2000).

Despite a myriad of complaints within the context of body perceptual disturbance, the plethora of literature has focussed predominantly on illness associated body changes. The primary focus of disease-specific studies concerns: (a) changes in body appearance and function; and also (b) the diagnostic experience, experiences of living with life-threatening illness, and the practical consequences of altered bodily functions. In consequence, it remains debatable as to how much these studies actually inform us of the relationship between changes to body appearance and function on the one hand and body perception and its disturbance on the other (Newell, 2000).

Worldwide there exist many people who, in the absence of suffering from any current illness, are faced with the difficulties and challenges of living with altered body appearance and function. In South Africa there are many common diseases and illnesses that result in body disfigurement or that require surgical intervention for disease eradication or life preservation. The psychological and psychosocial experiences of these women are however, largely unexplored.

Despite an extensive review of the literature, South African studies investigating the psychological and psychosocial experiences of women who, in the absence of illness, and as a consequence of having suffered from a common ailment, live with body disfigurement of some kind, appear to be a literary scarcity.

## **1.2 Motivation for the Study**

There are three motivations for the study:

### **1.2.1 *Body Perceptual Disturbances Following Recovery of Illness***

The main motivation is the conviction that many women who live with altered body appearance and function as a result of having suffered from a common illness, continue to suffer disturbances in body perception years later and that this is so despite being illness free. The study's demonstration of this in real-life intervention serves to highlight such.

### **1.2.2 *To Create an Awareness of the Psychological and Psychosocial Dilemmas***

A second motivation is the conviction that the experiences of these women needs to be voiced in order to create more publicly, an awareness of the psychological and psychosocial dilemmas that underscore body disfigurement.

### **1.2.3 *Psychopathology, Common Ailments and Visibility of the Disfigured Body Part(s)***

The final motivation concerns the conviction that the onset of psychopathology is possible in individuals who suffer body disfigurement as a consequence of common illness or disease and that this is so irrespective of the visibility levels of the disfigured body part(s). Although limited in scope, this study addresses these concerns.

### **1.3 Goals of the Study**

Informing the goals of this study are the many illnesses and diseases in South Africa that are so common that treatment and management of this has become a matter of procedure that oftentimes overlooks the possibility for the onset of psychopathology as a consequence of this. More specifically:

#### **1.3.1 *Exploration of Self-Concept and Depression***

The main goal is to simply and clearly explore the motivational concerns raised through the investigation of self-concept in women who, after having suffered from a common illness, now live with body disfigurement of some kind. This entailed: (a) comparing the mean scores for depression and self-concept as measured by the Beck Depression Inventory II, the Self-Description Questionnaire III, and the Six Factor Self-Concept Scale for Adults in three groups of participants, namely, women who have undergone hysterectomy, mastectomy or vulvectomy; (b) exploring self-concept as this relates to levels of body disfigurement visibility (whether or not the area of disfigurement is visible to the self and/or others); (c) ensuring only the selection of participants who suffer from body disfigurement after having suffered from a common illness; and (d) ensuring all participants were free of illness, for at least six months, at the time of investigation.

#### **1.3.2 *To Inform Follow-Up Study***

A second goal is to utilise this study as a springboard to the main inquiry of the follow-up study and also to integrate the observed results so as to inform the construction of a body self-concept scale and the development of a body self-concept booklet in the ensuing year.

### **1.4 Implementation Value of the Study**

The implementation value of the study is arguably very high. The following paragraphs discuss this.



#### **1.4.1 *To Inform the Development of a Body Self-Concept Measure***

In South Africa, there does not appear to be a measure of body self-concept. This study provides valuable information that informs the development of a measure of body self-concept in the follow-up study to this. Similarly, the need of for acknowledgement, guidance, direction and ultimately, psychotherapeutic intervention in the area of body disfigurement, and as will be discussed in booklet format during the course of the follow-up study, are also informed by this pilot run.

#### **1.4.2 *Orientation, Pre-Testing and Fine-Tuning***

Investigating body self-concept and body disfigurement is complicated, difficult in terms of participant accessibility and a difficult research undertaking. This pilot study enabled for invaluable insight to be gleaned in terms of the thoughts, feelings and struggles of these women prior to the main inquiry that follows on from this research. Similarly, orientation into the study was enabled, as was a method of pre-testing and fine-tuning in preparation for Phase Two.

#### **1.4.3 *Contribution to Current Literature***

The role of the physical body in relation to a sense of self, following body disfigurement, is scarcely ascribed to in the literature. This study contributes by adding to this sparse volume of literature.

#### **1.4.4 *To Stimulate Research Interests and Awareness of Therapeutic Needs***

The study may stimulate others to conduct similar research in a simple and pragmatic way. Consequently, this serves to add to the literature and help create an awareness of the therapeutic needs of women who, in the absence of illness, live with body disfigurement.

## 1.5 Research Design

The research design is an exploratory quantitative design. Specifically, the investigation compares levels of depression and self-concept in three groups of women with varying degrees of body disfigurement visibility, namely: women who have undergone hysterectomy, mastectomy and vulvectomy. The Mann-Whitney and Kruskal-Wallis statistics were utilised as the nonparametric tests of choice and which was deemed pragmatic given the small sample size. Results yielded inform the follow-up study to be conducted in 2004.

## 1.6 Summary of Chapters

*Chapter One* essentially provides an overview of the study. Sections on the opening remarks to the study, motivations for the study, goals and implementation values of the study as well as the research design were presented with the aim to provide, clearly and concisely, a contextual and conceptual map of the project.

*Chapter Two* commences the literature review and describes the role of the media and other societal prescriptions in defining feminine self-concept and the impact of this on women who live with body disfigurement as a result of illness or surgery. The development of complex body perceptual disturbances that result from living with altered body appearance and function are explored, as are methods of disclosure and the efficacy thereof, in the process of healing following trauma.

*Chapter Three* explores the many faces of mastectomy. This section reviews the symbolism of the breast as well as the psychological, psychosocial and psychosexual consequences of mastectomy. Additionally, the various methods of coping following mutilative surgery are explored.

*Chapter Four* reviews the psychological, physiological and psychosexual difficulties following hysterectomy or vulvectomy. Additionally, the impact of gynaecological malignancy on a woman's psychosexual well-being in terms of femininity, sexuality and sexual functioning are discussed. This chapter acknowledges that the image a woman has of her body includes the internal self and as such, surgical procedures such as hysterectomy can influence perceptions of self.

*Chapter Five* explores the distinction between body image and self-concept and also provides an historical overview of self-concept that commences with William James (1899 - 1963). A theoretical discussion of the hierarchical and multidimensional model of self-concept proposed by Shavelson et al. (1976) introduces the use of Marsh's (1992) Self Description Questionnaire III in this study. Finally, in differentiating between self-concept and body image, this chapter explicates briefly the reasons governing the use of measures of self-concept over measures of body image for use in this project.

*Chapter Six* is devoted to the research methodology and of which includes passages on the research problem, quantitative design, participant selection, selection criterion, descriptive data, instrumentation, procedure, analyses of data, and ethical considerations.

*Chapter Seven* outlines the results of participant responses to the Beck Depression Inventory-II (BDI-II), the Self Description Questionnaire III (SDQ-III), The Six Factor Self-Concept Scale (SFSCS) and also the Biographical Questionnaire. A discussion of the results and areas of statistical significance follow the result outline.

*Chapter Eight* concludes the study by providing an evaluation of the study as well as a discussion of the strengths and limitations encountered. Recommendations for future research are discussed and concluded with a final comment from the author of this study.

## **1.7 Summary of Chapter**

An overview of this study was presented with the aim being to provide a clear and concise contextual and conceptual map of the project. A statement of the problem was provided in the opening remarks and which describes the difficulties and challenges faced by many women who live with body disfigurement of some kind. Motivation for the study was presented, with three points relating to the conviction that: (a) body perceptual disturbances exist in individuals who, in the absence of illness and as a consequence of having suffered from a common ailment, live with body disfigurement of some kind (b) a need exists to voice the silenced experiences of many women as described in point (a); and (c) the onset of psychopathology is possible in body disfigured individuals irrespective of the visibility of the disfigured body part(s).

Two main goals of the study were delineated: (1) to simply and clearly explore the motivational concerns raised through the investigation of body self-concept in three groups of women who, in the absence of illness, live with varying degrees of body disfigurement; and (2) to utilise the study as a springboard to the main inquiry of the follow -up study to be conducted in 2004.

The implementation value of the study was made explicit: (i) to direct and guide the construction of a body self-concept scale and body self-concept booklet from the information gleaned from this study; (ii) to gain valuable insight into the thoughts, feelings and struggles of disfigured individuals; (iii) to pre-test and fine tune the project prior to the main inquiry; (iv) to contribute to the sparse volume of literature; and (v) to hopefully stimulate others in this area of research.

The research design was outlined, namely: an exploratory, comparative quantitative research design that draws upon the Mann-Whitney and Kruskal-Wallis tests as the nonparametric statistics. Finally, a summation of each ensuing chapter was provided.

The following chapter commences the literature review. Additionally, the ensuing chapters expand upon this overview providing a solid base in terms of the importance of this study and also the need for psychotherapeutic intervention at the level of body perceptual disturbance following body disfigurement in the absence of illness. Furthermore, in emphasising the psychological and psychosocial difficulties of women who suffer from varying degrees of body disfigurement following a common ailment, the literature serves to support the development of a body self-concept scale and booklet on body disfigurement that is to take place in the follow -up study to this. Notwithstanding the research methodology, results and discussion, the strengths and limitations of the study are outlined. A brief discussion for future research in the area of body-disfigured individuals in the absence of any illness completes this study.

## Chapter Two

### **Societal Prescriptions of the Feminine Self-Concept, Perceptions of Self and Disclosure as a Method of Healing**

#### **2.1 Introduction**

The effects of mass media in their prescribing what it means to be a woman in South Africa are well documented. Throughout their lives women retain and constantly form images of their body that follows a body image hype constructed through the medium of public and private mass media (Newell, 2000). When illness inscribes the body and body disfigurement results, ones wonders as to the impact of such media dictates on the body self-concept of these women. Similarly, with limited reference only to the elite athletes and those versed in physical education, the role of the physical body in relation to a sense of self is scarcely ascribed to in the literature. The problem with this is that many dilemmas associated with a sudden or unexpected interruption in the body narrative is largely, silenced (Francis, 2002). The following paragraphs discuss this.

#### **2.2 Dictating the Body Beautiful**

Industries in fashion, cosmetics, sports and leisure ensure conformity to their trend setting and established norms by targeting public perception through a range of products and expensive advertising. Perhaps out of a desire to express their individuality or to conform to the dictates of mass advertising, individuals move through extremes of body image alteration (Newell, 2000).

With a myriad of meanings attached to all body parts, the female self-concept is loaded with overtones of not only what it means to be female within a particular culture, but also contains both cultural and individual elements in its description (Kuny, 1984). In amplifying both the emotional and psychological significance attached to the various body parts, Fisher (1973) has this to say:

*"The face... is not simply the front of the head, it is also the site of emotional expression, a prime visible representative of yourself or identity, a major criterion of personal attractiveness..."* (p.8).

Research has shown the physical self or the image one has of one's body to be an integral aspect of the self-image (Jacobs & Very, as cited in Theron, Nel & Lubbe, 1991). In a study by Theron, et al. (1991) a significant negative correlation between body image and scores of public self-consciousness (awareness of self as a social object) and social anxiety (discomfort felt in the presence of others) was observed. The results emphasise the importance of having a positive body image as well as the importance of feeling competent in social interactions. In this light, and with the concept of oneself as a woman being the essence of self-concept and of which involves an awareness of one's psychological identity, it is perhaps unfortunate that one's psychological identity is so richly ascribed to by the attitudes of other women and sexual attractiveness by that of the opposite sex (Kuny, 1984).

### **2.3 Body Image Disturbance in Illness and Health**

Altered body appearance and function through illness and disease can invariably result in highly complex psychological and psychosocial disturbances for many individuals (Newell, 2000).

Countless studies have shown a loss of femininity to be the experience of women who had undergone surgical treatment that involved the removal of her reproductive organs. Similarly, a marked reduction in a woman's sense of feeling attractive and with significant alterations to body image perceptions was also experienced (Andreasson, Moth, Jensen & Bock, 1986; Corney, Everett, Howells & Crowther, 1992; Green, Naumann, Elliot, Hall, Higgins & Grigsby, 2000; Hamilton, 1999).

Despite the plethora of literature confirming the phenomenon of body perceptual disturbance following body disfigurement, studies focus predominantly on such disturbances in the presence of illness and disease rather than an absence of it. The scarcity of such research might be thought a consequence of the frequency by which certain illnesses and diseases manifest and as such, the difficulties experienced by individuals living with body disfigurement following recovery from illness remains largely, unexplored (Newell, 2000).

## 2.4 Dividing the Body into Alienated Body Parts

It is perhaps in times of body disfigurement that the body becomes so alienated from the whole self that such individuals might choose to refer to their body in terms of its parts. It can become, as Francis (2002) so aptly states in her own experiences, a "violence" against one's sense of self - a feeling state many remain oblivious to (p. 112).

Illness that involves pain of this kind inscribes the body so that the mind and body can no longer remain separate. The experience of a disruption to the body as was known before it was so rudely interrupted becomes reduced to mechanisms and measurements of technical objectivity by the medical model that denies the person identity as anything other than "patient" (Francis, 2002, p. 115). Body disfigurement is not an attack on the body but rather an intrusion on the embodied self, the self through which one reads the world and in turn, is read. From her experiences following a cerebral haemorrhage, Francis writes:

*"Self-concept, self-esteem, glorified self's, and Cartesian theories imply a conscious knowing that is built over time in particular contexts. I now believe that the self is neither coherent nor stable. It is provisional, contingent, and positioned in multiple, shifting discourses" (p. 115).*

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Many women living with body disfigurement, irrespective of visibility, might feel in some way connected to Francis when she says, "...it is not the intensity of the pain or vulnerability of the psychi, nor is it the level of visibility, social awareness or altered body functions that first serve to disempower but rather, it is the process of knowing, of knowing something about the body is suddenly very different that it serves to interrupt the body narrative and slowly starts to deconstruct the physical body into sites of diagnosis and pathology" (p. 117).

In echoing what this study commits to, Francis (2002) has this to say, "... when the process of knowing is fractured in a sudden catastrophe, when knowing of the external surfaces of the familiar body is interrupted, the sense of being at home in ones body becomes problematic" (p. 108).

The following passages discuss the consequences of being able to disclose ones traumatic experience and the impact of this on emotional healing.

## 2.5 To Disclose or Not to Disclose

In 1979, following a survey carried out with Dr. Billy Barrios of eight hundred women, psychologist James W. Pennebaker discovered a link between traumatic sexual experiences and binge/purge behaviour. Extrapolating from these results and speculating as to the effects of disclosure versus non-disclosure of any given trauma, a positive correlation was observed between physical health and being able to verbalise one's traumatic experiences to others (as cited in King & Holden, 1998).

Later studies by Pennebaker (1979), researching the difference between writing and language reveal how people somehow organise their experiences emotionally when thoughts and feelings are put to paper. In this particular study, from the idea by the participants that someone caring was about to read their written experiences, many therapeutic benefits, in the absence of dialect, were derived. It is studies such as this that alert therapists as to the importance of creating a space for the client that is nurturing, containing and that enables for the freedom and safety to reveal feelings and put them together (as cited in King & Holden, 1998). However, creating a space for the disclosure of trauma might not necessarily guarantee healing in all areas of traumatic experience.

## 2.6 The Therapeutic Benefits of Disclosure

In a study assessing group therapy for post-mastectomy women over a one-year period, Kriss and Kraemer (1986) observed that improvement occurred only in terms of positive affect and sexual adjustment. In other words, their continued dislike of the amputated breast region remained unchanged by therapy and with no change effected in either sexual receptivity to partners or in increased sexual activity. The author's assumptions that learning to cope with a major illness and problems of sexual identity would change sex-appropriate behaviour, was not supported.

Quantitatively, Kriss and Kraemer (1986) note that statistical data alone did not convey the extent of the difficulty that women experienced in trying to accept their bodies. The participants would describe their scars as resembling a "railway track that a heavy train had run over," or as "ugly" and "cruel." They talked about the loss of a breast as the loss of an erogenous zone where they had previously felt sensation and sexual arousal. Negative sentiments such as these were expressed by virtually all participants and thus confirmed the



depth to which the women were affected by their breast loss and the magnitude of their inner struggle in attempts to overcome these negative feelings (p. 449).

Perhaps addressing this somewhat, Pennebaker (1979), in his practise as a psychologist, states emphatically that whilst emotional release in instances of trauma is important, a therapist's ability to actually cope with upsetting material is an art that is learnt over time. Important to this study is Pennebaker's observation that highlights the fundamental importance of professional psychotherapeutic intervention in the treatment and management of traumatic experience as opposed to, for example, the releasing of emotions in the doctors surgery rooms (as cited in King & Holden, 1998).

### ***2.6.1 Recognising the Inhibition Phase of Trauma***

Pennebaker's more recent investigations accentuate the existence of the delayed effects of trauma and to which he refers to as the inhibition phase. By and large, most patients are in hospital at the time of the inhibition phase and consequently present as recovering well emotionally. The myriad of emotions that lurk beneath the surface however are not always evident. It is this phenomenon of delayed onset that helps explain depressive symptomatology experienced weeks following hospitalisation. Pennebaker advises that the greatest benefit derived from mental health intervention is actually three to eleven weeks post trauma (as cited in King & Holden, 1998).

In their study of the psychosocial aspects of mastectomy, Jamison, Wellisch and Pasnau (1978) note both the timing and necessity of therapeutic intervention as fundamental to recovery. In fact, in contrast to Pennebaker, 42% of the participants of this study judged the pre-mastectomy period as the worst period for them emotionally and a time when stress levels are at their maximum. Clearly, intervention at this level is also advised.

## **2.7 Psychotherapy and the Process of Healing**

Despite conflicting results in terms of the time of intervention, all studies emphasise the need for therapeutic intervention by qualified professionals as paramount and that such intervention is fundamental to the overall process of healing.

Bard and Sutherland (1955) observed that some women had predicated body attractiveness on their acceptance as a woman and sense of self-worth practically their entire lives. In this instance, the mere thought of losing a breast led these women to feel that life was not worth living. Similarly, a study by Fitzpatrick (1970) shows that a woman's concept of her own femininity impacts greatly on her response to mastectomy. Fitzpatrick postulates that it is not surprising, given our sex symbol orientated society, that women invariably react to the amputation of a breast as a "mutilating assault on femininity" (as cited in Polivy, 1977, p. 78).

Studies such as Bard and Sutherland (1955) and Fitzpatrick (1970) are among the many studies that serve to highlight the observation of King and Holden (1998) in terms of Pennebaker's admonition not to substitute writing or talking for effective action in the wake of emotional challenges.

## 2.8 Summary of Chapter

The dictates of mass media and society influence the way many individuals perceive of themselves physically and emotionally. Maintaining the ideal female form as this pertains to such dictates is especially difficult for many women who feel the need to conform. One can only but imagine the psychological impact of living with body disfigurement in a world that predicates social acceptance on the body ideal.

Despite many studies confirming the experience of body perceptual disturbance in body disfigured individuals to persist long after health has been restored, the relation of the physical self to ones core sense of self is a literary scarcity that became evident to Francis (2002) following her suffering a brain haemorrhage.

As a well respected academic, Francis (2002) discovered the power of both public perceptions and media stereotyping in their prescriptions of what it means to uphold ones position as a respected professional intellectually, emotionally and of course, in terms of the physical self. When illness prescribed her body and rudely interrupted her body narrative, Francis felt lost in a body that would no longer function as before. It was only then that she realised the consequences of what it means to live only within the realms of the glorified self.

Doctors approached Francis as a patient retarded by stroke rather than a vulnerable being who had been violated by the intrusion of illness. Although Francis was able to conquer and overcome, she cites many experiences that left her feeling reduced to a physical body that became the object of pathology and diagnosis.

For years Francis (2002) had lived her life and moulded her mind and body to communicate the dictates of societal prescriptions of what it means to be a learned individual. In illness, Francis was forced out of her familiar comfort zone and in her knowing that something was very wrong, she became alienated within her body, feeling helpless and disempowered in her struggle to return home to a self that she had once known.

Using the experiences of Francis (2002) in her realisation of the impact of society on her perceptions of self and her bodily experiences in illness, one might ask whether, in this instance, psychotherapeutic intervention at this level would have been of some comfort.

Following much research that explores the effects of disclosure and the inhibition of traumatic experiences on an individual's mental and physical health, the results of studies by clinical psychologist James W. Pennebaker and colleagues find psychotherapeutic intervention to be fundamental in the treatment and management of traumatic experiences. Additionally, studies reveal that many patients undergo an inhibition phase during the course of hospitalisation, which simulates good emotional recovery and as such, the possibility for depression and other psychopathology, are overlooked (as cited in King & Holden, 1978).

The inhibition phase is important to this research as it helps to explain, in part, why many doctors might assume good emotional health in hospital patients who, for example, have undergone disfiguring surgery in the treatment of illness and disease. Additionally, studies show a tendency for patients to hold back on their emotions when hospitalised or during follow-up visits to their doctor. For the most part, hospitals and doctor's surgery rooms have not been found to be conducive to the psychotherapeutic experience and emotional healing of individuals who have experienced physical trauma of this kind (Pennebaker, as cited in King & Holden, 1998).

Although studies by Pennebaker show therapeutic benefits to derive from non-verbal interventions, therapists are alerted to the importance of providing a contained and

nurturing environment that enables for the freedom and safety of emotional expression and that talking, as a means of emotional release, is perhaps among the most effective therapeutic interventions in the wake of psychopathology (King & Holden, 1998).

In the presence of illness, many women seem more concerned with the possibility of suffering body disfigurement than they are with their physical health. It is highly probable, given the above discussions that, in the absence of illness and presence of body disfigurement, body perceptual disturbances and difficulties in the body self-concept are a constant in the lives of these women.

In light of the scarcity of studies investigating the psychological and psychosocial experiences of women who live with body disfigurement after having suffered from a common illness, the discussions that follow explore the experiences of women who have undergone mastectomy, hysterectomy and vulvectomy within a framework that focuses predominantly on difficulties observed in the presence of illness.



## Chapter Three

### The Many Faces of Mastectomy

#### 3.1 Introduction

Given the importance attached to breasts in contributing to a woman's self image, the loss of a breast may well have far reaching consequences. Based on the results of a copious amount of studies conducted in Western breast-conscious societies, one of the most pervasive assumptions about breast removal is that it is a total annihilation on a woman's femininity (Kuny, 1984). According to Polivy (1977) mastectomy has a potentially profound negative impact on a woman's body image and self-concept.

#### 3.2 The Breast and the Physical / Sexual Self

Much psychological stress underscores breast cancer diagnosis and treatment. The following paragraphs review this relationship in terms of body disfigurement and sexual dysfunction.



##### 3.2.1 *Mourning the Breast in Mastectomy*

Undergoing any surgical procedure following the diagnosis of breast cancer is an emotionally distressing experience. Similarly, the psychological ramifications can be especially substantial as these women face the distress and disfigurement caused by the loss of the breast in addition to suffering from a life-threatening illness. Investigating the psychosocial aspects of mastectomy, Jamison, Wellisch and Pasnau (1978) report emotional suffering to far outweigh the physical pain experienced by women who have undergone mastectomy. Salient features such as a sense of mutilation, fear of death and a loss of femininity support the findings of an earlier study by Asken (1975).

##### 3.2.2 *Sexual Dysfunction and Breast Cancer*

In a study by Meyerowitz, Desmond, Rowland, Wyatt and Ganz (1999) on sexuality following breast cancer, a survey of 863 breast cancer survivors revealed that the majority

of the women felt breast cancer to impact negatively on some aspect of their sex life. Generally, it would seem that hormonal changes are a cause of sexual dysfunction in terms of these women experiencing partnership problems and physical discomfort and pain around the site of surgery. In the experience of these changes, psychological stress is increased.

Perhaps, in the diagnosis and treatment of breast cancer, the mind and body become somewhat dissociated and reconnected by mechanisms of coping that results from a need to develop a positive mindset.

### **3.3 Breast Cancer and Methods of Coping**

Few studies have attempted to examine specifically either the strategies employed as a method of coping or the precise nature of the stressor faced by women with mastectomy and breast reconstruction (Harcourt & Rumsey, 2001). However, of the attempts made, results of studies do evidence the use of coping strategies as a method utilised by many women diagnosed with breast cancer. In addition, although such tactics appear to be multi-faceted in nature, the choice of the method(s) of coping employed is an individual one and one that might be psychologically and psychosocially influenced. The following paragraphs provide insight into the various coping strategies utilised.

#### **3.3.1 Emotional Coping**

In a report of her experiences as a victim to breast cancer, Molly Ivins (2002) identified some of the psychosocial nuisances and psychological pitfalls when she says:

*"I suspect that cancer doesn't give a rat's ass whether you have a positive mental attitude. ...whether you are admirably stoic or weeping and wailing. The only reason to have a positive mental attitude is that it makes life better. It doesn't cure cancer" (p.52).*

In terms of the correlation between certain coping strategies utilised and positive psychological outcome, Weisman (as cited in Harrison & Maguire, 1994), found that the most effective strategies were to confront or redefine the problem and to comply with medical advice in relation to health concerns. The least effective strategies were attempts at

denial, stoic acceptance, tension reduction (smoking or drinking), distraction, social withdrawal, and projecting blame onto others or the self.

### ***3.3.2 Coping with Social Support***

A study conducted by Dunkel-Schetter et al. (as cited in Harrison & Maguire, 1994) found stress reduction to occur in those individuals who coped by drawing on their social support network. An increase in distress levels was observed when cognitive/behavioural escape/avoidance was utilised as a method of coping. The results of a study by Bloom and Spiegel (1984) investigating the relationship between social support and adjustment to cancer, show that whilst social support positively affected well-being, social functioning remained unaffected.

Psychosocially, one of the first things that Ivins (2002) noticed was the different manner in which people treated her from the unnerving hushed tones to the fearful enquiries. The loss of a breast, according to Ivins, has obvious psychological consequences in terms of self-image, a sense of self and sexual desirability as a woman. For Ivins, draining herself of any emotional connection to her body acted as her primary coping mechanism. In a wonderful analogy, Ivins extrapolates saying, "I tend to treat my emotions like unpleasant relatives - a long-distance phone call once or twice a year is more than enough. If I got in touch with them they might come to stay" (p.52).

### ***3.3.3 Coping Through Reconstructive Surgery***

The results of a rare prospective study show the use of defensive coping strategies prior to reconstruction to be a method of coping with the cancer diagnosis and forthcoming mastectomy. In a later study of breast cancer patients, breast reconstructive surgery following mastectomy was posited as an elective woman utilise in attempts to cope with their overall condition (Gross, Burnett & Borrelli, 1996; Rowland, Holland, Chaglassian & Kinne, 1993).

In identifying strategies utilised whilst in the process of deciding whether or not to undergo reconstructive surgery, vigilance and option satisfaction was found to be associated with higher quality decision-making whilst complacency and defensive avoidance was conjoined with lower quality decision-making (Reaby, 1998b).

Although much of the surgical literature purports the option of breast reconstructive surgery aims to improve the quality of life and assist in patient adjustment to being diagnosed with breast cancer, the psychological benefits of reconstructive surgery remain largely unsupported by sound research evidence. Be this as it may, for many women who have undergone successful breast reconstructive surgery, good psychological outcome is reported (Anderson & Kaczmarek, 1996).

### **3.4 Psychopathology and Breast Cancer Diagnosis**

Clearly, receiving the diagnosis of breast cancer is devastating not only to the sufferer but to all loved ones concerned. The possibility of death that conjoins the uncertainty as to the course of the cancer, the disablement of the treatment, the toxic effects of drugs utilised, relationship and role challenges as well as financial issues are among the major concerns that engulf sufferers during the many months following diagnosis (Harrison & Maguire, 1994).

Similarly, it is not surprising that voluminous literature now exists detailing psychiatric morbidity, as it is associated with diagnosis and treatment of breast cancer. Alarming however is that psychiatric morbidity within this context is largely under-diagnosed by health professionals (Harrison & Maguire, 1994).

A number of thorough research studies have shown a high incidence of psychological, social and sexual morbidity to be associated with mastectomy. Following the conclusion of a review article, Fallowfield (as cited in Harrison & Maguire, 1994) notes that the prevalence of psychiatric morbidity is similar whether women undergo mastectomy or conservative treatment.

#### **3.4.1 Psychopathology and Adjuvant Treatment**

Studies comparing the psychological outcome in breast cancer patients participating in randomised controlled trials of adjuvant chemotherapy report an incredible excess of psychological, social and sexual problems to exist among women receiving chemotherapy (Harrison & Maguire, 1994).



The psychological consequences of radiotherapy in the treatment of breast cancer persisted beyond six months and were only significantly lower than the morbidity levels among chemotherapy patients after twelve months. It was also found that adjuvant chemotherapy is oftentimes counterproductive in that, whilst the medical benefits are realised, the effects of the treatment are such that it becomes a constant reminder to patients that they had cancer and also that it could reoccur (Harrison & Maguire, 1994).

### ***3.4.2 Psychopathology and the Need for Psychotherapy***

Excluding cervical cancer, a survey of the Research Report posits breast cancer as the most prevailing tumour in women in South Africa (as cited in Schlebusch & van Oers, 1999). However, despite the alarming rates at which breast cancer is attacking the female population and in stark contrast to identifying patient distress, clinicians have failed to offer intervention at this level feeling distress to be rather a natural progression of receiving cancer diagnosis and treatment (Walker & Eremin, 1996).

In recognising the impact of breast cancer on body image and the self-concept, studies investigating the psychosocial adjustment of these women concur as to the increased probability for the development of psychological difficulties (Derogatis, 1986; Schlebusch, as cited in Schlebusch & van Oers, 1999). In recognition of this, the need to identify women at greater risk for psychological distress is paramount in order that psychotherapeutic intervention be made available (Schlebusch & van Oers, 1999).

Symptomatically, depression and anxiety are common disorders experienced during the onset and course of cancer (Massie, 1989; Stanton & Snider, as cited in Schlebusch & van Oers, 1999), whereas post-traumatic stress disorder is a primary symptom reported in those women who are in remission (Schlebusch, as cited in Schlebusch & van Oers, 1999)

It would appear that the mere receiving of cancer as a diagnosis is sufficient to throw individuals into an emotional roller-coaster of sadness and grief similar to that experienced by individuals grieving a threatened or actual loss. In this instance however, mourning is related to the loss of a body part and the impact of this on the physical self (Schlebusch, as cited in Schlebusch & van Oers, 1999).

Taylor, et al. (as cited in Schlebusch & van Oers, 1999) posit instances of breast loss to be equated to male castration in terms of it constituting an insult on a woman's sexuality, femininity and motherhood. Of paramount concern is that insult of this magnitude attacks the very essence of femininity and as such paves the way for depressive symptomatology that varies on a continuum from normality to pathology (Massie, 1989; Schlebusch, as cited in Schlebusch & van Oers, 1999).

Similarly, observations by Tarrier (as cited in Schlebusch & van Oers, 1999) bring to the fore the difficulties of integrating and accepting altered body appearance by women who have undergone mastectomy and the existence of varying degrees of depression for many years post-operatively.

### **3.5 Challenges of the Psychologists**

The challenge facing psychologists is to identify those factors contributing to a woman's psychological adjustment if improved prevention, detection and management of psychological disorders are to be successful (Dean 1987; Ford, Lewis & Fallowfield, 1995).

In terms of reviewing the relationship between disease, treatment variables and psychological morbidity in breast cancer, results are not as clear-cut as one might expect. Similarly and perhaps rather surprisingly, the introduction of less mutilating procedures has not always translated into lower levels of anxiety and depression than would be expected when compared to mastectomy patients (Fallowfield, Hall, Maguire & Baum, 1990; Kissane et al., 1998). In addition, mixed results have been reported in terms of the relationship between adjuvant treatments and psychological morbidity (Dean, 1987; Kissane et al., 1998).

### **3.6 Summary of Chapter**

Most studies concur that mastectomy impacts profoundly on a women's sense of femininity, sexuality, and self-concept (Meyerowitz, et al., 1999; Polivy, 1977) and is the cause of much psychological distress (Walker & Eremin, 1996). Additionally, the effects of surgery and treatment are such that oftentimes, psychiatric morbidity is increased.

Although studies show pre and post-operative psychological, psychosocial and oncological support to be most beneficial in terms of overall recovery (Harrison & Maguire, 1994), support of this nature remains sadly lacking in the treatment and management of breast cancer patients (Hames, 1987).

Whether or not a support structure exists, many breast cancer patients employ a multitude of coping strategies that either serve to reduce negative emotions or inadvertently increase levels of distress through tactics of simple escape and avoidance (Harrison & Maguire, 1994).

Although many studies cite the elective of breast reconstructive surgery as a coping mechanism associated with improved psychological outcome (Anderson & Kaczmarek, 1996; Gross, Burnett & Borrelli, 1996) there remains a great number of medical professionals who feel the benefits of this procedure to be inadequately substantiated (NHS, as cited in Harcourt & Rumsey, 2001). In light of this and in the absence of financial backing, many women are denied the freedom of choice.

Given that all studies show a high correlation between breast cancer and psychopathology, one might think it a little peculiar or seemingly bizarre that, no matter the looking glass utilised, psychiatric morbidity is largely unrecognised within the medical profession (Harrison & Maguire, 1994). Similarly, and although breast cancer features as the second leading cause of death for women in South Africa, identification of patient distress is, for the most part, overlooked or severely downplayed (Walker & Eremin, 1996).

Studies timelessly show the negative psychological and psychosocial ramifications associated with breast cancer and the loss of a breast to exist not only at diagnosis but also for many years following remission (Schlebusch, as cited in Schlebusch & van Oers, 1999). It is therefore imperative that the difficulties experienced by mastectomy patients in terms of integrating and accepting altered body appearance be made known (Tarrier, as cited in Schlebusch van Oers, 1999).

The following chapter discusses the psychological, physiological and psychosexual difficulties in women who undergo hysterectomy or vulvectomy.

## Chapter Four

### Psychological, Physiological and Psychosexual Difficulties Following Hysterectomy or Vulvectomy

#### 4.1 Introduction

The impact of gynaecological malignancy on a woman's psychosexual well-being in terms of femininity, sexuality and sexual functioning can be devastating and this being primarily in light of the organs involved (Kew, Nevin & Cruickshank, 2002). Surgical intervention, such as hysterectomy and vulvectomy, in the treatment of gynaecological malignancy, is often mutilative and with many psychological, physiological and psychosexual implications. Commencing with the multifactorial implications of hysterectomy and vulvectomy, the following paragraphs discuss these concerns.

#### 4.2 The Multifactorial Implications of Hysterectomy and Vulvectomy

Psychological, psychosexual and physiological in nature, the effects of having undergone hysterectomy or vulvectomy are multifactorial. Although many studies attest to the physiological difficulties following hysterectomy and vulvectomy, few studies extend beyond this to include the psychosexual difficulties and even more so in terms of the psychological implications of surgery in women who have this (Butler, Banfield, Sveinson & Allen, 1998; Moore & Trolley, 1976).

In terms of hysterectomy for example, Patterson and Craig (1963) reason that by virtue of the body's integrity being dependent upon external appearances, hysterectomy, as something internal to the body, fails to feature as a psychological difficulty experienced in women who have this. It is unfortunate that some theorists fail to take cognisance of the link between the levels of hysterectomy, vulvectomy and the onset of psychopathology irrespective of visibility in terms of the operation site (Kew, et al., 2002).

#### ***4.2.1 The Psychological Effects of Hysterectomy***

Whilst the state of being physically attractive might refer more specifically to external parts of the body, the image a woman has of her body includes that of her internal self and as such, hysterectomy can affect the way women feel about themselves as a woman. To date, the uterus continues to play a significant role in terms of childbirth functions, menstruation, its association with youthfulness, identification with being female, its role in reproduction as well as the hormonal contributions that it makes (Bachmann, 1990; LaLinec-Michaud & Engelsmann, as cited in Leiblum, 1990).

Supporting this, and endowed with symbolic and emotional significance, the uterus plays a fundamental role in what it means to be woman and has done so since ancient times (Veith, 1965). In a review of the literature, Wolf (1970) describes the uterus as fundamental to perceptions and attitudes of social gender function and body perception in women and that this is so by virtue of its role in menstruation, pregnancy and childbirth.

Although women clearly differ in terms of their emotional investment in the uterus, how she feels about herself and whether she regards hysterectomy as a threat to her health, several studies suggest that a premorbid psychiatric history of depression and anxiety as well as surgery performed without a clear history of pelvic disease, are associated with a negative surgical aftermath (Bachmann, 1990; LaLinec-Michaud & Engelsmann, as cited in Leiblum, 1990).

#### ***4.2.2 The Psychological Effects of Vulvectomy***

The psychological effects of vulvectomy include misbeliefs about the origin of cancer, guilt related to these misbeliefs, coexisting depression, changes in body image after surgery and stresses to personal relationships, which occur secondary to cancer (Ganz, Rowland & Desmond, 1998).

Although the amount of tissue resected has not been found to be a good predictor of post-operative sexual satisfaction, decreased morbidity has been noted in instances of partial vulvectomy whereby the vulvar tissue has been spared as opposed to radical vulvectomy (Marshall, Mostwin & Radebaugh, 1991). Irrespective of the type of vulvar surgery, sexual problems remain a common experience post-operatively and as such, appropriate

psychotherapy and treatment for depressive symptomatology is fundamental in the overall management of this patient population (Green, et al., 2000).

### ***4.2.3 The Psychosexual Ramifications of Hysterectomy***

Complaints of sexual dysfunction following hysterectomy range from as low as 10% (Huffman, as cited in Leiblum, 1990) to as high as 46% (Zussman, Sunley & Bjornson, as cited in Leiblum, 1990). Among the many difficulties described, painful intercourse, negative changes in orgasmic quality, reduced sexual sensations and a reduction or cessation of sexual desire feature most prominently. Of the sexual problems experienced postoperatively, women who have undergone the removal of their ovaries and uterus are primarily affected and especially since this procedure catapults women into menopause (Leiblum, 1990).

In considering the impact of hysterectomy on sexual behaviour and functioning and in recognising the need to extend treatment and management of these women beyond the confines of illness, Leiblum (1990) notes the importance of adopting a bio-psychosocial model that includes environmental, cultural, interpersonal and biological factors. This view is perhaps among the more promising in that it exceeds the boundaries of the medical model and alludes more towards the postmodernist stance upon which this study is premised.

### ***4.2.4 Psychosexual Morbidity and Vulvectomy***

Significant sexual morbidity is commonly associated with radical gynaecological surgery and which might be a consequence of disfigurement and disturbance of the external genitalia as is the case of vulval surgery. In the event of the clitoris being removed following radical vulvectomy, orgasmic functioning will be inhibited. In addition, surgery may reduce or even obliterate the introitus making penetrative intercourse painful and oftentimes, impossible for approximately 40% of cases studied (Andreasson, et al., 1986).

Alterations in genital sensitivity are known to occur in about 60% of women. Although not yet confirmed, minimising the extent of surgery might reduce the degree of dysfunction experienced. Even if the clitoris remains intact and the introitus remains adequate, psychological morbidity from the alteration in body appearance can cause significant

dysfunction. In such instances, as much as one third of vulvar cancer patients never resume intercourse post-treatment (Andreasson, et al., 1986) and with a reduced frequency of coitus noted as common in the remaining numbers (Green, et al., 2000).

#### ***4.2.5 The Physiological Effects of Hysterectomy***

It would appear that the severity of psychopathology in women following hysterectomy is conjoined with the level of hysterectomy in terms of the physical symptoms experienced. Radical hysterectomy, for example, that includes the removal of the ovaries, not only shortens the vagina but also results in the onset of menopause (Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 1999).

Oftentimes, atrophic vaginitis results as a consequence of a reduction in oestrogen levels (Hamilton, 1999) and which invariably causes sexual difficulties such as dyspareunia (Thranov & Klee, 1994). Furthermore, the development of marked vasomotor symptoms and increased rates of incontinence can be extremely distressing as well as embarrassing and which invariably impacts adversely on sexual functioning (Lalos & Lalos, 1996).

Kew, et al. (2002) point out that the knowledge by the patient that she is no longer fertile and the experience of diminished sensation and orgasmic disturbance that might result due to nerve and vascular disruption of the pelvis all serves to provoke psychosexual morbidity.

#### ***4.2.6 The Physiological Effects of Vulvectomy***

The most commonly reported physiological effects of vulvectomy are a loss of desire for sexual activity and dyspareunia (pain with intercourse) in women (Schover, Montague & Lakin, 1997). Women may experience changes in genital sensations due to pain or a loss of sensation and numbness, as well as a decreased ability to reach orgasm.

Premature ovarian failure as a result of chemotherapy or pelvic radiation therapy is a frequent antecedent to sexual dysfunction, particularly when hormone replacement is contraindicated in light of the hormonally sensitive nature of the malignancy (Ganz, et al., 1998).

Physical factors include functional damage secondary to cancer therapies, fatigue and pain. Additionally, cancer therapy, such as surgery, chemotherapy, radiation and bone marrow transplantation may have direct physiological impact on sexual functioning. Unlike many other physiological side effects of cancer treatment that resolve following treatment cessation, sexual dysfunction tends to remain constant and severe years following a disease-free diagnosis (Prev, 2001).

### **4.3 The Effects of Treatment in Gynaecological Malignancies**

In that the quality of life issues feature secondary to cure and remission, psychosexual morbidity remains an area of study that is lacking in medical literature (Butler, et al., 1998). Various studies attest to the traumatic effects on sexual functioning as a result of diagnosis and treatment of gynaecological malignancies. With many studies relying on the frequency with which sexual intercourse takes place as a surrogate marker as to what constitutes sexual dysfunction, this is to ignore the other fundamentals that exist outside of intercourse such as orgasmic capability, sexual contact and sexual persona (Kew, et al., 2002)

In that gynaecological malignancies are more frequently observed in older women, age is perhaps an important factor for the neglect of psychosexual morbidity in literature (Lalos & Lalos, 1996). Simply put, despite the fact that women purport to remain sexually active beyond the age of 70, sexual activity in later years is often treated as taboo in science. Similarly, relatively little information exists detailing psychosexual morbidity in women suffering from endometrial or ovarian cancer and with studies concentrating largely on cervical cancer and, to a lesser extent, invasive and pre-invasive vulvar lesions (Kew, et al., 2002).

One premorbid factor in personality that might impede sexual functioning is sexuality (e.g. whether or not ones own sexuality is regarded in a positive light). Ultimately, women with negative self schema's appear less likely to resume sexual intercourse or enjoy healthy sexual functioning post-treatment for gynaecological cancer (Andersen, Woods & Copeland, 1997).

Invariably, adjuvant therapies that follow surgical interventions in instances of gynaecological malignancy result in an experience of secondary trauma for the patient. The following passages discuss this in relation to chemotherapy, cytotoxic agents and radiation:



### **4.3.1 Chemotherapy**

Coupled with an altered sense of taste and smell, nausea, vomiting, diarrhoea, constipation, mucositis, and weight changes (gain or loss) are cited as being among the most common side-effects of chemotherapy that are primarily associated with a marked decrease in the desire for and frequency of sexual intercourse (Schover, 1997). Asexual feelings are also heightened by the onset of alopecia and the loss of pubic hair and of which can be as uncomfortable as it is distressing.

The physical changes in appearance experienced by women during the course of chemotherapy include changes to a woman's physical appearance, such as hair loss or skin changes and weight gain. Physical alterations such as these might increase a woman's sense of feeling unattractive during this vulnerable period of her life and as such, features predominantly in the development of psychological morbidity (Spence, 1991).

### **4.3.2 Cytotoxic Agents and Radiation**

In women, the experience of vaginal dryness, dyspareunia, reduced ability to reach orgasm, and, in older women, an increased risk for ovarian cancer are primarily the consequence of the cytotoxic agents utilised during treatment (Schover, 1997). Invariably, it is the premature failure of the ovaries secondary to chemotherapy or radiation that is the nuisance involved in the sudden onset of menopausal symptoms.

Associated sexual changes following a sudden loss of oestrogen and androgen production from the ovaries include: vaginal atrophy, a thinning of the vagina and vulvar tissue, a loss in tissue elasticity, hot flushes, decreased vaginal lubrication, heightened susceptibility to urinary tract infection, fatigue, irritability and mood swings (Ganz, et al., 1998).

Radiation therapy produces many of the symptoms described above as well as a reduction in feelings of sexuality. Pelvic radiation in particular has a tendency to irritate the intestinal lining. The change in bowel habits and a constant sense of feeling fatigued all add up to a loss in libido and decreased sexual activity in women (Auchincloss, 1991).

Of note is that both external radiation and implants during pelvic radiation connote physiological changes for women that results in damage to the vaginal epithelium and basal

layer of the mucosa and invariably leads to stenosis and vascular fibrosis. Long-term complaints include painful pelvic examination, dyspareunia, infertility, potential genital toxicity and sexual dysfunction (Auchincloss, 1991).

#### **4.4 Psychopathology and Myths in Gynaecological Malignancies**

A common post-treatment experience for women diagnosed with gynaecological malignancies is psychiatric morbidity with as high as one third of the women reporting severe depression following vulvectomy (Green, et al., 2000) and with depression and anxiety commonly reported in women following surgery for cervical cancer (Corney, et al., 1992).

Although inaccurate in their assumptions, women commonly believe the cause of their cancer to be a consequence of past sexual activity, an extramarital affair, sexually transmitted disease, or abortion. Another false assumption widely held by many women is that sexual activity may promote a recurrence of their tumour and is a misconception especially partial to individuals with malignancy of the pelvic or genital area (Southern & Herrington, 1998).

The above misconceptions support the notion for education and psychotherapeutic intervention at the level of the patient. It is often the case that women with squamous cell carcinoma of the cervix have read, from whatever source they find available to them, that this cancer type is associated with the sexually transmitted Human Papilloma Virus (HPV) (Southern & Herrington, 1998). In this light, guilt arising from thoughts of past sexual activity or concern about potential harm to a current partner are among the many issues that must be addressed in these patients.

#### **4.5 Challenges for Medical Professionals and Psychologists**

No clear guidelines exist addressing sexuality during the pre and post-stages of gynaecological malignancies. When therapeutic decisions are being made, providers should offer education and information to patients, ideally with the partner present, regarding risks of sexual morbidity associated with cancer treatments (Ganz, et al., 1998).

Professionals in the field of oncology and gynaecology can assist their patients by asking specific open-ended questions to validate the importance of sexual health concerns and as such, provide an environment in which the patient/couple are encouraged and feel safe to express concerns (Ganz, et al., 1998). Although this might work in theory, by and large, medical professionals tend to deal mainly with the physical issues and ignore psychosexual and psychological factors (Kew, et al., 2002).

It has been the researchers experience that studies of hysterectomy and vulvectomy concentrate predominantly upon the surgical procedures and psychosexual dysfunctioning and with psychological trauma, a seemingly prominent side effect, either omitted or discussed to a far lesser degree. The reasons for this are varied but include a lack of education and training in this field with regards to the nature of these issues, a lack of time that is available as well as feelings of discomfort, on the part of the health professionals, when discussing topics that are intimate (Butler, et al., 1998).

Importantly, health care professionals need to examine their own thoughts and feelings regarding sexuality and where problematic, referrals should be offered as an alternative rather than mere ignorance or dismissal of issues that are raised. Although acknowledged that many patients may not wish to discuss, for whatever reasons, their sexual health, this form of intervention should, at the very least, be made available to them and the message conveyed that sex is a topic that is appropriate to discuss and the environment for discussion is safe and containing (Ganz, et al., 1998).

Post-treatment, many patients continue routine follow-up treatments with their general practitioner as opposed to the oncology specialist and as such, space for therapeutic intervention is never created. Many researchers note that the need for therapeutic intervention is brought up time and again by patients with gynaecological malignancy and who have expressed the desire to speak about their psychosexual problems with other women who have experienced the same (Corney, et al., 1992).

It has also been established that approximately two-thirds of women who have already experienced the traumas of surgery are prepared to talk to pre-surgical patients as to the sexual ramifications of the treatment (Green, et al., 2000). Similarly, psychosexual-educational groups might prove most beneficial in fear reduction about sex following gynaecological cancer in women of all ages (Robinson, Faris & Scott, 1999).

## 4.6 Summary of Chapter

The symbolic significance of the uterus and the psychological difficulties faced by many women who undergo hysterectomy is oftentimes severely undermined by those researcher's who feel hysterectomy, as an internal procedure and therefore not visible, fails to impact on women in any way negatively (Moore & Trolley, 1976).

Irrespective of the level of hysterectomy (e.g. simple or radical), the symptoms that manifest postoperatively as side effects that follow hysterectomy are unwanted by the women who experience them. From diminished sensation and orgasmic disturbance to atrophic vaginitis, dyspareunia and premature menopause, hysterectomy does not always follow the cliché: 'out of site therefore out of mind.' With an ever increasing literature purporting a woman's perception of physical attractiveness to include her internal self, it becomes clear that the uterus and indeed, hysterectomy, cannot be excluded in a woman's overall perceptions of self (Veith, 1965; Wolf, 1970).

In terms of vulvectomy and despite high and severe instances of sexual dysfunction and physical disturbances that might result following surgery and as a consequence of adjuvant treatments (Ganz, et al., 1998), the psychological impact of vulvectomy is rarely referred to in the literature (Butler, et al., 1998) and as was experienced during the course of this study.

Resultant sexual dysfunction that is frequently referred to in studies appears to be multifactorial in nature and an area of disturbance that remains constant and severe years following surgery and treatment. A decreased sense of sexuality is also cited as a premorbid factor in personality that conjoins a women's negative self-schema and impedes sexual functioning (Andersen, et al., 1997).

Psychiatric morbidity is invariably high following vulvar surgery with many women developing severe depressive symptoms (Green, et al., 2000). With a tendency for many women to form inaccurate assumptions as to the cause of their cancer, education and psychotherapeutic intervention is clearly warranted at the level of the patient (Basaria, Lieb & Tang, 2002).

With medical professionals approaching gynaecological disorders primarily in terms of physical symptoms and disease eradication, psychologists and sexologists face a multitude

of challenges that incorporate the psychological, psychosexual, sexual educational and psychosocial elements in the treatment and management of each patient (Butler, et al., 1998).

In attempts to create an awareness of the disturbances in body self-concept that persist in women who, after having suffered from a common ailment, now live with body disfigurement in the absence of illness, and, in appreciating the depth of these body perceptual disturbances, the term 'self-concept' needs to be defined and distinguished from body image. The following chapter discusses this and introduces the notion of a theoretical model based on the hierarchical and multidimensional nature of self-concept.



## Chapter Five

### The Hierarchical and Multidimensional Self-Concept

#### 5.1 Introduction

In the presence of illness, many women seem more concerned with the possibility of suffering body disfigurement than they are with their physical health. It is highly probable that, in the absence of illness and presence of body disfigurement, body perceptual disturbances and body self-concept issues remain part of a woman's experience. In attempts to create an awareness of this, and in appreciating the depth of body perceptual disturbances, the term 'self-concept' needs to be defined and distinguished from body image.

In making a distinction between body image and self-concept, Schilder (1935) posits one's individual mental construct of the body to be a sufficient definition of body image, whereas self-concept is related to an individual's most fundamental perceptions of self and as such, forms the very essence of personality (Combs, Richards & Richards, 1976). The following paragraphs discuss the multidimensional nature of self-concept.

#### 5.2 Constructing the Construct

Many early researchers claim the construct of self-concept to be uni-dimensional or so severely dominated by a general self-worth factor that all other factors are rendered unidentifiable (Rosenberg, 1979). In a state of being uni-dimensional, self-concept was positioned as a static entity that described a stabilised or generalised self-view. More recent scholarly papers however, now recognise the general, overall self-worth factor as but one of many dimensions that collectively define self-concept. In this way self-concept connotes a multidimensional, multifaceted and dynamic structure that is used by the individual in all spheres of social information processing (Markus & Wurf, 1987).

### 5.3 The Historical Self-Concept

Historically, the evolving of 'self-concept' as a hypothetical construct is conjoined to the contributions of psychologist William James (1890/1963) who made four important conceptions: (a) distinguishing between the I (self as knower or subject) and the Me (things objectively known about the self); (b) the multifaceted and hierarchical nature of self-concept that positions the bodily self at the bottom, the social and material selves in between and with the spiritual self at the helm; (c) the social self - based on peer recognition received or a generalised/potential social self construed by the evaluations of God, a future generation or higher authority; and (d) the definition of self-esteem as the ratio of success to pretensions and subjective importance so that a person must select carefully "the strongest, truest, deepest self on which to stake his salvation" (as cited in Marsh & Hattie, 1996, p. 38).

According to Marsh and Hattie (1996), James opened the doors to future multidimensional and hierarchical models of the self. Similarly, James's notions of self-concept is well recognised in practically all accounts of self-concept.

### 5.4 The Multidimensional and Hierarchical Nature of Self-Concept

Of the many theoretical models of self-concept that exist, few theories have undergone empirical scrutiny. More specifically, few theoretical models have been evaluated statistically in terms of construct validity. The multidimensional nature of self-concept (Harter, as cited in Byrne, 1996), underscores not only this study and indeed the follow-up study to this, but also the theoretical notion underpinning the hierarchical model of Shavelson and from which all of the Self-Description Questionnaires have been developed (Marsh, 1990c, 1992b, 1992c; Marsh, Richards, Johnson, Roche, & Tremayne, 1994; Marsh, as cited in Byrne, 1996).

The following paragraphs provide some insight into the hierarchical model of self-concept.

### **5.4.1 *General Self-Concept as a Higher Order Factor***

The theoretical notion underlying the hierarchical model conceives general self-concept as a higher order factor comprising multiple, domain-specific self-concepts, and of which the domain-specific self-concept constructs can be interpreted separately (Byrne, 1996).

Shavelson et al. (1976) were among the first to propose a hierarchical model of self-concept that enabled for empirical testing. The hierarchical model, hereon referred to as the Shavelson model, portrayed a multidimensional and hierarchically ordered structure of self-concept. General self-concept was positioned at the apex and with actual behaviour at the base (Byrne, 1996).

General self-concept was divided into two branches, namely, academic and non-academic self-concepts. The three facets comprising the non-academic branch are: the social, physical and emotional self-concepts. The academic facet and the three non-academic facets branch separately into more specific self-concepts such as mathematics, peers and physical appearance (Byrne, 1996).

In accordance to the Shavelson model, multidimensionality implies that the inter-correlated self-concept facets can be interpreted as separate constructs. Thus, for example, the body self-concept as a non-academic facet would be a dimension of the physical self-concept construct that one interprets as a separate entity.

The hierarchical structuring of general self-concept suggests that the strength of the correlations between self-concept facets varies in a systematic pattern (Byrne, 1996). In keeping with the aims and goals of this study and the follow-up study to this, the non-academic physical self-concepts will be utilised to demonstrate the hierarchical structuring as follows: (a) general self-concept correlates highest with the non-academic physical self-concept, next highest with body self-concepts and lowest with the physical ability self-concepts; (b) physical self-concept correlates highest with body self-concept than with physical abilities and (c) physical abilities correlate higher with their matching physical ability achievements (such as running the marathon) than with non-matching physical self-concept scores (such as interpersonal relations).



In terms of construct validity bearing on the non-academic branch of the Shavelson model, a study by Marsh and Redmayne (as cited in Byrne, 1996) reported findings that support the hierarchical model of self-concept. In this way, Marsh and Redmayne were able to validate that the global physical self-concept can be subdivided into components related to endurance, balance, flexibility, strength and appearance.

As noted by Marsh (as cited in Byrne, 1996), the strength of the versatility of the hierarchical model is that it provides a broad framework within which to study the structure of self-concept. Developing an instrument of self-concept from the Shavelson model, the following paragraphs discuss Marsh's Self-Description Questionnaire III (SDQ-II).

#### ***5.4.2 The Self-Description Questionnaire III (SDQ-III)***

The Self Description Questionnaire III (SDQ-III; Marsh, as cited in Byrne, 1996) was designed to measure multiple dimensions of self-concept in college students and other adults. Firmly entrenched within the theoretical model proposed by Shavelson et al., (as cited in Byrne, 1996), the SDQ-III comprises a multidimensional structure designed to measure self-concepts related to eight non-academic areas, four academic areas, and a single global perception of self.



As an extensively validated measure of self-concept available for use with adults the eight non-academic facets of the SDQ-III were utilised for the purpose of this study and as a means by which the information gleaned might inform the follow-up study to this.

### **5.5 Self-Concept Defined**

In keeping with James's foresight, and in encompassing much of the researchers own beliefs, Shavelson et al. (as cited in Marsh & Hattie, 1996) provides the following broad definition of self-concept: (a) self-concept is a mishmash of an individual's perceptions of self; (b) the self-perceptions culminate from experience with and interpretations of an individuals environment; (c) self-perceptions are influenced by the evaluations of significant others, through reinforcements and attributions for the individual's actions; (d) self-concept is a hypothetical construct that is useful to explain and predict behaviour; and (e) behaviour is influenced by an individuals self-perceptions and vice-versa.

Katz, Rodin and Devins (1995) posit self-concept as a state of self that is constantly changing. Self-concept is here defined as the sum of all a person's feelings about the self and which includes five major interrelated elements namely, alteration in bodily experience; discrepancy between the actual and ideal self; disruption of personal relationships; and self-depreciating meaning of illness and also depression. During ill health, any or all of the elements may be affected.

In assessing whether to use body image or self-concept as a means by which to evaluate participants, the writer resorted back to the overarching purpose and aim of this study in forming a decision. In that this study intends to view various perceptions of self as this might be perceived by women who live with altered body appearance and function and with this area being the least tapped to date, self-concept as opposed to body image is preferred. In this way, the writer concurs with the above authors in terms of their definition of self-concept as multidimensional and hierarchically structured.

## **5.6 Relating Self-Concept to Body Disfigurement**

According to Reaby, Hort and Vandervord (1994), and in keeping with the above definitions, a change in body structure affects a woman's perception of her body. Where altered body appearance and function is the result of body disfigurement, the altered state of the physical self will be perceived as negative. This observation is in light of ones perceived self as forming the crux of self-concept and self-esteem. It is primarily this premise that formed the basis for this study.

## **5.7 Summary of Chapter**

In that body perceptual disturbances in body disfigured individuals appear to continue years following surgery and with society and various media dictating and emphasising the ideal female form, the self-concept in women who live with body disfigurement, plummets (Anderson, et al., 1997; Francis, 2002; Newell, 2000). In that the information gleaned from this study was to ultimately inform the development of a measure of body self-concept and body self-concept booklet, a definition of self-concept that distinguished it from body image was required.

In this way, the theoretical model offered by Shavelson et al. (as cited in Byrne, 1996) was accepted in light of the multidimensional nature and hierarchical structure of self-concept. The theoretical notion underscoring this model conceives general self-concept as a higher order factor comprising of multiple, domain-specific constructs of self-concept and of which can be interpreted separately.

A study by Marsh and Redmayne (as cited in Byrne, 1996) reported findings that support the hierarchical model of self-concept in terms of its construct validity. In line with the Shavelson et al. (1976) model of self-concept, Marsh developed the Self-Description Questionnaire III. As an extensively validated measure of self-concept available for use in adults, the eight non-academic facets of Marsh's self-concept scale were utilised in this study. It is hoped that the information gleaned from this pilot run will inform the follow-up study to this in 2004.

The following chapters discuss the research methodology and results of this study.



## Chapter Six

### Research Methodology

#### 6.1 Introduction

Five primary motivations underscore the study in its entirety, namely the conviction that, (a) many women who live with altered body appearance and function following a common ailment suffer disturbances in body self perceptions; (b) body perceptual disturbances in these women continue to exist years later despite cure of the common ailment; (c) the psychological and psychosocial experiences of these women needs to be articulated; (d) the onset of psychopathology in these women is possible irrespective of body disfigurement visibility; and (e) an outreach programme for body disfigured individuals and measure of body self-concept is required.

Implementing the study in a manner that encompassed all five primary motivations proved complex and as such, necessitated its division into two phases. This study completes Phase One. This chapter describes the research problem and hypotheses, research methods, participants, method of data collection and analysis and also describes the measuring instruments utilised in this study.

#### 6.2 The Research Problem

The role of the media is well documented in prescribing the "body beautiful" and dictating the ideal female form. When illness inscribes the body and body disfigurement results, one wonders as to the impact of such media dictates on the body self-concept of these women.

Few studies describe the impact of the media on body-disfigured individuals and fewer still describe the impact of body disfigurement in the absence of illness (Newell, 2000). No studies could be found that investigate body perceptual disturbances in individuals who live with body disfigurement after having suffered from a common ailment. One might speculate that by virtue of having suffering a common ailment, the possibility for body perceptual disturbances is undermined by many medical professionals. Invariably, many women who suffer from body perceptual disturbances, suffer in silence (Francis, 2002).

According to the reasoning of Patterson and Craig (1963), the integrity of the body is dependent upon external appearances and as such, anything internal to the body (e.g. hysterectomy) would fail to feature as a psychological difficulty experienced in women who have this. In light of the above, the convictions that epitomise the study as a whole, and in challenging the reasoning of Patterson and Craig, the following hypotheses were formulated for this study:

- (a.) Body perceptual disturbances exist in women who live with body disfigurement after having suffered a common ailment.
- (b.) Body perceptual disturbances persist in these women despite being cured of the common ailment.
- (c.) Body perceptual disturbances exist in these women irrespective of the level of disfigurement visibility to the individual concerned or to others.

In cognisance of the above hypotheses, this study explored depression and self-concept in three groups of women who, after having suffered a common ailment, live with varying degrees of body disfigurement visibility namely, women who have undergone mastectomy, hysterectomy or vulvectomy.

### **6.3 Quantitative Research**

Quantitative research is but one methodological paradigm in the research rubric. Taking scientific explanation to be nomothetic (Schurink, 1999), quantitative research represents positivist, experimental and empiricist schools of thought (Creswell, 1994). As a pilot study, quantitative research methods were utilised in the process of data collection, analysis and interpretation in the exploration and comparison of depression and self-concept in three groups of participants.

The Mann-Whitney, Kruskal-Wallis and Wilcoxon Signed Ranks tests were utilised as the nonparametric statistics of choice and which was deemed pragmatic given the small sample size.

## 6.4 Phase One

This pilot study helped to determine the adequacy and appropriateness of the research methodology, sampling instruments and analysis (Bless & Higson-Smith, as cited in Strydom, 2002). In this way, the researcher was better able to orientate herself to the project and to provide a method of pre-testing prior to Phase Two. Additionally, this study provided for the fine-tuning prior to the main inquiry that is to be conducted in 2004.

## 6.5 Selection of Participants

Three different modes of appeal were utilised in an attempt to gain participants, namely: (a) the placement of an advertisement in a local newspaper and which ran for two consecutive weeks; (b) the assistance of the chairperson from Reach for Recovery and (c) the aid of a medical specialist who approached his patients to ask for their consideration for participation in the study.

Three participants were selected by means of snowball sampling. Such a sampling technique requires approaching a small number of people in the target population who are asked to introduce the researcher to other people who, in turn, are invited to help recruit others to assist. In this way, an initial small sample may 'snowball' into a larger one (Breakwell, Hammond & Fife-Schaw, 1997). This type of sampling is based on the analogy of a snowball, which begins small but becomes larger as it is rolled on wet snow (Neuman, 1997).

It was anticipated that, in using snowball sampling, news of the proposed study would be spread by means of word-of-mouth to colleagues, friends, and acquaintances with the request that they, in turn, announce the proposed study to people within their respective social circles. Although this resulted in several individuals expressing their interest in the study, only three people qualified for participation. Similarly, of the 20 candidates referred by Reach for Recovery, only five qualified for participation. From the medical specialist, all six candidates referred were selected. Of this sample, one lady withdrew and one participant failed to return the questionnaire. Following the newspaper appeal, 16 of the 19 applicants qualified for participation.

## **6.5.1 Selection Criteria**

Participants were selected for inclusion in the study on the basis of the following criteria:

### **6.5.1.1 Racial Group**

In attempts to minimise cultural influences, the sample was restricted to White women only and who met the criteria for hysterectomy, mastectomy or vulvectomy.

### **6.5.1.2 Marital Status**

Although research does seem to indicate that stable marriages may act as an important buffer in a woman's reaction to perceptions of self (Northaire & Swain, 1987), many difficulties were encountered in obtaining participants within the specified groups. Consequently, and although marital status is a potentially important variable, it was not possible to control for in this study.

### **6.5.1.3 Age**

To reiterate the difficulties encountered in obtaining participants, the only age restriction was that participants be over the age of 21.

### **6.5.1.4 Mental Health**

Participants with a previous history of mental illness that fell outside of that experienced as a consequence of living with body disfigurement were excluded from the study on the basis that they were not representative of the normal hysterectomy, mastectomy and vulvectomy population.

### **6.5.1.5 Length of Time Since Illness/Disease and Treatment**

In terms of post-operative morbidity, studies have concentrated primarily on mastectomy patients. Literature on mastectomy and trauma patients suggest denial as the most frequently used coping mechanism in protecting the self against negative emotions evoked

by body disfigurement and resultant depression (Polivy, 1975; 1977; Harrison & Maguire, 1994). As a consequence of this, the full effects of hysterectomy, mastectomy and vulvectomy might not be evident for months post-operatively.

In that this study investigates specifically, the effects of body disfigurement on mood and body self-concept in the absence of illness, all participants were free of disease/illness at the time of participation and had been so for at least six months.

### **6.5.1.6 *Reconstructive Surgery***

Studies indicate that psychiatric morbidity is oftentimes counteracted with reconstructive surgery as in the case of mastectomy and vulvectomy patients. To control for this variable, only participants who had never undergone reconstructive surgery were selected (Anderson & Kaczmarek, 1996; Gross, et al., 1996).

### **6.5.2 *Descriptive Data***

A total of 28 participants were selected for participation in the study. All participants suffered body disfigurement of some kind and which varied in terms of disfigurement visibility. That is to say in terms of whether or not the disfigured body part was visible to the individual and/or to others. None of the women suffered any illness at the time of the study and with no history of mental illness prior to surgery. Of the 28 participants, 26 were English-speaking and two were Afrikaans-speaking. Both Afrikaans participants were fluent in English.

In terms of the groups, eight had undergone mastectomy, 16 participants had undergone hysterectomy, and four participants had undergone vulvectomy. With respect to the age of the participants, five were below the age of 35; six fell between the ages of 36 to 45; five participants were aged between 46 to 54 and nine participants fell within the age group of 55 to 64. Only three participants were older than 65. The mean age of the participants within the three groups was 50.00 years (SD = 13.78). In terms of the age at diagnosis of the illness and which resulted ultimately in the women undergoing disfiguring surgery, the mean age was 38.7 (SD = 13.6). The mean age at which surgery was performed for all participants was 42.4 (SD = 12.9).



In terms of marital status, 19 participants were married (67.9%), four widowed (14.3%), three divorced (10.7%), and two participants (7.1%) were single. With regards to family, 10 participants had two children (35.7%); six had four children (21.4%); six had one child (21.4), five participants had three children each (17.9%) and one participant did not have children (3.6%).

In terms of those participants who had undergone surgery consequential to cancer, one (3.6%) participant had been in remission for a period of six months, two (7.1%) had been in remission for one year, three (10.8%) participants had been in remission for between two and four years, two (7.1%) participants for five years, two (7.1%) participants for 11 years, one (3.6%) participant for 15 years, two (7.2%) participants had been in remission for between for 17 and 18 years and 15 (53.5%) participants did not suffer from cancer. In terms of those participants who did not suffer from cancer, all had undergone hysterectomy as a consequence of excessive bleeding during menstruation.

When asked the question whether or not the participants felt they were cured of their illness, 21 (75.0%) participants said yes, four (14.3%) participants felt they were cured but also felt the question was difficult to answer in that their illness might return, two (7.1%) participants responded as being uncertain in that their remission period for cancer did not guarantee that the cancer would not return and one (3.6%) participant felt this question did not apply to her.

Although no participants claimed to suffer any illness during the course of the study, in terms of their physical health ratings, four (14.3%) rated their health as being excellent, 15 (53.6%) felt their health to be good, six (21.4%) rated their health as being satisfactory and three (10.7%) participants felt their health to be fair. With regards to receiving medical treatment at the time of the study, eight (28.6%) remained within the five-year period in which they continued to receive chemotherapy, whilst 20 (71.4%) were not receiving any medical treatment at the time of the study.

## **6.6 Instrumentation**

The focus of this study was on body self-concept as opposed to body image. Combs, et al. (1976), in making a distinction between the two concepts, define body image as an

individual mental construct of oneself whereas self-concept is related to an individual's most fundamental perceptions of self and as such, forms the very essence of personality.

Katz, et al. (1995) define self-concept as the sum of all a person's feelings about the self and which includes five major interrelated elements namely, alteration in bodily experience; discrepancy between the actual and ideal self; disruption of personal relationships; self-depreciating meaning of illness and also depression. During ill health, any or all of the elements may be affected. Although related, by its definition, body image contrasts from self-concept referring rather to the sum of one's state of health, body care and outer appearance, body functioning and the fitness of the body.

Although 'self-concept' was more fitting to the focus of study, this in itself presented with a paradox, namely: there did not appear to exist a suitable measure of body self-concept and of the self-concept scales that were available, the construct under investigation was not fully represented by these measures. With no measure of body self-concept in South Africa, Dr. Herbert Marsh of the Research Centre, University of Western Sydney and Dr. Jane Stake of the University of Missouri - St. Louis made their self-concept scales available for use in this study.

Data was collected using numerical self-report scales, namely: the Beck Depression Inventory II (BDI-II), the Self-Description Questionnaire III (SDQ-III), the Six-Factor Self-Concept Scale and a Biographical Questionnaire. To ascertain whether the three groups (mastectomy, hysterectomy and vulvectomy) differed in terms of each of these scales, the nonparametric Kruskal-Wallis test was performed. The following passages discuss each of the four scales.

### **6.6.1 *The Beck Depression Inventory II : BDI-II***

In terms of the impact of body disfigurement on mood, the Beck Depression Inventory II (BDI-II) was utilised. The BDI is one of the most widely used instruments for detecting possible depression (Piotrowski & Keller, as cited in Beck, Steer, & Brown, 1996) and with the BDI-II in line with the depression criteria as specified in the Diagnostic and Statistical Manual of Mental Health Disorders - Fourth Edition (DSM-IV) (Beck, et al., 1996).

After testing original and new items on a large sample (n=500), test developers compared item-option characteristic curves. The new editions showed improved clinical sensitivity. Moreover, the reliability of the BDI-II (Coefficient Alpha for psychiatric outpatients was .92 and .93 for college students) is higher than the BDI (Coefficient Alpha was .86) (Beck, et al., 1996).

Like its predecessor, the BDI-II consists of 21 items for measuring the severity of depression in adults and adolescents aged 13 years and older. Each item is a list of four statements arranged in increasing severity about a particular symptom of depression. Participants were to select one statement in each group that best described the way they had been feeling during the past two weeks and which included the day of their test.

### ***6.6.2 Self-Description Questionnaire III (SDQ-III)***

Consistent with research findings, most published self-concept measures emphasize domain-specific concepts such as the multifaceted view by Marsh's (as cited in Strein, 1995) set of scales, namely, the Self-Description Questionnaire (I, II, & III) and which covers the ages of seven to young adulthood. For the purpose of this study, Marsh's SDQ-III was utilised.

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Shavelson, Hubner and Stanton (as cited in Marsh, 1992) were the first to propose a sophisticated model of a multidimensional self-concept. Starting with Shavelson's model, Marsh developed what are now some of the best measures of self-concept. The SDQ-III is based on the understanding of and empirical support for self-concept as a multidimensional construct (Strein, 1995).

The SDQ-III consists of 136 statements that are to be rated in accordance to an eight-point Likert-Type scale. Additionally, 12 Importance and Accuracy statements are included in the SDQ-III and which are to be rated in accordance to a nine-point Likert-Type scale. The 13 facets of self-concept measured by the SDQ-III are: Mathematics; Verbal; Academic; Problem-Solving; Physical Ability; Physical Appearance; Same Sex Peer Relations; Opposite Sex Peer Relations; Parent Relations; Spiritual Values/Religion; Honesty/Trustworthiness; Emotional Stability and General Self-Esteem.

Based on a full set of responses comprising a normative sample of ( $n = 2,436$ ), Marsh (1992) reported that the internal consistency reliability (Cronbach's alpha) for the 13 subscales ranged between .76 for Honesty/Trustworthiness to .95 for Spiritual Values/Religion, with a mean alpha of .90.

Marsh, Richards and Barnes (as cited in Byrnes, 1996), reported a test-retest reliability of the SDQ-III based on a study in which they examined the responses of 361 participants in a 26-day residential Outward Bound programme. Subjects completed the SDQ-III at four different time points: one month before ( $T_1$ ), on the first day of the programme ( $T_2$ ), on the last day of the programme ( $T_3$ ) and 18 months following completion of the programme ( $T_4$ ). Based on the full sample of participants who completed the questionnaire at all four time points ( $n = 229$ ), the reliabilities over the one month control interval was .87 compared to the reliabilities over the 18 month period to be .74. Thus, the SDQ-III appears to have strong temporal stability.

Regarding convergent validity between the Tennessee Self-Concept Scale of Fitts (1965) and the non-academic subscales of the SDQ-III, Marsh and Richards (as cited in Byrnes, 1996) report correlations to be highest for the Physical Ability ( $r = .53$ ) and Physical Appearance ( $r = .71$ ); Social Peer Relations - Same Sex ( $r = .61$ ) and Peer Relations - Opposite Sex ( $r = .59$ ); and Parent Relations ( $r = .68$ ) subscales. Furthermore, findings from rigorous within-and-between network research provide exceptionally strong support for the construct validity of the SDQ-III (Byrnes, 1996).

Correlating to body attitude, the General-Esteem, Physical Appearance, Physical Ability, Parent Relations, Same-Sex and Opposite-Sex facets add support to the soundness of Marsh's multifaceted approach to self-concept. With the addition of Emotional Stability and Spiritual Values/Religion, the eight facets listed here were selected for this study. The five remaining facets (Mathematics, Academic, Verbal, Problem-Solving and Honesty/Trustworthiness) were omitted in that they were not thought to be representative of mood and the body self-concept construct under measure.

Participants were to rate each of the 136 statements as each statement applied to them at that moment in time, from: 1 = definitely false, to 8 = definitely true. Responses to the 12 Importance and Accuracy statements ranged from: 1 = very inaccurate/very unimportant, to 9 = very accurate/important.

### **6.6.3 *Six-Factor Self-Concept Scale for Adults (SFSCS)***

Defining self-concept as a multidimensional construct that is the domain of self-descriptions that have a self-evaluative connotation, Stake (1994) developed the Six-Factor Self-Concept Scale (SFSCS), and which is among the few multidimensional measures of self-concept available for testing with adults. Designed to have broad applicability across life settings, roles and activities, the measure consists of six subscales: Likeability; Morality; Task Accomplishment; Giftedness; Power; and Vulnerability.

Yanico and Lu (2000) reported that the internal consistency reliabilities (Cronbach's alphas) for the six subscales ranged between .76 for Vulnerability and .86 for Likeability and Power, with a mean alpha of .82. The reliabilities may be regarded as satisfactory for research purposes.

Stake (as cited in Yanico & Lu, 2000) reported a test-retest reliability over a six-week period of between .68 for Vulnerability and .85 for both Task Accomplishment and Power scores. The test-retest reliability for the Composite score was .97. Thus, the SFSCS scores appear to have strong temporal stability. Among the evidence supporting convergent validity, the multiple correlations between the six subscale scores and self-esteem scores of Rosenberg's Self-Esteem Scale (RES) was .62 (Stake, as cited in Yanico & Lu, 2000).

The SFSCS consists of 36 descriptions about people and which are to be rated in accordance to a seven-point Likert-Type Scale. For each one, participants would indicate how often they thought the description was true of them from: 1 = never to almost never true, to 7 = always to almost always true.

### **6.6.4 *Biographical Questionnaire***

The biographical questionnaire was constructed as a means of data collection to ensure the full criterion for participation in the study was met. In addition, the personal details included herein enabled for the categorisation of the participants in accordance to age and body disfigurement type. The questionnaire was divided into the following five sub-sections: Personal Details; Family; Participatory Group; History of Illness and Current State of Health.

The descriptives of the Biographical Questionnaire included for calculation between the three groups are represented in Table 6.1 below.

Table 6.1

*Descriptives of the Biographical Questionnaire*

Age	Age at Diagnosis	Belief of Being Cured	Current Medical Treatment
Marital Status	Age at Surgery	Age at Diagnosis/Surgery	Current/Previous Psychotherapy
Number of Children	Period of Remission	State of Health	

*Note: A copy of the Biographical Questionnaire can be found under Appendix A.*

## 6.7 Procedure

Once the research goals, design, intervention, and method of analysis had been determined, the procedure was as follows:

Of the initial 30, 28 participants were recruited. Each participant was briefed on the study with special emphasis being placed upon the purpose of the research, the inherent risk of undertaking psychological change, the time required for completion of the selected questionnaires, and the level of commitment required should they wish to participate in Phase Two. Formal consent to take part in the study was subsequently obtained.

Twenty questionnaire packs were hand delivered and then collected within three days of delivery. Ten questionnaire packs were posted with a stamped addressed return envelope. This was in light of the lengthy distance from which each participant resided from the other. Of the 10 questionnaire packs posted, eight completed packs were returned within a nine-day period. One participant withdrew from the study and one participant failed to return her questionnaire pack and avoided future contact.

Twenty-six of the 28 participants committed to continue through into Phase Two in 2004. When asked, all participants felt a support group for body-disfigured individuals was paramount. Arrangements for this were made and which is to commence in January of 2004. Such intervention is to take the form of group therapy and will be made available once monthly.

## 6.8 Data Analysis

In the general description of all participants in accordance to the five sub-sections of the Biographical Questionnaire as described in section 6.6.4, frequency and descriptive statistics were utilised (see section 6.5.2).

In accordance to the SDQ-III, the subsection containing statements of accuracy and importance were tabulated. In view of the small sample size, the Wilcoxon Signed Ranks test was the non-parametric statistic utilised in detecting possible significant differences between how important a particular statement was for the participants when compared to how accurate the same statement was thought to be of them.

To detect differences between mean scores for the BDI-II, eight facets of the SDQ-III, and the six factors of the SFSCS, the nonparametric Kruskal-Wallis test was utilised.

## 6.9 Ethical Considerations

In the selection, participation and conduction of this study, the following ethical considerations were adhered to:



### 6.9.1 *Harm to Participant*

All participants were briefed thoroughly prior to intervention. Participants were informed as to the nature of the study and that, in answering certain questions, emotional issues might arise. In the event of this, debriefing was made available by the researcher. Additionally, participants were given the opportunity to withdraw from the study at any stage (Strydom, 2002).

### 6.9.2 *Informed Consent*

Information regarding the aim of the study, participant requirements and a detailed explanation as to each phase of the study was provided in the form of a cover letter. A letter of informed consent accompanied this explaining that participation is voluntary.

Informed consent helps to ensure the full knowledge and cooperation of subjects, whilst relieving any insecurity that might arise (Williams et al., as cited in Strydom, 2002).

### **6.9.3 Confidentiality and Anonymity**

Confidentiality and anonymity applied to ensure the privacy of each participant. All participants were informed that only the researcher would review their personal details and her primary supervisor's and that this would be treated professionally and in the strictest confidence (Strydom, 2002).

### **6.9.4 Competence**

In light of the sensitive nature of this study, it was ensured that the researcher is adequately skilled to undertake the proposed study and will undertake to work and report all findings ethically and correctly (Strydom, 2002).

Participants were informed of the findings as a token of appreciation and recognition and to maintain future good relationships with the community concerned (Huysamen, as cited in Strydom, 2002). The results of the study were reported objectively and in a manner that did not impair the principles of confidentiality.

## **6.10 Summary of Chapter**

This chapter outlined relatively simple and conceptually sound methodology designed to yield practical and relevant data in attempts to delineate significant group differences in areas that best relate to mood, disturbances in perceptions of self and body self-concept. The research problem introduced the dilemma of suffering a common ailment in terms of the consequential psychosocial and psychological difficulties that might be downplayed by many medical professionals by virtue of the frequency with which certain ailments manifest. Similarly, body perceptual disturbances that result subsequently to common ailments were highlighted.

The use of quantitative research methodology was defined in introducing this pilot study and with reference to the Mann-Whitney and Kruskal-Wallis tests utilised as the



nonparametric measures of choice. The selection of participants was discussed, as was the criterion under which selection of the participants was governed. Additionally, an in-depth discussion of the descriptive data provides for a full account of the biographical details of the three groups of participants.

The method of data collection was described, as was the analysis of data. Similarly, the purposefulness, reliability and validity of the instrumentation were noted. Finally, this chapter presented the various ethical considerations undertaken by the researcher.

The following chapter reviews the results of this study and provides a discussion of the results.



## Chapter Seven

### Results and Discussion

#### 7.1 Introduction

In presenting and discussing the results of this study, participant responses to the BDI-II, SDQ-III, SFSCS and Biographical Questionnaire are considered.

#### 7.2 Comparison of Mean Scores for the BDI-II, SDQ-III & SFSCS

The null-hypothesis in each case was that the three groups come from the same population or have the same population mean. The alternate hypothesis was that at least one of the groups has a mean, which is different from the others. The null and alternate hypotheses were represented as follows:

$$H_0: m_1 = m_2 = m_3$$

$$H_1: m_1 \neq m_2 \neq m_3$$



The mean scores of the three groups for the BDI-II, SDQ-III, SFSCS and the results of the Kruskal-Wallis test are summarised in Table 7.1 overleaf.

Table 7.1

*Differences between Mean Scores for the BDI-II, SDQ-III and SFSCS (Kruskal-Wallis test)*

Scale	Hysterectomy (N=16)		Mastectomy (N=8)		Vulvectomy N=4)		$\chi^2$	p
	Mean	SD	Mea	SD	Mean	SD		
BDI-II	19.25	13.49	6.25	4.65	17.50	9.03	7.29	0.026
SDQ-III			n					
SV/R	4.85	0.39	4.42	0.31	4.56	0.32	6.76	0.034
GE	4.67	0.31	4.26	0.20	4.45	0.14	8.84	0.012
OSPR	4.64	0.46	3.93	0.39	4.15	0.30	10.77	0.005
SSPR	4.93	0.47	4.52	0.48	4.45	0.23	5.74	0.057
PA	4.56	0.71	4.06	0.50	4.32	0.43	3.19	0.202
ES	4.87	0.42	4.75	0.37	4.65	0.19	1.59	0.450
SFSCS								
L	5.60	1.40	6.25	0.47	5.66	0.73	1.13	0.567
TA	6.05	0.72	5.97	0.65	6.00	0.49	0.22	0.893
P	4.93	0.96	4.80	0.77	3.67	0.55	6.44	0.040
V	4.51	1.37	3.45	0.95	4.33	1.25	4.03	0.133
G	5.05	1.41	5.37	0.81	4.600	0.90	1.56	0.458
M	6.56	0.53	6.56	0.28	6.70	0.28	0.84	0.656

*Note. The Facets of the SDQ-III are as Follows: SV/R = Spiritual Values/Religion; GE = General Esteem; OSPR = Opposite Sex Peer Relations; SSPR = Same Sex Peer Relations; PA = Physical Appearance and ES = Emotional Stability. Of the SFSCS: L = Likeability; TA = Task Accomplishment; P = Power; V = Vulnerability; G = Giftedness and M = Moral.*

Inspection of Table 7.1 shows significant differences between the three groups for the BDI-II,  $\chi^2 (2) = 7.299$ ,  $p = 0.026$ , the SDQ-III Spiritual Value s/Religion facet,  $\chi^2 (2) = 6.766$ ,  $p = 0.034$ , the SDQ-III General Esteem facet,  $\chi^2 (2) = 8.840$ ,  $p = 0.012$ , the SDQ-III Opposite Sex Peer Relations facet,  $\chi^2 (2) = 10.77$ ,  $p = 0.005$ , and the SFSCS Power facet,  $\chi^2 (2) = 6.66$ ,  $p = 0.040$ .

For the BDI-II, the Hysterectomy group obtained a higher score ( $\bar{X} = 19.25$ ), followed by the Vulvectomy group ( $\bar{X} = 17.50$ ) and lastly, the Mastectomy group ( $\bar{X} = 6.25$ ). For the

SDQ-III Spiritual Values/Religion facet, the Hysterectomy group obtained the higher score ( $\bar{X} = 4.85$ ), followed by the Vulvectomy group ( $\bar{X} = 4.56$ ) and lastly, the Mastectomy group ( $\bar{X} = 4.42$ ). For the SDQ-III General Esteem facet, the Hysterectomy group obtained the higher score ( $\bar{X} = 4.67$ ), followed by the Vulvectomy group ( $\bar{X} = 4.45$ ) and lastly, the Mastectomy group ( $\bar{X} = 4.26$ ).

In terms of the SDQ-III Opposite Sex Peer Relations facet, the Hysterectomy group obtained the higher score ( $\bar{X} = 4.64$ ), followed by the Vulvectomy group ( $\bar{X} = 4.15$ ), and lastly, the Mastectomy group ( $\bar{X} = 3.93$ ). For the SFSCS Power factor, the Hysterectomy group obtained the higher score ( $\bar{X} = 4.93$ ), followed by the Mastectomy group ( $\bar{X} = 4.80$ ), and lastly, the Vulvectomy group ( $\bar{X} = 3.67$ ).

### **7.2.1 Comparison of Importance and Accuracy for the SDQ-III**

The null hypotheses in each case was that no significant differences would be observed between the participants on each of the twelve Accuracy and Importance statements in terms of how important a particular statement was for the participants when compared to how accurate the same statement was thought to be of them. The alternate hypothesis was that differences between participants would be observed. The null and alternate hypotheses are represented below.

$$H_0: m_{Importance} = m_{Accuracy}$$

$$H_1: m_{Importance} \neq m_{Accuracy}$$

The results of the comparison of the Importance versus Accuracy facets of the SDQ-III reveal a significant difference in four body perceptual / self-concept focused statements and is represented in Table 7.2 overleaf. To ascertain whether differences exist in terms of the seven Importance versus Accuracy statements of the SDQ-III subsection, Wilcoxon Signed Ranks test was utilised as the nonparametric statistic. Additionally, the Spider Graph that follows Table 7.2 overleaf provides a graphical account of these areas of difference.

Table 7.2

*Comparison of Importance and Accuracy for the SDQ-III (Wilcoxon Signed Ranks Test)*

	N	Mean Rank	Sum of Ranks	Z	p
SDQ-III - Importance: Q1 - Negative Ranks	6	7.17	43.00	-1.861 <sup>a</sup>	0.063
SDQ-III - Accuracy: Q1 Positive Ranks	12	10.67	128.00		
Ties	10				
Total	28				
SDQ-III - Importance: Q1 - Negative Ranks	9	10.39	93.50	-2.094 <sup>a</sup>	0.036
SDQ-III - Accuracy: Q1 Positive Ranks	17	15.15	257.50		
Ties	2				
Total	28				
SDQ-III - Importance: Q2 - Negative Ranks	7	7.43	52.00	-4.57 <sup>a</sup>	0.648
SDQ-III - Accuracy: Q2 Positive Ranks	8	8.50	68.00		
Ties	13				
Total	28				
SDQ-III - Importance: Q3 - Negative Ranks	3	5.50	16.50	-1.495 <sup>a</sup>	0.135
SDQ-III - Accuracy: Q3 Positive Ranks	8	6.19	49.50		
Ties	17				
Total	28				
SDQ-III - Importance: Q4 - Negative Ranks	1	7.00	7.00	-3.315 <sup>a</sup>	0.001
SDQ-III - Accuracy: Q4 Positive Ranks	16	9.13	146.00		
Ties	11				
Total	28				
SDQ-III - Importance: Q5 - Negative Ranks	2	7.00	14.00	-3.286 <sup>a</sup>	0.001
SDQ-III - Accuracy: Q5 Positive Ranks	17	10.35	176.00		
Ties	9				
Total	28				
SDQ-III - Importance: Q6 - Negative Ranks	1	5.50	5.50	-2.081 <sup>a</sup>	0.037
SDQ-III - Accuracy: Q6 Positive Ranks	8	4.94	39.50		
Ties	19				
Total	28				

( $\alpha$  Based on Negative Ranks)

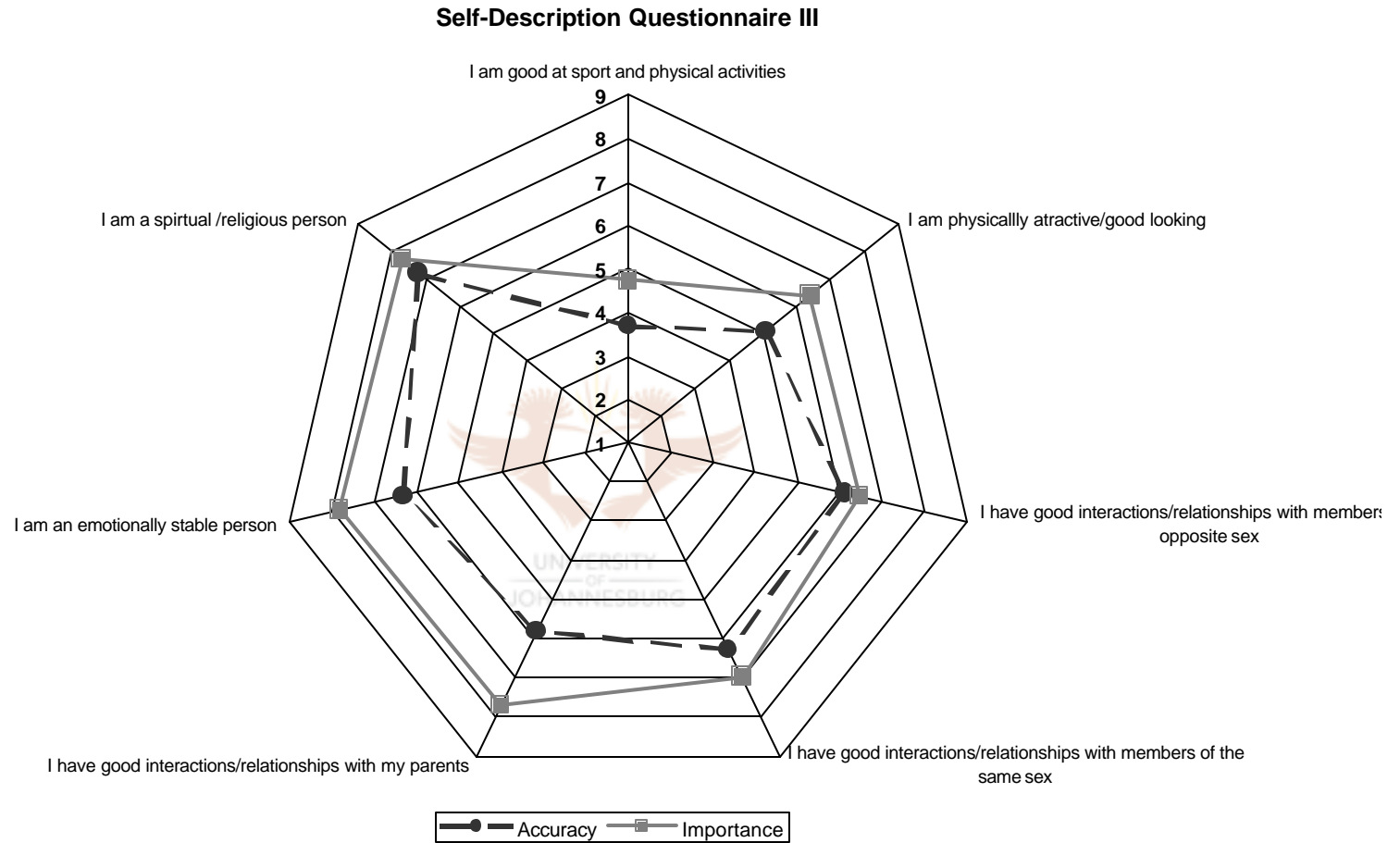


Figure 1. Spider Graph: Comparison of Importance and Accuracy for the SDQ-III (Wilcoxon Signed Ranks Test)

Statistically significant differences between Importance and Accuracy were observed for the following statements (see Table 7.2): Statement Q2,  $Z = -2.094$ ,  $p = 0.036$ , Statement Q5,  $Z = -3.315$ ,  $p = 0.001$ , Statement Q6,  $Z = -3.286$ ,  $p = 0.001$ , and Statement Q7,  $Z = -2.081$ ,  $p = 0.037$ .

Statements Q1 to Q7 are presented below:

SDQ-III - Q1: I am good at sport and physical activities : Importance > Accuracy

SDQ-III - Q2: I am physically attractive/good looking : Importance > Accuracy.

SDQ-III - Q3: I have good interactions/relations with members of the opposite sex:  
Importance > Accuracy.

SDQ-III - Q4: I have good interactions/relations with members of the same sex:  
Importance > Accuracy.

SDQ-III - Q5: I have good relations with my parents : Importance > Accuracy.

SDQ-III - Q6: I am an emotionally stable person : Importance > Accuracy.

SDQ-III - Q7: I am a spiritual/religious person : Importance > Accuracy.

The following paragraphs discuss the results of the study.

### 7.3 Discussion

There are many theories and viewpoints concerned with the process of psychological change. This study is concerned with the psychological and psychosocial impact of living with body disfigurement in the absence of illness.

### 7.4 The Self in a Constant State of Process

In terms of the constructivist orientation of change and the self, the person is made up of multiple selves (Wetherell, 1996) that combine to create an infinitely unique self (Mahoney, 1991). The individual can be seen as a system (Neimeyer, 1995), which is open, non-linear, and dynamic and is characterised by a dialectical interplay with the world. Consistent with the lifespan approach, the individual is ever-changing and adapting to internal and external demands (Hultsch & Deutsch, 1981). In dealing with the demands of life the person, as a dynamic system, is in a constant state of process (Butz, 1998).

The self constantly attempts to organise and reorganise its patterns of action and experience in relation to engagements with the world, and this necessarily entails psychological change (Mahoney, 1991). Change is thus endemic to human life, is ongoing, and occurs at both surface and deeper levels of being (Neimeyer, 1995).

This is most profound in illness associated body changes and when illness leaves the body in some way disfigured. This study has examined, in the broadest sense, disturbances in body perceptions as this is related to women who, in the absence of illness, continue to experience disturbances of self and of the body.

Worldwide, many common illnesses and diseases result in altered body appearance and function following necessary surgical intervention for disease eradication or life preservation. The gift of living disease or illness free following disfiguring surgery as a consequence of suffering a common ailment does not however, presuppose the absence of psychopathology. Investigating the psychological and psychosocial experiences in how this might relate to mood and body self-concept in women who, after having suffered a common ailment, live with body disfigurement of some kind, this study marks the beginning in terms of being able to contribute somewhat to the sparse volume of literature that give credence to their experiences.

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In the exploration of issues relating to mood and self-concept, this study undertook to investigate three groups of women who had undergone mastectomy, vulvectomy or hysterectomy and as such, represent women who, in the absence of illness, suffer varying degrees of body disfigurement and disfigurement visibility as this relates to the individual concerned and/or others. The following paragraphs explore this further.

#### ***7.4.1 Living with Cancer in the Absence of Cancer***

Interestingly, and although all participants who had undergone disfiguring surgery as a result of cancer were now cancer free, many continued to believe, at some level, that they were still ill. Of the 13 participants for whom cancer had been the result of their now living with altered body appearance and function, at least six lived in fear that their cancer might return. It is highly probable then that, even in the absence of cancer, many women continue to live life as if with the illness. Consequently, such beliefs might also serve to impact negatively on an individual's ability to adjust to body disfigurement and, in turn, body



disfigurement might serve as a constant reminder of cancer (Kriss & Kraemer, 1986). The results of this study add support to the findings of the authors 1986 study.

Similarly, with at least 21.4% of participants rating their health as satisfactory and 10.7% of the participants rating their health as fair (see section 6.5.2 of Chapter Six), the fear of illness returning might serve to distort ones current perception of wellness even in the absence of ill health. What does seem to impact at a cognitive level in terms of wellness is the ongoing receiving of chemotherapy once in remission in instances where cancer was diagnosed. Thus, in at least 46.1% of the participants of this study who were previously diagnosed as suffering from cancer (n = 13), six felt their remission period (anything between 6 months to 5 years) to be insufficient as a marker to full-recovery.

#### **7.4.2 *Levels of Depression***

Patterson and Craig (1963) posit that by virtue of the body's integrity being dependent upon external appearances, hysterectomy, as something internal to the body, fails to feature as a psychological difficulty experienced by women who have this. Contrary to their findings, a significant difference was observed in the hysterectomy group in terms of increased levels of depression when compared to both the mastectomy and vulvectomy groups. Interestingly, of the 16 hysterectomy participants, only one had received a cancer diagnosis and of which had been successfully treated eleven years previously.

It might thus be posited that, whilst the state of being physically attractive might refer more specifically to external parts of the body, body perceptions might very possibly include the internal self. In this way, this study supports the emotional element attached to the symbolic significance of the uterus in its association with the feminine identity (Bachmann, 1990; Kuny, 1984; LaLinec-Michaud & Engelsmann, as cited in Leiblum, 1990; Veith, 1965; Wolf, 1970).

#### **7.4.3 *The Spiritual/Religious Self***

Although one might consider to the contrary given the differences in levels of depression across the three groups, Spiritual/Religious Values appear higher among the hysterectomy group when compared to either the mastectomy and vulvectomy group. Although there do

not appear to be any methods of coping cited in studies on hysterectomy and vulvectomy, perhaps spiritual and religious values might be an important consideration.

Similarly, and although many coping strategies are cited in the literature on mastectomy from reconstructive surgery to social support networks, denial, stoic acceptance, tension reduction and the projection of blame (Gross, et al., 1996; Ivins, 2002), no mention could be found in the literature in terms of spirituality or ones religious affiliation in terms of forming part of the coping system. In that all mastectomy participants claimed to have a strong spiritual or religious affiliation, it is surprising that the mean of the mastectomy group in terms of these two variables is lower than both the hysterectomy and vulvectomy group.

In recognising the psychological impact of hysterectomy on body perceptual disturbances and disturbances in self-concept, identifying spiritual and religious factors as forming part of the overall healing process might be an important consideration for any therapeutic intervention.



#### **7.4.4 *General Esteem***

As might perhaps be expected, the General Esteem factor of the SDQ-III was significantly lower in the mastectomy group and highest in the hysterectomy group. This observation supports mastectomy studies that stress the importance attached to breasts in contributing to a woman's perceptions of self (Kuny, 1984) and the substantial psychological ramifications as many mastectomy patients mourn the loss of a body part (Schlebusch, as cited in Schlebusch & van Oers, 1999). The high score obtained by the hysterectomy group on this factor is surprising given that this group also exhibited increased levels of depression when compared to either the mastectomy or vulvectomy group. It is possible that the conflicting results are hormonally related and as such would require further investigative research.

#### **7.4.5 *Opposite Sex Peer Relations***

A significance difference was observed in the Opposite Sex Peer Relations (OSPR) facet of the SDQ-III in terms of the mastectomy group receiving a lower score overall when compared to either the hysterectomy or vulvectomy group (see Table 7.1). This observation is surprising given that, during interview discussions, all participants within the

mastectomy group claimed to share good relations with members of the opposite sex when compared to the participants of the hysterectomy and vulvectomy groups who rated their relations with members of the opposite sex between the ranges of good through to fair. Additionally, given the wide variation in terms of coping strategies utilised by individuals of mastectomy, the OSPR factor might be thought to be higher in this group, especially given that neither the hysterectomy or vulvectomy groups are noted to make use of coping mechanisms.

Although the results of this study do not reflect difficulties experienced in their engaging with members of the opposite sex, all participants to the hysterectomy group claimed to feel less attractive sexually and with a decreased sense of femininity. The extent to which hysterectomy, as a disfigurement internal to the body, negatively impacts a woman's body self-concept outside of hormonal and physiological influences is not clear from this study and thus requires further research with a much larger sample group than was here possible.

#### **7.4.6 *The Power Factor***

Although the null hypothesis was rejected in favour of the alternate hypothesis as this applies to the Power factor of the SFSCS, the significance value for this variable is not supported for the purpose of this study in that it is not considered to be representative of the mood or body self-concept constructs under investigation. None of the other factors of the SFSCS revealed any observable differences of significance.

#### **7.4.7 *Importance versus Accuracy***

Perhaps the most striking observation in this study concerns the responses aligned to the Importance versus Accuracy subsection of the SDQ-III. Remarkably, of the seven statements considered for use in this study, all three groups rated each of the seven statements as being more important to them than the statements were considered accurate of them. Significant differences were observed in terms of: Parent Relations, Spiritual/Religious Values and, of particular importance in terms of the focus of this study, Emotional Stability and Physical Appearance.

Although no mention is made to spiritual/religious values as forming part of the coping mechanisms utilised for either of the three groups, this factor does seem to feature as being significant in terms of how important this variable is to the participants.

Interestingly, no studies have yet been observed that research specifically the parental relationships and the impact of this as a deciding factor in the overall psychological and psychosocial well-being of disfigured individuals. Based on the observations of the Spider Graph, parent relations show the most significant difference in terms of this factor being more important to the participants, on average, than is actually experienced as being accurate of them.

## **7.5 Summary of Chapter**

This chapter presents and discusses the results of this study. The participant responses to the Biographical Questionnaire, BDI-II, SDQ-III and SFSCS are discussed.

In terms of the descriptive elements of the Biographical Questionnaire, the receiving of cancer as a diagnosis seems to remain a stress factor for many participants even when in remission. Importantly, fears that cancer might return could pose problematic in terms of ones ability to heal not only from cancer but also in ones ability to adjust to now having to live with body disfigurement.

In terms of the results obtained on the BDI-II scale, significant differences were observed in the mean BDI-II scores of the three groups with the mean score of the hysterectomy group observed as being significantly higher when compared to the mean scores obtained for the mastectomy and vulvectomy group. This observation suggests increased levels of depression in the hysterectomy group and which might be considered counter to studies claiming hysterectomy as insignificant in a woman's overall sense of physical attractiveness.

Notwithstanding the relationship between depressive symptoms and hormonal imbalance that oftentimes accompany hysterectomy, it is interesting to note that only one participant from this group underwent surgery as a consequence of cancer. Although a recent study by Kew, et al. (2002) report a negative relationship between gynaecological malignancy and a

woman's psychological well-being in terms of femininity and sexuality, this does not appear to be the case in this particular study.

Spiritual/Religious Values feature as an important variable for all participants. Interestingly, and although during interview discussions the mastectomy group seemed to draw strongly on this factor as a possible means of coping when compared to the other groups, the mean score for these variables were observed to be lower in the mastectomy group. Similarly, Spiritual/Religious Values were also observed to be extremely important to all three groups and yet was found to be significantly lower in terms of how accurate this factor was of the participants.

With regards to the General Esteem and Opposite Sex Peer Relations facets of the SDQ-III scale, the mean scores for both factors were observed as higher for the hysterectomy group and lower in terms of the mean scores for both facets between the three groups for the mastectomy participants. Coupled with the Spiritual/Religious Values, significant differences were also observed in terms of statements pertaining to Parent Relations, Emotional Stability and Physical Appearance as being more important to the participants than was thought accurate of them.

Although the only difference of significance in terms of the SFSCS was the Power factor, this was not considered to be a factor relevant to the constructs under investigation for this study and as such, could not be taken into cognisance.

As a final point to note, and although it is appreciated that many limitations exist in terms of the generalised nature of this study, all significant differences herein observed, were observed in individuals who live with body disfigurement in the absence of illness and after having suffered a common ailment.

Countless studies have shown a loss of femininity and the existence of self-perceptual disturbances, in one aspect or the other, to be the experience of women who undergo disfiguring surgery (Francis, 2002; Hamilton, 1999; Ivins, 2002; Schlebusch & van Oers, 1999). However, and despite the plethora of literature confirming body perceptual disturbances in women following disfiguring surgery, the focus of such studies is predominantly in the presence of illness rather than the absence of it.

Similarly, psychological and psychosocial disturbances in terms of the body self-concept following body disfigurement consequential to suffering a common illness is given practically no attention in research. As Newell (2000) points out, and as this study demonstrates, many difficulties in terms of body self-concept and self-concept in general, continue to persist in women who, in the absence of illness and through suffering a common ailment, live with body disfigurement of some kind.

The scarcity of such research might be thought a consequence of the frequency by which certain illnesses and diseases manifest and as such, the difficulties experienced by individuals living with body disfigurement following recovery from illness remain, according to Newell (2000), unexplored.

In taking heed of this, it is hoped that this study, at the very least, serves to draw the attention and interest of other researchers to this largely unexplored terrain and in so doing, gives voice to many silenced experiences and also creates an important and necessary public awareness and awareness at the level of the medical professionals in terms of the experiences of these women. It is from such undertakings that many therapeutic benefits can be derived in making available a more holistic approach in the overall management of women who live with body disfigurement in South Africa.

The ensuing chapter discusses the strengths and limitations of the study. Additionally, recommendations for future research are discussed. A final comment from the author concludes this paper.

## Chapter Eight

### Conclusion

*"Each to each a looking glass  
reflects the other that doth pass"*  
(Harter, 1996, p. 3).

#### 8.1 Evaluation of the Study

Although much research exists exploring body perceptual disturbances in disfigured individuals, the primary focus of such research is in the presence rather than the absence of illness. As Newell (2000) recognises, there exist many people who, in the absence of suffering any current illness, are faced with the difficulties and challenges of living with altered body appearance and function. Similarly, no studies could be found that investigate body perceptual disturbances in individuals who live with body disfigurement after having suffered a common ailment.

Although the reasons for this are not known, it might be suggested that the frequency with which certain ailments manifest serves to undermine any psychological difficulties individuals might experience. In terms of the levels of body disfigurement visibility either by the individual concerned or to others, Patterson and Craig (1963) reason that the integrity of the body is dependent upon external appearances and as such, anything internal to the body (e.g. hysterectomy) would fail to feature as a psychological difficulty experienced in women who have this.

In cognisance of the above, and wishing to challenge the convictions of Patterson and Craig, five motivations for the study were put forward (see section 6.1 of Chapter six). This then led to the formulation of three hypotheses that underscore this study, namely: (a) body perceptual disturbances exist in women who live with body disfigurement after having suffered a common ailment; (b) body perceptual disturbances persist in these women despite being cured of the common ailment; and (c) body perceptual disturbances exist in these women irrespective of the level of disfigurement visibility.

Developing on from this, the aim of this study was to compare depression and self-concept in three groups of women who, after having suffered a common ailment, live with varying degrees of body disfigurement visibility namely, women who have undergone mastectomy, hysterectomy or vulvectomy.

Investigation entailed comparing depression and self-concept in the three groups of participants; addressing levels of disfigurement visibility and commonality of illness in the selection of women who had undergone hysterectomy, mastectomy or vulvectomy; and ensuring all participants were free of illness at the time of investigation.

The implementation value of this study is arguably high. For example, in South Africa, there does not appear to be a measure of body self-concept. The need for and value of a psychometric measure of body self-concept was made most clear by this study. Similarly, the need for acknowledgement, guidance and direction, as will be described in booklet format during the course of the follow-up study, was also made clear during this pilot undertaking. Finally, the results of this study both highlighted and confirmed the need to integrate qualitative research with the quantitative research rubric. The integration of both qualitative and quantitative approaches are to be included in the follow-up study to this.

Investigating body self-concept and body disfigurement is complicated, formidable in terms of participant accessibility and a difficult research undertaking and as such, necessitated a pilot run. Consequently, this study enabled for invaluable insight to be gleaned in terms of the thoughts, feelings and struggles of these women prior to the main inquiry that follows on from this research. Similarly, orientation into the study was enabled as was a method of pre-testing and fine-tuning in preparation for Phase Two.

The role of the physical body in relation to a sense of self in individuals who, after having suffered a common illness, live with body disfigurement, is scarcely ascribed to in the literature. This study contributes by adding to this sparse volume of literature. It is hoped that this study serves to stimulate others to conduct similar research in a simple and pragmatic way. Consequently, the results of this study serves to add to the literature and help create an awareness of the therapeutic needs of these individuals.



## **8.2 Strengths of the Study**

### **8.2.1 *Orientation, Pre-Testing and Fine-Tuning***

Despite the many limitations of the study, this project is not without its strengths. The object of a pilot study was to enable the researcher to orient herself into the project and to provide a method of pre-testing prior to the second phase of this study. Additionally, this also provided for critical scrutiny of the methodology, sampling instruments and analysis as a means to determine effectiveness, adequacy and appropriateness in terms of the constructs under investigation. Similarly, the implementation of this pilot undertaking provided for the fine-tuning of the study prior to the main inquiry.

### **8.2.2 *The Strengthening of Future Endeavours***

In addition, the many difficulties encountered during the course of this project might not otherwise have been made available in the absence of an undertaking of this nature. Of equal importance, of the many obstacles anticipated as a consequence of the sensitive nature of the research and uniqueness of the area under investigation, there were many obstacles encountered that was not anticipated. This study has better equipped the researcher in her future endeavours in this line of research and from which the many valuable lessons gleaned will serve to inform future approaches to this field of study.

## **8.3 Limitations of the Study**

The study of body self-concept in women who, in the absence of illness, and as a consequence of having suffering from a common ailment, live with body disfigurement of some kind, is a relatively novel area of exploration. Coupled with the scarcity of literature in this field of enquiry as well as the sensitive nature of the constructs under investigation, embarking on this project was fraught with many obstacles that ultimately served to limit the study. The following paragraphs discuss this.

### ***8.3.1 The Limitations of Time***

Time was an extremely limiting factor in this project. The sensitive nature of this research undertaking and uniqueness in terms of the area of enquiry served to hamper important areas of data collection as this pertains to obtaining literature for review in the study and subject participation. Similarly, the lack of time available prevented the inclusion of qualitative input. Participant narratives from focus group discussions would have brought a richness and meaningfulness to this study in a manner that quantitative data cannot encapsulate.

The difficulties encountered at the level time proved to be tedious and laborious. Similarly, with each obstacle that would manifest, no time was available to re-visit and re-formulate areas of concern.

### ***8.3.2 Participant Dilemmas***

Obtaining participants for this study was a near impossible task. Countless efforts to obtain participants through mediums of media, medical specialists, medical institutions and snowball sampling proved to be futile in many instances. Additionally, in recognising the area of exploration as extremely sensitive and personal, the criteria for inclusion in the study was not as stringent as perhaps it should have been and that any participant who met the newly constructed broad criterion for inclusion in the study was accepted irrespective of the complexities that this might introduce.

Reducing the stringency of the selection criterion resulted in unequal numbers of participants for each of the three groups under investigation. Additionally, matching the participants in terms of age, age at diagnosis, length of time since recovery from illness, marital status and the like, was an arduous and invariably impossible task. Although, if given sufficient time, these variables might have been accounted for, the difficulties experienced in obtaining participants and the necessary leniency of the selection criterion for participation in the project most definitely served to detract from the richness and fullness of the study. Similarly, certain pertinent factors of the SFSCS, such as Likeability and Vulnerability, might have featured with statistical significance in terms of perceptions of self had it been possible to overcome the difficulties mentioned.

The third variable influences described above further served to complicate the results of this study. For example, 17.9% of the participants had undergone surgery more than eleven years previously. Although all women from this group experienced tremendous trauma post-operatively and following their recovery from illness, over the many years, many women had adapted coping strategies that detracted greatly from the severity of trauma experienced.

Similarly, 42.3% of participants were over the age of 56 years. It is possible that this group might feel more settled in life in being able to cope with or adapt to living with altered body appearance and function. The obstacle here is that many of the difficulties experienced by the younger participants might feature secondary as a consequence of this.

Additionally, the difficulties encountered in obtaining participants severely reduced any form of control that the researcher might have had in terms of which persons participated in the study. Coupled with the highly sensitive nature of this field of enquiry, it might be hypothesised that women who experienced difficulty adjusting in terms of living with body disfigurement of some kind, would be unlikely to participate in the study. In light of this, any adjustment levels across the three groups might not be representative of the norm. In this way, and notwithstanding the small sample size, any inferences that might be made to the larger population, was prevented.

### ***8.3.3 Healthy Matched Sample Comparison***

Although insufficient time available served as the primary source of preventing the inclusion of a healthy matched sample comparison group, the absence of this group limits the study considerably. Importantly, the inclusion of this sample would have better informed the study and made for more meaningful results.

### ***8.3.4 The Impact of Life Experiences***

The limited sample size and difficulties experienced in terms of obtaining participants made third variable influences extremely difficult to account for. In view of this, the follow-up study hopes to include a Life Experiences Survey Scale (LES), or the like, and which is an instrument developed to assess the impact of life changes.

The LES was designed to allow for the separate assessment of positive and negative life experiences, as well as individualised ratings of the impact of these events. In this way, the researcher is better able to control for the impact of other life events on body self-concept and body perceptual disturbances because it provides a means of determining those events experienced by the participants during the past year as well as, (a) whether the participant viewed the event as being positive or negative; and (b) the perceived impact of the particular event on their life at the time of occurrence (Sarason, Johnson & Siegal, 1978).

### **8.3.5 *Self-Concept Scales***

In distinguishing between body image and self-concept, body image is defined as an individual mental construct of the body (Schilder, 1935), whereas self-concept is related to an individual's most fundamental perceptions of self and as such, forms the essence of personality (Combs, et al., 1976). In this way, body image describes the mental picture one has of one's body whereas body self-concept, as a facet of general self-concept, refers to the probable causes underlying the reasons for the image one has of one's body.

Although many measures of body image exist, there seems to be a scarcity of measures to be found locally or internationally that measure specifically, body self-concept. Consequently, the selected self-concept scales did not adequately represent body self-concept as the construct under investigation. Perhaps it would have been more useful for this particular study to compare the results of all three groups with that of a healthy control group. However, and as has already been acknowledged, the time required for this was simply not available.

## **8.4 Recommendations for Future Research**

This study focused on the psychological and psychosocial aspects of mood and body self-concept in women who, in the absence of illness and as a consequence of suffering a common ailment, live with body disfigurement of some kind. Practically no studies exist that research specifically, body disfigurement in the absence of illness. This complex, yet emotionally charged and dynamic terrain is fraught with a magnitude of possibilities for future studies and which can take an infinite number of directions.

Future research in any area of body disfigurement in the absence of illness would serve to expand knowledge and understanding of all parties concerned (e.g. patient, family and friends, medical professionals, etc). Many disfigured individuals live in silence by virtue of their disfigurement being a consequence of common illness or disease. As Newell (2000) states, there exist many victims to the port wine stain who suffer tremendous psychological trauma. Investigations to this area are however limited in light of the frequency with which the port wine syndrome is experienced in treating medical institutions and also the fact that, although severely debilitating emotionally for many sufferers, the port wine syndrome is not considered a serious life-threatening illness worthy of study.

Despite the many limitations of this study, many valuable elements and important observations have been introduced and upon which any form of research that investigates the experiences of disfigured individuals in the absence of illness might build.

## **8.5 Final Comment**

This study was entered into on the conviction that many women who live with altered body appearance and function following trauma, continue to suffer disturbances in body perception years later and that this is so despite being illness free. The study's demonstration of this in real-life intervention serves to highlight such.

Additionally, on the basis of the results of this study and the fact that 92.3% of the participants felt the need to join or formulate support groups and engage in group therapy as a means by which to voice and better come to terms with past and current traumatic experiences encountered as a result of living with body disfigurement, the need for future research in the area of body disfigurement in the absence of illness, is strengthened.

Similarly, the plight of the participants for group therapy suggests that many continue to experience emotional difficulties in terms of self-concept and body perceptions. It is therefore probable that the difficulties experienced in obtaining more accurate measures of the body self-concept construct served to downplay body perceptual disturbances experienced.

Finally, this study provides some insights into the possible difficulties that future researchers in this field might encounter and as such, not only better equips the researcher

of this project in the experience of such insight but also better prepares future researchers. As Francis (2002) so aptly states, that with limited reference to the role of the physical body in relation to a sense of self when the body narrative is so rudely interrupted, many dilemmas associated with this sudden or unexpected interruption in the body narrative is largely, silenced.

It is hoped that, albeit in some small way, this study adds volume to the silenced experiences of women who, in the absence of illness and as a consequence of suffering a common ailment, continue to experience the effects of the body narrative interrupted. Similarly, this study hopes to provide the foundation from which many silenced experiences can be voiced.



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# APPENDIX

## A

### Biographical Questionnaire

The logo of the University of Johannesburg, featuring two stylized hands in a light orange color, palms facing each other, with a sunburst effect above them.

UNIVERSITY  
OF  
JOHANNESBURG

## Biographical Questionnaire

Dear Participant

The following six sections (A to F) contain questions concerning your personal details. These details are required in the process of data collection for this study and a means by which I might remain in contact with you during our time together. Please be assured that you will remain anonymous and your personal details confidential.

\*\*\*\*\*

### SECTION A: PERSONAL DETAILS

<b>Date of Assessment: (d/m/y):</b>							
<b>Full Name(s):</b>							
<b>Physical Address:</b>							
<b>City:</b>					<b>Postal Code:</b>		
<b>Postal Address:</b>							
<b>City:</b>					<b>Postal Code:</b>		
<b>Date of Birth: (d/m/y):</b>					<b>Age:</b>		
<b>Telephone: W.</b>				<b>H.</b>		<b>Cellular:</b>	
<b>Marital Status Mark with X</b>	<b>Single</b>	<b>Partner</b>	<b>Cohabiting</b>	<b>Married</b>	<b>Separated</b>	<b>Divorced</b>	<b>Widowed</b>
<b>Occupation:</b>				<b>Religious Affiliation:</b>			

### SECTION B: NUMBER OF CHILDREN

Please place an **X** against the appropriate answer:

**0 Children**      \_\_\_\_\_      **3 Children**      \_\_\_\_\_  
**1 Child**         \_\_\_\_\_      **4 Children**      \_\_\_\_\_



2 Children \_\_\_\_\_ More than 4 \_\_\_\_\_

### SECTION C: PARTICIPATORY GROUP

Please indicate to which group you are participating by marking the appropriate box with an **X**:

Hysterectomy		Mastectomy		Vulvectomy	
Simple	Complete	Unilateral	Bilateral	Simple	Radical

### SECTION D: PARTICULARS OF ILLNESS

1. Please state reasons for undergoing either: hysterectomy, mastectomy or vulvectomy.

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2. At what age were you diagnosed with this condition?

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3. At what age did you undergo the surgical procedure?

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4. If the surgical procedure was as a result of cancer, for how long have you been in remission?

---

5. In your opinion, are you cured of your illness?

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## SECTION E: CURRENT STATE OF HEALTH

1. Please rate your current state of health by marking the appropriate box with an **X**

<b>Excellent</b>	<b>Good</b>	<b>Satisfactory</b>	<b>Fair</b>	<b>Poor</b>
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2. Are you currently receiving any medical treatment?

 **YES**
 **NO**

3. If you answered 'yes' to question 2, please state the nature and reasons for treatment?

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4. Have you ever been diagnosed with depressive illness?

 **YES**
 **NO**

5. If you answered 'yes' to the question 4, please provide a brief overview.

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6. Are you currently undergoing psychotherapy?

 **YES**
 **NO**

7. If you are not undergoing psychotherapy currently, have you done so in the past?

YES

 NO

8. If you answered 'yes' to question 6 or 7, please provide a brief description of this.

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9. Should you wish to include any additional information that you feel has not been sufficiently discussed or that is not included in this questionnaire, please do so below.

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#### SECTION F: SUPPORT GROUP

1. In your opinion, do you feel a support group would have offered you some comfort in terms of your experiences of hysterectomy, mastectomy or vulvectomy?

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2. Do you feel a support group would be of benefit to you currently?

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3. A support group is to be formed in the beginning of the New Year (2004). This should take the form of group therapy and which is to be made available to all participants of this study. Please place a cross in the 'yes' box below should you wish to join.

YES

4. Should you not feel the need to join a support group of this kind, please would you state why you do not feel this to be necessary for you.

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5. Following the letter of introduction, please tick the yes box below if you would like to participate in Phase Two of this study (2004-2005).

 YES

6. Should you not wish to participate in Phase Two of this study, please would you state the reason for your decision as your response is extremely important to this study and future studies.

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The logo of the University of Johannesburg, featuring two stylized birds facing each other with a book between them, and the text "UNIVERSITY OF JOHANNESBURG" below.

**THANK YOU FOR YOUR PARTICIPATION**