

**THE PERCEPTIONS OF WOMEN WITH FIBROIDS FROM DIVERSE CULTURES
REGARDING HYSTERECTOMY**

by

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DECLARATION

I declare that "The Perceptions of Women with Fibroids from Diverse Cultures regarding Hysterectomy" is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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THE PERCEPTIONS OF WOMEN WITH FIBROIDS FROM DIVERSE CULTURES REGARDING HYSTERECTOMY

ABSTRACT

The purpose of this study was to explore and describe contributing factors that influence the perceptions of women with fibroids from diverse cultures regarding hysterectomy. The area of research was delimited to issues of hysterectomy among women with fibroid uterus.

The study employed a descriptive explorative method and data were collected by means of structured questionnaires. The study was conducted in one academic referral hospital, over a period of six months. The respondents were the patients with fibroid uterus and the doctors and nurses in the gynaecological units of the hospital. The majority of the patients indicated that they were afraid of undergoing a hysterectomy because of the social stigma associated with this life-saving procedure, such as alienation or marginalization by members of their respective communities. The nursing staff and gynaecologists in the unit emphasized the deep-seated fear of hysterectomy amongst women from diverse cultures.

The study found that women need information about their bodies and how they function. Health education is also needed for women and their communities. Research is needed amongst members of different communities and diverse cultures to voice their perceptions of women undergoing hysterectomy because of ill health.

KEY WORDS

CULTURE; FIBROID; HYSTERECTOMY; MYOMECTOMY; MULTI-DICIPLINARY TEAM; PERCEPTION; SEXUAL RELATION; TRADITIONAL; UTERUS; WOMEN.

DEFINITION OF KEY CONCEPTS

Confidentiality: The ability to maintain non-disclosure of information to any unauthorized persons. In this study, it refers to the binding agreement in principle between healthcare providers and their patients to withhold any patient-related details or information from any person without the prior knowledge of the patient concerned.

Culture: The beliefs, behaviour, lifestyle, language and entire way of life of a particular group of people at a particular time (Encarta Encyclopaedia Standard 2004; Tulloch 1993:348-349). In this study, reference is made to diverse cultural backgrounds of women with fibroid uterus.

Endometrial hyperplasia: The pre-cancerous changes of the inside lining of the womb (Crowe & Reider, 1998:663).

Endometriosis: The presence of the endometrium layer in an abnormal situation outside the uterus (Kasner & Tindall 1984:133).

Fibroid: Growth or benign tumour of muscular and fibrous tissues, one or more which may develop in the wall of the womb (Kasner & Tindall 1984:151; Tulloch 1993:550).

In this study, the presence of fibroids in the uterus is the issue around which the removal or non-removal of the uterus is perceived.

Hysterectomy: Surgical removal of the womb (Kasner & Tindall 1984:198; Tulloch 1993:736). Is linked to the presence of fibroids in the uterus, its acceptance or non-acceptance is also determined by the extent of the patient's understanding of the removal of the fibroid uterus.

Informed Consent: The agreement signed by the patient and the medical practitioner, to ensure that she understands the implications of a surgical procedure or any examination, after a thorough explanation has been offered by the healthcare providers (Burns & Grove 2001:196-206).

Malignancy: A growth which has the properties of invasion and metastatisation (Kasner & Tindal 1984:241).

Myomectomy: Surgical removal of fibroids, preserving the uterus (Walters 1998:117).

Multi-disciplinary team: A team whose members represent the widest possible spectrum of individuals and organizations concerned with, or involved in any aspect that has a bearing on the health and welfare of the community, in an attempt to provide effective comprehensive healthcare that will assist the achievement of optimal health for all people (Dennill, King & Swanepoel 1999:70).

Perception: The understanding, knowledge, and insight of an impression presented to senses (Kasner & Tindall 1984:294; Tulloch 1993:1129).

Sexual relation: Association based on sexual intimacy, intercourse, or lovemaking (Tulloch 1993:1417).

Spiritual: Of the realm of the innermost self (Tulloch 1993:1497). In this study reference is to spiritual healer.

Traditional: Customarily well known aspect of culture (Tulloch 1993:1654). In this study it refers mostly to a traditional healer.

Uterus: Womb (Kasner & Tindall 1984:408; Tulloch 1993:1735).The child-bearing organ inside the woman's body, in which fibroids manifest their presence.

Women: Adult human beings of the female gender (Tulloch 1993:1805-1806). In this study, emphasis is laid on the cultural variables under which women with fibroid uterus construct their understanding and perception of hysterectomy.

Structure and Organization of the Dissertation

Chapter 1: Overview of the research project

In this chapter, the broader outline of the research process and its methods and procedures of implementation are presented. Information obtained from primary and secondary sources have been integrated with the empirical domain in an attempt to construct a unified approach towards fulfilling the intended outcomes. The introductory remarks highlight characterisation of hysterectomy as surgical procedure for the severance of the pathological uterine wall or organ. Using the description provided by Crowe and Reider (1998:63) in which the authors state that the procedure is usually performed on women who manifest with malignancy; "severe" untreatable infections, bleeding, uterine complications during child birth including uterine rupture among other serious conditions that warrant emergency operation to save the women's lives. Elaborating on the causes, life-threatening conditions justify hysterectomy procedure to help preserve the life of the woman, relieve pain and discomfort. Furthermore this chapter includes all indications which are regarded as non-life threatening identified as endometrial hyperplasia, severe pelvic infections-not responding to antibiotics, extensive endometriosis involving other organs-causing excruciating pains, extensive large fibroid and prolapsed uterus which causes failure in functioning of nearby related organs e.g. bladder. The chapter proceeds to deal with other methodological aspects as well as providing relevant definitions of related terms and concepts among others significant orientation of the study requirements.

Chapter 2: Literature review

The literature review focused extensively on various themes pertaining to the environment and various conditions under which perceptions on hysterectomy are constructed. While different perception frameworks have been outlined, the cultural domain of the broader research problem has been presented as the pivotal point of departure shaping the narration logic of the study. The chapter critiques and analyses other scholars' previous work on the subject; describing their research findings on the perceptions of women with fibroid uterus from diverse cultures. Establishing what was previously discovered using relevant methodologies to reach conclusions, authors from different parts

of the world, including America, South Australia "mentioned that inadequate information or insufficient counselling of women undergoing hysterectomy must be alleviated and that a proposal was formulated for all nurses committed to counselling and health education to help clients or patients in the gynaecological units. Some studies in how women in South Australia raised concerns about not being adequately briefed on issues related to hysterectomy prior to operation by Le Cornu (1999:46-52).

Chapter 3: Conceptual framework

The primary objective of this chapter is to present a graphical representation of the conceptual environment that is associated with the construction of variable, but interconnected perception-inducing factors. Hysterectomy is presented as the pivotal variable around which all the other interconnected variables gravitate. The variables also have the collective effect of establishing and creating patterns or trends for understanding the construction of the different variables associated with the construction of perceptions. The chapter paraphrases specific patho-physiological issues as well as the physiological foundations so as to enable appreciation of health needs of women with uterine fibroids. Highlighting the need for in-depth information that is necessary for effective decision-making based on factual dissemination of simple and detailed explanations; explaining that it is critical that all cultural factors be taken into consideration so that pre-emptive measures are addressed especially when the woman faces life threatening conditions particularly in cases where an emergency operation is required or situations that demand hasty decisions. Women, who are quite bold and normally turned to take concrete steps in deciding to undergo hysterectomy, may usually refuse this radical, medical treatment because of cultural influences or factors within dire consequences for if explanations are not appropriate. The woman's refusal to have the uterus removed as a symbol of fertility is one such example, as a reproductive organ, or the misconception that it is intended to sustain youthfulness so as to ensure that regular menstrual flow- a sign of femininity is sustained. The report proceeds with an anecdote which is later substantiated that "Women often know best the pain and complications associated with keeping a uterus that may continue to exacerbate the deteriorating general health conditions. Despite this knowledge there are still constant refusals to undergo this medical, radical treatment, hysterectomy. Authorising the procedure was in the past the sole responsibility of the spouse".

Chapter 4: Research design and methodology

The chapter is basically an outline of the processes and procedures that were utilized in establishing a framework for the collection and presentation of data. Participant observational techniques, questionnaire administration, and interview scheduling have been the primary methods of instrumentation in the study. For the women as the core of the sample size, the probability sampling approach was opted for, in order that as many of them were included in a manner that is culturally representative. Ethical considerations are also outlined, considering that the respondents' engagement had to be considered in the context of both a human rights culture and professional healthcare conduct. Women of diverse culture, in Johannesburg Hospital's gynaecology ward 196, Gauteng Province in South Africa. Different categories of nurses enrolled and registered by SANC working in gynaecological wards and GOPD, in Johannesburg Hospital, for two years and above. Different categories of medical practitioners registered with SAMHC working in Johannesburg hospital gynaecological wards.

Chapter 5: Data presentation, analysis and interpretation

The presentation, analysis and interpretation of data were conducted in accordance with the integration of both qualitative and quantitative approaches. The three sampled categories of doctors, nurses, and the women with fibroid uterus. No respondents were externally sampled. In that regard, the gynaecological wards and GOPD section of the hospital became the main domain within which the research process unfolded. Some aspects of the questionnaire schedules had an 'overlap effect' in that points of similarities emerged from the responses of the three sample categories. Tables and figures in the chapter have been utilized as a graphic mechanism to create an intelligible framework for making meaning from the huge quantities of accumulated raw data.

The generated data; explains how the "...pre-analysis phase was conducted where coding of data, corrected inherent flows such as misreporting that might have cropped up in the Codebook. In addition; data qualify was scrutinised, elimination of existing bias and scanning existence of

supplementary data. Analysis is concurrently interpreted and the credibility of the research findings, as well as the meaning of the research findings, significance and whether these are generalisable or not.

Chapter 6: Conclusions, findings and recommendations

The main aim of the chapter is to establish a framework for the configuration of data into meaningful and practical application. The main conclusions arrived at necessarily translated into the findings which the study established. The recommendations themselves were largely drawn from the empirically-derived main conclusions/findings. The broader framework from which the recommendations are premised, applies reciprocally to both the healthcare providers/institutions, the direct recipients of healthcare services (women with fibroid uterus) and the indirect beneficiaries (immediate/extended family members, as well as the community as a whole). The inherent weaknesses in the study have been utilized as the terrain from which further studies in the multicultural environment of hysterectomy could be advanced.

The final chapter reflected on the details of the research process, reviewing whether the objectives of the investigation were achieved, describing the perceptions of women with fibroids from diverse cultures and eventually presenting relevant and implementable recommendations.

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Dedication

I dedicate this research report to all South African women

Chapter 1

An overview of the research project	1
1.1 INTRODUCTION	1
1.2 BACKGROUND OF THE RESEARCH PROBLEM	3
1.3 PROBLEM STATEMENT	4
1.4 RESEARCH QUESTION.....	5
1.5 PURPOSE OF THE STUDY.....	5
1.6 OBJECTIVES OF THE STUDY	6
1.7 SIGNIFICANCE OF THE STUDY	6
1.8 RESEARCH DESIGN AND RESEARCH METHODOLOGY	8
1.9 ETHICAL CONSIDERATIONS	9
1.9.1 Respondents' familiarity with the research	9
1.9.2 Permission from relevant healthcare authorities.....	10
1.9.3 Informed consent of respondents and participants.....	10
1.9.4 Privacy, confidentiality and anonymous participation	10
1.9.5 Withdrawal/termination from participation.....	11
1.10 SUMMARY	11
1.11 CONCLUSION.....	11

Chapter 2

Literature review	12
2.1 INTRODUCTION	12
2.2 FACTORS SHAPING PERCEPTIONS OF HYSTERECTOMY BY WOMEN WITH A FIBROID UTERUS.....	13
2.2.1 The psychological environment of perception construction	14
2.2.2 The physiological environment of perception construction	15
2.2.3 The socio-cultural environment of perception construction.....	18
2.2.4 The socio-economically induced environment of perception construction	19
2.2.5 Educational status and the construction of hysterectomy perceptions	20
2.2.6 The moral/ethical environment of perception construction	20
2.2.6.1 Consent for women to be treated after a diagnosis of the fibroid uterus	21
2.2.6.2 The professional obligation for professional conduct.....	22
2.2.6.3 Refusal of hospital treatment (RHT)	23

Table of contents	Page
2.3	TRAITS OF WOMEN WITH UTERINE FIBROIDS WHO HAVE UNDERGONE HYSTERECTOMY 26
2.3.1	Parity and the occurrence of fibroids 26
2.3.2	Race and the occurrence of fibroids 26
2.3.3	Age and the occurrence of fibroids 27
2.4	SUMMARY 28
2.5	CONCLUSION..... 28
Chapter 3	
Conceptual framework 30	
3.1	INTRODUCTION 30
3.2	THE INTERCONNECTED DOMAIN OF HYSTERECTOMY PERCEPTIONS 30
3.2.1	The psychologically-induced environment 32
3.2.2	The physiologically-induced environment 33
3.2.3	The culturally-induced environment 34
3.2.4	The socio-economically-induced environment..... 35
3.2.5	The educationally-induced environment 36
3.2.6	The morally-/ethically-induced environment 36
3.2.7	Traits as a conceptual factor..... 37
3.3	SUMMARY 38
3.4	CONCLUSION..... 38
Chapter 4	
Research design and methodology..... 39	
4.1	INTRODUCTION 39
4.2	RESEARCH DESIGN 39
4.2.1	Exploratory 40
4.2.2	Descriptive..... 40
4.2.3	Pilot study 40
4.3	RESEARCH METHODOLOGY 41
4.3.1	Development of the research instruments 41
4.3.2	The research setting and negotiated entry 42

Table of contents		Page
4.4	SAMPLING METHODS AND SAMPLING PROCEDURES	43
4.4.1	Population.....	43
4.4.2	The inclusion criteria.....	45
4.4.2.1	The nurses' inclusion criteria	45
4.4.2.2	The inclusion criteria for women patients	46
4.4.2.3	The inclusion criteria for doctors	47
4.4.3	Sampling procedures.....	47
4.4.3.1	Sampling of the women with fibroids	48
4.4.3.2	Sampling of the nurses.....	48
4.4.3.3	Sampling of the doctors.....	49
4.5	THE INTERVIEWS	50
4.5.1	Structured interviews with fibroid women patients.....	51
4.5.2	Structured interviews with medical practitioners.....	51
4.5.3	Structured interviews with nurses.....	52
4.6	DATA ANALYSIS	52
4.6.1	Process of analyzing	53
4.6.1.1	Qualitative data analysis.....	54
4.6.1.1.1	Validity.....	54
4.6.1.1.2	Reliability	56
4.6.1.1.3	Credibility.....	56
4.7	ETHICAL CONSIDERATIONS	57
4.7.1	Permission to conduct the study.....	57
4.7.2	Voluntary participation	58
4.7.3	No harm to participants	59
4.7.4	Anonymity.....	59
4.7.5	Confidentiality	59
4.7.6	Right to self-determination.....	59
4.8	SUMMARY	60
4.9	CONCLUSION.....	60

Chapter 5

Data presentation, analysis and interpretation		61
5.1	INTRODUCTION	61
5.2	DATA ANALYSIS	61

Table of contents		Page
5.2.1	Process of data analysis.....	62
5.2.2	Analysis of women with fibroid uterus' interview schedule	62
5.2.3	Demographic information.....	63
5.3	ANALYSIS OF NARRATIVE STATEMENTS	73
5.3.1	Thematic categories	74
5.3.2	Interpretation of patterns of narrative responses	75
5.3.2.1	Attitudes derived from narrative statements	76
5.4	ANALYSIS OF HEALTHCARE PRACTITIONERS' QUESTIONNAIRE	78
5.4.1	Analysis of medical practitioners' questionnaire	78
5.4.2	Analysis of nursing practitioners' questionnaire	81
5.4.2.1	Health education for women.....	81
5.4.2.2	Attitudinal differences between women who received pre- and post-operation education	83
5.4.2.3	Frequently asked questions about fibroids and hysterectomy.....	83
5.4.2.4	The responsibility of obtaining informed consent.....	84
5.4.2.5	Overview of nurse practitioners' views on fibroids and hysterectomy.....	85
5.5	SUMMARY	85
5.6	CONCLUSION.....	86
Chapter 6		
Conclusions, findings and recommendations.....		87
6.1	INTRODUCTION.....	87
6.2	FINDINGS	88
6.2.1	Objective 1.....	88
6.2.2	Objective 2.....	89
6.2.3	Objective 3.....	90
6.2.4	Objective 4.....	91
6.2.5	Objective 5.....	92
6.3	REHABILITATIVE PHASE.....	93
6.3.1	Pre-hysterectomy	93
6.3.2	Post-hysterectomy.....	94
6.4	LIMITATIONS OF THE STUDY.....	96
6.4.1	Nationality.....	96
6.4.2	Literature-based limitation	97

Table of contents		Page
6.5	RECOMMENDATIONS	97
6.5.1	Practice improvement in the provision of healthcare education.....	97
6.5.2	Formation of multi-disciplinary teams in the healthcare facilities	98
6.5.3	Involvement of the family	98
6.5.4	Mobile clinics for women	99
6.5.5	Conferences and seminars and initiation schools	99
6.6	FURTHER RESEARCH.....	99
6.7	SUMMARY	100
6.8	CONCLUSION.....	100
	BIBLIOGRAPHY	101

Table 4.1	Number of hysterectomies conducted in Ward 196: 2001-2005.....	42
Table 4.2	The sample range of research participants (N=92)	45
Table 4.3	The sample range of nurse participants (N=15)	46
Table 4.4	The sample range of participating female patients (N=55)	46
Table 4.5	Sample range of doctors (medical practitioners)	47
Table 5.1	Age distribution of respondents	63
Table 5.2	Respondents' educational level.....	64
Table 5.3	Marital status of patients.....	65
Table 5.4	The racial distribution of respondents.....	66
Table 5.5	Women with fibroid uterus' languages.....	67
Table 5.6	Respondents' employment status	68
Table 5.7	Respondents' religious affiliation	68
Table 5.8	Parity category of respondents.....	69
Table 5.9	Regional distribution of women with fibroids.....	70
Table 5.10	Medical history of women patients	71
Table 5.11	Gender distribution of all respondents.....	72
Table 5.12	Thematic categories of description	74
Table 5.13	Congruence of clinical manifestations of fibroid uterus	75
Table 5.14	Women's concerns during counseling.....	79
Table 5.15	Provision of knowledge on informed consent sufficient or not.....	80
Table 5.16	Provision of hysterectomy knowledge to women patients	82

Figure 2.1	Location of fibroids in the uterus	16
Figure 3.1	The conceptual environment of factors/trends that influence the acceptance and non-acceptance of hysterectomy.....	32
Figure 4.1	Total number of participants (N=92).....	44
Figure 4.2	Profile of sampled nurses.....	49
Figure 4.3	Profile of sampled doctors.....	50
Figure 5.1	Profiled distribution of respondents' marital status (N=52).....	65
Figure 5.2	Pie chart of patients' racial distribution (N=52).....	67
Figure 5.3	Gender of participants	73
Figure 6.1	Pre-hysterectomy issues.....	94
Figure 6.2	Post-hysterectomy issues	96

List of abbreviations

DOH	Department of Health
GHD	Gauteng Health Department
GOPD	Gynaecological Outpatient Department
LAVH	Laparoscopic assisted vaginal hysterectomy
RHRU	Reproductive health unit
RHT	Refused Hospital Treatment
RSA	Republic of South Africa
SAMHC	South African Medical Health Council
SANC	South African Nursing Council
TAH	Total abdominal hysterectomy
TOP	Termination of pregnancy
WHO	World Health Organization
UN	United Nations
USA	United States of America
UNISA	University of South Africa

List of annexures

- APPENDIX A Clearance Certificate from Unisa Health Studies Research and Ethics Committee
- APPENDIX B Letter of Permission from the Gauteng Department of Health
- APPENDIX C Letter of Consent from Johannesburg Hospital Medical Superintendent
- APPENDIX D Letter of Consent from Johannesburg Hospital Head of Obstetrics and Gynaecology
- APPENDIX E Explication of the Study
- APPENDIX F Informed Consent of Respondents
- APPENDIX G Informed Consent of Women Patients
- APPENDIX H Background Information of Fibroid Women Patients and questionnaires in eight Languages: English, Tshivenda, Afrikaans, Sizulu, Sepedi; Xitsonga, Isixhoza, Setswana
- APPENDIX I Questionnaire for Nurses
- APPENDIX J Questionnaire for Doctors

CHAPTER 1

An overview of the research project

1.1 INTRODUCTION

Women from diverse cultural backgrounds have been afflicted by the painful condition of the fibroid uterus over a considerable period of time. Hysterectomy has been found to be the most effective treatment for this condition. Crowe and Reider (1998:663) define hysterectomy as "... the surgical removal of the uterus". According to these two authors, the hysterectomy procedure is performed on women with malignancy, 'severe' uncontrolled infections and bleeding, uterine complications during childbirth including rupture. These conditions are regarded as life-threatening and the hysterectomy procedure is done to preserve the lives of the women, relieving them of the pain and discomfort.

Other indications which are regarded as non-life threatening for hysterectomy are endometrial hyperplasia, severe pelvic infections not responding to antibiotics, extensive endometriosis involving other organs and causing excruciating pain, extensive large fibroids, tumours and uterine prolapse which causes failure in the functioning of nearby related organs such as the bladder. Alternative methods can be used to treat the non-life threatening conditions (Crowe & Reider 1998:663).

Despite the prevalence of a variety of treatment approaches, some degree of their non-acceptance has been found to exist. This observation constitutes one of the objectives of this research project; namely, the exploration of factors contributing to the women's reluctance to undergo this seemingly life-saving procedure. Cultural factors have been identified as having an impact on the extent to which hysterectomy is accepted or rejected as a form of treatment. For the study to maintain a maximum degree of fulfilling both its objectives and efficacy, it then became imperative to explore the cultural factors associated with the denial, rejection or refusal by women with fibroid uterus to undergo the hysterectomy procedure.

The women's refusal to undergo hysterectomy through the signing of RHT form is an indication of a larger unresolved societal issue that has probably not received adequate

research attention before. The statement of the research problem attempts to relate the societal affinity to the problem by demonstrating the behaviour and attitude of a particular woman who refused to undergo the surgical procedure, largely as a consequence of a lack of information and knowledge, on the subject of hysterectomy as a medically appropriate resolution of the problem of the uterus condition, as indicated in the statement of the research problem.

The need to investigate the refusal dynamic was prompted by the researcher's encounters and experience of more than a decade, with a substantial number of women with fibroids in the gynaecological wards at the hospital refusing to sign the informed consent form for hysterectomy. The consent form is a written agreement that the woman consented to hysterectomy being performed on her on account of the fibroid uterus. Despite the detailed explanation for the justification of hysterectomy, refusal by women prompted the research to be done.

It is expected that women with fibroids would receive morale-uplifting support – spiritually, psychologically, physically, socially and financially – from their next-of-kin. Instead, some women are overcome by external pressures that prevent them to make independent decisions on their own regarding the acceptance or refusal of hysterectomy. In many instances, they wait for their spouses, husbands, parents, in-laws and community members – including religious leaders, to come to the hospital and offer their opinions. In another instance, one particular woman patient was 'advised' by her family to sign the RHT form. The family members recommended the preferred services of a traditional healer. The pressures exerted is such that in many instances the women with fibroid uterus succumb rather than face the psycho-social and cultural consequences of refusing to take heed of the 'counsel' offered.

It would seem that in some South African cultural contexts, women apparently have to conform to the pressures of their own environment; including such private and personal issues as the right to decide about their own bodies. Such a state of affairs is a stark contradiction to the spirit of the Bill of Rights, as entrenched in the Republic of South Africa (RSA) Constitution (South Africa (Republic) 1996:6-24). In spite of the prevalence of such noble constitutional ideals, the violation of women's rights in general is seemingly an extant phenomenon. The study's intentions is to determine whether or not demeaning circumstances other than those culturally-induced – such as lack of self-

esteem and lack of knowledge or ignorance – account for the decision to accept or reject the surgical removal of a fibroid uterus.

1.2 BACKGROUND OF THE RESEARCH PROBLEM

In South Africa, many women conform to the cultural pressure of their own environment in deciding about their bodies, despite their rights stipulated in the *Act 92 of 1996* (South Africa (Republic) 1996:6-7). Is this lack of self-esteem due to ignorance or a lack of knowledge?

This raised the following questions for the researcher:

- What is the extent of refusal of this life-saving procedure (hysterectomy) amongst women?
- What are the exact reasons for the refusal of hysterectomy from women of diverse cultures?
- Is quality counselling available to women diagnosed with fibroids and do health care providers advise them in favour of hysterectomy?
- Are health care providers well informed for the purpose of educating women with a fibroid uterus?

The researcher's more than a decade years' involvement in a gynaecological unit with women from different cultures who declined to sign informed consent to undergo a hysterectomy, in spite of a detailed explanation of and justification for the procedure, prompted her of the need to investigate this phenomenon. In addition, the researcher assumed that cultural factors contributed to the women's denial of the need for a hysterectomy. In some African cultures, the women who signed the RHT were advised by their families to go to traditional healers. Some women are unable to make decisions on their own and wait for their spouses, partners, parents, in-laws and communities, including religious leaders, to make decisions for them. These people are supposed to give moral support: spiritually, psychologically, physically, socially and financially to these women. Many women, then, sign RHT because of the consequent psychosocial-cultural effects if they act against their own people's advice and customs.

While providing care to patients, the researcher was deeply concerned because many patients with fibroid uterus refused to have a hysterectomy out of fear of: - social exclusion or isolation, loss of their womanhood, losing of their partners, and fear of losing their lives, should something go wrong during or after the operation (hysterectomy). Another important reason in the African context is fear of losing their marriage. Many women do not care about their lives, but care for their psychosocial-cultural relationship and thereby neglect their physical aspect. Women fail to realize that a person is healthy, when holistically well. That is when the psychological, spiritual, financial, sociological and physical (the body), aspects of their lives are well.

The researcher was motivated to explore this topic in order to gain insight into and understand the women's fears, the origin and impact of their fear, and how to alleviate the fear of hysterectomy.

1.3 PROBLEM STATEMENT

The number of women suffering from fibroid uteruses is increasing, rather than decreasing (Ward 196 Registers of 2001-2005) (see table 4.1). Among culturally-steeped and consecutive communities, these numbers are prone to increasing even more unabatedly. In South Africa, legal and health regulatory mechanisms have been instituted to safeguard and promote women's issues in general, and their health needs in particular. Their autonomous right to determining how their bodies are to be treated is to be respected. Despite many legal and regulatory instruments locally, women's rights in general continue to be violated. In specific instances, "culture" has been presented as the wherewithal in 'defining' the role and 'place' of women in society. The statement by one of the research participants is reflective of how some women actually believe their condition as being "natural": "I do not want to be useless in life by removing my womb". It is clear that usefulness in life is the primary function of an un-removed womb – even if its removal would alleviate further pain and other potentially life-threatening symptoms. The mindset already created here is that "woman-hood" is determined only by the child-bearing function.

The research problem and its statement in this context are multifaceted. In a legal context, it is not an understatement to declare that any action depriving women of their rights is unconstitutional and illegal, therefore criminal. That is to say, denying women of the right to determine how their bodies are to be treated would be tantamount to

oppression and discriminatory (South Africa (Republic) 1996:6-24). The people who preside over some "cultural" issues and lay claim to a "naturalistic" perspective of leadership, determine for themselves how their own bodies are used and treated. In a broad context then, the problem transcends issues relating to hysterectomy, it is about women's rights in the context of a culture of human rights. In a specific context, the problem relates to the effects of cultural stereotyping in the understanding of hysterectomy as a treatment for women suffering from the fibroid uterine condition. The problem statement, relates to factors associated with the refusal by women with fibroid from diverse cultural backgrounds to undergo hysterectomy.

1.4 RESEARCH QUESTION

The broader premises of the study – as outlined in more detail in the research background and the research statement – is located in the acceptance and rejection domains of hysterectomy. The following question was selected on relation to the acceptance-rejection domain of hysterectomy as a treatment for the fibroid uterus:

Why do women of different cultures not want to be operated on when diagnosed with a fibroid uterus?

1.5 PURPOSE OF THE STUDY

The purpose of the study refers to a broad statement of what the researcher intends to investigate systematically, in order to improve a particular area of practice or life (Ehlers 1998:2, 4, 8; University of South Africa 2005:23-24). The healthcare sector is the particular area of practice within which the study and its practical applicability are located (Brink & Wood 1998:7-8).

The purpose of this study is to explore and describe the perceptions of hysterectomy of women from diverse cultures with fibroids. The study also examined contributing factors that influenced the women's perceptions of hysterectomy, amongst women with fibroid uterus.

1.6 OBJECTIVES OF THE STUDY

The objectives of this study refer to the specific/narrower statements of intentions and goals to be attained at the end of the entire research process (Huberman & Miles 1998:180-182). The study wished to explore the reasons for the reluctance to undergo the life-saving procedure of hysterectomy for women with uterine fibroids, including cultural factors associated with denial or refusal of the operation. Women's refusal or signing of the RHT form indicated a bigger, unresolved issue or problem.

The objective was to investigate and determine why women of different cultures did not want to be operated on when diagnosed with uterine fibroids. Located within the research problem and its background, the objectives of the study were constructed as follows:

- Why women from different cultures diagnosed with a fibroid uterus were reluctant to be treated and did not go for medical consultation even though the abdominal enlargement was not pregnancy related.
- Why women who bleed profusely do not seek medical advice.
- Why is it difficult for women to accept their condition and seek medical intervention instead of "shop around" for alternative treatment when diagnosed positively of fibroid uterus.
- What perceptions of hysterectomy instilled fear of the operation in these women.
- Why women avoided discussing treatment with their husbands or partners.

1.7 SIGNIFICANCE OF THE STUDY

The significance of the study relates to the practical implications which the study will have on society and the corpus of knowledge (in the specific field of hysterectomy) (Mouton 2001; University of South Africa 2005:23).

In the broader societal context, the study's utility is envisaged to provide a frame of reference against which some culturally stagnant views are challenged. Concerns that led to the researcher's reflection on what exactly has to do with the rising of statistics of the refusal to undergo hysterectomy by some women, is linked to the problem of maternal morbidity concerning fibroids and its complications in South Africa. For instance, it would be highly abnormal for fibroid women to die (on suspicions of 'witchcraft', curable by traditional means) when tried-and-tested surgical interventions

are medically available. In this realm, the study is valuable for helping particularly culturally-steeped societies to reconfigure some aspects of their references to current realities; that is, separate fact from fiction and myth. In other words, the study's orientation is that of the realignment (as opposed to extinction) of some frames of reference to current realities – such as the promotion of women's rights as fellow citizens in a democracy.

In the specific and scientific context, the study and its findings are expected to contribute to the body of knowledge in the field of hysterectomy and its dynamic relations to culture and human rights. The results of the study will enlighten healthcare providers on the basis of empirically-derived knowledge; especially that research in this particular mode of enquiry among patients suffering from the fibroid uterus is not expansive. The healthcare providers are envisaged to benefit from the findings, which will broaden their understanding of the different cultures of their patients. The information will additionally provide further understanding on the pathology of the women's condition, thus enabling the healthcare sector to provide balanced and multidisciplinary treatment options through meaningful counselling and informed consent; taking into cognisance the culturally diverse backgrounds of the women.

By contributing to the increase of knowledge in the provision of healthcare, the study necessarily advocates for the rendition of quality services to healthcare clients. Well-informed and competent to make informed decisions, women with fibroid uterus could become agents of educating their spouses, families, and communities on the benefits of the surgical removal of a fibroid uterus. The available literature reflects some missing information of women's perceptions of hysterectomy. The study is then significant in addressing that gap (University of South Africa 2005:18-20).

In 1994 for instance, Mwaba and Letloenyana conducted a study concerning attitudes and knowledge amongst women who were to undergo hysterectomy in Bophutatswana homeland. Many of the women participants in the study showed ignorance concerning their reproductive health (Mwaba & Letloenyana 1994:2-3). However, they still expressed willingness to engage in extensive knowledge relating to reproductive health. This surely points to the need for thorough and extensive research to be conducted and for the results of such a study to be effectively communicated to women, especially that category of women for whom the fibroid uterus is a serious health problem.

1.8 RESEARCH DESIGN AND RESEARCH METHODOLOGY

A descriptive explorative method was used. The study was conducted in one academic referral hospital, over a period of six months. The researcher used structured interviews to collect data from patients, nurses and medical doctors.

The study is qualitative in its orientation to addressing the stated problem and achieving the desired objectives. The research design *relates* to the broader 'plan' of how the study was conducted; while the research methodology relates to the specific instrumentation used in the collection of data (Mouton 2001:55).

To the extent that the study is qualitative in its focus, the processes and methods of achieving the intended outcomes are descriptive, exploratory, and participatory. Notwithstanding the numerically measurable and defined aspects, the qualitative constructed aspects enable an in-depth interpretation and analysis of every step of the research (Adler & Adler 1998). The most essential aspect of the descriptive process has been the focus of the hospitalized women with fibroid uterus. While the researcher acted as an observer, the women from various cultural backgrounds and influences acted as "first-hand" narrators of their own cultural experiences and individual perceptions of hysterectomy. Their involvement actuated a process of participation in the research process itself, an element deemed crucial in defining an aspect of the findings. The design of the research and its methods of enquiry facilitated a triangulated approach for both data collection and authentication of the findings (Polit & Hungler 1999).

Participant observation, questionnaires, and interviews constituted the primary methods by which the research data as its primary point of reference. The women suffering from the fibroid uterus condition were interviewed in a hospital setting, with little intervention from external pressures, such as those forms of pressure exerted by either family or members of society. The triangulation of both data collection and methods of enquiry then, provided a point of departure on whose basis the validity, reliability, and credibility of the findings could be established (Polit, Beck & Hungler 2001:302-304).

1.9 ETHICAL CONSIDERATIONS

The right to fair treatment of respondents and participants constituted the pivotal tenet of ethical considerations in the research process (Polit & Hungler 1999:136-138). The nature of hysterectomy – as the primary unit of study in the research – warrants that a multiple approach to ethical considerations be applied. The fact that hysterectomy is a medical condition, necessitated that health- and medically-appropriate standards of behaviour/practice be taken into serious consideration by the researcher. The argument of undue pressure having to be eliminated from the women’s capacity to decide independently – conflates the women’s perceptions of hysterectomy as a tenet in the broader terrain of both feminism and women’s rights in the context of human rights. While a broad range of ethical considerations do exist, the following considerations could not be overlooked (see Appendices E and F).

1.9.1 Respondents’ familiarity with the research

For the study to obtain maximum approval and cooperation from the respondents/participants, it was very critical that the purpose of the study be explained to them. It was also necessary that they be informed what their involvement in the study entailed; that is, how the results will be used. No aspect of the research was hidden, as this would generate a great degree of mistrust. Accountability and transparency were the guiding principles in ensuring that the respondents were familiar with the purpose of the study, and the use of its findings. By easing all of the respondents’ concerns, the researcher was at the same time ensuring that the principles of freedom from harm and exploitation were applied (Polit et al 2001) (see Appendices E, F and G).

1.9.2 Permission from relevant healthcare authorities

The study was conducted at research sites under the jurisdiction of the Gauteng Health Department (GHD). Relevant permission was sought from, and granted by the GHD. The Superintendent of the hospital was contacted for approval. Both the GHD and the Superintendent ensured that the research did not violate any of the provincial and national healthcare statutes, as well as the patients’ rights.

1.9.3 Informed consent of respondents and participants

While the study involved a broad range of participants, women with fibroid uterus, nursing and medical healthcare practitioners in the gynaecological wards, the women with fibroid constituted a constituency whose responses would inform on their perceptions of hysterectomy. It was ensured that all the facets of the research were made known to them in a very transparent manner. The main purpose was to obtain their informed consent, which would underline their understanding of their voluntary involvement in the research process. The informed consent of respondents and participants constitutes a significant aspect of the respect for human dignity. This enabled the respondents to be accorded the right to voluntarily make autonomous decisions -whether or not they want to undergo hysterectomy, and be entitled to full disclosure of the consequences of participation in the study (Polit & Hungler 1999:134-136).

1.9.4 Privacy, confidentiality and anonymous participation

Considering that the women with fibroid uterus were faced with external pressures from spouses/husbands, family and other community members, it was necessary that the interviews and questionnaire administration sessions be held in the privacy and confines of the hospital. They were also not required to indicate their names in any manner during the implementation of the research instrumentation. The same was also extended to other participants outside of this category. All participants were guaranteed in the informed consent form that their privacy and anonymity would not be made unknown to any unauthorized person. By ensuring the privacy, confidentiality and anonymous participation of all the participants, justice was also being instituted (Polit & Hungler 1999:139).

1.9.5 Withdrawal/termination from participation

The human rights culture (in which individuals have the freedom and the right to decide and choose for themselves without undue external pressures) the rights of the women with fibroid uterus are protected, irrespective of such variables as race, gender, socio-economic origins, creed or ethnicity. That is why the respondents were informed of their right to withdraw or terminate their participation at any stage of the research process, when they felt that their rights as human beings, as women, were violated by either the study itself or the researcher.

1.10 SUMMARY

In this chapter, an overview of the research project has been presented. The aspects of the overview gravitated on how the research process was expected to unfold. The empirical domain of the study is viewed here as presenting the relevance and meaningfulness of hysterectomy in both the narrower (contribution to the body of knowledge) and broader socio-cultural contexts. The nature of the problem being investigated the perceptions of women with fibroid regarding hysterectomy in their diverse culture necessitated that ethical considerations be reined-in to reflect the legalistic , medical, and health environments within which “rights” are viewed.

1.11 CONCLUSION

This section described how the hysterectomy procedure is performed on women whose condition has manifested with malignancy, severe uncontrolled infections, bleeding and uterine complications during childbirth including uterine rupture. These conditions are regarded as life-threatening and the hysterectomy procedure is conducted to preserve the lives of the women with fibroid uterus, as well as relieving them of the incessant pain and discomfort that they may continue to experience. The next chapter will deal with the practical and conceptual review of relevant literature.

CHAPTER 2

Literature review

2.1 INTRODUCTION

The main purpose of literature review is to explore what other scholars have contributed in a particular field of study, including the methods and instrumentation of research (Mouton 2001:86-87). The author differentiates between “literature review” and “scholarship review”.

Literature review is essentially concerned with the compilation of the accumulated body of literature on a particular research topic. Literature review is ‘quantified’ by the number of consulted sources appearing in the list of references or bibliography of a study. The above author argues for the usage of “scholarship review” since it collates with “research” on any particular field of study. The review of scholarship is then more thematically-focused, emphasizing on the quality of the contribution to knowledge by other scholars. It is not merely concerned with the listing of consulted sources (Mouton 2001:86-87).

The focus adopted here, is one in which the accumulated body of literature is thematically constructed to determine the extent of its contribution to what is already known in the research field (perceptions of women with fibroid uterus regarding hysterectomy), and how this knowledge will further provide new insights (Mouton 2001:86-87; Polit & Hungler 1999:78) in the understanding and treatment of this disease against the backdrop of “culture” and “rights” as integral variables. The following themes have been derived from the accumulated body of literature based on what other scholars in the field of fibroid uterus and hysterectomy have contributed.

2.2 FACTORS SHAPING PERCEPTIONS OF HYSTERECTOMY BY WOMEN WITH FIBROID UTERUS

Perceptions are mental frames of reference that could be based on either founded or unfounded statements, a real or imagined state of affairs. On their own, perceptions could wittingly or unwittingly create the basis for a reality. The psychological, physiological, socio-cultural, and socio-economic domains have created an environment within which women with fibroid uterus have constructed their perceptions of hysterectomy.

The phenomenon of women with fibroid uterus is worldwide, and is not only confined to South Africa's culturally-diverse population. The main differences between and among societies could be located within the extent to which the respective societies' culturally-defined norms and values are adaptive to modern conditions and circumstances. Many scholars and academic commentators have argued that while the new world economic order is reconfiguring the planet into a "global village", it is not yet conceivable to have a homogenous world culture (Teasdale & MaRhea 2000).

In 1997, the American population regarded the presence of fibroid as the most common indication for the need to undergo hysterectomy (Farquhar & Steiner 2002:234; Walters 1998:113). Le Cornu (1999:46-52) mentions that in South Australia, a proposal was formulated by healthcare authorities for all nurses committed to counseling and health education to help clients or patients in the gynaecological units, understand the importance of relevant information and knowledge. Some women in South Australia had apparently complained and raised concerns that they were not adequately and sufficiently briefed on issues relating to hysterectomy before any operation was conducted on them, and that information on hysterectomy was less discussed. These two examples indicate that inadequate information and insufficient pre-counseling of women undergoing hysterectomy are issues necessitating immediate interventions.

The United Nations-sponsored Beijing Women's Conference held in September 1985 provided clarity on policy issues in relation to women's health. It was emphasized that for developmental politics, decision-making and international cooperation to reach the desired goal for world peace; there is a need for women to be at the peak of their health, be equipped with knowledge through their assertiveness, being keen to be

taught and to learn. (Dennill, King & Swanepoel 1999:184-185). Hence, the need for women to be well informed in every aspect of their society.

The Patients' Rights Charter of 1994 empowers women to have direct participation in any final decisions relating to their health and their bodies. Expert and second opinions are still valuable insofar as they provide professional guidelines and suggestions, before the patients embark on some irreversible decisions relating to their cure. Women should be allowed to choose health care providers or a particular facility for treatment and a right to be informed (South Africa (Republic) 1996:13).

2.2.1 The psychological environment of perception construction

Le Cornu's comment about the prevalence of insufficient and inadequate hysterectomy information/knowledge and pre-counseling of women, in South Australia, prior to the performance of the surgical procedure, consequently engendered fear and myths among women, who mistook idle talk for authentic information/knowledge in their respective communities. Women's decision-making regarding hysterectomy depends also on the information they had gathered from skilful and knowledgeable healthcare providers (Linderberg & Nolan 2001:603-616). The continued prevalence of fear and uncertainty is a condition that propels psychological and sexual instability (Azadeh-Ghamsari, Gill, Moerdyk, Oberleitner & Rademeyer 2002). The author observed how these women were psychologically affected and traumatized by the lack of prior information and pre-counseling, which could have stood them in good stead during their periods of fibroid suffering. Prolific forms of intervention in this regard would require that a balance be struck between quality health education and the provision of comprehensive counseling services (Azadeh-Ghamson et al 2002:).

The psychological impact of hysterectomy remains a contentious issue (Kuny 1984:35-39). For instance, in their 1940–1960 research report, Nolan and Mock (2000:156) reflected that compared to any other form of surgical procedure, women who underwent hysterectomy showed signs of post-surgical depression. Other studies contended that there was no evidence of post-hysterectomy psychological trauma; while findings in some other studies reported that such experiences of depression were largely due to the denial of intolerable feelings of the impending loss of the uterus.

The results of research conducted in 2001 indicated that a vast majority of women were mentally, physically and socially relieved of the unpleasant symptoms they had experienced as a result of uterine difficulties. The purpose of the study was to find out if physiological and psycho-social symptoms in women who were suffering from gynaecological disorders – including the fibroid uterus – were alleviated through the implementation of hysterectomy. Furthermore, these women were free from the pressure of the community's alienation due to the myth allotted to women's monthly menstruation, the fear of pregnancy, and the possibility of developing cancer of the uterus (Cabot 1990:179-182; Rannestad, Eikland, Helland & Qvarnstrom 2001:579-587).

It is evident that while there are divergent viewpoints on the psychological impact of hysterectomy on fibroid women. Availability of knowledge (health education) on hysterectomy is an indispensable component of any intervention strategy intended to alleviate the pain and suffering of many women; irrespective of their socio-economic, cultural, and other material considerations. Insufficient availability of knowledge about hysterectomy and its diagnosis affected women's psychological acumen and capacity for autonomy, both of which should be maintained and respected for any patient expected to sign consent for health care provision (Walters 1998:203-205).

2.2.2 The physiological environment of perception construction

Women who underwent hysterectomy are still vulnerable to risk of post-surgical physiological complications, including infection, thrombo-embolic diseases, haemorrhage, urinary tract infection, bladder injuries, as well as wound dehiscence (Nolan & Mock 2000:167). These physiological forms of discomfort indicate some of the reasons that make or enforce the women of diverse cultures to avoid hysterectomy, or be doubtful of its efficacy. Despite the abundance of pre-surgical counseling, fear of the unknown – that something may go wrong during the operation – and the possibility of complications mentioned above, some women steadfastly refuse to undergo the hysterectomy operation. The following diagrammatic representation shows the location of fibroids in the uterus.

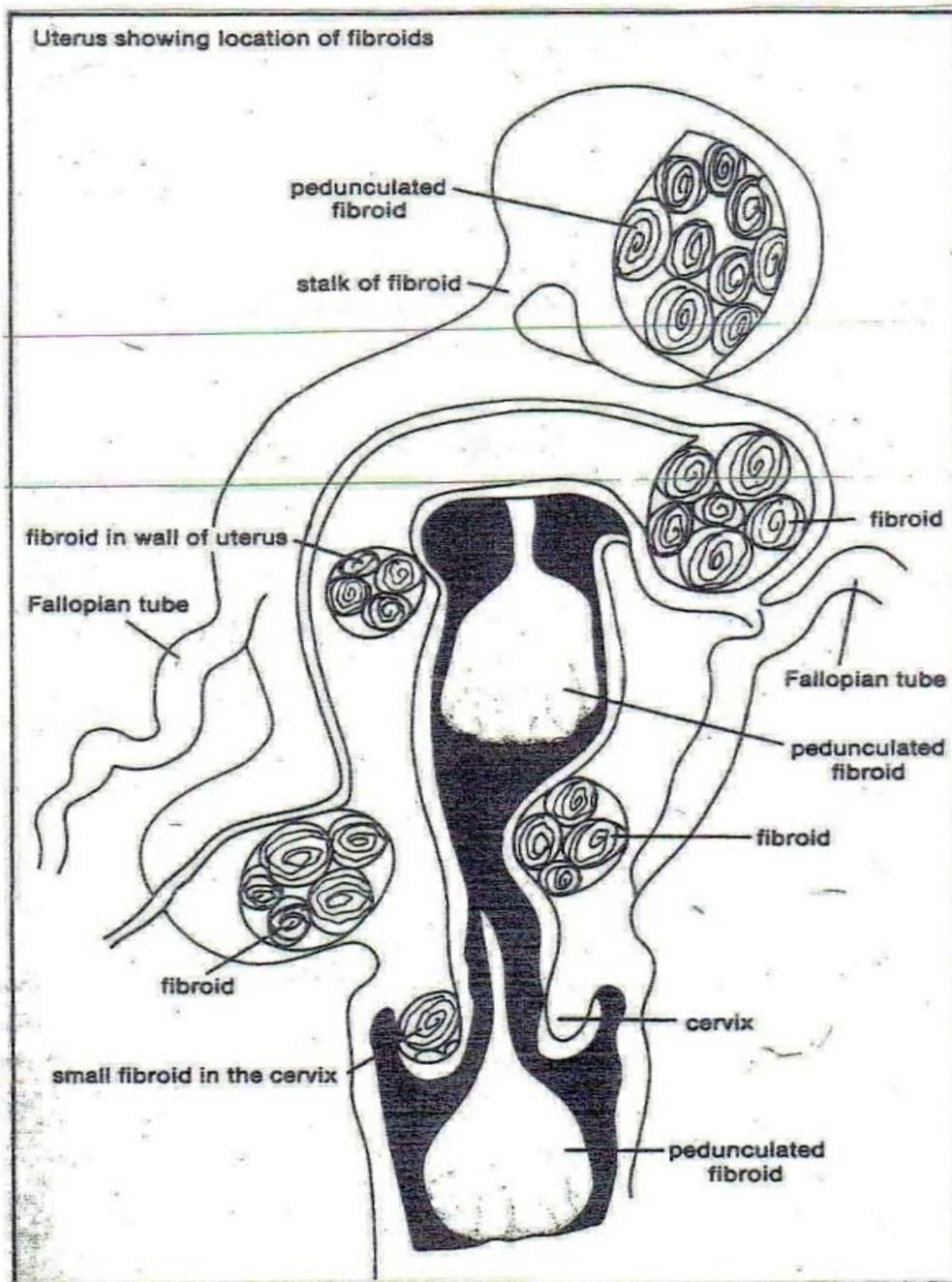


Figure 2.1
Location of fibroids in the uterus
 (Source: Cabot 1990:165)

Women suffering from the fibroid uterine condition tend to experience profuse and abnormal vaginal bleeding (Walters 1998:116-117). While some women do not show any symptoms, others complain of physical problems such as: abdominal pain; dyspareunia; a distended abdomen due to large fibroids with a pregnancy-like appearance; as well as pressure in the urinary tract system resulting in for example:

anuria and urinary frequencies. The physiologically-based forms of discomfort which some women experience are the result of symptoms experienced when diagnosed with fibroids in their uterus. These symptoms are manifested by the size of the fibroids and their location in the uterus (Walters 1998:116) (see figure 2.1) for the size and location of fibroids in the uterus). As is the case with the psychological environment of perception construction, the physiological symptoms experienced by these women contribute in deciding whether or not the hysterectomy surgical procedure will be undertaken – depending on information obtained from the counseling sessions from the women's doctor (Walters 1998:116, 193).

There are two physiological functions of the uterus that could be adversely affected by a hysterectomy procedure – the reproductive and the menstrual functions. In some cultures, the regular occurrence of the monthly menstrual cycles – whether a woman is capable of child birth or not – are a visible confirmation of her unique feminine role and visible indicator that the uterus is alive and well. Similarly, the cessation of menstruation is a reminder that a woman cannot fulfill her gender role as expected. The woman is regarded as infertile and 'incomplete' due to her 'loss' of the child-bearing potential especially when the womb has been removed for example in black women, even if the reason for the hysterectomy was to save her life – could further result in her 'condemnation' or castigation in such societies (Kuny 1984:5, 25-29). Equating the removal of the womb with an abomination is clearly discriminatory and a violation of the concerned woman's autonomous right to decide what should happen to her own body.

This reasoning affects women's perceptions of hysterectomy when diagnosed with fibroid uterus (Kuny 1994:5, 25-29). The white women accept the removal of the diseased womb with no connotations applied to it, but for promoting health and prevent further complications (Kuny 1994:5-9). The choice to reject surgery is usually regarded as reasonable if physiological symptoms are not severe or when the woman is close to menopausal stage, at which point many symptoms are expected to be resolved completely or start to subside (Walters 1998:116-117).

2.2.3 The socio-cultural environment of perception construction

The fear of losing the uterus by many women is sometimes rooted in the socio-cultural environment as defined by their value and belief systems. Under such circumstances, the preservation of the uterus is opted for. Consequently, myomectomy (surgical removal of only the fibroids in the uterus) is opted for, based on the hope that the uterus would be restored to its original functional state (Doenges, Moorhouse & Geisste 2000:660; Walters 1998:117). Despite the severe and excruciating pain that requires hysterectomy, the desire to keep their child bearing dream alive influences these women to even withstand the psycho-social and cultural pressures. The basis of their hopes is constructed on the notion of the importance of retaining their uterus in the bodies as a symbol and true reflection of womanhood – completeness of being a woman and prospects of fertility.

It would seem that some of the women are more concerned with their self esteem and are fearful that any decision to remove their uterus will impact negatively on their personal lifestyles. It has been well documented that women are afraid of losing their femininity, sexuality and physical changes. In many instances, losing their ability to fulfill their reproductive role has been accompanied with grief and emotional stress. As a result, they would rather suffer silently than face alienation and excommunication from their own society (Doenges et al 2000:661-662; Kuny 1984:25-32).

Women from different cultural backgrounds and orientations react to the loss of their uteruses differently. In some cultures for instance, the uterus is regarded only as a procreation organ, and its removal would thus be construed as a necessary life-saving mechanism; whereas in some cultures its significance transcends the childbearing function. In the latter instance, the women perceive that the removal of the uterus threatens their self-esteem as human beings and complete women (Kuny 1984:5-9) and would cause their spouses to seek 'worthier women'.

In most instances, these fears are premised on misconceptions; a lack of accurate information, or knowledge deficit; myths and falsehood; taboos inherent in the belief and value systems; as well as lack of exposure to informed topics on the issue of hysterectomy amongst women of diverse cultures (Doenges et al 2000:665-666; William & Clark 2000:515-525).

2.2.4 The socio-economically induced environment of perception construction

The condition of a fibroid uterus has socio-economic implications that could influence the decision to undergo or refuse the implementation of a hysterectomy procedure. Many women with uterine fibroids incur heavy expenses on consultation fees and diagnostic tests, going from public health care facilities to private doctors and then to traditional healers. When the results indicate uterine fibroids, many go into denial syndrome, a condition that needs to be dealt with psychologically. Some consult other doctors for a second opinion, thereby incurring further expense which only the financially viable would be able to afford. After counseling sessions have been exhausted, and the cultural – traditional and religious pressures come to bear, some of these women with fibroid uterus refuse to undergo hysterectomy and the health institutions are not obliged to reimburse their patients. In some other cultures, money paid to some traditional healers cannot be claimed back if there is no betterment on the side of the patient. Those with deep seated traditional religious beliefs will console women for their losses as homage for the appeasements of the “gods”.

The Patients’ Rights Charter of 1996, in the South Africa constitution, empowers women to have a say, participate in decision-making and to have second opinions before embarking on an irreversible decision for their cure. Women should be allowed to choose any health care providers or a particular facility for treatment and have a right to be informed (Republic of South Africa 1996). Financial expenses can be minimized through counseling and the promotion of health education, which become effective means of helping communities improve their health systems, lifestyles and their understanding of issues that can be dangerous to hygienic lifestyles in their respective communities (Clark 2003:234; Dennill et al 1999:148-152).

Socio-economically challenged women with fibroid uterus may regard hysterectomy as prohibitive from a monetary viewpoint, and regard it as a ‘luxury’ afforded only by the rich. Cast against a socio-economically-determined background, perceptions of women regarding hysterectomy could become projected in a way as to reflect the socio-economic imbalances in society.

2.2.5 Educational status and the construction of hysterectomy perceptions

Researchers have discovered that women of lower socio-economic and educational status felt more frequently de-feminized than their middle class counterparts (Dennill et al 1999:148-152). This is due to misinformation and uninformed decisions imposed on these women, by conditions of lack of sufficient access to information/knowledge and proper expert counseling; which would provide them the latitude to ask relevant questions concerning their reproductive health, and hysterectomy in particular. On the other hand, middle class women have the benefits afforded by exposure to formal education, which empowers them to have access to information/knowledge, expert advice, and the financial means to pay for any number of consultations and surgical expenses, especially in the case of private healthcare provision.

An analysis of women with fibroid uterus on the one hand, and their rich or poor condition; would suggest that the more exposure to formal education, the more progressive the perceptions on hysterectomy. Similarly, the less exposure to formal education, the more conservative the views on hysterectomy are upheld. Together with their spouses, the category of women in the latter instance tends to be reined-in by the tradition-steeped view that the role of women is strictly defined by their procreation capacity only. Accordingly, a woman who has had hysterectomy conducted on her would be deemed to be less of a woman. Despite the vigorous counseling the women might have gone through, societal influences tend to lead to self-condemnation as the women believe that they have lost their child-bearing abilities (Kuny 1984:26-27).

2.2.6 The moral/ethical environment of perception construction

Ethics relates to a behavioural framework (code of conduct) within which moral principles are constructed (Tulloch 1993:505). In this study, “ethics” is construed as various principles pertaining to a code of acceptable conduct, according to which physicians, nurses and other members of the health fraternity and its multi-disciplinary teams employ for the appropriate management of the fibroid-suffering women’s health needs (Walters 1998:192). The following issues have loomed large as a framework in which the construction of the nuances of ethical conduct/morality has materialised:

- Consent for women to be treated after a diagnosis of the fibroid uterus.
- The consent for hysterectomy or the removal of uterus to be implemented.

- The right to the RHT.

2.2.6.1 Consent for women to be treated after a diagnosis of the fibroid uterus

“Consent” applies when the woman with fibroid uterus signs an authorized hospital form as an indication of her unwavering personal commitment and agreement to be treated by health practitioners and other members of the multi-disciplinary team. The informed consent is validated from the time of its signing, until the hysterectomy procedure has been completed. The signing of the informed consent form does not in any manner imply that the patient has ‘surrendered’ her rights to the health institution. She is still entitled, for instances, to be informed of any diagnostic procedures and tests conducted on her before, and after the surgery.

She will be kept abreast of every procedure to be performed on her by members of the multi-disciplinary surgical and healthcare team. The information will include benefits and the risks involved as reflected in the Consent Form, and she will have to append her signature as reflecting her understanding of its contents. If risks and benefits are not fully and satisfactorily explained and discussed, such failures render the whole exercise of the consent meaningless and invalid (Curtin & Flaherty 1982:227).

Consent is regarded as peculiar to each person, and is not transferable. As applying to all human interactions, patients also react differently to the idea of “Informed Consent”. Curtin and Flaherty (1982:227) state that for informed consent to be deemed acceptable, the following attributes have to apply:

- Un-coerced: it should not have been forced on the patient.
- Valid: it should have legally acceptable merits: to be executed with proper formalities.
- Should not have expired: enforceable.

The signing of the informed consent form is an important ethical and legally binding agreement between the patient and the medical practitioner, or healthcare provider or institution. The agreement also protects healthcare providers/institutions from unnecessary litigious action by patients during and after treatment (Seaman 1982:173).

When the woman patient finally decides to sign the consent form for the alleviation of fibroid-induced pain, complex psychological, social, religious and economic factors are considered in relation to the patient's health problems. Nevertheless, the patient's illness is in the body, which is the physical aspect mostly affected. The emotional and the psychological aspects of the patient inform on what is happening to the body. It is for this reason that the five afore-mentioned perception construction aspects of the patient's being must be holistically addressed in order that an unambiguous recommendation for treatment can be prescribed upon signing of the informed consent forms (Walters 1998:192).

While informed consent is a necessary component for patient treatment, oversight could be applied in the event that imminent death prevents the patient from signing. In such instances, healthcare institutions are faced with a dilemma. On the one hand, the patient is in a potentially life-threatening situation but cannot sign the form; while on the other, the healthcare providers be accused of proceeding with the surgery without the patient's informed consent. This is one of the ethical and moral issues confronting the professional healthcare providers from taking risks in an attempt to save lives (Curtin & Flaherty 1982:227). The consent form is usually signed after thorough explanation has been conducted with the patient. This is in alignment with the patient's rights as enshrined in the Bill of Rights Act 108, in the Constitution (South Africa (Republic) 1996:6-24).

2.2.6.2 The professional obligation for professional conduct

The principle of ethics has a number of obligations that medical and nursing practitioners and other professionals have to observe in the treatment of patients and management of the healthcare system. The Hippocratic Oath taken by medical practitioners is an example in this context. Service to the patient is viewed above any other interest, thus elevating the saving of life of the woman above all her materially restrictive circumstances. Embedded in the Hippocratic Oath are principles of non-maleficence and beneficence. Non-maleficence refers to the patients' freedom from harm at any time during her stay at the healthcare providing institution; while beneficence relates to a commitment to do good. The two terms are complementary, rather than contradictory. In certain unfortunate however, the latter might seem to contradict the other. When a patient is booked in for hysterectomy, the objective is to

save life. If complications occur during these endeavours and results in a botched operation, it will be harmful to the health of the patient. This illustrates that during the act of beneficence, non-maleficence act is violated. It is therefore of paramount importance that thorough explanation and professional counseling are conducted to the satisfaction of the patient in order to harmonize the two principles cited above. Prior to the signing of any informed consent, the patient should also be informed of the risks involved, and be allowed to ask questions and seek clarification where necessary; as this gives the patient the right to determine whether or not to sign (Walters 1998:191-192, 209)

Nursing practitioners who witness the signing of consent forms by patients should not take it upon themselves to explain the nature and extent of the operation, as this is the function of the medical practitioner – in this case, a gynaecologist who is sufficiently equipped with the skills and the knowledge on what he intends doing (Seaman 1982:173). Nursing practitioners are to maintain the Nightingale pledge of being the patient's advocate, being faithfully dedicated to nursing care and to educating patients on healthcare matters.

2.2.6.3 Refusal of hospital treatment (RHT)

Any patient has a legal right to refuse medical treatment at anytime, despite the consent signed or given previously (Annas 1998:714; Entwistle, Williams, Skea, MacLennan & Bhattacharya 2006:449-450). In South Africa, the individual's rights are embedded within the Human Rights Bill as enshrined in the constitution. When individual rights are respected and maintained, human society is preserved. But when the rights are neglected, society is corrupted (Curtin & Flaherty 1982:3). In the healthcare context, the patient's responsibility towards these rights should not be compromised. In addition, the fibroid-suffering women patients should be allowed to express full control of what happens to their bodies, to choose the type of any alternative treatment deemed to be suitable, and to have the final decision (autonomy) on the costs involved in the treatment process (Linderberg & Nolan 2001:603-605).

The Patients' Rights Charter of 1994 allows the patient, or any other competent person with delegated authority, to withdraw or reverse any consent signed during the admission process in relation to any surgical procedure and treatment options. The competent adult must be the sole non-coerced and trusted choice of the patient herself.

The person assuming such a role should be able to withhold sensitive and confidential patient information from any unauthorized persons (Annas 1998:714-715).

The competent person means a mature adult relative, friend, or legal representative appointed by the patient. Such trustees also include a nurse acting as an advocate. The healthcare proxy form is then signed to authorize any of the above-mentioned persons to take full responsibility in the event that the patient becomes incompetent to exercise this responsibility (Annas 1998:714; Linderberg & Nolan 2001:603-605). The RHT form is signed after the medical practitioner in the presence of a professional nurse acting as a witness, has fully explained the legal implications of signing an RHT form. The explanation should include the advantages and disadvantages of signing RHT forms, as well as the rights and responsibilities, ethics and legal rights of the patient. The explanation in itself is intended to prevent unnecessary litigations instituted against healthcare providers or the institutions (Curtin & Flaherty 1982:228; Walters 1998:192-193).

The following are some of the reasons compelling patients or their proxy appointees to opt for the RHT choice:

- After weighing the pros and cons, the patient or relatives might decide to remove the patient due to dissatisfaction, or feeling that the institution is trampling the patient's personal wishes, or allegations of patient abuse in the healthcare facility.
- The need to seek a second opinion about the disease and the care to be offered.
- In some cultures, the patient might sign the RHT in order to be given ample time to seek guidance from the ancestors before receiving any medical treatment.
- Others, because of their socio-culturally rooted beliefs, sign the RHT in order to create time for consulting traditional healers (Annas 1998:714; Clark 2003:85-87; Swenson, Sanford & Nortigan 1998:680-684).

Some of the actions influencing the RHT option might be generated by fear based on some myths associated with Western medicinal approaches to particular ailments. These actions might impact negatively on the health condition of some women patients (Annas 1998:717-718; Tulloch 1993:1005).

A woman's quality of life as a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity (World Health Organization (WHO) 1992). This quality of life is affected by the changes in the physical appearance, mental state, personal and social factors. For women with fibroid uterus, quality of life is negatively affected by the long processes of consultations based on traditional beliefs that sometimes seek to pinpoint witchcraft as a causative factor rather than undergoing treatment for the diagnosis (Shaw, Soutter & Staton 2003:724). Many myths about hysterectomy suppress formal counseling offered by health institutions and negatively impact on women diagnosed with the condition. Some of the most common symptoms are poor body image, sense of worthlessness, personal physical negligence, lack of self-appreciation as well as the loss of libido or sexual pleasure (Shaw et al 2003:724).

When the quality of life of a woman is affected, and no further counselling is done, the woman can refuse or withdraw from care or treatment even though such an action could lead to death. But if the patient is in a health care institution and decides to sign the RHT forms, she cannot be held against her will except in some psychiatric cases (Annas 1998:713-714; Curtin & Flaherty 1982:228). Many women are not aware, however, that being admitted to a health care facility, and accepting or consenting to a treatment plan, does not mean ethical acceptance of all the treatment plans. This is where health education becomes a prerequisite (Annas 1998:713).

2.3 TRAITS OF WOMEN WITH UTERINE FIBROIDS WHO HAVE UNDERGONE HYSTERECTOMY

Uterine fibroids are the most common neoplasm that any woman is likely to develop. Medical research has given little attention and priority to this condition, however, and studies on it are poorly funded (Cramer & Patel 1990:94; 435-438). According to Shelton, Lees and Groff (2001:732), hysterectomy rates based on uterine fibroids vary from woman to woman and in accordance to parity, race, and age.

2.3.1 Parity and the occurrence of fibroids

Parity is defined as the undisturbed function of a woman's reproductive health (Tulloch 1993:1105). This function is likely to determine the number of children that a woman is likely to bear under normal conditions. Fibroids do not appear before a girl reaches the

menarche stage, and their reduction in size occurs after the menopause stage (Heally, Vollenhoven & Weston 2003:480). At least half of the women population is affected by the uterine fibroid condition during their reproductive age. A woman's reproductive status, together with the site or location of the fibroids in the uterus, determines the clinical presentation of the fibroid uterus (Heally et al 2003:481).

In some though not all women, the fibroids can result in infertility because of the enlargement and distortion of the uterus through the disturbance of uterine blood flow. This adversely affects parity (Heally et al 1990:481, 491). Fibroids tend to occur in nulliparous and low parity women (Kuny 1998:26-27; Marivate & Siebert 2007:201-210; Phillipott 1972:259-270). In the United States, African-American women with no children were found to be more prone to undergo hysterectomy than their White counterparts (Meilahn, Matthews & England 1989:319-329; Shelton et al 2001:733).

2.3.2 Race and the occurrence of fibroids

Epidemiological studies in the United States of America (USA) indicated that there are consistent differences between women of different cultures and races regarding the occurrence of the fibroid uterus .African-American women in the USA are three times more likely to develop fibroids. The fibroids are most commonly benign tumours and occur particularly in women of African descent (Blaunstein 2002:564; McIntyre 2001:169-170; Menru, Washahl, Onura, Hecht & Hopkins 2001:105; Robbins 1999:103). African-American women are diagnosed more frequently than Caucasian women and undergo hysterectomy and myomectomy three times more than women of other races (Crowe & Reider 1998:662-664; Ligon & Morton 2001:8-14; Office of Research on Women's Health 2003:1; Williams & Clark 2000: 515-525).

These women have more and larger fibroids than other women (Heally et al 1990:481; Marshall, Spiegelman & Barbieri 1997:967-973). African-American women are more likely to be affected by fibroids on the outside, inside or within the walls of the uterus (Crowe & Reider 1998:662-664) (see figure 2.1). Regarding the variation in the incidence of uterine fibroids in pre-menopausal women by age and race, Marshall et al (1997:967-973) found consistent differences between African-American, Caucasian, Hispanic (Latino), and Asian-American women.

2.3.3 Age and the occurrence of fibroids

Marshall et al (1997:967-973) and Shelton et al (2001:733) found that African-American women are diagnosed with uterine fibroids much earlier in their developmental stage than White women. In addition, there is a higher prevalence of hysterectomy under the age of forty years in South America than in North America.

The researcher found little literature available on the effects of age or menopausal status of women on the risk or benefit of treatment for symptomatic fibroid uterus. Fibroid uterus is present in the muscular wall of the uterus between the ages of twenty-five and thirty years (Cabot 1990:164-165; Office of Research on Women's Health 2003:2).

Eighty percent of Black women and approximately seventy percent of White women develop fibroids before they reach menopause (Office of Research on Women's Health 2003:2). Fibroids do not present clinical problems before puberty and do not grow after menopause (Marivate & Siebert 2007:187, 191). Crowe and Reider (1998:662) and Marivate and Siebert (2007:191) found that between five and twenty percent of women over the age of thirty-five are diagnosed with fibroids, and the peak incidence of fibroids uterus in women is between thirty-five and forty-five years of age.

In the USA, the highest incidence of hysterectomy is between the ages of thirty and forty-nine year age group (Augustus 2002:296; Kuny 1984:26-27; Shelton et al 2001:732). In Australia, hysterectomy was a fairly common occurrence among middle-aged women, even at the reproductive age of forty years (Dennerstein, Shelley, Smit & Ryan 1994:311-313). In East Africa, Otieno, Parker and Thagana (2004:264) found that laparoscopic-assisted vaginal hysterectomy for benign uterine pathology is the second most frequently performed major surgical procedure amongst women of reproductive age. Otieno et al (2004:264) maintain it is time to change this situation.

Amongst the Danish communities, cases have been reported of women below the fifty year age category undergoing hysterectomy procedures. In France, women in the perimenopausal stage were found to have developed the fibroid uterus condition, and had opted for undergoing the hysterectomy procedure. After the caesarean section, hysterectomy is the second most frequently performed major surgical procedure

amongst women of reproductive age (Otieno et al 2004:264; Pokray & Hufregal 1998:852-853).

2.4 SUMMARY

In order that a reasonable framework be constructed, it is imperative that the perceptions on hysterectomy by women with fibroid uterus from diverse cultures be understood from multiple perspectives and environments. The basis for such understanding has been constructed through the thematic review of existing and accumulated literature in the sphere of hysterectomy as a context-specific medical field of knowledge.

2.5 CONCLUSION

This section of the research report differentiated between “literature review” and “scholarship review”. The latter as cited from Mouton (2001:86-87) was essentially concerned with the compilation of the accumulated body of literature on a particular research topic. In addition, literature review is ‘quantified’ by the number of consulted sources appearing in the list of references or bibliography of a study. Scholarship review meant collation of research-based literature on any particular field of study. This focus was in consonant with the accumulated body of literature thematically constructed to determine the extent of its contribution to the research field related to perceptions of women with fibroid uterus specifically in relation to hysterectomy. The following chapter is on conceptual framework of the study.

CHAPTER 3

Conceptual framework

3.1 INTRODUCTION

The conceptual framework in this study is intended to provide an outline or framework within which the major and critical concepts have been organised. Most importantly, the affinity and inter-connectedness between, and among these conceptual variables is established within graphically-constructed 'boundaries' (Miles & Huberman 1994:18-19). The conceptual framework constructed relates to all the constituent variables of the environment in which perceptions of women from different cultures with fibroid uterus regarding hysterectomy are constructed. The conceptual framework/model attempts to explain the phenomenon and the perceptions of women with fibroid uterus regarding hysterectomy (Burns & Grove 2001:133). As opposed to theory development, a conceptual framework is a loosely structured model indicating the multiple environments from which multiple perspectives on hysterectomy and its perceptual base have been drawn (Miles & Huberman 1994:18-19).

In chapter one of this study, the background of the problem, its significance, and justification of the study have been presented. The purpose of establishing such an introductory background and framework was to create a conceptual point for the discussion of significant issues relating to the problem of perceptions on hysterectomy as constructed and/or shaped by various factors, including culture.

3.2 THE INTERCONNECTED DOMAIN OF HYSTERECTOMY PERCEPTIONS

An understanding of women with fibroid uterus' health needs has to be constructed on a holistically-determined perceptual environment. The critical factors shaping perceptions of hysterectomy's acceptance or non-acceptance (by women in general, and women with fibroid in particular) have been identified as being constituted within a conceptual framework/environment of the following inter-connected levels or spheres of perception construction:

- the psychologically-induced conceptual environment
- the physiologically-induced conceptual environment
- the culturally-induced conceptual environment
- the socioeconomically-induced conceptual environment
- the educationally-induced conceptual environment
- the morally-/ethically-induced conceptual environment

The researcher's figure 3.1 is an integrated graphical representation of the acceptance or non-acceptance framework or environment of hysterectomy, based on contributory factors as discussed in this study. In spite of these factors being 'demarcated' into different spheres or zones, they are inter-related. The degree of interrelatedness might shape the sphere's/zone's affinity with the pivotal sphere or zone of hysterectomy as the gravitational centre of all the other spheres.

The nature of interconnectivity among these variables does not necessarily follow the linear or rotational axis reflected below. Any single sphere could become the 'product' of multiple other variables/factors acting in unison or 'independently. For instance, the educational environment could shape all other factors; or it could inversely be influenced by all the other spheres or factors. On the other hand, the three variables of traits (parity, race, and age) could become the product of cultural construction alone.

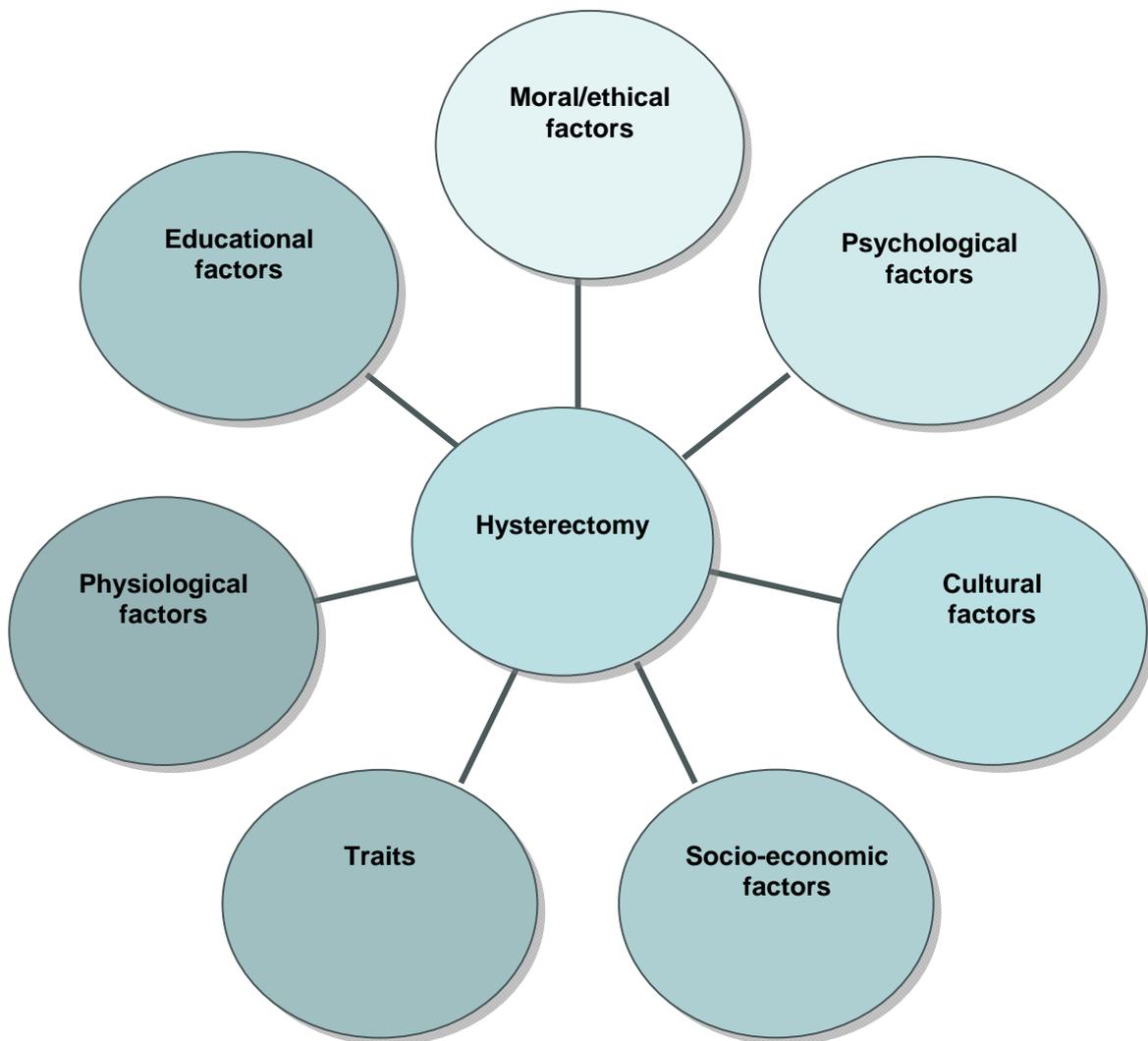


Figure 3.1

The conceptual environment of factors/trends that influence the acceptance and non-acceptance of hysterectomy

3.2.1 The psychologically-induced environment

The psychological environment exerts different forms of pressure on women with fibroid uterus. This environment is the terrain in which all the other forms of perception

formation is accumulated and expressed in ways that might tend to affect the normal functioning of the mind. Professional counselling plays a crucial role in helping to maintain the self-esteem of the affected women. Women who are dismembered by their peers or communities for 'defying' the conventional wisdom of non-experts might feel the pressure of being 'disowned'. Others could find hysterectomy-induced changes in their body difficult to accept and understand. The 'loss' of womanhood due to the removal of the womb might also cause strenuous conditions of the concerned woman's self image. The accumulation of pressure from within the woman herself, as well as from others, might result in great emotional instability, including the reduction of interest in sexual Intercourse (Azadeh-Ghamsari et al 2002:517-518). In such circumstances, professional help and counseling could resolve such a state of instability.

Some of the women patients are highly secretive and would be contented if their disease and the removal of fibroids or womb remain but a highly kept secret. This can only be divulged to their personal confidantes. Emotional trauma about the disease or condition, lack of financial resources and in-depth information about remedial steps to be taken, are the only reasons why they end up admitted at public health institutions where they are known by some members of the team of health providers. They feel unsafe and vulnerable than if they were admitted in some private facilities far away from their environment of abode.

3.2.2 The physiologically-induced environment

The physiological environment of the conceptualisation and perception of hysterectomy is mainly characterized by physical appearance and reproductive functionality as factors considered when the option of hysterectomy is to be considered (Nolan & Mock 2000:155-168). Lack of insufficient knowledge and counseling has adversely impacted on the better understanding of the surgical removal of the uterus. Counseling plays a critical function not only in the psychological domain, but in the realm of reassuring operated fibroid sufferers that their physical shape and well being have not been destroyed by the application of hysterectomy. Knowledge has to be imparted to these women that the main aim of implementing hysterectomy was to save their lives, and not to bring about physiological disfigurement.

Women with fibroid uterus, despite their cultural backgrounds, often know best the pain and complications associated with keeping a uterus that may continue to exacerbate

their deteriorating general health conditions. The hysterectomy procedure is still sceptically regarded in some certain conditions and there are no justifiable reasons for such scepticism. An example of such conditions is the endometrial hyperplasia, severe pelvic infections (not responding to antibiotics), extensive endometriosis and pelvic relaxation; of which most conditions can be treated without subjecting patients to radical surgery of hysterectomy (Crowe & Reider 1998:663).

3.2.3 The culturally-induced environment

In some culturally-rooted communities, males make all the decisions, even those regarding the general health of their spouses, particularly on the reproductive function of the woman's body. The reproductive health of women seems to be dependent on the regulation of their reproductive capacity. Spouses then became the main 'custodians' who could authorize the implementation or non-implementation of the hysterectomy surgical procedure. The Choice of Termination of Pregnancy Act (*Act 92 of 1996*) empowers women to make independent decisions as adults responsible for their own bodies (South Africa (Republic) 1996:6-7).

Despite the knowledge accruing from the new legislative and health regulatory dispensation, there are still women with fibroid uterus who vehemently refuse to undergo the hysterectomy procedure. There are still incidents in South Africa where women continue to be dictated to by cultural factors in the acceptance of procedures that disproportionately affects them on a daily basis. They would not prefer their partners, husbands and family members to know of their condition because of some taboos associated with hysterectomy. The woman's refusal to have the uterus removed is that it is regarded as a symbol of fertility, or to ensure that there is regular menstrual flow – a sign of feminine qualities and reproductive ability. On the other hand, the males in that custom-bound context would view the womb as mainly an organ intended to sustain their partners' youthfulness, and as some form of an arousal organ that could guarantee their libido is continuously functional.

Cultural contexts also do contribute and affect personal decision making processes relating to the signing of the consent for the implementation of the surgical procedure. Cultural beliefs inculcated the mentality of women as perpetual minors who cannot take personal responsibilities for their well-being. Social enculturation (for example, initiation

schools and vaginal inspection practices) saw to it that their worldview is embedded with the notion of the womb as only a child-bearing organ; whether or not the fibroid status threatens the woman's life is obviously a secondary consideration.

3.2.4 The socio-economically-induced environment

In male-dominated communities, women are mostly dependent on their men-folk for their financial well being and maintenance of their families. Such an arrangement is disadvantageous in that it ties hysterectomy decisions to the same source. If the male and other members of the family, who wields financial power, are opposed to hysterectomy, it is that they will also withdraw any financial support aimed at advancing any of its aspect, including pre-counseling. This form of dependency highlights deep cultural factors already discussed above, which make women suffer in silence, even on matters relating to their personal well being in general. Contrarily, financially and socio-economically independent women with fibroid uterus exercise their sole prerogative on whether or not to undergo hysterectomy.

In some socio-economically constrained communities, the mortality rate of children is much higher. As a survival mechanism, some have adopted the maxim that: the more the children, the higher the rate for some offspring to survive. This truth, especially among poorer socioeconomic classes is also based on the belief that the more children a family has, the higher the chances for them to augment family income when they grow up. These communities do not seem to take into consideration the expenses involved in their offspring's rearing and nurturing process; the psycho-social pressures on parents and to the siblings themselves. In all these, the health status of the woman is least considered. That is why in some instances, some women are not allowed to utilise available family planning methods. For acceptability in society, women decide to refuse treatment in the midst of the unbearable excruciating pains that sometimes contributes to the deterioration of their general health status.

3.2.5 The educationally-induced environment

The legal empowerment of women with rights on matters affecting their reproductive health or organs should have put them on a higher pedestal in accessing readily available information about their health status. Ironically, there are still some women

who are ill-informed, uneducated and not empowered to take decisive steps on issues relating to available life-saving procedures. Some of the women who have been admitted for hysterectomy have had very limited access to formal education opportunities. Consequently, their low levels of illiteracy limit their understanding of hysterectomy and the associated dangers of not undergoing the operation when the uterus is with fibroids.

Their lack of formal education could be ascribed to the socialization and enculturation processes which emphasized that – as being subservient to their spouses – males are therefore more ‘entitled’ to formal learning. Though they may be versatile when it comes to linguistic expressions, the mere fact that they are unable to read and write, relegates them to positions of inferiority as compared to their male counterparts. For illiterate or semi-literate women with fibroid, reading and understanding crucial documents such as RHTs and informed consent forms becomes problematic, and may be used by their relatively literate spouses to justify their authority.

3.2.6 The morally-/ethically-induced environment

The moral/ethical environment determines the rights of both the women patients and the professional healthcare providers. On the one hand, the patient’s legally and constitutionally protected rights should be observed at all times while she is under the healthcare institution’s care. On the other hand, the healthcare providers’ professional codes of conduct (for example, the Hippocratic Oath and Nightingale Oath) bind them to take the interests of their patients as supreme to any other considerations. The right to refuse treatment should be appropriated to all patients with in-depth information that can lead to effective decision-making based on factual dissemination of simple and detailed explanations. This will facilitate timely corrective action/intervention. Healthcare providers are sometimes confronted with moral and ethical dilemmas when their patients sign RHT forms. On the one hand, they are obliged to safeguard the lives of their patients (for example, through the Hippocratic Oath); while on the other, they cannot coerce the same patients to act against their decisions.

The researcher has witnessed a scenario in which a woman with fibroid uterus vehemently refused hysterectomy, on the verge of death and even signed the RHT form due to the unbearable pressure exerted on her by family members. This research would

therefore advocate for a vigorous approach in teaching women about their status in society and their personal responsibilities in accessing best medical interventions for the promotion of personal health and alleviation of pain.

3.2.7 Traits as a conceptual factor

In the previous chapter (section 2.3), the notion of traits and its concomitant variables of parity, race and age, has been presented as a factor that characterizes perceptions on hysterectomy. In this particular context, it is represented as a factor that contributes to the conceptualization of hysterectomy. The notion of depicting women as a “garden” creates expectations that they need to bear as many children as possible.

The reproductive capacity of a woman to conceive (parity) is understood differently in different racial and cultural milieus. In some (conservative) contexts, the removal of the uterus could become conceptualized as taboo; while in other (progressive) contexts it would be justified and easily understood as a necessary life-saving procedure. Similarly, age as a determinant of the appropriateness of the child-bearing age has also been understood differently in different societies. Hysterectomy should not be performed in the event of conditions such as mild dysfunctional bleeding, asymptomatic fibroids and pelvic congestion, which includes menstrual irregularities and low back pains (Crowe & Reider 1998:663-664).

National and international organizations have made tremendous contributions to place more resources into reproductive healthcare services than in primary healthcare. Historically, contraception used to be administered to African women in South Africa as a political instrument to regulate population growth, and was the only free healthcare service available to these women. The “Health for All” approach used to be a contested terrain, but it has changed, as the new dispensation makes healthcare available to all including women irrespective of their age, race, or creed. However, more women are still more susceptible to suffer, example: contracting fibroids and not advocating for their own lives to be totally relieved through hysterectomy and their human rights.

3.3 SUMMARY

The conceptual framework has been located within the premise of the interconnectedness of variables or factors associated with the perceptions of women with fibroids uterus regarding hysterectomy. The exponential increase in the rates of ignorance necessitates that women in general be adequately informed of its prevalence, as well as the range of alternative treatment options available. The apparent lack of information and knowledge results in uninformed decision being made by the fibroid sufferers themselves, or those usurping the right to act on their behalf. In this regard, it is incumbent on healthcare providers/institutions to ensure that prolific education and awareness interventions are instituted.

3.4 CONCLUSION

The section on the conceptual framework constructed dealt with the constituent variables of the environment in which perceptions of women from different cultures with fibroid uterus regarding hysterectomy were constructed. Citing instances in which vigorous counseling is essential in which women might need to ease societal influence to preclude self-condemnation or instances in which women perceive “self imposed barrenness” or failure of child-bearing abilities as the confounding variable in the phenomenon on perceptions of women regarding hysterectomy. The following chapter deals with methodology of the study.

CHAPTER 4

Research design and methodology

4.1 INTRODUCTION

The objective of this chapter is to present the stages and processes of data collection of the study. A survey was conducted to determine the extent of the participants' understanding of fibroid uterus and the operation, hysterectomy. Although women with fibroid uterus were the main participants, doctors and nurses, worked closely with these women, who are patients, and their input was helpful to compare in detail an integrated framework within which the women with fibroid uterus formulated their perceptions regarding hysterectomy.

4.2 RESEARCH DESIGN

The research design is a plan or blueprint of how the research will be conducted (Mouton 2001:55; Polit & Beck 2006:55). The research design focuses on the end product and the logic of research methodology (Mouton 2001:56). For this study, the researcher selected a descriptive exploratory design.

The study was conducted in one academic referral hospital. The study was conducted over a period of five months, from May 2006 to September 2006. The research design focuses on the end product and the logic of research methodology (Mouton 2001:56). The researcher used questionnaires and structured interviews to collect data from nurses, medical doctors and patients.

4.2.1 Exploratory

Exploratory research explores the dimensions of a phenomenon or develops or refines a hypothesis about relationships between phenomena (Polit & Beck 2006:5). This study was exploratory, as it would provide new knowledge on a perceived problem. The study was expected to provide new knowledge regarding factors that influence women's perceptions of and decision to undergo or refuse hysterectomy.

4.2.2 Descriptive

According to Johnson and Christensen (2000:302), the purpose of descriptive research is to provide an accurate description of the situation. Polit and Beck (2006:498) describe the main objective of descriptive research as the accurate portrayal of the characteristics of persons, situations, or groups, and/or the frequency with which certain phenomena occur. This study was descriptive because it wished to describe the perceptions of hysterectomy of women from diverse cultures with uterine fibroids. A descriptive exploratory qualitative design was the means to maximise the fulfilment of the stated objectives (Morse 1997:231-232). Such integration was intended to narrow any gaps (Polit et al 2001:216-218). In addition, the integration in the design of the research allows for the authenticity and transferability of the study's findings (Polit et al 2001:216-218; Polit & Hungler 1999:257-258).

The researcher used questionnaires and structured interviews to collect data from nurses, medical doctors and patients from May 2006 to September 2006.

4.2.3 Pilot study

A pilot study was conducted for purposes of familiarizing the researcher to the field of study under investigation, to pre-test the research instrument and determine if any modifications were necessary, as well as to assess the appropriateness of the questionnaires and relevance of the sampling procedures (Burns & Grove 2001:40-41). The pilot study was conducted among the women with fibroid uterus for hysterectomy. The pre-test conducted on the women enabled the researcher to determine which aspects of the interview schedule (for those who could not read and write) and the questionnaires needed improving. The pre-testing at the gynaecological wards enabled

the researcher to facilitate both the negotiated entry and familiarity with the conditions under which the actual research instrumentation would be implemented (Burns & Grove 2001:41).

4.3 RESEARCH METHODOLOGY

As opposed to the research design, the research methodology focused on the specific means by which the study was to be executed (Mouton 2001:55-56). Various processes and procedures were utilised in the collection and analysis of the data for the study; all of which was intended to explore, describe and explain the phenomenon of hysterectomy perceptions by women with fibroids, from different cultural backgrounds.

4.3.1 Development of the research instruments

The instrumentation used in this study primarily consisted of structured interviews and questionnaires. The interviews were designed for three categories of respondents, namely: the women with fibroid uterus, medical practitioners and nursing practitioners all in the gynaecological wards of the Johannesburg hospital. Medical practitioners from different categories (i.e. those who admitted and operated on patients) and nursing practitioners from different categories (who admitted and rendered health care throughout) participated in the study and responded to the questionnaires distributed to them. The interviewing schedule with women with fibroid uterus was between 45 and 60 minutes, while the completion of forms by nurses and doctors was expected to be completed within 30 minutes.

4.3.2 The research setting and negotiated entry

Johannesburg Hospital is a referral academic, tertiary hospital which was chosen for the pilot study. Consists of two gynaecological wards and four speciality clinics .known as GOPD (Gynaecological outpatient clinics).

Ward 196 is for booked cold cases – long staying patients, those suffering from pelvic cancer; ward 197 is for emergency cases only, which are later transferred to ward 196; 159 is a gynaecological clinic for patients who are booked for surgery; 176 is for uro-gynaecological patients, pelvic-abdominal oncology, and infertility problems. Ward 196 was chosen as it admitted women booked for hysterectomy, for different indications for example: pelvic cancer, endometriosis and other pelvic problems including fibroids and the high number of hysterectomies done, for fibroids. Table 4.1 illustrates the rate of hysterectomy procedures conducted in this ward.

In this ward, only cases booked for major operations and transfers from other wards and referrals from other hospitals were admitted, including those from outside of Gauteng Province and private clinics.

Table 4.1 Number of hysterectomies conducted in Ward 196: 2001-2005

YEAR	INDICATION (FIBROID)	NUMBER OF HYSTERECTOMIES
2005	Fibroids	157
2004	Fibroids	153
2003	Fibroids	144
2002	Fibroids	151
2001	Fibroids	149
2000	Fibroids	125
TOTAL		879

The GOPD is the clinic where women with any gynaecological problems are consulted, assessed, investigated and given appointment bookings for operation in ward196 if necessary. Minor ailments not for admission and operation are treated and follow-ups are done. Reassurance is given spiritually, psychologically, physically, socially and financially, which involves all members of the multidisciplinary team in this clinic before admission. The financial re-assurance of patients is done before admission in156/7, for patients to decide how to deal with their hospital financial issues.

4.4 SAMPLING METHODS AND SAMPLING PROCEDURES

The following figure is a diagrammatic representation of the three groups of the participants or population engaged in the implementation of the sampling.

4.4.1 Population

The population includes all the elements (individuals, objects or substances) that meet certain criteria for inclusion in a given universe (Burns & Grove 2001:47; Polit & Hungler 1999:278; Polit & Beck 2006:56). For the purposes of this study, the population consisted of three groups:

- Women of diverse cultures, in the Johannesburg Hospital's gynaecology ward 196, Gauteng Province in South Africa.
- Different categories of nurses enrolled and registered by the South African Nursing Council (SANC), working in gynaecological wards and the **GOPD** in Johannesburg Hospital.
- Different categories of medical practitioners registered with the South African Medical Health Council (SAMHC), working in the gynaecological wards and **GOPD** in Johannesburg Hospital.

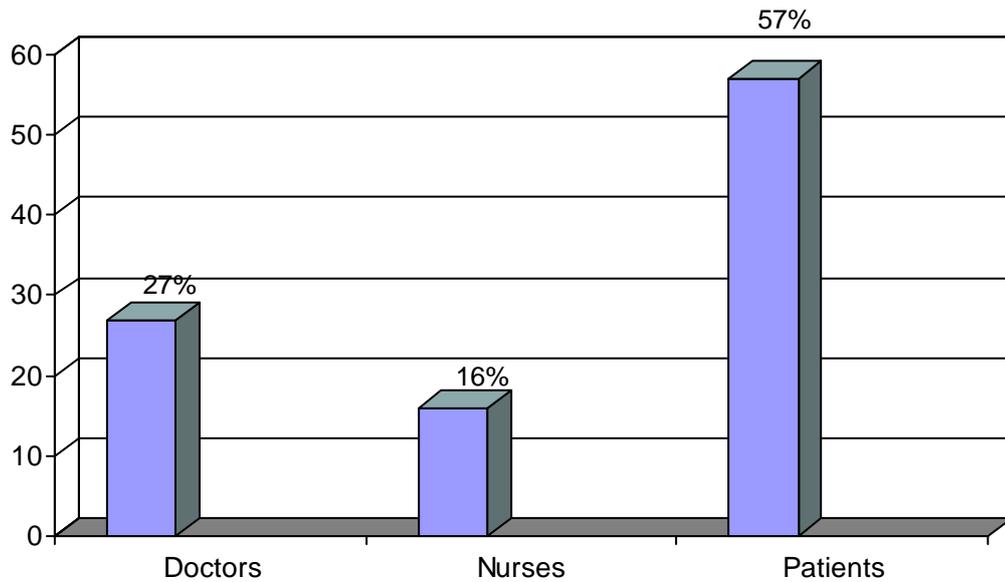


Figure 4.1
Total number of participants (N=92)

Figure 4.1 indicates that a total of 92 participants were selected for the study. This sample size consisted of three categories, namely: doctors 25, nurses 15, and women with fibroid uterus 52. The sample size represents a larger number of participants or population with approximately the same characteristics as those observed. The probability sampling was applied to maximise each participant's constituency equal chances of representation. The women with fibroid uterus constitute the largest sample size, because they are the representative category whose views and perceptions of hysterectomy have the most bearing on the critical aspect of the research topic (see table 4.2).

Table 4.2 The sample range of research participants (N=92)

FEMALE PATIENTS	52 (57%)
DOCTORS	25 (27%)
NURSES	15 (16%)
TOTAL	92 (100%)

4.4.2 The inclusion criteria

The inclusion criteria became the researcher's mechanism for selecting those participants whose participation would reflect the major features and characteristics of a particular group, or sample size within the population. The nature of the topics studied determined in advance each participant constituency to be represented (Polit et al 2001:305-306).

4.4.2.1 The nurses' inclusion criteria

The 15 nurses in table 4.2, registered and enrolled with the SANC, and were also from different categories. They all worked in the gynaecological wards and the GOPD of Johannesburg Hospital. An additional criterion was that their work experience was of two years' duration and above. This ensured that the level of patient-nurse relationship had been developed within this time frame. As nursing practitioners, in the gynaecological wards, it was envisaged that they would have acquired sufficient knowledge on the perceptions of women with fibroid uterus regarding hysterectomy.

Table 4.3 represents the different categories of nurses, who participated in answering of the research questionnaires. It is apparent from the figures that the registered nurses were targeted more for their expected responsibility to the patients, according to their scope of practice as envisaged by the SANC.

Table 4.3 The sample range of nurse participants (N=15)

CATEGORIES OF NURSES	ENROLLED NURSES (EN)	ENROLLED ASS (ENA)	REGISTERED NURSES (RN)	TOTAL
TOTAL	4 (27%)	4 (27%)	7 (46%)	15 (100%)

The percentages illustrate the ratio of the nursing categories to the overall sample size of 15 respondents in the nursing category. All the 15 nurses indicated above worked in the different gynaecological sections of the hospital.

4.4.2.2 The inclusion criteria for patients

These 52 participants in table 4.2 had to be women with fibroid uterus from different cultural environments. The women were to undergo hysterectomy procedure within five days of their admission into ward 196. Table 4.4 indicates the patients of diverse cultures who participated in the research.

Table 4.4 The sample range of participating female patients (N=52)

CULTURAL ORIGINS	NUMBER OF PATIENTS
ENGLISH	3 (6%)
AFRIKAANS	1 (2%)
ZULU	20 (38%)
VENDA	2 (4%)
TSONGA	3 (6%)
TSWANA	5 (10%)
SEPEDI	6 (11%)
INDIAN	3 (6%)
COLOURED	1 (2%)
OTHER	8 (15%)
TOTAL	52 (100%)

The total number of patients sampled was 52 from more than eight cultures and with eight languages (see Annexure H). The percentage figures indicated the ratio to the overall number of participants in the women with fibroid uterus.

4.4.2.3 The inclusion criteria for doctors

The 25 doctors from different categories of medical practitioners who were registered with the SAMHC, and working in the gynaecological wards and GOPD at Johannesburg Hospital for two years or more. Table 4.5 illustrates the different categories from which the doctors were sampled.

Table 4.5 Sample range of doctors (medical practitioners)

CATEGORIES OF DOCTORS	CONSULTANTS	REGISTRARS	MEDICAL OFFICERS	TOTAL
TOTAL	11 (44%)	9 (36%)	5 (20%)	25 (100%)

The percentiles reflect the ratio to the overall 25 sampled doctors. The consultants are the senior medical practitioners who counsel and explain to the patients about fibroids, and the hysterectomy treatment available for the women and the reasons why. Also allowing the women to ask questions and further explanations, if needed. The success rate of the acceptance of the hysterectomy operation as a treatment of fibroid uterus, depend on the explanation and counselling done by the consultant and other members of the medical team. The women are allowed to have their next of kin with them if their relationship will not be compromised, and the patient’s rights be infringed with. The women have a choice about their own bodies and lives despite their different cultures as stipulated in TOP Act (*Act 92 of 1996*) (South Africa (Republic) 1996:6-7).

4.4.3 Sampling procedures

The sampling of the women from diverse cultures, different categories of doctors and nurses was made feasible due to their availability (Brink & Wood 1998:140; Polit & Hungler 1999:244). Whereas the women with fibroid uterus were selected on the basis of their representative probabilities, the doctors and nurses were selected on a random basis. Unlike the women with fibroid uterus – whose inclusion criterion was more culture-specific; the doctors and nurses did not have to comply with any cultural identity. The main criterion of inclusion for the doctors and nurses was the different occupational categories they were known with in the gynaecological areas in the hospital. This section focus on the processes leading to the participants’ selection.

4.4.3.1 Sampling of the women with fibroids

The 52 female patients were selected from the categories of those who were diagnosed with fibroids, and were to undergo hysterectomy within five days of their admission in ward 196. A thorough explanation of the research had been made to the women. These women had granted permission for their participation in the research, and were given questionnaires to complete. Some patients were unable to read or write, yet showed great interest in the study and agreed to be interviewed by the researcher. Consequently, they were integrated into the core sample size.

4.4.3.2 Sampling of the nurses

The 15 nurses were also chosen through random sampling from among the registered, enrolled nurses and the enrolled nursing assistants from both wards 196 and 197 and the GOPD areas. A pre-trial of the questionnaires indicated that the nurses would require further verbal clarification of the contents of the questionnaires, before they could embark on completing them. A meeting was then scheduled between the nurses selected for participation, and the researcher. All their concerns were addressed, and an undertaking by the researcher, ensured that they offered their undivided participation. They could complete their questionnaires in their own languages. Figure 4.2 illustrates the different categories of the sampled nurses.

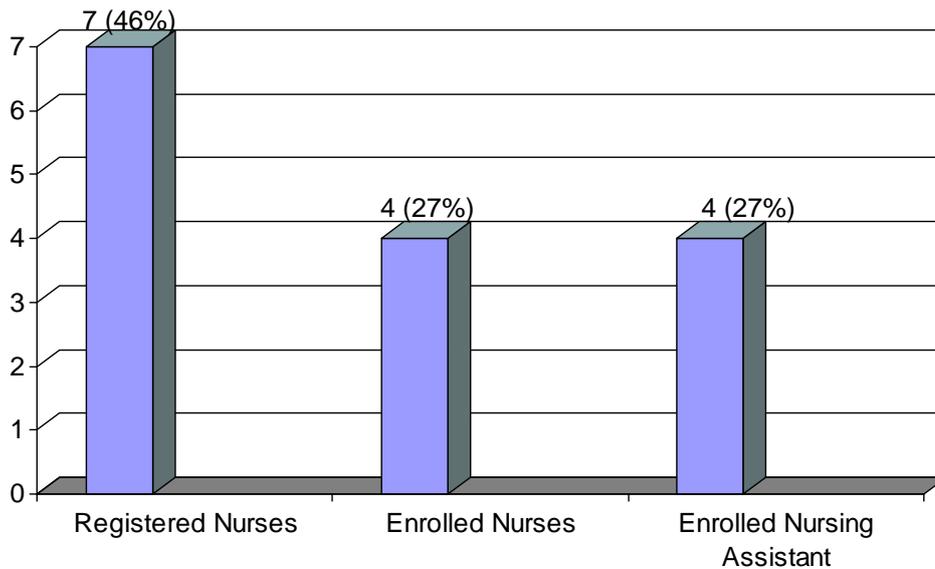


Figure 4.2
Profile of sampled nurses

The percentage numbers in brackets indicate the ratios in relation to the overall number of nurses 15, sampled in this nursing practitioner's category.

4.4.2.3 Sampling of the doctors

Random sampling was implemented in the selection of the medical practitioners in gynaecological department. Twenty five doctors complied and were given questionnaires to fill-in and complete. No hindrance was encountered with the doctors, as they all completed the questionnaires, except only one that was never returned. However, the unreturned questionnaire did not have an adverse effect in the analysis and interpretation of the data. Figure 4.3 illustrates the sampling profile of the participating doctors.

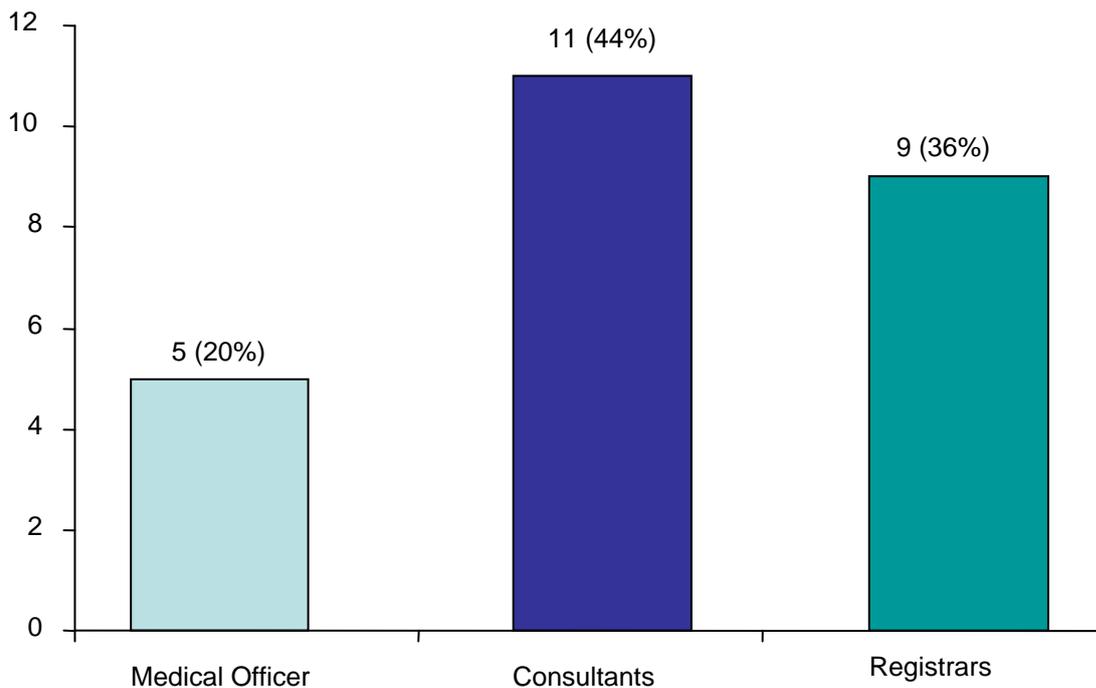


Figure 4.3
Profile of sampled doctors

The percentage figures indicate the ratios in relation to the overall number 25, of medical practitioners in their different categories. The consultants are in the majority as they are to teach the other medical juniors practitioners as their supervisor and mentor and advice an appropriate treatment action for the women with fibroid uterus, relating to the performance or non-performance of hysterectomy to these women.

4.5 THE INTERVIEWS

Structured interviews were implemented in advancing the collection of relevant data for the research project other than participant observation, questionnaire formulation and distribution. Each sample category had its own separate interview schedule. The structured interview session with the women with fibroid uterus, was important in that it provided another opportunity for the researcher to observe the feelings, emotions, and personal interactions of the respondents. Data collection refers to gathering information to address a research problem (Polit & Beck 2006:498). Data from the patients was collected between May and September 2006, with interview periods of between 45 minutes and one hour. The doctors and nurses completed their forms in approximately 30 minutes. The total number of hours spent gathering data was approximately 100

hours for patients and approximately 20 hours for health practitioners. The distance travelled by the researcher to Johannesburg Hospital was 2 km per visit to conduct the study.

4.5.1 Structured interviews with women with fibroid uterus

The questionnaire consisted of questions relating to demographic information of the patients, which would project the age, educational level, race, religious affiliation, language, employment status, marital status, region, parity and patients' family background, included their past medical and surgical history. The questions explored the patient's knowledge regarding fibroids in the uterus; the family's knowledge of the problem; their advice to the patient and recommendations for treatment and its effect; the treatment of choice that they were admitted for at the hospital; different health facilities used; the attitude of the patient's community/society as a whole about fibroid uterus and hysterectomy; the impact of uterine fibroids on these women, and their thoughts about what effect hysterectomy would have on them as patients in totality.

The African women who could not respond to the questionnaires written in English were interviewed in their own languages as questionnaires were prepared in eight different languages (see Annexure H).

4.5.2 Structured interviews with medical practitioners

The nature and types of questions in this schedule were meant to determine the extent to which women with fibroid uterus from diverse cultural backgrounds, were provided with appropriate pre- and post hysterectomy advice, treatment options, and counselling services by the medical practitioners or not. The importance of the pre- and post hysterectomy emphasis of the questions, is that it reveals on the information imparted to the patients with regard to RHT incidences and signing of informed consent forms. These questions assess the preparedness of these women to be operated on, which helps to establish the women perceptions of hysterectomy as a life-saving procedure. Additionally, the questions are designed to explore the doctors' own opinions about the state of the women's knowledge levels and personal experiences from their various cultural contexts. Determining the nature of the advice given to the patients by doctors, reveals on whether there was a relationship between the advices and the women's final

decisions to accept or reject the performance of hysterectomy on their bodies. The purpose was to establish the doctors' understanding of the perceptions of these women with fibroid uterus, regarding hysterectomy, when they examined them, discussed the diagnosis and advised the treatment (hysterectomy) before signing consent.

4.5.3 Structured interviews with nurses

The nurses' interview schedule is different from the medical practitioners'; mainly due to the time the nurses usually spend with the women in the rendering of their duties. Secondly, and from a practical observational perspective, the women appeared to have "openness" (freedom of speech) relationship with the nurses than with the doctors. The purpose was the same as for the doctors, namely to establish the nurses' own understanding of the perceptions of hysterectomy of women of diverse cultures, with fibroid uterus.

4.6 DATA ANALYSIS

Qualitative data analysis was used in this study. Data collection was done simultaneously with data analysis because the two are integrated. The results of each analysis guided the continuation of data collection. Data analysis is done to synthesize the raw data collected into ideas, which gives or creates meaning of the topic of study (Burns & Grove 2001:604-615; Johnson & Christenson 2001:420, 425; Neuman 1997:420).

The study is qualitative in orientation, with quantitative aspects integrated to maximize the collection and analysis of data. The qualitative nature of the study implies that descriptive characteristics (e.g. questionnaires, interviews, and participant observation) advance the main intentions of the study. The quantitative aspect of analysing data gave a statistical value to the study under investigation. The statistical value could be construed as establishing quantifiable parameters for the data to be analysed (Polit & Hungler 1999:439).

A professional statistician analysed the data, using the Statistical Program for Social Science (SPSS) version 14.0.

Raw data is analysed during collection of data in the field interviews and during participants' observation. This continuous process is known as interim analysis (Johnson & Christenson 2001:425). The data is collected in massive form and reduction and interpretation of data is done during data analysis. This exhibits a consolidated picture of the study (Johnson & Christenson 2001:424-425; Neuman 1997:329). Data collected must be recorded, as this is the analytic insight of what is happening or notes of the researcher or memos. Researchers avoid using their own memory and being biased (Burns & Grove 2000:592; Johnson & Christenson 2001:425-426; Neuman 1997:335).

4.6.1 Process of analyzing

Field notes and tape recordings were analysed by the researcher and an independent expert who is a specialist in gynaecology.

The researcher and the independent expert coded the data independently. Sentences or lines were arranged into meaningful units of data, using numbers, colours, letters and words as codes. The coders used bracketing (placing preconceived ideas within brackets) and intuiting (focusing on the perceptions of hysterectomy of women of diverse cultures with uterine fibroids, within five days of admission before operation) when reading through all the field notes and transcripts.

Main categories (same issues grouped inductively) were identified. Meanings related to identify categories were distinguished and sub-categories within categories identified. Same issues or relationships between the major and sub-categories were identified and reflected as themes. The interpretation of the same issues was done according to the settings in which they occurred.

The researcher and the independent coder reached consensus on the general interpretation. Results were reflected within the category of nursing a patient as a whole (Brink & Wood 1998:325-326; Neuman 1997:329, 421, 426-427).

4.6.1.1 Qualitative data analysis

For data to be effectively analysed, it has to be displayed, reduced, and interpreted (Johnson & Christenson 2001:424-425). The process by which data analysis occurred

facilitated the narrative reduction of large units of data into themes or categories that could be explored, defined and interpreted (Polit & Hungler 1999:427). Data display was facilitated with the presentation of the processes by which the information/knowledge from the questionnaires and the interviews was broken down into themes or categories. The actual responses from the three categories of participants appear in chapter 6.

The collection and analysis of data relating to the perceptions of hysterectomy by women of diverse cultural backgrounds with fibroids, was pursued with the integration of various forms of triangulation. Data triangulation -the availability of data from various sources, was facilitated with obtaining and listening to the personal testimonies of women when the researcher was still observing the suffering and experiences of these women, during the researcher's professional service in the gynaecological wards. A tape recorder was used to store the data of the women who were interviewed (see Annexure F).

The review of available literature on fibroid uterus and hysterectomy in a cultural context provided more insights as to what other practitioners and researchers in this field have already contributed (Mouton 2001:55).

4.6.1.1.1 Validity

Validity is a data measurement concept referring to the extent to which the measurement instrument measures what it actually intended to measure (Polit et al 2001:512). Validity could be related to the efficacy and effectiveness of the measuring instrument. For the effectiveness of measurement to occur, three forms of validity had to be utilised.

- **Construct validity**

The “construct” is the concept that was investigated. The study sought to investigate the perceptions of hysterectomy by diverse culture women with fibroid uterus at a specific designated research site. The construction of these perceptions obviously occurs within environments that are shaped and influenced by multiple factors. It was imperative that the research instruments (questionnaires and interviews) incorporate factors that indicated the circumstances under which perceptions of hysterectomy are constructed. These circumstances established a value between the construct and its perception. The questions generated aspects of human behaviour that brought new insights in the understanding of hysterectomy by women with fibroid uterus from culturally diverse backgrounds (Talbot 1995:279-281).

- **Content validity**

The pivotal focus of the questions framing the research instrumentation was the extent to which their content depicted a balanced reflection on all the aspects identified as generating new insights and knowledge into the area of knowledge under investigation. It is for the equitable validation of data through the content areas of the various instrumentation means, that pre-testing was implemented. All the experiences gained during the pre-testing of women facilitated a much-needed process by which the content of the questionnaires and/or interview schedule could be refined. The refinement was in the form of re-wording of some questions for clarity, some discarded and additional words added; especially those that were unclear, ambiguous, too long, or deemed by respondents to be biased. The refinement process could be viewed as having established some internal consistency or stability of the measuring instrument (Polit & Hungler 1999:183; Polit et al 2001:497).

- **External validity**

External validity relates to the extent to which the research instrument to various constituencies regarded as being representative of the sampled units of the population (Polit et al 2001:328; Talbot 1995:280-281). This study consist of three categories of its population namely, the women with fibroid uterus, the doctors working in different capacities within the gynaecological wards and nurses in gynaecological wards and in the

GOPD. Probability sampling was applied to effect inclusively of as much representative variability as possibility. By establishing a framework for representatively of the population outside of the main sample, the questionnaire design has affected the groundwork for both the generalisation and reliability of the main findings of the study.

4.6.1.1.2 Reliability

Reliability refers to “the extent to which the instrument yields the same results on repeated measures. Reliability is then concerned with consistency, accuracy, precision, stability, equivalence and homogeneity” (LoBiondo-Wood & Harber 2004:373). The refinement process of the research instrumentation attempted to ensure that among others, the data accruing from the instruments would be applicable elsewhere under the same conditions. Pre-testing revealed those aspects of instrumentation that were harmful to the effectiveness of those instruments. The refined questionnaires were the basis on which precise and unambiguous responses were elicited. A consistent research instrument was enhanced with the questionnaire translated in eight different languages, in order that the same content could be communicated to participants in a language with which they are very conversant. This latter orientation was a measure of ensuring that, despite the variability of circumstances and conditions, the same content was repeatedly administered; in this way, stability and consistency were achieved (see Annexure H).

4.6.1.1.3 Credibility

Credibility refers to the degree to which the quality of the data and the instrumentation used in its acquisition yield findings that are trustworthy. To generate findings that are dependable, confirmable, and trustworthy/truthful (Polit et al 2001:314-315), a wide ranging basis for population’s participation was observed. By utilising probability sampling in all the three population groups, each group of doctors and nurses would provide complementary perspectives on hysterectomy-related issues. The extended periods of participant observation during the professional engagement with women was in itself a mechanism for ensuring that the execution of the research instruments was based on social construct perceptions of hysterectomy by women with fibroids that was reflective of human behaviour in context-specific application. The research instruments – the questionnaires and interview schedules with the nurses and the doctors – became

the mechanisms for establishing the extent of conformability in that, each group would independently provide its own opinions regarding the perception of hysterectomy by culturally diverse women with fibroid uterus in the gynaecological wards of the Johannesburg Hospital.

4.7 ETHICAL CONSIDERATIONS

Ethics is associated with morality and deals with matters of right and wrong. This implies that anyone involved in social scientific research should be aware of agreements shared by researchers and participants about what is proper and improper in the conduct of the research (Babbie & Mouton 2002 :470).

In this study, the following ethical considerations were observed:

4.7.1 Permission to conduct the study

Before commencing the study, the researcher requested permission from:

- The head of Department of Health Studies, UNISA, Pretoria (see Annexure A).
- The Department of Health, Gauteng Province, to conduct the study in the Johannesburg Hospital (see Annexure B).
- The medical superintendent of the Obstetric and Gynaecological Department in the Johannesburg Hospital (see Annexure C).
- The head of Department of the Obstetric and Gynaecological areas in Johannesburg Hospital where the research or study will be conducted (see Annexure D).

4.7.2 Voluntary participation

The researcher explained the research process to the participants and the implications of involvement in the study. The following principles were explained:

- Purpose and significance of the study to the respondents.
- Their participation was completely voluntary (Babbie & Mouton 2002:470).
- There are no benefits to be had from their participation, except the acquisition of knowledge on this topic and the improvement of health care provision for female patients, to have a gynaecological friendly set-up in hospitals around South Africa.
- How long the research study will be done.
- No experimentation or clinical trials were involved (Uys & Basson 1985:98-99) (see Annexure E).

Informed consent means that participants “have adequate information regarding the research, comprehend the information and have the power of free choice enabling them to consent to or to decline participation in the research voluntarily” (Polit & Hungler 1999:134).

The researcher explained the nature, purpose and significance of the study to the participants and informed them of their right to voluntary participation, respect, anonymity, confidentiality and no harm. The participants were informed that they were free to withdraw from the study at any time, without being coerced to participate because of fear of being negatively affected with regard to their care, if they refuse (Burns & Grove 2001:196-206). The researcher obtained consent from the:

- Patients diagnosed with fibroids for hysterectomy (see Annexure G).
- Medical practitioners of different categories (see Annexure G).
- Nurses of different categories (see Annexure G).

4.7.3 No harm to participants

The ethical norms of voluntary participation and no harm to respondents are formalised in the concept of informed consent. Participants must base their voluntary participation on a full understanding of possible risks involved (Babbie & Mouton 2002: 471). Accordingly, the respondents were informed that they had the right to withdraw at any time and could refuse to provide information (Polit & Hungler 1999:133). Participants in research need to be free of harm or exploitation, and their dignity respected (Polit & Hungler 1999:134).

The participants' information was treated with honesty and raw data could be given to them only. The researcher was not to subtract or add any information given by the participants (Burns & Grove 2001:199, 201, 203).

4.7.4 Anonymity

The researcher informed the participants that their anonymity would be assured because no names would appear on the questionnaires. Furthermore, no one involved in reading, listening to the tape recorder or analysing the data would be able to identify respondents with any given responses (Burns & Grove 2001:201). The researcher assured the anonymity of participants in the study report (see Annexure E).

4.7.5 Confidentiality

The researcher informed the respondents that their responses would be treated with strict confidentiality and their identities would not be divulged to anyone (Babbie & Mouton 2001:472; Burns & Grove 2001:201). The questionnaires were numbered to have some control in terms of completed questionnaires received back by the researcher.

4.7.6 Right to self-determination

Polit and Hungler (1999:133) point out that participants have the freedom to control their own activities, including their voluntary participation in research. The right to self-determination includes freedom from coercion, which involves explicit or implicit threats

of penalty when failing to participate or agreeing to participate. The researcher informed the respondents that they were free to participate or refuse to participate, and could leave the study at any time should they so wish.

4.8 SUMMARY

The chapter outlined and presented the research design and the methods of research used to achieve both the general purpose and main objectives of this study. Participants or population were sampled from women of diverse cultures with fibroid uterus, doctors and nurses. Through questionnaires and interviews for each participant category, the researcher was able to gather the information needed for this study, though some people were still not free to participate in the research. The observance of ethical issues also ensured the study's successful completion.

4.9 CONCLUSION

This chapter dealt with the salient stages and processes of the practical research process including data collection for the research project. An investigation was conducted to determine the extent of the different participants' understanding of hysterectomy and its critically related issues. Although women with fibroid uterus constituted the critical tenet of the stakeholder constituencies, it was also important that the survey not be confined to them only. Doctors and nurses for instance, worked closely with these patients, and their input was helpful in collating an integrated framework within which women with fibroid uterus formulated their perceptions on hysterectomy. The following chapter discusses the data presentation analysis and interpretation.

CHAPTER 5

Data presentation, analysis and interpretation

5.1 INTRODUCTION

This research project focused on the perceptions on hysterectomy by women with fibroid uterus from diverse cultures. The first methodological consideration was whether the methods applied rendered the analysis of the research results meaningful. The implementation of method triangulation (for example, through structured questionnaires, participant observations, literature reviews, interviews and focused group discussions) collectively ensured that the pre-analysis phase was conducted on the basis of creditably-acquired data (Polit & Beck 2004).

The collected data was coded in accordance with the Codebook, and subjected to a verification process. Where necessary, data was tape recorded and corrected, especially for what may have been some inherent statistical and factual mistakes and any misreporting that might have accrued. The verification process was also a mechanism for eliminating the researcher's bias; enhancing the quality of the data. Given the purpose of the research project which is to explore and describe the perceptions of women with fibroid uterus from diverse cultures regarding hysterectomy, it was necessary to interpret the credibility, meaning and the significance of the collected data.

5.2 DATA ANALYSIS

The significance, implications, credibility, and generalisability of data were determined through a process of integrating qualitative approach, which enhanced the complementarities and validity of the findings of the study (Polit et al 2001:214-216). Raw data was recorded and analysed during collection of data in the field interviews and during participant observation sessions. This continuous process, (Johnson & Christenson 2000:425), facilitated the on-going analysis and identification of inherent flaws (Burns & Grove 2001:592). The data was collected in massive form, and had to be reduced into

statistically quantifiable and meaningful constructs, in order that a consolidated picture of the study is presented in graphic images (Johnson & Christenson 2000:424-425; Neuman 1997:329). The data to be analysed are from the three sets of different questionnaires which have been used during the process of data collection.

5.2.1 Process of data analysis

Fieldwork, especially in the case of participant observation, was facilitated through notes, and tape recordings. An independent expert, who is specialist in gynaecology, was also incorporated into the data analysis process. The coding and interpretation of data (transcribed interviews and field notes) was implemented by both the researcher and independent expert. Coding of data was reflected with the marking of sentences or lines into meaningful units of data. Various means of coding were used for numbers, colours, letters and words. When reading through all the field notes and transcripts the coders will use bracketing (placing preconceived ideas within brackets) and intuiting (focusing on the perceptions of women of diverse cultures with fibroid uterus, regarding hysterectomy within five days of admission before operation). Major categories and sub-categories of same issues were identified and grouped inductively. Same issues or relationships among the major and sub-categories will be identified and reflected as themes. Interpretation of the same issues was in accordance with the settings in which it occurred.

Generalisation of interpretation during the interim analysis phase was achieved by consensus between the researcher and the independent coder. Results ensuing from the data analysis will be reflected within the category of nursing a patient as a whole (Brink & Wood 1998:325-326; Neuman 1997:329, 421, 426-427).

5.2.2 Analysis of women with fibroid uterus' interview schedule

The following graphical presentation and analysis of the statistical information is in accordance with the three categories of the participants; namely, the women with fibroid uterus, the doctors, and the nurses.

5.2.3 Demographic information

The section consisted of 12 questions. The following is an analysis and interpretation of the data collected.

Question 1: Age of respondents

Table 5.1 Age distribution of respondents

Age distribution	Frequency	Percentage
50-59	13	25
40-49	29	55.77
30-39	10	19.23
TOTAL	52	100.0

The age factor creates some interesting phenomenon in view of the fact that those between the ages of 40 and 49 years reflected the highest rate of uterine fibroids, which amounted to fifty-five percent. Contrary to expectation, the age group of 50 to 59 years did not vary much from the 30 to 39 years age group. The only disparity was six percent (6%). The high percentage group is predominantly the child bearing stages and has a high propensity for fibroids (see table 5.1).

Question 2: Educational level

Table 5.2 Respondents’ educational level

Age	Nationality	Educational levels	Frequency	Percentage	
30-39	Indian	Matric	1	1.92	
	Black		3	5.77	
	White	Std 8	1	1.92	
	Black		4	7.69	
	Black	Std 5	2	3.85	
40-49	Indian	Matric	1	1.92	
	Coloured		1	1.92	
	Black		4	7.69	
	White		1	1.92	
	Black	Teacher	1	1.92	
	Black	Std 9	2	3.85	
	Black	Std 8	2	3.85	
	Indian		1	1.92	
	Coloured		1	1.92	
		Black	Std 7	1	1.92
			Std 6	2	3.85
			Std 5	2	3.85
			Std 4	2	3.85
	Std 3		3	5.769	
	Std 2		1	1.92	
	Std 1		1	1.92	
	Low literacy levels	3	5.769		
50-59	Black	Matric	1	1.92	
		Std 9	1	1.92	
		Std 8	1	1.92	
		Std 6	2	3.85	
		Std 5	2	3.85	
		Std 4	1	1.92	
		Std 3	1	1.92	
		Std 2	1	1.92	
		Std 1	1	1.92	
		Low literacy levels	1	1.92	
TOTAL			52	100%	

Women with lower levels of formal education are overly represented. While this might be a reflection of disparities in the availability and accessibility to healthcare services for this cohort, lack of awareness might not be ruled out. This might also suggest that lower socio-economic groups, blacks; tend to be over-represented at public health institutions. This is supported by the fact that socio-economic factors are closely related to individual educational levels; hence those who are categorized as not being poor women of other nationality; have the socio-economic means to access private healthcare institutions (see table 5.2).

Question 3: Marital status

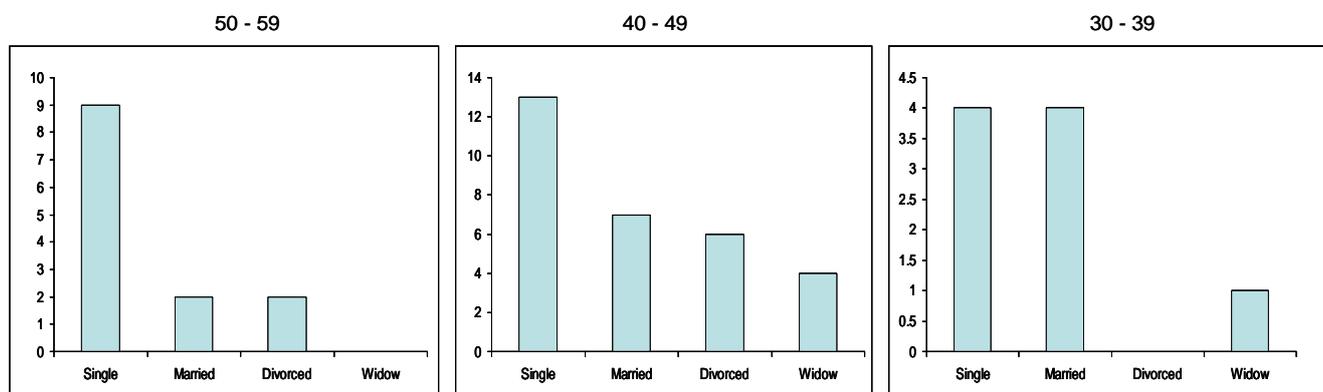


Figure 5.1

Profiled distribution of respondents' marital status (N=52)

The marital status of the participants has been considered in the light of the numerous misconceptions and derogatory statements associated with post hysterectomy experience. As shown in the figure 5.1 and table 5.3, there is a predominance of women who are single especially in the 50-59 and 40-49 age groups.

Table 5.3 Marital status of patients

Age	Marital status	Frequency	Percentage
50 – 59	Married	2	3.85
	Single	2	3.85
	Single, living with a boyfriend	6	11.539
	Divorced	1	1.92
	Divorced, living with a boyfriend	1	1.92
	Separated, living with a boyfriend	1	1.92
40 – 49	Married	4	7.692
	Separated	1	1.92
	Separated, living with a boyfriend	2	3.85
	Widow	1	1.92
	Widow, living with a boyfriend	3	5.769
	Divorced	3	5.769
	Divorced, living with a boyfriend	3	5.769
	Single	2	3.85
	Single, living with a boyfriend	11	21.154
30 – 39	Married	4	7.692
	Widow, living with a boyfriend	1	1.92
	Single, living with a boyfriend	4	7.692
TOTAL		52	100.0

From table 5.3, single women constitute the majority of the 52 respondents, at 26 (50%). From these, the majority are 13 (25%) from the 40-49 age group; 9 (17%) from the 50-59 age group; and 4 (7%) from the 30-39 age group. It is insightful that single women as a female category would be in the majority.

Question 4: Racial distribution

Table 5.4 The racial distribution of respondents

Age	Racial distribution	Frequency	Percentage
50-59	Black	13	25
40-49	Black	24	46.15
	Coloured	2	3.85
	White	1	1.92
	Indian	2	3.85
30-39	Black	8	15.39
	Indian	1	1.92
	White	1	1.92
TOTAL		52	100.0

In this racial distribution, a high percentage of women with fibroid uterus has materialized among black patients. Despite these reflections, it would be proper to resort to analytic specificity that would be required to deal with the skewed representations due to the over-representation of black female patients in this category. It is interesting to note that, there seems to be a relationship between race and fibroid occurrence in table 5.3, White and Indian women collectively present a very low incidence of the fibroid when compared to their Black counterparts in all the age groups. Furthermore, of all racial groups in table 5.2, Black women patients reflect the lowest levels of literacy in all age groups.

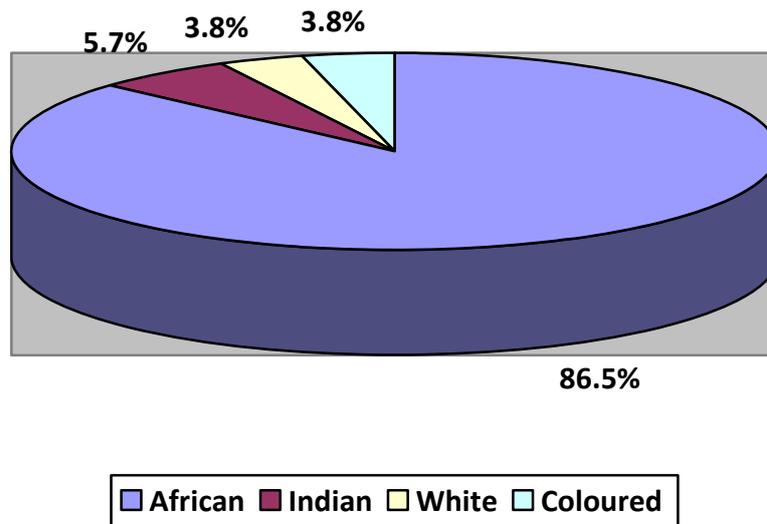


Figure 5.2
Pie chart of patients' racial distribution (N=52)

Question 5: Languages

Table 5.5 Women with fibroid uterus' languages

Racial group	Languages
White	English Afrikaans
Coloured	English Afrikaans
Indian	English Afrikaans
Blacks	Sepedi; Isizulu; Xitsonga; Tshivenda; Isixhosa; Setswana

South Africa consists of 11 language groups, with the sign language still battling for official validation and recognition. Most patients interviewed use more than one language for their daily communication and interactions. The multi-lingual and multi-cultural origin of the women patients at the Johannesburg Academic Tertiary Hospital necessitated the translation of the interview schedules for the women patients. Translations resulted in eight languages of the interview schedules for the women with

fibroid uterus so that the women were conversant with the interview schedule's requirements(see table 5.5).

The healthcare practitioners did not experience much difficulty in completing the interview schedules in English. It was important for these women to express their psycho-social and cultural opinions thoroughly in order to facilitate unambiguous communication and understanding (Gilbert, Selkow & Walker 1997:4).

Question 6: Employment status

Table 5.6 Respondents' employment status

Item	Frequency	Percentage
Employed women	40	76.92
Unemployed women	12	23.08
TOTAL	52	100.00

Amongst the seventy-seven percent of the women were fully employed as domestic employees and other types of work, for example a teacher. The domestic workers have limited time at their disposal for personal physical assessment by medical practitioners, because of their daily working schedules. The lack of time to consult for their health result in the progressive growth of the tumour or fibroid.

Question 7: Religious affiliation

Table 5.7 Respondents' religious affiliation

Item	Frequency	Percentage
Religiously affiliated	51	98.08
Not religiously affiliated	1	1.92
TOTAL	52	100.00

Table 5.7, reflects the statistical distribution of religious identities, rather than the role of religion in decisions of hysterectomy. For that specific reason, it does not necessarily prove that the majority or minority supports, or is opposed to hysterectomy.

Question 8: Parity

Table 5.8 Parity category of respondents

Age distribution	Parity	Frequency	Percentage
50-59	P7	1	1.92
	P5G6	1	1.92
	P4G5	1	1.92
	P3G4	1	1.92
	P3	1	1.92
	P2G3	1	1.92
	P2	2	3.85
	P1G4	1	1.92
	P1	1	1.92
	P0	2	3.85
40-49	P5G6	1	1.92
	P4G6	1	1.92
	P4G5	1	1.92
	P3G4	2	3.85
	P3	7	13.462
	P2G3	3	5.769
	P2	3	5.769
	P1G2	2	3.85
	P1	2	3.85
	P0G1	4	7.69
	P0	3	5.769
30-39	P3G4	1	1.92
	P3	1	1.92
	P2G6	1	1.92
	P2G3	1	1.92
	P1G3	1	1.92
	P1	2	3.85
	P0	3	5.769
TOTAL		52	100.00

In the various parity distribution categories in table 5.8, no significant differences came forth in the data analysis, except for the fact that a significant difference existed for groups with more or less three off-springs. The differences in the number of pregnancies whether full term or not, did not seem to have any bearing on the development of fibroid uterus.

Question 9: Regional distribution

Table 5.9 Regional distribution of women with fibroids

Age distribution	Regional distribution	Frequency	Percentage
50-59	Soweto	3	5.77
	Suburbs (Johannesburg)	8	15.39
	Alexandra	1	1.92
	East rand	1	1.92
40-49	Soweto	4	7.69
	Informal settlements	2	3.85
	Alexandra	3	5.77
	Hill brow	3	5.77
	Suburbs (Johannesburg)	8	15.39
	East rand	3	5.77
	Secunda (OFS)	1	1.92
	Johannesburg City	5	9.615
30-39	Alexandra	3	5.77
	Johannesburg City	1	1.92
	Hill brow	3	5.77
	Suburbs (Johannesburg)	3	5.77
TOTAL		52	100.00

For the 50 to 59 age group, as well as the 40 to 49 years age cohort, there is a high frequency of suburban residents. These are domestic employees who might be resident at other non-suburban areas. Soweto (South Western Townships) has the second highest representative figures, except in the 40 to 49 age categories; with the Johannesburg City comprising the third largest group. This is an indication of the employability status of the 40 to 49 age category. The research also indicated that within this 40 to 49 age category, there are some respondents who resided in the informal settlements. According to Burger and Beard (1998:139), in the South African year book, “a rapid growth of informal settlements contributes to increasing competition between urban land-users”. Regional disparity therefore was difficult to control, given the temporary residential arrangements.

In the age categories of 50-59, 40-49 and 30-39 years, Hillbrow and Alexandra areas are the third most densely populated areas. The 40-49 and 30-39 age groups tend to have high frequencies of occupation in these areas than among the 50-59 age groups. The 40-49 and 30-39 age groups as employable and are caught up in the urbanization process taking place in the country, which influences the health status of people living in informal houses around the city. People from rural areas, because of the uneven economic developments in the country, migrate to urban metropolitan areas in search

employment opportunities. The age group between 50 and 59 years age group has a lower frequency of 1 (one). This is associated with the exodus of this age category back to areas of their origin as they are out of work and are beginning their pension days. Poor living conditions and unemployment, which result in health problems and lower standards of living within the poverty-stricken communities, are mostly found around urban areas (Roux 1995:177).

Urbanization factors, such as the regional placement and distribution of people in socio-economically differentiated residential areas, was a significant observation in terms of the post-operative management of a variety of diseases; including hysterectomy. For instance, Burger and Beard (1998:139) emphasizes that "... pollution and related diseases results from the reliance of such communities on untreated water, wood or coal as sources of domestic fuel. These are exacerbated by lack of health sanitation conditions". In such conditions, the rehabilitation or post- hysterectomy follow-up of a recuperating woman would be immensely challenging.

Question 10: Medical history

Table 5.10 Medical history of women patients

Age	Medical History	Frequency	Percentage
50-59	Depression	1	1.9
	HIV	1	1.9
	None	8	15.4
40-49	Endometriosis	1	1.9
	Hypertension	6	11.5
	Thyroid	1	1.9
	Diabetic	1	1.9
	None	18	34.6
	Nervous system disease	1	1.9
	Hypertension	1	1.9
	Renal TB & Heart disease	1	1.9
30-39	Ulcers	2	3.9
	Diabetic		
	Hypertension	1	1.9
	Renal		
	Hypertensive	5	9.6
None	5	9.6	
TOTAL		52	100.00

Table 5.10 indicates that women of all age categories are admitted into the gynaecological ward with some kind of physiological ailment. Such women were already

receiving treatment assistance from personal or family medical practitioner. The 50 to 59 age category is of interest by showing a null occurrence of hypertension, as it is the disease associated with the anxieties and other psycho-social disorders that make the woman vulnerable. The only two cases of depression in this age group were those of depression by one woman who underwent TOP twice, and the other one was HIV positive. The hypertension suffering groups also had excessive bleeding and severe abdominal pains as a result of excessive worries or anxieties. This is exacerbated by patients' daily contemplations about the causes of fibroids and many socio – cultural connotations attached to uterus with fibroid by the society these women find themselves in. Hypertension's manifestations include headaches, anxiety, worry, dizziness, pallor, fatigue, irritability, and are prevalent in the women with fibroids. There is a high incidence of hypertension in female especially those that are overweight. A further study is needed to check on the correlation between fibroids and hypertension (Cramer & Patel 1990:437; Gilbert, Selikow & Walker 1997:3-4; Walters 1998:118).

The 40-49 age cohorts are the most afflicted with frequencies of various illnesses prior to their hospitalization. Women with fibroid uterus in this age category, with a total of 29 from the overall total of 52, constitute a majority 56%. Attention to this particular group is also of particular interest in that it is a category which exhibits a relatively high degree of parity (see table 5.7).

Question 11: Gender

Table 5.11 Gender distribution of all respondents

Item	Frequency	Percentage
Females	81	88.04
Males	11	11.96
TOTAL	92	100.00

The gender distribution frequencies indicated above apply across all participant categories; that is, nurses, doctors, and the women with fibroid uterus. The dominantly female population (in addition to the 52 women patients) has the cumulative effect of yielding an approximately accurate depiction of the hysterectomy perspective from women's experiences. On that basis, there was an increased potential that females would tend to exhibit patterns of empathy.

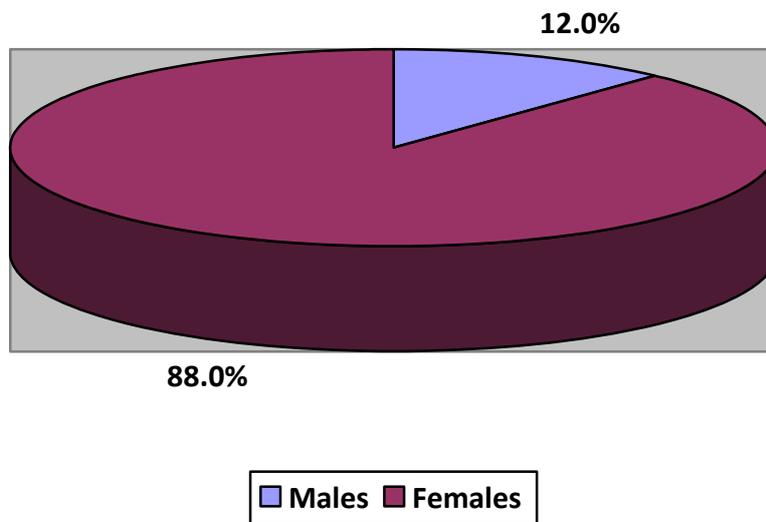


Figure 5.3
Gender of participants

5.3 ANALYSIS OF NARRATIVE STATEMENTS

The narrative statements are those orally obtained responses obtained during the focus group discussion, and through tape recorder interview. The focus of these discussions and interviews was on determining the general knowledge levels on hysterectomy, through questionnaires (see Annexure H). The thematically data reflects the understanding and perceptions from the viewpoint of the respondents.

5.3.1 Thematic categories

Table 5.12 Thematic categories of description

	Category (dominant)	Frequency	Percentage
1	Pregnancy	4	12.5
2	Growth	20	62.5
3	Sore	3	9.4
4	Lump/mole	3	9.4
5	Foreign body/"animal"	2	6.3
TOTAL		32	100.0

Table 5.12 depicts the thematic categorization of descriptions of hysterectomy by respondents. Twenty (62%) of the respondents described the fibroid as a “growth”. There were some correlations between the traditional healers’ life-world and the meaning attached to the fibroid. Respondents who usually consulted traditional healers were generally told by the traditional healers that it was a “foreign object” in their uterus – described as an “animal”, or a piece of flesh that gradually increased in size. Other similarities cited in the descriptions were “sore lump, mole, pregnancy, as well as an enlargement”. The shape of the fibroid seemed to have influenced the descriptions as well as the attachment of meanings. Some respondents describing the fibroid as a kind of “potato” (see chapter 2, figure 2.1).

The meaning attributed to fibroid as “clots” was equally revealing in that the post-partum bleeding is acceptable as an act of “cleansing”. The perception that bleeding is a requisite for “cleansing” a uterus with fibroid seemed a dominant theme among others. That was construed as the reason for women enduring excessive bleeding without consulting their health practitioners for help. The clinical manifestations of fibroid uterus seemed to be regarded as “sequelae”, instead of symptoms, as a result of the presence of fibroids.

Table 5.13 Congruence of clinical manifestations of fibroid uterus

Clinical manifestations	Frequency	Percentage
Bleeding	8	25
Pelvic abdominal pains	8	25
Headache	4	12.5
Dizziness	2	6.3
Pallor	3	9.4
Urine retention	2	6.3
Abdominal distension	3	9.4
Oedema of the legs	2	6.3
TOTAL	32	100.0

The symptoms of fibroid uterus which are most frequently mentioned by respondents included bleeding, pallor, urine retention and pelvic abdominal pains. These clinical manifestations are precisely what the scientific investigations have revealed over the year. The degree of congruence or correlation between the respondents’ descriptions and the scientific/ clinical perspectives is high. Information from the various respondents was pertinent as it specifically focused on similarities or congruence of meaning attached to fibroids and hysterectomy by the health practitioners. Pallor for example, is a result of constant bleeding as a result of fibroids. Rather than expecting respondents to give meanings that are known – which was essential information – cultural meaning was also necessary since this study is primarily concerned with the dearth of culture and sub-culture data on hysterectomy due to fibroids.

By categorizing the narrative statements according to known clinical symptoms, this process assisted the research to discern certain patterns in the types of descriptions and meanings of what exactly fibroid and hysterectomy entail according to the respondents.

5.3.2 Interpretation of patterns of narrative responses

The interpretation of these patterns reinforced the descriptions and meanings, and the respondents’ connotations of the meanings resulted in narrative analysis. A closer examination of the descriptions of the respondents who consulted traditional healers shed certain commonalities in their meanings. The women’s choice of words varied from group to group. The women with fibroid uterus seemed to use words that justify the need to blend the required intervention. For instance, perceptions based on the

presence of “a foreign object” seemed to guide the women’s desire in assisting healthcare practitioners in the choice of their (women’s) preferred intervention. A traditional healer does not perform surgical procedures for instance; an operation is therefore considered an appropriate solution for the effective removal of fibroids in the uterine.

The belief that adequate post-partum bleeding is necessary is in total harmony with the belief of respondents who use traditional healers. For them, adequate health is achieved through bleeding, regarded as “cleansing”- an apparent culturally appropriate phenomenon associated with expectation. The view that some supernatural force is involved resulted in the descriptions of the fibroid as some kind of “animal” embedded in the uterus. Contrary to the meaning of “growth”, the concept “animal”, requires total removal of the “animal”; thus justifying a total removal of the womb or uterus. In this case, perception is still congruent with the surgical procedure in the removal of “the animal” as the traditional healers’ approach would be incapacitated by its non-surgical orientation. Cultural diversity was evidenced in the meanings which reflected inter-group disparities. The selection of the meaning seemed to determine what the respondents or the practitioners deemed desirable intervention.

The narrative analysis incorporated themes regarding clinical manifestations such as sequelae, supernatural force, animal, potato, to name a few. This further provides multiple frameworks of meaning-making about the use of words to support or promote a particular point of view deemed as the desired health intervention for a woman whose fibroid uterus could not be saved. The total removal of the uterus is regarded in a particular cultural context as the most severe surgical procedure that a woman can ever undergo – ‘the severance of her reproductive organs’. Some of the terms mentioned in association with the severance of reproductive organ (post-hysterectomy) mentioned were: “curse”, “hole”, “empty vase”, “cold”, “bridge”, “river/dam/water pool”, “nothing”, “man” and “barren”.

5.3.2.1 Attitudes derived from narrative statements

The descriptions and meaning given to hysterectomy indicated the negative notions that could hamper a woman’s rehabilitation after a hysterectomy. A woman who had undergone hysterectomy was regarded as a man; considered cold; a “plastic” inserted

in the place where the womb was; an empty vase, and a hole amongst many other derogatory and abusive dehumanizing descriptions. A woman, who had undergone hysterectomy, would therefore often develop negative feelings and a lack of self-esteem because of the intensity of these negative notions.

Upon the researcher's examination of the attitudes towards hysterectomy and the degree of negativity towards the procedure or the woman who had undergone such an operation (hysterectomy) reported by the respondents, convinced the researcher of the need to highlight and expose the negative sentiments. The purpose was to find ways and means to alleviate the emotional and psychological traumas to which such women are subjected. The fact that the society or community represented by these women associated hysterectomy with a curse indicated that measures might have to be taken to protect women who had undergone the operation and equip them with skills to cope within their environment.

In addition, there are diverse attitudes that are not necessarily culturally approved reactions. Cultural orientation to hysterectomy and women who had undergone hysterectomy created a certain pattern of behaviours that contributed to harmony.

The descriptions such as a curse, vase, hole, and bridge lacked indigenous substitutes. In a rural setting, for example, communities describe the meaning of hysterectomy as undesirable, cold, tasteless, useless, and empty. The way the notions of hysterectomy were used directly insinuated "erotic" meanings as opposed to the "violence" or negativity associated with a curse, a hole, a vase, or a bridge as espoused in an urban setting

Attitudes appeared to hinder or contribute to the rehabilitation process because the community's cohesion and attitudes frequently promoted a speedy recovery. Hysterectomy is undesirable but inevitable because even traditional healers concede by sending their clients to hospital for the removal of the "foreign animal" in them.

5.4 ANALYSIS OF HEALTHCARE PRACTITIONERS' QUESTIONNAIRE

This section focuses on an integrated descriptive/qualitative analysis of data respectively from medical practitioners and nurses. The respondents in this case were sampled on the basis of their knowledge and experience; that is, having worked in the gynaecological unit of the hospital for two years or more. The written questions posed to the doctors were different in focus from those posed for the nurses. The questions are aimed at eliciting the doctors' and nurses' views and understanding of the environment in which women with fibroid uterus construct their perceptions of hysterectomy.

5.4.1 Analysis of medical practitioners' questionnaire

A profile of medical practitioners outlined in chapter 2, indicates that these professionals were from the categories of consultants (11), registrars (9), and medical officers (5).

Consultants are the highest qualified practitioners and together with specialists, head the gynaecology sections of the hospital. Registrars have a Diploma in Gynaecology and Obstetrics, and medical officers are qualified doctors working in gynaecological areas. The doctors' questionnaire covered questions that women asked them before the operation and the counseling that women received.

Question 1: Questions asked by women during counseling session

Table 5.14 Women’s concerns during counseling

	Category of Concerns	Frequency	%
1	Will I have babies after undergoing hysterectomy?	11	44
2	Will I enjoy sex after undergoing hysterectomy?	13	52
3	Will I menstruate after undergoing hysterectomy?	9	36
4	Are there alternatives to the operation?	9	36
5	Will I lead a normal life after the operation?	7	28
6	What form of pain will I feel during, and after the operation?	4	16
7	What will happen to my ovaries?	7	28
8	How is the operation going to be done?	5	20
9	Complications of operation	6	24
10	Is there any association with breast cancer?	5	20
11	What is the timeframe allocated for going back to work after the date of the operation?	7	28
12	What causes menstrual bleeding?	5	20
13	What are the causes of fibroids?	3	12
TOTAL		52	100

Most of the women patients took a great deal of pains to seek information from the medical practitioners on a range of topics such as: sex, babies, menstruation and ovarian functions. Table 5.14 indicates the higher frequencies on these issues. Very few women sought information about the advantages of hysterectomy; that is, what will happen with their bleeding, wounds and pain as a strategy to fence themselves off from derogatory attacks that might be leveled against them. Less frequency was shown to highlight the impact hysterectomy would create on the lives of these women. Questions relating to post-hysterectomy impact on their sexual lives (52%) indicate that their relationships with their spouses is a major issue of concern, and may influence the decision on whether or not hysterectomy is opted for.

Question 2: Do these women receive sufficient counseling to enable them to sign informed consent forms?

Table 5.15 Provision of knowledge on informed consent sufficient or not

Response	Categories of medical practitioners	Frequency	Percentage
Yes	Consultants	8	32
Yes	Registrars	8	32
Yes	Medical officers	0	0
SUB TOTAL		16	64
No	Consultants	3	12
No	Registrars	1	4
No	Medical officers	5	20
SUB TOTAL		9	36
GRAND TOTAL		25	100

Counseling is an important service in the provision of healthcare. According to table 5.15, Sixteen (64%) of the medical practitioners excluding medical officers, were satisfied with the counseling processes and procedures conducted with the fibroid-suffering women before the signing of the informed consent forms. Only 9 (36%) of all the medical practitioners had raised serious concerns to the contrary. The concerns were largely premised on language barriers between patients and medical practitioners, and very busy GOPD Clinics made it very difficult for the medical practitioners to pay much more individualized attention to their patients during ward rounds. A suggestion was raised by the doctors that a detailed information booklet of different languages be produced for the benefit of the women with fibroid uterus and the public. The information brochure would be freely distributed among patients in the GOPD Clinics and during the counseling sessions.

Counseling and health education are components of communication in health care services. The National Health Care Services Plan promotes the quality of life through the recognition of and addressing issues related to sexual performance through the utilization of skilled personnel who could be trusted and accepted by the patients during health education counseling sessions (Shaw et al 2003:728).

Communication should be reciprocal for it to be effective in the health care sector. A lack of appropriate professionalism in this regard might result in complaints and litigations and is thus a Clinical risk. These can be avoided, reduced or eliminated

through effective, continuous training and the development of suitably qualified Health Care Providers (Shaw et al 2003:983-984).

Situations where patients' whose intellectual capacity is undermined and those with uterine fibroids are forced into operating theatres should be completely abolished because consent must first be sought from women affected in order to arrive at an amicable agreement for hysterectomy to be performed (Walters 1998:110).

5.4.2 Analysis of nursing practitioners' questionnaire

As indicated in table 4.2 and table 4.3, the total number of sampled nurses (15) constituted 16% of the total number (92) of the entire sampled respondents. The professional nurses' questionnaire schedules consisted of ten items. These questionnaires were handed over to 15 nursing practitioners; 7 of whom were registered professional nurses, 4 enrolled nurses and 4 enrolled nursing assistants. All 15 nursing practitioners were under the supervision of experienced registered nurses whose period of professional service in the gynaecological areas ranged from two to eighteen years.

The work-related and professional experiences of the nurse practitioners guaranteed that high standards of healthcare delivery were applied and implemented, as required by the SANC's Rules and Regulations; as well as its Scope of Practice (South Africa (Republic) 1978:50).

5.4.2.1 Health education for women

Questions 1, 3, 4 and 6 of the nurses' questionnaire schedule specifically address the provision of healthcare information and knowledge to women patients in the gynaecological wards. The most ethically appropriate question that can be raised is whether nursing practitioners are responsible for the provision of health education of women with uterine fibroids. The 15 nursing practitioners unequivocally admitted that, apart from their treatment of the women with fibroid uterus, it was part of their duty to impart healthcare-related education, according to Regulation 2598 of the SANC (Regulation R2598 of 1978, as amended) (South Africa (Republic) 1984). Table 5.16 illustrates the nursing practitioners' response on the provision of healthcare education

relating to hysterectomy and fibroids. Some of the information and knowledge disseminated to women patients included the following:

- definition and explanation of fibroids and hysterectomy
- how fibroids and hysterectomy manifest themselves/ causes of fibroids
- effects of hysterectomy
- cultural beliefs about hysterectomy
- differentiation between medically appropriate facts and unsubstantiated claims

Table 5.16 Provision of hysterectomy knowledge to women patients

Item	Frequency	%
Information provision before the operation	4	27
Information provision before and after the operation	11	73
TOTAL	15	100

The majority of nursing practitioners (73%) affirm that women patients are health-educated before, and after the hysterectomy surgical procedure. Contrarily, 27% of these nurses are of the view that the educating of patients should only be conducted before the performance of the operation. The main purpose of health education is to ensure that the women understand both their rights and the conditions under which hysterectomy is performed. The establishment of such an understanding is for creating an atmosphere that is conducive for trust between patients and the healthcare practitioners. The patients tend to bond more easily with nurses than with the medical practitioners, as medical practitioners do not appear to have more time with their patients. The latter view was supported by some nursing practitioners in support of responses reflected in the questionnaires from medical practitioners. The women come from diverse cultures, speak different languages and have been socialized into different norms and myths that have been instilled in them from an early age. As members of different societal categories (such as racial, ethnic, cultural, and socio-economic), most nurses are themselves no strangers to some of these practices. They may have heard, or been exposed to some of these norms and myths through their own upbringing.

Education imparted by nursing practitioners to the women with fibroids should strive to give unambiguous definitions of key concepts such as “fibroids” and “hysterectomy”; and also provide a range of available coping mechanisms and treatment options. These forms of healthcare information and education provision have the positive effect of

alleviating unnecessary fears concerning hysterectomy by the women, their relatives and next-of-kin. Some ignorant people go about spreading false information that the uterus has been replaced with plastic material.

5.4.2.2 Attitudinal differences between women who received pre- and post-operation education

Question 5 of the nurse practitioners' questionnaire the majority of the nurses revealed that patients who received health education about their condition before signing consent for the operation, though emotionally upset, were able to accept their situation and were psychologically better prepared for hysterectomy. They accepted ownership of their own health care plans. However, women who received education and counseling after the operation were angry, aggressive and in a state of denial. Some of the women were confused and afraid that failure to bear children might lead to divorce or the break-up of the existing intimate relationship.

On the other hand, women who received education and counseling after the operation displayed characteristics of anger and aggression, and were in an unprecedented state of denial. Some of the women were confused and filled with fear that failure to bear children might lead to divorce or the break-up of their existing relationships with their partners.

5.4.2.3 Frequently asked questions about fibroids and hysterectomy

Question 9 of the nurses' questionnaire schedule provides some insights into the terrain of the most critical concerns raised by fibroid-suffering women. It is also worth noting that a degree of congruence exists between these questions and those that were posed to the medical practitioners (by the selfsame category of women patients) in table 5.14. The nurses indicated that the following were the most frequently raised concerns (by the selfsame category of women patients):

- the effects of hysterectomy on pregnancy and their sex lives;
- possible complications arising from hysterectomy
- the causes of fibroids
- myths surrounding fibroids and hysterectomy

- divorce issues
- physical changes

Most questions asked by the women with fibroid uterus who underwent hysterectomy show some similarities with those raised with medical practitioners. They were mostly around active sexual life and pregnancy. It was noted that the patients were more open in talking to the nurses, as they could talk about any subject from myths to cultural-social issues affecting their communities. Nurses could easily make referrals to relevant experts if they themselves could not be of help. This was a good example off the “*Batho Pele*” (“people first”) principles.

5.4.2.4 The responsibility of obtaining informed consent

Question 10 of the nurses’ questionnaire schedule focused on the responsibility of obtaining informed consent from the women with fibroid uterus. The main intention of the question was to find out whose responsibility it was to obtain the informed consent process.

All the respondents 15 nurses indicated that since the medical practitioner and the surgeon was part of the team consulting the patient, it would be best to entrust them with the responsibility of obtaining the patient’s consent. The nurses’ responsibility would be to reinforce and reassure the patient after the counseling sessions. Experienced registered nurses are equipped with skills and the know-how to answer patients’ questions or to make referrals to the medical practitioners for further explanation.

5.4.2.5 Overview of nurse practitioners' views on fibroids and hysterectomy

Questions 7 and 8 of the nurses' questionnaire schedule addressed the nurses' views insofar as fibroids and hysterectomy is understood.

Some of the registered nurses and enrolled nursing assistants regarded the fibroid condition as a common disease afflicting women. According to them, the disease was medically incurable, except if it was surgically removed. Some points of correlation existed between the nurses' views and those of the women patients. The former shared the latter's perceptions for instance, that: A woman whose uterus has been removed is but a "hole", "cold", "has lost her womanhood", is "psychologically negative" and that "her sex life is doomed". Despite these seemingly negative attitudes, it is still interesting to note that they still respect the rights of the patients and their autonomy in:

- seeking information
- making their own decisions; seek second opinion and alternative consultations
- being accorded privacy and confidentiality relating to any information about the disease and types of interventions opted for
- the right to refuse of hospital treatment

The above are also principles supported and endorsed by the Patients' Rights Charter of the Constitution of the RSA (South Africa (Republic) 1996: 6-24). From a public service point of view, the above principles also from the Bathopele initiative. From the observable and articulated feedback and responses obtained from the nurse practitioners, it is evidently clear that much still needs to be done in educating some nurses despite their professional exposures and experiences over the years. Some of them uplifted conservative views and attitudes perpetuate refusal of hysterectomy done by some of the women with fibroid uterus.

5.5 SUMMARY

The presentation, analysis, and interpretation of data relied primarily on the accumulated data from the interview and questionnaire schedules. Points of convergence emerged from some of the responses from all three sample categories. These points of convergence are understandable, since the questions posed to both the

nurses and the doctors were all premised on the women with fibroid uterus understanding of hysterectomy – from the perspective of the doctors and the nurses; insofar as their daily contact with these women could reveal. Of critical note is the observation that, abundant education and information dissemination initiatives are earnestly needed to bring the available medical treatment options into the consciousness of those who are apparently still bound by alternative treatment options that neither heal nor advance more insightful understanding.

5.6 CONCLUSION

This research project focused on the perceptions on hysterectomy by women with fibroid uterus from diverse cultures. The first methodological consideration was whether the methods applied rendered the analysis of the research results meaningful. The implementation of method triangulation (for example, through structured questionnaires, participant observations, literature reviews, interviews and focused group discussions) cumulatively and collectively ensured that the pre-analysis phase was conducted on the basis of creditably-acquired data (Polit & Beck 2004). Chapter 6 will address findings, conclusions and recommendations.

CHAPTER 6

Findings, conclusions and recommendations

6.1 INTRODUCTION

The purpose of the study was to explore and describe the perceptions of women with fibroids from diverse cultures regarding hysterectomy, present guidelines and help communities learn from its empirical findings. Throughout this study, the extent to which the aim and objectives of the study were achieved was of utmost importance in determining its contribution to the women's health.

The objective was to investigate and determine why women of different cultures did not want to be operated on when diagnosed with fibroid uterus. Accordingly, the study examined the following aspects: In its investigative approach, the focus has been to determine the underlying reasons behind the refusal to undergo operation by probing the following aspects:

- Why women from different cultures diagnosed with a fibroid uterus were reluctant to be treated and did not go for medical consultation even though the abdominal enlargement was not related to pregnancy.
- Why women who bleed profusely do not seek medical advice.
- Why is it difficult for women to accept their condition and seek medical intervention instead of "shop around" for alternative treatment when diagnosed positively of fibroid uterus.
- What perceptions of hysterectomy instilled fear of the operation in women.
- Why women avoid discussing treatment of fibroid uterus with their husbands or partners.

6.2 FINDINGS

6.2.1 Objective 1

Why the participants were reluctant to be treated and did not go for medical consultation even though the abdominal enlargement was not related to pregnancy.

The study found that most of the participants were middle aged and still of childbearing age. Many of them believed that they were pregnant. Illiteracy itself plays a part when those suffering from it assume that certain situations are “natural”. For instance, despite being fully aware that they are not pregnant, many women still refuse to be treated for abdominal enlargement when diagnosed with the fibroid uterus condition. Such women are still dominated by beliefs; such as the notion that the presence of a womb, even when it is fibroid, is the supreme manifestation of “womanhood”. Table 5.1 illustrated that 29 (56%) of those in the 40-49 years age group constituted the majority of those women suffering from the fibroid uterus. Those interviewed were of the view that they were pregnant. Due to cultural beliefs of keeping secrets, these women would not seek medical advice and stayed at home until there were serious, life-threatening complications such as severe lower abdominal pains, excessive bleeding with clots, dysmenorrhoea, dyspareunia, swelling of lower limbs due to pressure of the fibroids on the inguinal nodes, affecting the venous drainage of the lower limbs and anuria due to hydronephrosis of the ureters as the enlarged uterus presses on the ureters, which then compelled them to seek medical assistance. By this time, they had incurred serious physical damage for example: anaemia due to excessive bleeding with clots; where blood transfusion must be administered before hysterectomy can be done on the patients. Psychologically, the women are worried and afraid to loose their marriages especially those who are infertile and still have serious questions about their condition. Women who have not advanced far with formal education form a higher percentage of those with the uterine fibroid. Seemingly, ignorance plays a part in depriving them of the opportunity to benefit from easily available treatments.

6.2.2 Objective 2

Why, though bleeding profusely, the women never sought medical help.

Most of the participants had little formal education, lack of adequate information and knowledge and appeared to be ignorant of access to treatment, which was easily available. It is usual for public hospital to have a high number of low income patients who will procrastinate in seeking medical check-ups on time.

For most of the participants, postpartum bleeding was acceptable as an act of “cleansing”. If postpartum bleeding was arrested, the respondents regarded the existence of a fibroid as a “as a “clot”. The meaning attributed to fibroid as “clots” was equally revealing in that the post-partum bleeding is acceptable as an act of “cleansing”. The perception that bleeding is a requisite for “cleansing” a uterus with fibroid seemed a dominant theme among others. That was construed as the reason for women enduring excessive bleeding without consulting their health practitioners for help. The clinical manifestations of fibroid uterus seemed to be regarded as “sequelae”, instead of symptoms as a result of the presence of fibroids.

The perception that bleeding was a requisite to pre-empt non-fibroid uterus was a dominant theme. This has been cited as a reason why the respondents endured excessive bleeding without consulting their health practitioners for help. Moreover, the belief that adequate post-partum bleeding was necessary was in total harmony with the belief of those respondents who used traditional healers. For them, adequate health was achieved through bleeding regarded as cleansing, an apparent culturally appropriate phenomenon associated with expectation. These myth are taken as the true basis for constructing their perceptions, whereas informed knowledgeable women of diverse cultures will consult immediately due to their exposure to information about the danger of bleeding in a woman’s life.

6.2.3 Objective 3

Why the participants “shop around” for help when diagnosed with fibroid uterus.

Of the participants, 77% (n=40) were employed as domestic workers. Their medical history included previous conditions such as depression, endometriosis, hypertension, diabetes, thyroid problems, ulcers, TB and heart diseases (see chapter 4, table 4.9). These women were diagnosed with the disease before admission to the hospital and were already receiving treatment from personal or family sources including the traditional healers in certain cultures. The participants suffering from hypertension also had excessive bleeding and severe abdominal pains as a result of some anxieties. This was exacerbated by their concern over the causes of fibroids and socio-cultural connotations attached to fibroid uterus by the communities in which they found themselves. Some of the hospitals have long lists of gynaecological consultations and prospective patients to be operated on, and as such those in desperation will seek help from other avenues. It has also emerged from the observations that some working women would rather assemble with fellow workers and engage in idle talk, instead of visiting healthcare providers. These talks are usually regarded as therapy sessions and often lead to some unscientific and medically untested pieces of advice that complicate their condition, because they ultimately use non-researched cultural remedies (for example, aloe and enema) which further complicate their condition as it may even lead to the RHT.

Some of the participants described the fibroid as a kind of “potato”. There were some correlations between the traditional healer’s intervention and the meaning attached to the fibroid. Cultural diversity reflected intergroup disparities. The view that some supernatural forces were involved resulted in descriptions of the fibroid as some kind of “animal” embedded in the uterus. The selection of the meaning seemed to determine what the respondents or the practitioners deemed desirable intervention. For example, contrary to the meaning of “growth”, the concept “animal” required the total removal of the “animal” thereby justifying the total removal of the womb or uterus (the hysterectomy). The narrative analysis incorporated themes regarding clinical manifestations, sequelae, and supernatural force. This further provided meaning about the use of words to support or promote the desired health intervention for a woman whose fibroid uterus could not be saved. The total removal of the uterus was regarded,

culturally, as the most severe surgical procedure that a woman could ever undergo – “the severance of her reproductive organs”. The severance of the reproductive organs (post-hysterectomy) was described as: curse, hole, empty vase, cold, bridge, man, river/dam/water pool, nothing and barren. The women consult different practitioners, in order to avoid the severance of their reproductive organs, seeking the second opinions that might agree with their beliefs.

6.2.4 Objective 4

The participants’ perceptions of hysterectomy that instilled fear of the operation.

Some of the participants feared that failure to bear children might lead to divorce or the break-up of their existing intimate relationship. Among these themes, it emerged that, especially among women (patients) from conservative and culturally-steeped communities, paternalistic and male domination still reared its ‘supremacy’; with the consequent manifestation of fear being induced. Some men will usurp authority and the prerogative to sign the RHT. Some women asked what effect hysterectomy would have on their marital lives and relationships. This was exacerbated by their concern over the causes of fibroids and socio-cultural connotations attached to fibroid uterus by the community in which they found themselves. A woman who had undergone hysterectomy was regarded as for example: a man; cold; an empty vase, and a hole. Consequently, women who had undergone a hysterectomy often developed negative feelings and a lack of self-esteem because of the intensity of these negative notions. Derogatory words such as a curse, vase, hole, and bridge emphasised that communities considered hysterectomy as being undesirable, cold, tasteless, useless, and empty. The myth of women being inserted a plastic after removal of the womb also instils some fear to the women. There are diverse attitudes that do not reflect culturally approved reactions. Cultural orientation to hysterectomy and women who had undergone hysterectomy thus resulted in certain behaviours and fears. Consequent to lack of relevant and informative knowledge, these women became willing or unwilling ‘victims’ of socialisation processes in which unfounded stories, rumour/hearsay and myth were construed as the true basis for constructing perceptions and forms of reality.

6.2.5 Objective 5

Why the respondents' avoid discussing treatment of fibroid uterus with their husbands or partners.

The participants' marital status was considered in the light of the numerous misconceptions and derogatory statements associated with post-hysterectomy experiences. Most of the participants revealed that they were not knowledgeable and would hardly raise discussions around hysterectomy within church circles or with their husbands and partners. Severance of the reproductive organs was discouraged and not upheld because of different societal interpretations. That is why the majority would opt for an operation without informing or consent from their partners, despite that these women had dyspareunia. They need well-researched scientific information disseminated from health institutions about hysterectomy to help them take full control of their lives and personal health, including basic human right ethos.

Despite the prevalence of appropriate or relevant legislation (including the Constitution) that outlaws sexism and gender inequality, traditionally-socialized men made the 'final' decision regarding hysterectomy. To such men, the wombs of 'their' wives/spouses was an organ of 'their' control – in which women are relegated to the status of "property" whose value is determined by the number of (male) children they are able to bear. As child-rearing 'objects', they are then regarded as being subservient to the 'wisdom' of their male counterparts. In this regard, the study was able to establish a trend in which women are also 'oppressed' externally by among others, in-laws and other community members who will advise them to sign the RHT. The magnitude of the fear is such that even when the concerned woman realizes that it is only through the removal of her uterus that she could be permanently healed, they end –up succumbing to these pressures. They cannot bear the humiliating thought of being ostracized, divorced or viewed as having lost the 'essence' of womanhood.

6.3 REHABILITATIVE PHASE

This is to restore to previous state or condition of normal health by means of training, of these women before and after hysterectomy, which affects all the five aspects of an individual as it was discussed throughout the research (Tulloch 1993:1291).

Attitudes appeared to hinder or contribute to patients' rehabilitation. The rehabilitative phase starts before the operation and continues after. This phase covers psychological, physiological, social, spiritual and financial aspects. Figure 6.1 and Figure 6.2 can be given to the women in GOPD during counseling sessions.

6.3.1 Pre-hysterectomy

Pre-hysterectomy rehabilitation is done in the GOPD and in the Ward before the operation.

- **Psychological**
Fear and anxiety:
 - informed consent signing
 - anaesthetist's consult
 - nurse practitioner's reassurance
 - pastor's reassurance

- **Physiological**
 - Body preparation
 - Shaving
 - Drips
 - Bowel preparations
 - Starving from 22:00 the night before
 - Food – well-balanced diet (dietician)
 - Exercise – physiotherapist and nurse

- **Social**
 - Family support
 - -Social worker

- **Spiritual**
 - Pastor

- **Financial**
 - Family
 - Accounts (own)
 - Hospital bill

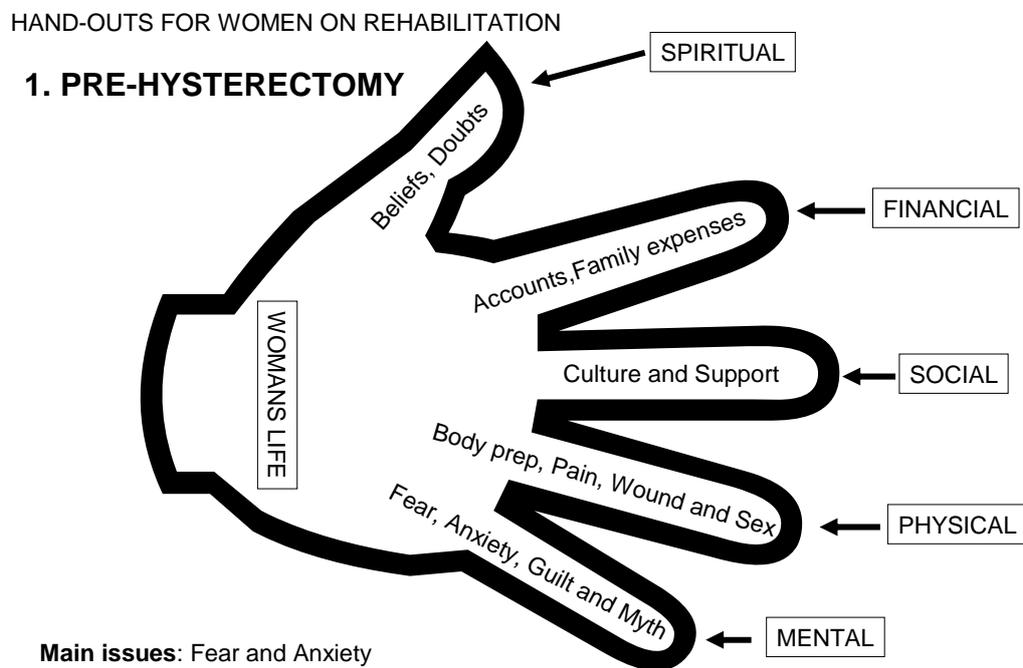


Figure 6.1
Pre-hysterectomy issues

6.3.2 Post-hysterectomy

Post-hysterectomy rehabilitation is done in the ward, at home, and in the GOPD.

- **Physiological**
 - Diet and starve (if needed) (nurse and dietician)
 - Exercises (nurse and physiotherapist)
 - Wound care (nurse)
 - 6 weeks' GOPD date
 - Medication
 - Do's and don'ts

- **Psychological**
 - Counseling (physician and nurse)
 - Women's groups
 - GOPD
 - Work areas
 - Churches
 - Societies
 - Referrals
 - Oncologist, palliative groups

- **Social**
 - Social worker
 - Family

- **Spiritual**
 - Pastor, other members and groups in the parish/congregation (e.g., prayer group, Bible study group)

- **Financial**
 - Social worker
 - Family

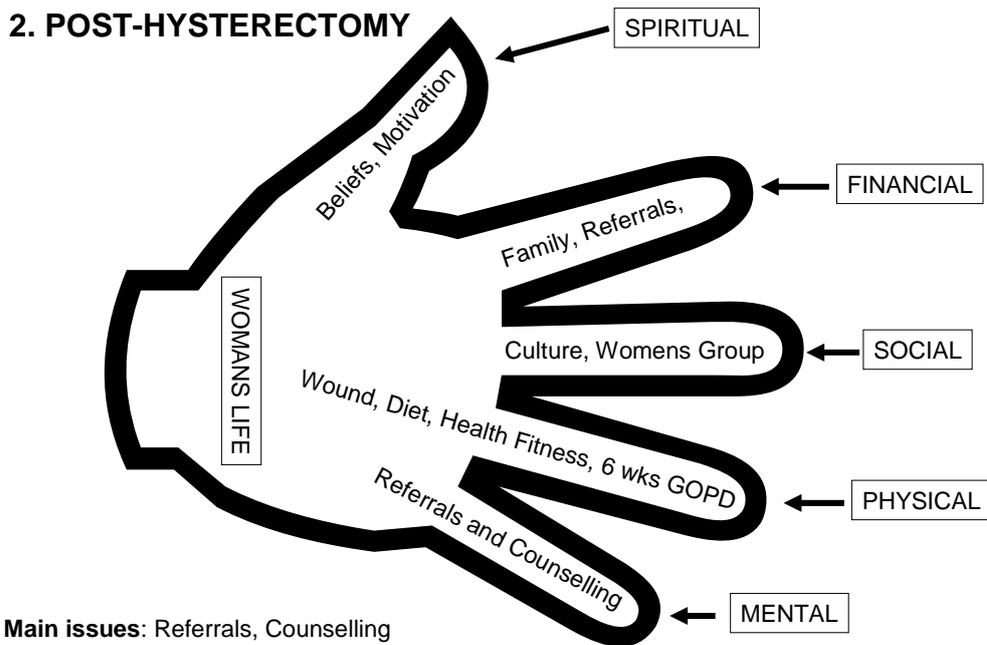


Figure 6.2
Post-hysterectomy issues

6.4 LIMITATIONS OF THE STUDY

The limitations of the study relate to the shortcomings of the study, and how these could have been avoided by the researcher (Babbie & Mouton 2002:569).

6.4.1 Nationality

This study was restricted to one hospital in an urban area. Although many of the participants came from rural areas, most of the participants were Black therefore the views and beliefs of White, Indian and Coloured women from different cultural backgrounds were not fully explored.

It will be better in future to deal with one culture only or look for an equal specific number for each nationality.

6.4.2 Literature-based limitation

The conclusions and recommendations of the study have shown the missing information locally in the multicultural domain of fibroid and hysterectomy. The study relied mainly on empirically-generated knowledge. As a variable of knowledge, the concept of “culture” would provide more insights into the construction of perceptions regarding fibroids and hysterectomy. Increased research funding would encourage the increase in the knowledge base of this crucial aspect of socio-economic development and multi-cultural understanding.

6.5 RECOMMENDATIONS

Based on the findings, the researcher makes the following recommendations for practice and further research.

6.5.1 Practice improvement in the provision of healthcare education

The Department of Health should make information about fibroids in the uterus, hysterectomy and post-hysterectomy information available at clinics and hospitals. For women, this information would dispel fears based on ignorance or misinformation. Some women may want to read extensively and should be given a list of resources. Others prefer verbal communication and may need informational sessions with the nurse and other members of the multi-disciplinary team. This suggests that the healthcare education campaigns should not be confined to healthcare-providing institutions only. Targeting women patients at the gynaecological wards has limited chances of success. Healthcare provision in the form of professional counseling should necessarily include affected family members, so that the woman with fibroid uterus is relieved from the psycho-social burden of being the only one to bear the ‘risk’ and consequences of undertaking hysterectomy. This must be done with the consent from the patient. Most of those interviewed revealed that they were not knowledgeable and would hardly raise discussions around hysterectomy within church circles, or with their husbands or partners. Healthcare institutions and providers are therefore well positioned to use this space of non-communication to educate their women. The fundamental purpose of healthcare education should be to supply accurate information about fibroids, the hysterectomy surgical procedure, and post-hysterectomy information

as indicated on the rehabilitation phase. For women, this information will help them dispel some fears that are based on lack of understanding or misinformation. Some women may want to read extensively and should be given a list of resources. Others may be caused by low literacy levels to prefer the oral method of information dissemination, and may need more extensive informational sessions with the nurse and other members of the professional multi-disciplinary team. During discussions, the women patients must be encouraged to express some of their own anxieties and discuss these in detail. The normality of anxiety, fear and tension should be discussed, which will improve the efficacy of counseling and ease these patients' psycho-social pressures. In-depth health education about the female genitalia will help in removing ignorance and traditionally-entrenched stereotypes. Women should be allowed to articulate their needs for information about and control over reproductive processes.

6.5.2 Formation of multi-disciplinary teams in the healthcare facilities

Multidisciplinary committee teams should be set up for intervention and involvement in health education and counseling of women with fibroids who need to go for hysterectomy in the GOPD set-up. Department of Health should open communication between hospitals and traditional healers. Information on the cause of fibroids and referral methods should be supplied to traditional healers, and this will soften the invitation for traditional healers to join the team.

The committees should include pastors/clergy, social workers, psychologists, laboratory technicians, doctors, traditional healers and nurses because of strong links between patients and their communities.

6.5.3 Involvement of the family

Information to educate men about fibroids and hysterectomy should be available at clinics and hospitals as well for them to be knowledgeable and helpful when confronted with such situations in the family. Encourage men to express their fears and anxiety and discuss them and to address abuse of women by the communities.

6.5.4 Mobile clinics for women

Mobile clinics should be set up for women, for screening, early detection, management, treatment and rehabilitation in order to avoid unnecessary complications. Gynaecologists, registered nurse, enrolled nurses and enrolled nursing assistants should staff these clinics. Awareness campaigns through distribution of detailed lists of associated taboos. Health education program strategy to eliminate misconceptions, invite male involvement.

6.5.5 Conferences and seminars and initiation schools

During cultural initiation rituals girls should be educated on fibroids and hysterectomy. This information should also be extended to those not participating in traditional/cultural rituals. The boys can be taught about care for women and girl – child during their initiation period Gender Equity Commission conferences or meetings should be held to emphasize and promote the rights of women.

6.6 FURTHER RESEARCH

Research should be done on:

- The relationship between hypertension and fibroid uterus.
- The correlation between fibroids and hypertension.
- Women with fibroid uterus not operated between 2000 and 2005.
- Community support for women who have undergone hysterectomy for fibroid uterus.
- Nurses' perceptions of hysterectomy and women who have undergone hysterectomy.
- The needs of women with fibroid uterus.
- Research on men's perception of hysterectomy done on women as a life saving procedure.

6.7 SUMMARY

The chapter was essentially concerned with the practical implications of the entire research process. The materialization and fulfillment of the study's objectives became the major determinant of the extent to which these objectives were fulfilled. The interpretation and analysis of the collected data were constructed and translated into practical meaningfulness on the conclusions reached, the recommendations advanced, the limitations of the study, and the suggestion for further research. The study is not an end in itself. By highlighting the study's strengths and weaknesses, the researcher sought to elevate the plight of women with fibroid uterus from diverse backgrounds. It is envisaged that the research process will argue for the free communication and observance of women's rights in the broader domain of a human rights culture. The theme of 'voicelessness' manifests itself throughout the analysis of the study. Concerted health education interventions have become indispensable in the demystification of hysterectomy as a viable and life-saving mechanism.

6.8 CONCLUSION

The main aim of this chapter is to present an overview of the practical implications of the study. The practical implications or usefulness of the study apply in both the scientific and socio-economic domains of society. The study found that there were various reasons why women of diverse cultures did not want to be operated on when diagnosed with fibroid uterus, including fear of losing their marriage, alienation, and cultural stigma. The severance of their reproductive organs seemed to be the most disturbing issue in their life. This study should contribute to a better understanding of fibroid uterus and hysterectomy, the trauma of women involved, and all the aspects of caring for these women.

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APPENDIX A: Clearance Certificate from Unisa Health Studies Research and Ethics Committee

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PAGE 07

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ADVANCING NURSING SCIENCE

PAGE 02/02



UNIVERSITY OF SOUTH AFRICA
Health Studies Research & Ethics Committee
(HSREC)
Faculty of Humanities and Social Sciences
CLEARANCE CERTIFICATE

Student No: 7759282

Project Title: The perceptions of women with fibroids from diverse cultures regarding hysterectomy
Researcher: Ms. Munyadziwa Dzebu
Supervisor/Promoter: Prof. O.N. Makhubela-Nkondo
Department: Health Studies
Degree:

DECISION OF COMMITTEE

Approved Yes

Date: 23/03/2006

A handwritten signature in black ink, appearing to read 'Mavundla'.

Prof TR Mavundla
RESEARCH COORDINATOR

A handwritten signature in black ink, appearing to read 'Mogotlane'.

PLEASE QUOTE THE STUDENT NUMBER IN ALL ENQUIRES

APPENDIX B: Letter of Permission from the Gauteng Department of Health



PROVINCIAL RESEARCH COMMITTEE.

**RESEARCH EVALUATION FORM FOR APPROVAL BY THE
HEAD OF THE DEPARTMENT.**

Submission date: 30-11-2005

Title: The perceptions of Women with Fibroids From
Diverse cultures Regarding Hysterectomy

Principal investigator: M DZEBU

Research Site(s): Johannesburg hospital

Type of research: Non trial

Summary:

A qualitative descriptive design will be used to explore and describe the perceptions of women with fibroids, from diverse cultures regarding hysterectomy. The objectives of the study were not specified in this protocol. Female patients of diverse cultures who have been admitted to the Gynaecology ward will be interviewed and observations will be made with field notes. The study will be conducted in 2 years period.

Motivation

This study is conducted for the partial fulfillment of a M.A.CUR degree at UNISA. The findings of this study will enlighten health care providers of the prevailing knowledge amongst clients pertaining to uterine fibroids and their understanding of the possible treatment options. The findings will hopefully allow to provide the appropriate

information not only to understand the pathology of their condition, but also to take a balanced treatment option through meaningful counseling and willing informed consent. Incorporating the different concepts and ideals, brought about by the diverse cultures of the community, will without doubt, empower these clients to accept management strategies that often requires radical surgery, namely hysterectomy, for a medical condition that is common.

Informed consent from the subject to participants consent will be obtained before the participants are included in the study.

The clearance certificate from UNISA is hereby attached. There is no financial implications to the Department of Health.

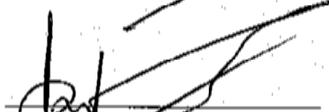
We therefore have no objection to recommend that the study be conducted in this province.

The Evaluator:



Dr ML Likibi
Specialist research and Epidemiology

Approved/not approved



Dr A Rahman
Acting HOD

Date: 12/01/06

APPENDIX C: Letter of Permission from Johannesburg Hospital Medical Superintendent

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PAGE 03



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PERMISSION FOR RESEARCH

NAME OF RESEARCHER Munyadziwa Jane Dzebu

TITLE OF RESEARCH PROJECT THE PERCEPTIONS OF WOMEN WITH FIBROIDS FROM DIVERSE CULTURES REGARDING Hysterectomy

METHODOLOGY (briefly or include a protocol) see protocol

CONFIDENTIALITY OF PATIENTS MAINTAINED yes - see protocol.

COST TO THE HOSPITAL NONE

APPROVAL OF HEAD OF DEPARTMENT [Signature]

APPROVAL OF CRHS OF WITS UNIVERSITY _____

CLINICAL EXECUTIVE PERMISSIONS

Signature Dr. D. Węclachowska Date 11/11/2007
Clinical Executive

Subject to any restrictions _____

**APPENDIX D: Letter of Permission from Johannesburg Hospital Head of Obstetrics
and Gynaecology**

18/12/2007 12:02 0124292244

UNISA TELKOM

PAGE 04

P.O. Box 31120
Braamfontein
2017

30/08/05

Permission granted
without reservation

[Handwritten signature]

Prof F. Guidozi
Departmental Head
Obstetrics and Gynaecology
AREA 179

RE : APPLICATION FOR A PERMISSION TO CONDUCT A
RESEARCH IN GYNAECOLOGICAL AREAS

[Handwritten signature: F Guidozi]

I hereby request permission to conduct a research on the following topic:-

- ❖ "The Perceptions of women with Fibroids from diverse cultures regarding Hysterectomy" in the gynaecological areas.

The research is for my M.A. CUR, at Unisa. I have included the letter from the Department of Health Sciences, accepting my application.

Hoping that my request will meet with your favourable consideration.

Regards,

[Handwritten signature]

MUNYADZIWA J. DZEBU
19TH AUGUST 2005
(011) 488-3196 (WORK)
(011) 643-2149 (HOME)

APPENDIX E: Explication of the Study

20/12/2007 09:09 0124292244

UNISA TELKOM

PAGE 08

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:02PM P02

PATIENT INFORMATION SHEET

I am Munyadziwa Dzebu, student for masters in nursing in the University of South Africa (UNISA). I am conducting a study on 'THE PERCEPTIONS OF WOMEN OF DIVERSE CULTURES WITH FIBROIDS REGARDING HYSTERECTOMY'. This study is done because of many women in this area I am working in who do not consent for hysterectomy and end up with a lot of complications and some die. I would like to explore the reasons why such issues and how the issue can be addressed, solved and for study purposes.

History of study

The study will be done by means of a questionnaire, which you will be asked to answer. You are diagnosed with fibroids (growth in the womb) and you are to undergo hysterectomy (removal of the womb). You are requested to read this information and give permission, allowing yourself to participate in this study. Again permission is asked from you, for me to tape record you when you are being interviewed and to allow me to take notes during our interaction on whatever you and me say.

If you are not willing to participate or you agree to participate and during the study or at any time you decide to stop participating, you are free to stop, with no reason. This will not affect the care to be given to you if you withdraw or stop participating. Participation is voluntarily your own choice.

Any question?

My phone number is (011) 488-3196
(011) 488-3195

Thank you
Munyadziwa Dzebu

APPENDIX F: Informed Consent of Respondents

20/12/2007 09:09 0124292244

UNISA TELKOM

PAGE 02

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:03PM P03

VERBAL AND WRITTEN INFORMATION

Title of study

The perceptions of women with fibroids from diverse cultures, regarding hysterectomy

The researcher: Munyadziwa Dzebu

**Telephone: (011) 488-3196 or
488-3195**

Purpose: To explore the perceptions of women of diverse cultures with fibroids regarding hysterectomy and why such perceptions. This will enable the health care workers to be knowledgeable on how to address this issue, to protect the lives of women and upgrade their life styles. To avoid unnecessary complications including death.

Procedure: *Questionnaire with participant's observation

***Tape recorder to record your information**

***Taking notes**

Risk on participating

None

Benefits on participating

***Knowledge required on this topic**

***Free to withdraw anytime you feel you want to, treatment and care will be continued in standard and professional manner. No alternative or alteration of treatment, if you decide to withdraw from study.**

***The information you give by answering the questions will be treated with confidentiality, including names and statements you give and records of you participating.**

***You are free to see and read the report any time and on completion of the study.**

APPENDIX G: Informed Consent of Women with fibroid uterus

20/12/2007 09:09 0124292244

UNISA TELKOM

PAGE 03

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:03PM P04

Name of patient: _____

Signature of patient: _____

Date: _____

Hospital: _____

Ward: _____

Investigator's signature: _____

Date: _____

Appendix H: Demographic information and questionnaires of Women with fibroid uterus

“Examples of Different languages used”

ENGLISH

1. DEMOGRAPHIC INFORMATION

1. NAME:

2. AGE:

3. HIGHEST STD. PASSED:.....

4. NATIONALITY:

B	W	I	C
---	---	---	---

IF BLACK
INDICATES ETHNICGROUP)

5. ADDRESS:
.....

6. EMPLOYED: If yes specify occupation
.....

YES	NO
-----	----

7. RELIGION: SPECIFY ATTENDANCE

NEVER	SELDOM	REGULAR
-------	--------	---------

8. LANGUAGE OF PATIENT:

9. PAST MEDICAL HISTORY.....
.....

10. PAST SURGICAL HISTORY.....
.....

11. HOW MANY CHILDREN ALIVE

12. HOW MANY PREGNANCIES

2.QUESTIONNAIRE FOR WOMEN WHO HAVE BEEN DIAGNOSED WITH A FIBROID UTERUS UNDERGOING HYSTERECTOMY

"Fill in or tick the answers"

1. What is a fibroid uterus?.....
- 2.1 When did you discover that you have fibroids.....
- 2.2 what was the problem at that time.....
.....
(For example heavy bleeding, lump or pain)
- 2.3 Symptoms
 - 2.3.1 PAINS
 - 2.3.2 PERIODS -NORMAL /ABNORMAL
-INCREASED/PROLONGED
 - 2.3.3 BLOOD LOSS
 - 2.3.4 OTHER
3. What did you do after discovering that you have fibroids:-
 - 3.1 DISCUSS WITH YOUR FAMILY
 - 3.2 DISCUSS WITH YOUR DOCTOR
 - 3.3 REQUEST AN OPERATION
 - 3.4 OTHER-WRITE DETAILS.....
4. Previous treatment options
 - 4.1 -ORAL CONTRACEPTIVE PILLS
 - 4.2 -DEPO INJECTION
 - 4.3 -ANALGESICS
 - 4.4 -CYCLOKAPRON
5. What is your feeling about having fibroids, and why do you have such a feeling:
 - 5.1 UNDERSTAND
 - 5.2 ANGRY
 - 5.3 CONCERNED
 - 5.4 OTHER-EXPLAIN.....
6. What is your marital status?
S – SINGLE
M – MARRIED
D - DIVORCED
W - WIDOWED
7. Does the fibroid affect your sexual relationship? If yes explain how:-

7.1 DECREASED INTEREST

7.2 PAINFUL

7.3 OTHER – EXPLAIN.....

8. How many health facilities or traditional facilities did you consult or seek help from and their response:-

NO 1 P.H.C. CENTRE-RESPONSE.....

.....

NO 2 LARGE HOSPITALS.....

.....

NO 3 TRADITIONAL HEALERS.....

.....

9. What are the reasons which made you to seek medical assistance or traditional assistance?

.....

10. Did the fibroids problem affect you: -

SPIRITUALLY	YES	NO	
PSYCHOLOGICALLY	YES	NO	
PHYSICALLY	YES	NO	
SOCIALLY	YES	NO	
FINANCIALLY	YES	NO	

IF YES PLEASE GIVE A BRIEF EXPLANATION.

.....
.....

11. What is the attitude of your religious community concerning a woman with no womb (post-hysterectomy)

.....

12. Is there anybody in the family (maternal / sisters) with fibroid problems?

IF YES WHAT WAS THE SOLUTION FOR THE PROBLEM.....

.....

13. What is your expected treatment for fibroids.....

.....

14. What is your biggest fear at the treatment option...

.....

15. What is your partner's attitude about you having a hysterectomy:-.....

.....

16. What is your personal attitude towards hysterectomy:-

16.1 IN FAVOUR

16.2 AGAINST

16.3 STRONGLY AGAINST (GIVE REASONS).....

.....
.....

17. How many children do you have.....

18. Did you discuss the problem of fibroids with your partner:-

N	YES
O	

19. Did your partner give consent for you to have the operation:-

19.1 YES

19.2 NO – GIVE REASON.....

19.3 DID NOT ASK-GIVE REASON.....

20. What is your society/community's understand and feeling concerning a fibroid uterus.....

.....

21. What is your society/community's attitude towards a hysterectomy: --

.....
.....

22. What does your community/society say about a woman with no womb.....

.....

23. How do you think you will cope after a hysterectomy with sex.....

.....
.....

ISIZULU

1. UMBUZO WE DEMOGRAPHY

- 1. IGAMA LAKHO
- 2. UNEMINYAKA EMINGAKI?
- 3. IBANGA OLIPHASILE ESIKOLENI?.....
- 4. UBUZWE, UNGUMHLOBO BANI?.....
- 5. UHLALA KUPHI?.....
.....
- 6. USEBENZA KUPHI?
- 7. INKOLO, CHAZA UKUTHI UYAKANGAKI

UYAPHUTHA	NOMA	UYANJALO
-----------	------	----------
- 8. ULIMI OLUKHULUMAYO.....
- 9. UMLANDU WAKHO WOKUGULA.....
.....
- 10. UMLANDU NGOKUHLINZWANOWAKE WAKWENZA.....
.....
- 11. UNABANTWANA ABANGAKI ABAPHILAYO.....
- 12. WAKE WAKHULELWA KANGAKI.....

2. UMBUZO WE BESIFAZANE BEMHLOBO EHLUKANE BA CHAZELWE UKUTHI BANE SIMILA NOMA ISIGAXA ESIBELETHWENI BAFANELE UKUTHI BA KHIPHE ESIBELETHO

1. Yini isimila noma isigaxa esise sibeledhweni?.....
- 2
 - 2.1 Wazi nini ukuthi unaso?.....
.....
 - 2.2 Inkinga kwakuyini ngalesosikhathi?.....
.....
(ingabe wawopha kakhulu noma wawuzwa ubuhlungu)
 - 2.3 Izibonakaliso
 - 2.3.1 ubuhlungu
 - 2.3.2 ukuya esikhathini ngendlela engajwayelekile
 - 2.3.3 ukapha kakhulu
 - 2.3.4 nokunye uma kukhona.....
.....
- 3 Wenza njani uma uzwa ukuthi une simila
 - 3.1 waxoxa nomndeni wakho
 - 3.2 waxoxa nodokotela
 - 3.3 wacela ukusikwa noma ukuhlwinzwa
 - 3.4 okunyeougakusho.....
.....

4.Ukwelasha noma wake wa sebenzisa

- 4.1AMAPILISI
- 4.2UMJOVO WE DEPO PROVERA
- 4.3AMAPILISI A UBUHLUNGU
- 4.4CYCLOKAPRON

5.Ingabe uzizwa kanjani ngokuba nale nkinga :-

- 5.1UYAYIQONDA
- 5.2AYIKUPHATHI KAHLE
- 5.3WAZI KABANZI NGAYO
- 5.4KUKHONA UKUNYE OKWAZIYO.....
.....

6.Isimo sakho somshado

AWUSHADILE	
USHADILE	
UHLUKANISILE	
UMFELOKAZI	

7.Ingabe ukuba nalesilima kuphazamisa ukulala nomlingane wakho?Umakunjalo chaza:-

- 7.1KWENZA UNGABI NOMDLANDLA
- 7.2KUBABUHLUNGU
- 7.3OKUNYE.....
.....

8Uye kangaki ukuyofuna usizo ezibhedlela noma kwabalapha ngo kwesintu?

- 8.1EKILINIKI.....
.....
- 8.2ESIBHEDLELA.....
.....

8.3KWABALAPHA NGO KWESINTU.....

9.Iziphi izizathu ezenza ukuthi ufune usizo lokulashwa.....

10.Ingabe lenkinga ayikuphathi kahle:-

NGOKOMOYA	YEBO	CHA
NGOKOMQONDO	YEBO	CHA
NGOKOMZIMBA	YEBO	CHA
EMPHAKATHINI	YEBO	CHA
NGOKWEZIMALI	YEBO	CHA

(CHAZA.....

11.Ithini imibono noma izinkolelo zomphakathi wangakini ngomuntu wesifazane okhiphe isibeletu.....

12.Ingabe ukhona emkhayeni wakho owake waba nale inkinga? (UMA UKHONA WAYIXAZULULA KANJANI?).....

13.Ikuphi ukwelashwa onga kulindela wena?.....

14.Yini oyisabayo ngokwelashwa.....

15.Uthini umbono womlinganii wakho ngokukhishwa kwesibeletu:-

16.Uthini umbono wakho ngokukhishwa kwesibeletu:-

16.1UYAVUMA

16.2AWUVUMELANI NAKHO

16.3UNEZIZATHU EZIQINILE ONGAVUMELANI NAZO(CHAZA)

17Unabatwana abangaki?.....

18.Uye waxoxa lenkinga nomlingane wakho?

YEBO	CHA
------	-----

19.Ingabe umlingane wakho uvumile ukuthi uhlinzwe?

19.1YEBO

19.2CHA- ISHO ISIZATHU.....

19.3AWUMUTSHELANGA-CHAZA.....

20Ingabe umphakathi wangakini uyayiqonda indaba yesimila esibeletweni.....

21. Umphakathi ubaphatha kanjani abantu abakhiphe isibeletho?...

.....
.....

22. Yini abakushoyo kubantu besifazane abakhiphe isibeletho?.....

.....
.....

23. Ucabanga ukuthi uyo kwazi ukulala emva kokwenza ukukhipha isibeletho nowa kwakho.....

.....

SEPEDI

1. DITABA TSA DEMOGRAPHY

- 1. LEINA:
- 2. NGWAGA:.....
- 3. O PASETSE SEKOLO TSA MPHAKO OFE:.....
- 4. MORAFE:.....
- 5. BODULO BJA GAGO:.....
- 6. O A SHOMA/ BEREKA: O SHOMA KAE?

EE	AOWA
----	------

- 7. O A KEREKA: KAYE

AOWA	MATSATSI A MANGWE	KA MEHLA
------	-------------------	----------

- 8. LELEME:.....
- 9. ONA LE BOLWETSEBJO O NANG LE BONA NTLE LE BYO O GO TSWERENG?
- 10. O KILE WA DIRA OPARESHENG ?.....
- 11. ONA LE BANA BA BAKAE?.....
- 12. O BILE MMELENG GAKAE?.....

2. DIPHOTSISO GO MOSADI YO A JWEDITSWE O NALE DIFIBROID A JA GO DIRA OPARESENG YA GONTSA POPHELO

1. Ke enge pophelo e nale difibroid?.....

2.1 O tsebile neng gore o na le difibroid?.....

2.2 Bothata e be e le eng?
 (go bona kgwedi gigolo, sehlabi, sesho mo pophelong)

2.3 Obone byang, o be o kwele eng?

- 2.3.1 Sehlabi
- 2.3.2 Kgwedi –yannete/ya gosetle ga botse
 -nako e telele/etletse
- 2.3.3 Go felelwa ke madi

3. O dirileng ge o se nokwa gore o na le difibroid?

- 3.1 O BOLETSI LE LAPA LA GAGO
- 3.2 O BOLETSI LE NGAKA YA GAGO
- 3.3 O GOPETSE OPARESHENI
- 3.4 NGWALA KA BOHLALO.....

4. Dikalafo

- 4.1 DIPILISI TSA O THIBELA PELEGO
- 4.2 NALETE YA DEPO
- 4.3 DIPILISI TSA SEHLABI
- 4.4 DIPILISI TSA CYCLOKAPRON

5. O ekwa byang ge o na le difibroid, go reng o e kwa jwalo:-

- 5.1 O KWESISA
- 5.2 O KWATILE
- 5.3 GO TSWENYEGA
- 5.4 SE SENGWE, HLA LOSA.....

6. Maemo a bophelo

GA A NYALWA	
O NYETSWE	
O HLADILE	
O MOHLOLOGADI	

7. E amana bjang fibroid le thobalano ya gago

- 7.1 GA O DUMA/GO FOKOTSA THAKATSO
- 7.2 GO BOHLOKO
- 7.3 TSE DINWE –HLA LOSA.....

8. Ana o ele go dipetlela goba go dingaka tsa setsho tsekae ,oyo nyaka thuso:-

- 1. KLINIKI.....

- 2.SEPETLELA SE SEGOLO
- 3. NGAKA YA SETSO.....

9. Ke mabaka ma fe a adirileng gore o kgopole /nyake thuso.....

10. Difibroid di o o tswenya bjangko:-

MOYENG	EE	AOWA	
MONAGANONG	EE	AOWA	
MMELENG	EE	AOWA	
BOITHOSILON G	EE	AOWA	
TSHELETENG	EE	AOWA	

A O DUMELA HLAALOSA KA BOHLALO

11. Batho ba geno ba borapedi ba naganang ka motho wa go hloka pophelo.....

12. A gona le motho o mongwe lapeng la gaho(mma /sesi) o a na le difibroid?
 GE O RE EE, EBELE ENG THROLO YA BOTHATA.....

13. O nagana go re khalafo ya difibroid ke eng

14. Otsabang ka kalafo ye.....

15. Maikhutlo a molekane wag ago a reng ka go ntsa pophelo?

16. Ke eng maikhutlo a gago ka go tsha pophelo:-

16.1 O A DUMELA

16.2 GA O DUMELI

16.3 O GANANA LE KALAFO KA PELO KA MOKA (HLALOSA).....

17. O na le bana ba kae ?

18. O boledisane le molekane wa gago ka difibroid

EE	AOWA
----	------

19. Aa molekane wa gago o o dumeletse go dira opereshene?

19.1 EE

19.2 AOWA-(HLALUSA).....

19.3 A WA BOTSISA-(HLALUSA).....

20. Setshaba sa geno ba kwesising ,ebile ba naganang ka pophelo ye enang le difibroid?

21. Setshaba sa geno se ekhutlwa bjang ka go ntsha pophelo?.....

22. Setshaba sa geno se naganang ka mosadi a se nang pophelo?.....

.....
23. O nagana gore o tla tswelapelo ka tsa thobalano ge o se no tsha
pophelo?.....
.....
.....

TSHIVENDA

1. Mafhungo a Demographic

1. Dzina:
2. Minwaha ya mabebo:
3. Kilasi ya ntho yo paswaho:
4. Murafho :

Mutswu	Mutshena	Mu-indiya	Mukhaladi
--------	----------	-----------	-----------

(arali vhe muthu mutswu lushaka lwa havho):
5. Direse yavho:
.....
6. Vha a shuma naa

Ee	Hai
----	-----

Arali phindulo i ee, mushumo wavho:.....
7. Vhurabeli havho, kha vha sumbedze ku dzhenele kwavho:

A vha yi	Tshinwe tshifhinga	Tshifhinga tshothe
----------	--------------------	--------------------
8. Luambo lwavho:
9. Malwadze e vha lwala:
10. Miaro ye vha itwa:
11. Vhana vha tshilaho ndi vha ngana?.....
12. Vho di hwala lungana?.....

2. MBUDZISO KHA VHAFUMAKADZI VHO WANALAHO VHE NA ZWILONDA MBUMBELONI VHO FANELWAHO U ITWA MUARO WA U BVISA MBUMBELO

“VHA KHOU HUMBELWA U FHINDULA NGA VHURONWANE DZOTHE MBUDZISO”

- 1 Mbumbelo i re na zwilonda zwi amba mini?
.....
2. 2.1. Vho zwi divha lini uri vha na zwilonda mbumbelo?
.....
- 2.2. Khaedu yo vha I mini nga tshetsho tshifhinga
.....
tsumbo- u vhavha kana tshithavhi
- u bva malofha a mageda
- ndunduma kha thumbu
- 2.3. Zwe vha vhona zwone:-
2.3.1.tshithavhi
2.3.2.u vhona nwedzi -zwavhudi /Lu si lwa vhudi
-malofha a bvesaho /tshifhinga tshilapfu
2.3.3.u fhelelwa nga malofha
- 3 Ndi zwifhio zwe vha ita musi vho zwi wana uri vha na zwilonda mbumbeloni?
3.1.vho ambedzana na vha muta wavho
3.2.vho ambedzana na nanga yavho
3.3.vho humbela muaro
3.4.zwinwe –vho zwe vha ita (vha nwale nga vhudalo)
.....
- 4 Dzilafho le vha newa tshifhinga tsho fhelaho
4.1.philisi dza u thivhela mbebo
4.2.nelete ya u thivhela mbebo
4.3.pilisi dza tshithavhi
- 5 Vha khou di pfa hani musi vhe na zwilonda mbumbeloni na hone ndi ngani Vha tshi tou ralo?
5.1.u pfesesa
5.2.u sinyuwa
5.3.vha na vhuronwani ngazwo
5.4.zwinwe (kha vha talutshedze)
.....
- 6 Vhuimo ha mbingano yavho
6.1.a vho ngo malwa
6.2.vho malwa
6.3.vho tala
6.4.vha tshilikadzi
- 7 Zwilonda mbumbeloni zwi a vha khakhisa kha zwa vhudzekani naa? Arali phindulo i ee, kha vha talutshedze
7.1.lutamo lwo fhungudzea
7.2.zwi a vhavha
7.3.zwinwe –vho [kha vha talutshedze]
.....

8 Ndi zwi imiswa zwi ngana zwa mutakalo kana ndi nanga nngana dza sialala dze vha dalela u toda thuso. Hone thuso yo vha ifhio?

8.1.kilniki ya hayani ha vhupo havho

8.2.zwibadela zwihulwane

8.3.nanga dza sialala

9 Ndi zwifhio zwe zwa ita uri vha ye u toda thuso kha nanga dza sibadela kana dza sialala?

10 Zwilonda mbumbeloni zwo vha kwama hani kha zwi tevhelaho

	Ee	Hai	Thalutshedzo arali phindulo i ee.
Zwa muya			
Zwa muhumbulo			
Zwa muvhili			
Zwa vha konani na vhathu			
Zwa masheleni			

11 Vha zwa vhureleli havho vha ri mini nga mufumakadzi o bviswaho mbumbelo?.....

12 Hu na shaka lavho lo vhaho na khaedu ya zwilonda mbumbeloni naa? Arali hu Ee, kha vha talutshedze thuso yo wanalaho.

13 Ndi zwifhio zwine vha tielelwa u ilaxwa ngazwo, kha zwilonda zwa mbumbeloni yavho?

14 Nyofho dzine vha vha nadzo nga ha ilaxwa kha iyi khaedu ndi dzifhio?

15 Mufarisi wavho vha ri mini, arali vhone vha tshi itwa muaro wa u bvisa mbumbelo?

16 Vhone vha ri mini nga u bviswa mbumbelo

16.1.vha a zwi funa

16.2.vha lwa nazwo

16.3.vha tou zwi vhenga lwa tshothe (kha vha talutshedze)

17 Vha na vhana vha ngana?.....

18 Vho ita nyambedzano na mufarisi wavho nga ha khaedu iyi ya zwilonda mbumbeloni naa?

Ee	Hai
----	-----

19 Mufarisi wavho vho vha nea thendelo uri vha itwe muaro uya naa?

19.1.Ee

19.2.Hai(thaluthedzo).....

19.3.A vho ngo humbela(thaluthedzo)

20 Vhahura vhavho, vha pfesesa mini nga ha zwilonda mbumbeloni?

- 21 Vhahura vhavho vha amba zwifhio nga ha muaro wa u bvisa mbumbelo?
.....
- 22 Vhahura vhavho vha amba zwifhio nga ha mufumakadzi a sina mbumbelo?
.....
- 23 Vha khou hambula uri vha do zwi tshila hani nga muravhu ha u bviswa
mbumbelo, musi vhe kha zwa vhudzekani?
.....

XITSONGA

1. MAHUNGU A DEMOGRAPHIC

1. Vito:.....

2. Malembe:.....

3. Dondzo ya lehenhla yi nga pasywa :.....

4. Muhlobo:

Mulungu	Mutima	Muyindiya	Mukhaladi
---------	--------	-----------	-----------

(Hlamusela rixaka loko uri mutima).....

5. Adirese ya wena:.....

6. Ntirho: Na tirha Ani tirhi
(Loko mi tirha hlamuselani).....

7. Vukhonger(iHlamuselani mangenele ya nwina)
A ndzhi yi Nkarhi wu nwani Nkarhi hikwawo

8. Rirhimi:.....

9. Vuvabyi lebyi mi nga tsama mi vabya:.....

10. Operexeni ta khale:.....

11. Vana va hanyaka:

12. Mi ti rwale kangani?.....

2. SWIVUTISO SWA VAVASATI VA NGA KUMEKA VA RI NI SWILONDZA KA XIVELEKO
VA FANELAKA KU HUMESIWA XIVELEKELO

“TATISANI HI KU TSALA KUMBE MI KOREKA HLAMULO”

1. Xana i yini xilondza xa xivelekele?.....
2. 2.1.Mi swi vhone rini kurhi mi na swilondza swa xivelekele?.....
.....
A kurhi yini xo hlupha hi nkarhi wolowo?.....
.....
Swi nga vonakala?
 - 2.3.1Ku vava
 - 2.3.2.Ku vona masiku kahle /swi nga ri kahle
Hi ku tala/Ku engeteka
 - 2.3.3.Ku heleriwa hi ngati
 - 2.3.4Swinwana.....
3. U endle yini endzaku ka loko u kumile leswaku u na swilondza swa xivelekele?
 - 3.1.U vulavule ni va ndhangu
 - 3.2. U vulavule ni dokodela wa wena
 - 3.3.U kombele oparexeni
 - 3.4.Swinwana (tsala vuxokoxoko).....
4. Kutsunguriwa loku ku nga endleka khale
 - 4.1.Tipilisi ta nkunguhato
 - 4.2.Nayiti ya Depo Provera
 - 4.3.Tipilisi ta ku horisa kuvava
 - 4.4.Tipilisi ta Cyclokapron
5. U ti twa njani loko u ri ni swilondza swa xivelekele, naku hi kwaho ka yini u ti twa tano?
 - 5.1.Wa twisisa
 - 5.2.U kwatile
 - 5.3.Swa ku khumba
 - 5.4. Swi nwana(Hlamusela).....
6. Hi xihhi xiyimo xa wena hi swa vukati?
 - 6.1.A wu tekiwanga
 - 6.2.U tekiwile
 - 6.3.Mi tsikanile
 - 6.4.U feriwile
7. Xana swilondza swa xivelekele swa ku kanganyisa loko u hlangana na nghamu ya wena? Loko swi ri tano hlamusela ku ri njani.
 - 7.1. Ku navela ku hungutekile
 - 7.2. Swa vava
 - 7.3. Swinwana (Hlamusela).....
8. Tingani tindzawu ta rihanyo kumbe ta tinyanga ta xikaya u nga ya kona kumbe ku kombela ku pfuniwa, na leswi va nga ku pfuna hi swona?
 - 8.1.Kliniki ya la ha u tsama ka kona
 - 8.2.Swibedlela le swikulu
 - 8.3.Tinyanga ta xintima

9. Xana i yini swi nga ku endla leswaku u ya kombela ku pfuniwa hi va rihanyu kumbe tinyanga?.....

10. Mhaka ya swilondza sa xivelekelo, swi ku kanganyisa hi ndlela yihi?

E moyeni (vukhonger)	Hiswona	A hiswona
E mihleketweni		
E ka swavushaka		
E ka swa timali		
E mirini (nyama)		

11. Hi bwihi vu ti twi ka vafumeri e ka mhaka ya nwasati a nga susiwa xivelekelo?.....

12. Xana u kona wa rixaka a hlupiwaka hi swilondza a ka xivelekelo?.....

(loko hlamulo yi ku u kona u , u pfuneke hi ndlela yihi?)

13. U langutela ku tsunguriwa hi ndlela yihi?

14. Hi kwihi ku chava u nga na kona e ka matsungulelo u nga byeriwa wona xana?.....

15. Nghamu ya wena u ri yini loko u fanela ku susiwa xivelekelo?.....

16. Wena u ri yini hi ku susiwa xivelekelo

16.1 Wa swirhandza

16.2. Wa lwa na swona

16.3. Wa lwa swinene na swona(Hlamusela.....)

17. U na vana vangani?.....

18. U vulavule na nghamu ya wena hi ku hlupheka hi swilondza a xivelekeloni xana?

Hiswona	A hiswona
---------	-----------

19. Nghamu ya wena u pfumerile xana kurhi u endhliwa oparexeni?

19.1. Hiswona

19.2. A hiswona(Hlamusela.....)

19.3A u kombelanga(Hlamusela.....)

20. Vaakisani na wena va twisisa yini na kuvula yini hi swilondza a xivelekeloni?

21. Vaakisani na wena va ri yini hi kususiwa ka xivelekelo?.....

22. Vaakisani va wena va vula yini hi nwasati a nga hava xivelekelo?.....

23. U ehleketa kurhi u ta hanya njani n anghamu ya wena a mikumbeni, loko u suse xivelekelo?.....

SETSWANA

1. KITSO YA TSA DEMOGRAPHY

LEBITSO:.....

DILEMO:.....

SEHLOPHA SEO O SE FEDITSENG SEKOLONG:.....

MORAFO:.....

BODULO:.....
.....

MOSEBETSI:

EYA	TJHE
-----	------

(HLALOSA MOFUTA WA MOSEBETSI)

BODUMEDI/KEREKE: MAKGETLO A HO TSAMAYA KEREKE
HO HANG KA NAKO ENGWE KA NAKO TSOHLE

PUO YA HAE:

MAFU A KILENG A BA TENG.....
.....

DI OPERATION :.....
.....

BANA BAPHELANG BA BA KAE:.....

O BILE MMELENG HA KAE:.....

“2. Tlatsa karabo”

1. Hlahala ya popelo ke eng?.....

2.1 Otsebile neng ka yona?.....

2.2 Bothata e ne ele eng?.....

(mohlala/ mahlaba, ho ya matsatsing/ kgweding ha holo

2.3 Ditletlebo

MAHLABA

HO YA KGWEDING-DIPHETOHO

MADI A TSWILENG HA HOLO

3. O entse eng ha o fumana hore ona le hlahala?

THALOSEDITSE LLAPA /BUA LE BS LELAPA

BUA LE NGAKA YA HAO

KOPA OPERATION

TSE DING.....

4. O kile wa phekolwa ka eng engwe

DIPILISI TSA HO THIBELA PELEHI

DEPO INJECTION

DIPILISI TSA MAHLABA

CYCLOKAPRON

5. O ikutlwa jwang ka ho ba le hlahala:-

UTLWISISA

PELO BOHLOKO

KGATHATSEHILE

MAIKUTLO A MANGWE.....

6. Tsa lenyalo

HA O A NYALWA

O NYETSWE

O AROHANE LE MOLEKANE

MOHLOLOHADI

7. Hlahala e tshwenya thobalano ya hao? Hlalosa jwang

THAHASELLO E FEDILE

MAHLABA /BOHLOKO

TSE DING.....

8. O kopile thuso di kliniking kapa dingakeng tsa Sesotho

kliniking.....

.....

sepetlele se seholo

.....

ngaka ya Sesotho.....

.....

9. Hlalosa mabaka a ho kopa thuso ko o.....

.....

10. Hlahala e o tshwentse ho kae?

MOYENG EYA TJHE

KELELLONG EYA TJHE

MMELENG EYA TJHE

SETJHABENG EYA TJHE

TJHELETENG EYA TJHE

(Ha karabo e le eya –hlalosa)

11. Maikutlo a badumedi tabeng ya mosadi a senang popelo ke a feng ?.....
.....
12. Ho na le motho e mong lapeng a nang le bothata ba hlahala?
HA A LE TENG –BA ETSENG KA BO THATA BO O?.....
.....
13. O lebeletse ho phekola bothata ba hao jwang?.....
.....
- 14.Ke eng e o etshabang ka pheko eo?.....
.....
15. Molekane wa hao o ikutwa jwang ka ho ntsha popelo?.....
.....
16. Wena o i kutwa jwang ka ho ntsha popelo?.....
.....
O A DUMELA
KGAHLANONG
KGAHLANONG HA HOLO (MABAKA).....
.....
17. O na le bana ba bakae?.....
18. O buisane le molekane ka bothata bo?
EYA TJHE
19. Molekane wa hao o dumetse ho re o ntshe popelo?
EYA TJHE- MABAKA.....
HA O A BOTSA – LEBAKA.....
20. Batho ba o o phelang le bona ba inkutlwa jwang ka hlahala popelong?.....
.....
21. Batho ba o o phelang le bona ba ikutlwa jwang ka ho ntsha popelo?.....
.....
22. Batho bar eng ka mosadi a senang popelo?.....
.....
23. O nahana hore o tlo kgona jwang ho etsa thobalano ha popelo e tswile?.....
.....

ISIXHOSA

1. ISAZISO NGE DEMOGRAPHY

1. IGAMA:.....

2. IMINYAKA:.....

3. IBANGA ELIPHEZULU OLIPHUMELELE:.....

4. UBUHLANGA:.....

5. IDILESI:.....

6. UYASEBENZA: EWE OKANYE HAYI
UMSEBENZI WAKHO:.....

7. UYAKHONZA: ACISA AWUZANGE /NGAMAXESHA ATHILE /OKANYE RHOQO

8. UTHETHA OLUPHI ULWIMI:.....

9. NDINIKE INGXELO NGEMPILO YAKHO:.....
.....

10. WAKHE WENZIWA UQHAQHO LOMZIMBA:.....
.....

11. BANGAPHI ABANTWANA ABAPHILAYO:.....

12. UYE WAKHULELWA KANGAPHI:.....

2. IMIBUZO KUMAMA EKWAYE KWATHIWA UNAMADLALA ESIBELEKWENI, KWAYE ISIBELEKO SIKHUTSHWE

(GCWALISA OKANYE UTYUMBE IMPENDULO)

1. Kuthiwa yintoni amadlala asesibelekweni?.....
 - 2.1.Uqwalasele nini ukuba unamadlala esibelekweni?.....
 - 2.2. Kwakuyintoni ingxaki ngeloxesha.....(umzekelo ingaba xa usexesheni ubusopha ngaphezu kwesiqhelo, ubuneqhuma okanye intlungu)
 - 2.3. Iimpawu
 - 2.3.1.IINTLUNGU
 - 2.3.2.EXESHENI UYA NGOKWESIQHELO/NGOKUNGAQHELEKANGA UYAKAKHULU/UTHATHA INTSUKU EZINGAPHEZU KWESIQHELO
 - 2.3.3. IGAZI ELIPHUMAYO LIKANGAKANANI
 - 2.3.4. OKUNYE ONGAKUKUCHAZA.....
3. Uye wenza ntoni wakufamanisa ukuba unamadlala esibelekweni
 - 3.1.WATHETHA NGALO MBAMBO
 - 3.2.WATHETHA NGALO MBA NOQHIRHA WAKHO
 - 3.3.WACELA UQHAQHO
 - 3.4.NIKA INCAZELO
4. Ubusebenzisa awaphi amayeza/unyango lipilisi zocwangciso-ntsapho
Umjovo ekuthiwa yi-DEPO
Amayeza okuthibaza iintlungu
Amayeza e-CYCLOCAPRON
5. Uziva njani ngokuba unamadlala esibelekweni, kutheni?
 - 5.1.UYAQONDA
 - 5.2. UNOMSINDO
 - 5.3. UYAKHATHALA
 - 5.4. CACISA NGOKUZELEYO
6. Ingaba
 - 6.1.AWUTSHATANGA
 - 6.2.UTSHATILE
 - 6.3.UMTSHATO WAQHAWUKA
 - 6 4.WABHUJELWA-NGUMYENI

7.Ingaba la madlala-esibeleko anegalelo ngokwasecantsini (ukuhlangana ne wakho ngesondo) Ukuba kunjalo cacisa:-

 - 7.1. UMDLA UYANCIPHA
 - 7.2.KUBUHLUNG
 - 7.3.CACISA NGOKULEYO
8. Mangaphi amaziko empilo /esintu oye wanxulumelana nawo ufuna uncedo, ncedo luni oye wa lufumana ?
 1. KWII KLINIKI.....
 2. ESIBJEDLELE
 3. KUBANTU BESINTU/AMAXHWELE

9. Ziziphi izizathu ezibangele ukuba ufune uncedo kusebe le zempilo/kumaxhwele/inyangha.....

10. Ingaba amdlala-esibekeko akuphathe kakubi

NGOKWASE NKOLWENI	Ewe	HAYI
NGOKWASE NGQONDWENI	Ewe	HAYI
NGOKWASE NYAMENI	Ewe	HAYI
NGOKWASE KUHLALENI	Ewe	HAYI
NGOKWASE ZIMALINI	Ewe	HAYI

UKUBA KUNJALO NCEDA USIPHE INCAZELO.....

11. Inkonzoyako imbona njani umama ongenasibekeko(uwenziwe utyando lwesibekeko)

12. Ukhona umntu ekhaya (kwicala lakulo mama/dade)unale ngxaki yamadlala esibekeko? Ukuba kunjalo saba yintoni isiphetho sale ngxaki?.....

13. Ucinga ukuba ungancedakala njani kwesisimo.....

14. Luyintoni uloyikolwakho olukhulu kucebiso ncedo olunikwayo.....

15. Isinqanda-mathe sakho siyibona njani into yo kukhutshwa kwesibekeko kosakho?.....

16. Uwubona njani lo mbono woku khutshwa kwesibekeko sakho:-

16.1. UYAMKELA

16.2. UYA WUCHASA

16.3. AKUVUMELANI NAWO KWAPHELA(NIKA INKCAZELO).....

17. Bangaphi abantwana onabo?.....

18. Uye wathetha-thethana no wakwakho malunga nale ngxaki yamadlala esibekeko unawo.

EWE	HAYI
-----	------

19. Ingaba isithandwa sakho sinikezele imvume yokuba wenziwe uqhaqholwe sibekeko.

19.1 EWE

19.2 HAYI-NIKA ISIZATHU.....

19.3. AWUCELANGA-MVUME, CHAZA.....

20. Ingaba abahlali bendawo okuyo bayithatha njani indaba yamadlala-esibekeko

21. Ingaba abahlali bendawo okuyo bayithatha kanjani indaba yomntu wesifazana okhutshwe isibeleko.....

.....
.....

22. Ingaba abantu bendawo ohlala kuyo bathini ngomama/umntu wesifazana ungena sibeleko.....

.....

23. Ucinga ukuba uya kwamkela njani ukuva encantsini nowakwakho ,emva koqhaqho lwesibeleko.....

.....

APPENDIX I: Questionnaire for Nurses

20/12/2007 09:09 0124292244

UNISA TELKOM

PAGE 05

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:04PM P07

QUESTIONNAIRES FOR HEALTH CARE PROVIDERS IN GYNAECOLOGICAL
AREAS
(FILL IN YOUR ANSWERS)

1. NURSES (ALL CATEGORIES)

- 1.1 How long have you been working in this area?.....
- 1.2 Qualification?.....
- 1.3 What information do you have regarding fibroids and hysterectomy which you impart to the patients?.....
.....
.....
.....
- 1.4 When do you health educate these patients?.....
.....
- 1.5 How is the attitudes of the patients who have been health educated before and those who have been educated after operation?.....
.....
.....
- 1.6 Is it your responsibility to participate in educating or counseling of women with fibroids before a hysterectomy? YES or NO.....
(give reasons).....
.....
- 1.7 What are your attitudes and feelings towards fibroids?.....
.....
.....
- 1.8 What are your attitudes and feelings towards hysterectomy?.....
.....
.....
- 1.9 What are the questions which women asks you, when you are having discussions about fibroids and hysterectomy?.....
.....

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:05PM P08

1.10. Who is responsible for obtaining the consent from this patient before operation?
NURES or DOCTORS (Tick and motivate the answer).....

.....
.....

APPENDIX J: Questionnaire for Doctors

20/12/2007 09:09 0124292244

UNISA TELKOM

PAGE 07

FROM : Johannesburg Hospital

PHONE NO. : 4884174

Dec. 19 2007 03:05PM P09

QUESTIONNAIRE FOR DOCTORS ADMITTING AND OR OPERATING
PATIENTS WITH FIBROIDS UTERUS FOR HYSTERECTOMY

1. What are the questions which women ask when you are counseling or discussing with women on fibroids and hysterectomy?

.....
.....
.....
.....
.....
.....
.....

2. Do you think your counseling is sufficient for women to sign informed consent for hysterectomy? YES OR NO (Tick and give reasons for your answer)

.....
.....
.....
.....

3. Are these women of diverse cultures prepared for hysterectomy or not? YES or NO (Tick and give reasons for your answer).....

.....
.....
.....