

# **The Effects of Endometriosis on South African Women's Perceived Quality of Life**

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## DECLARATION

I declare that this dissertation is my own work. It is being submitted for the fulfilment of the Degree Master of Arts in Psychology at the University of KwaZulu-Natal. It has not been submitted before for any other degree or examination at any other university.

A handwritten signature in black ink, appearing to read 'Romy Orator', is written over a horizontal dotted line.

Romy Orator

## **ABSTRACT**

Endometriosis is a painful and debilitating chronic gynaecological condition experienced by women in their reproductive years. This illness impacts on their fertility rate and on their general quality of life. Current research into the lived experience and perceived quality of life of women living with Endometriosis is lacking. Considering the prevalence of this condition, an understanding of women's lived experiences and the processes from which meaning is generated is essential to assist women and their families in coping with Endometriosis. Illness representation theory provided some insight into the meaning making processes involved in understanding and coping with a chronic illness. A phenomenological study was conducted to explore women with Endometriosis' lived experiences and the pervasiveness of this condition in terms of their perceived quality of life. I argued that dynamic relationships exist between the women's personal, social and medical worlds and that these interactions provide the context for the creation of women's lived experiences of Endometriosis.

## **CHAPTER ONE**

### **INTRODUCTION**

Endometriosis is a chronic gynaecological condition experienced by women in their reproductive years. The symptoms are often painful and debilitating and impact on women's reproductive health as well as on various aspects of their quality of life. The concept of quality of life is conducive to the exploration of the subjective experience of the disease in various aspects of one's health. Quality of life pertains to the perception of one's well-being related to goals and values and one's ability to lead, to varying degrees, a satisfying physical, psychological and social life.

Considering the relatively high prevalence of Endometriosis, an exploration of the lived experience of chronic illnesses, such as Endometriosis, assists in developing an explanation of the effects of disease on one's ability to lead a satisfying, well-rounded life. Further reasoning behind exploring Endometriosis is that it remains inadequately understood, both in terms of its aetiology and in terms of its psychosocial implications on the patient and the family. For example, Endometriosis affects a woman's reproductive functioning. As such, it impacts on the meanings associated with the psychological and social aspects of their lives such as the ability to reproduce, to be an adequate sexual partner and to have meaningful social relationships.

The way people appraise and cope with an illness is influenced by their representation of that illness. Illness representation theory provides a useful standpoint from which to explore Endometriosis as a lived experience. The way in which women generate meaning out of their experience of this condition impacts on how they cope. This study explores



and illustrates the complex social, psychological and cultural embeddedness of this meaning-making process. Considering the racial, cultural and ethnic varieties within the South African population an exploration into how women's experience of Endometriosis is created and negotiated could possibly improve the quality of services provided to women from a variety of communities. In addition to improving cultural and gender-specific health care practice the woman's increasing role in the workplace should be considered. Having increased demographic representation in the workplace it is possible that more women are entering the workplace who may experience Endometriosis. This study explores the effects the impact of this condition on one's occupational life and could be used to inform occupational health care practices so as to improve well-being of women workers and their families as well as improve affected women's functioning within an organisation.

Furthermore this study illustrates the development of the meaning making processes of within women's encounters with the medical profession and as well as their personal and social worlds. While studies have been conducted into the effects of chronic conditions on people's quality of life, few studies have explored women's experiences of the effects of Endometriosis on their health-related quality of life (Jones, Kennedy, Barnard, Wong and Jenkinson, 2001; Jones, Jenkinson and Kennedy, 2004). However, of the studies that have been conducted, Jones et al (2001) pointed out that five studies used psychometric evaluations that were generic in focus in that they studied the state of patients' health that suffered from a broad variety of diseases rather than specific illnesses. A shortcoming of generic studies is that they do not facilitate the collection of information in specific areas of well-being and functioning related to particular diseases, such as Endometriosis.

Understandings gained from such an exploration could be used to effectively inform therapeutic interventions, including social support to affected women and their families, as well as to inform the work of the medical practitioner such that intervention reaches into the specific dynamics related to this specific condition. The doctor-patient relationship, and empathetic understanding therein, has been identified as a vital professional tool and skill in providing informed medical treatment (Eide, Frankel, Haaverson, Vaupel, Graugaard and Finset, 2004). Increased insight into the various areas of impact of this condition on an affected individual's life would enable the generation of improved empathy during the medical encounter which, as is discussed in this study, would be communicated to the patient. The effects of the medical encounter on women's marital relationships, as well as other social relationships, is illustrated and discussed and further reinforces the importance of improved understanding of lived experience of this particular chronic condition.

In response to the need to understand the effects of Endometriosis on women's health and quality of life, a phenomenological investigation was conducted to explore the lived experience of Endometriosis among a select sample of South African women. The discussion herein attempts to answer the question asked as in what is the effect of Endometriosis on various aspects of affected women's quality of life? In the subsequent chapters a literature review will first be presented followed by the methodology, then the findings, the discussion and in the last chapter, a conclusion to the study will be presented.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

The literature review comprised of a discussion of Endometriosis as a physiological condition, its aetiology and treatment. Following this the impact of this condition on one's perceived quality of life in various aspects of functioning, such as physical, psychological and social is explored. The discussion then moves on to an exploration of the theoretical framework used in this study, which includes a consideration of illness representation theory, the lived experience of chronic illness, gender identity as well as the sociocultural meanings of illness.

#### **2.1 ENDOMETRIOSIS AS A PHYSIOLOGICAL CONDITION**

Endometriosis is a chronic gynaecological and painful disease in which endometrial tissue (which normally lines the uterus) detaches and grows on different parts of the body, such as the ovaries, fallopian tubes, bladder, intestines or in the abdominal cavity (Carlson, Eisenstat and Ziporyn, 1996). These growths are comprised of endometrial tissue and therefore respond to hormonal changes that occur during the menstrual cycle by building up and breaking down, as does the endometrium (uterus lining). This causes internal bleeding, cysts, inflammation and the subsequent development of scar tissue, with associated chronic pain in the pelvic area. Colwell, Mathias, Pasta, Henning and Steege (1998) state that Endometriosis affects approximately 10 percent of women in their reproductive years.

## 2.2 HOW ENDOMETRIOSIS DEVELOPS

In earlier years Endometriosis was labelled “the career woman’s disease” as it was commonly found in women in their late twenties and early thirties (Carlson, Eisenstat and Ziporyn, 1996). An understanding prevailed that Endometriosis was commonly found among white, affluent women characterised by nervous and anxious traits. This misunderstanding contributed to the belief that Endometriosis was preventable and that women afflicted with the condition were responsible for its onset. However, Endometriosis has since been found to exist among women from various ethnic groups, ages and who have varying histories of childbirth (Carlson, Eisenstat and Ziporyn, 1996). However, a genetic component in the development of Endometriosis has also been found, in that women who have a first-degree relative with the condition are at increased risk of developing it themselves.

The precise cause of Endometriosis remains unknown. Research has explored the correlation between Endometriosis and retrograde menstruation whereby menstrual fluid, in addition to exiting the cervix and vagina, travels up the uterus and outwards towards the fallopian tubes (Taymor, 1990). However, not all women with reversed menstruation develop Endometriosis. It has also been speculated that endometrial tissue has the ability to migrate to and implant on other organs without instigating an immune response that would otherwise hinder its growth. Other research also implicates the involvement of an environmental toxin named dioxin in the development of Endometriosis. It has been hypothesised that women exposed to excessive amounts of pollutants or pesticides containing dioxin may develop Endometriosis (Taymor, 1990).

## 2.3 THE EFFECTS OF ENDOMETRIOSIS

Because Endometriosis does not have any specific characteristic symptoms it is often confused with other conditions such as irritable bowel syndrome or ovarian cysts (Carlson, Eisenstat and Ziporyn, 1996). As a result, more exploratory procedures are frequently required to establish whether endometrial growths are present, such as ultrasound, laparoscopy (a procedure whereby a clinician looks directly into the pelvic region to ascertain whether there are endometrial growths on the uterus) and surgical exploration.

Commonly experienced complaints and symptoms among women with Endometriosis include painful menstrual cramping, pain during sexual intercourse (deep dyspareunia) and infertility (Garry, Clayton and Hawe, 2000). Other symptoms more rarely experienced are chest pain, leg weakness and symptoms of irritable bowel syndrome, such as bowel pain (Carlson, Eisenstat and Ziporyn, 1996). However, Colwell et al (1998) stated that not all women with Endometriosis would experience these symptoms.

A high percentage of women with Endometriosis are infertile (49%) because the endometrial growths and adhesions prevent fallopian tubes from 'capturing' the ovum (egg) during conception (Taymor, 1990). Other possible explanations are hormonal imbalances, the ovary's failure to release an egg and immune system disturbances (Taymor, 1990).

## 2.4 TREATMENT OF ENDOMETRIOSIS

In terms of treatment of the endometrial growths and the secondary pain symptoms, relief can be provided through surgical or drug treatment, both of which have various benefits and disadvantages. Surgical treatments usually have longer-lasting effects and are more effective in assisting women who are trying to conceive, although it is relatively expensive (Taymor, 1990). Surgery procedures involve the excision or destruction of endometrial tissue through laser surgery, electrocautery, scalpel excision or scraping. If a woman's adhesions are severe and extensive, she may need to undergo more radical surgery such as a hysterectomy or radical laparoscopic excision (Garry, Clayton and Hawe, 2000).

Drug treatment involves oral contraceptives and GnRH agonists (gonadotrophin-releasing hormone agonists) (Carlson et al. 1996). These drugs produce a reversible state of menopause thus allowing a disruption of the menstrual cycle and providing relief from chronic pain. Side effects associated with this form of treatment include hot flashes, vaginal bleeding, headaches, depression, insomnia, vaginal dryness, weight changes and hair loss. Because of chronic pain and infertility caused by Endometriosis on the one hand, and the unpleasant side-effects of drug treatment on the other, many women suffering from this disease are advised to alternate drug and surgical treatment so as to provide maximum pain relief with as few side-effects as possible (Carlson et al, 1996).

## 2.5 QUALITY OF LIFE

The World Health Organisation defines quality of life as an individual's perception of their life in relation to their culture and value systems as well as their goals and expectations for life (Forsberg, 1996). Quality of Life is a broad concept that is affected by the person's physical health, their psychological state as well as their capability for independence and the quality of one's social relationships.

Health-related quality of life is a patient-based concept that incorporates how one's perceived health can affect one's ability to live a fulfilling life and includes aspects of one's physiological as well as psychosocial well-being.

Health status is understood as being an aspect of quality of life. There are many existing definitions of health, each of which pertains to a particular perspective (Klang, 1997).

From a medical perspective health is defined as the lack of disease while from a sociological point of view health is understood as the maintenance of acceptable levels of mental health and physical fitness in order for one to adequately fulfil one's social roles.

From a humanistic perspective health is viewed as an ideal state of autonomy, personal strength and positive meaning of life. In addition to these perspectives, health is also a culturally relative concept. While health may be a goal common to all members of a social group and across social groups, the particular importance of health to individual members is assessed and evaluated relative to other goals embedded in that community (Klang, 1997).

However, Klang (1997) argues that there is a movement away from conceptions of health as the absence of disease or disability towards an evaluation of completeness and total functioning of mind, body and social efficacy. In line with this trend Antonovsky as cited in Klang (1997) proposes that health occurs as an entity existing along a continuum of ease and disease rather than health and disease as dichotomous constructs. He argues that an individual's positioning along this continuum is determined by their perceived sense of coherence and that it is essential to the development of coping capacity in the individual. This sense of coherence is defined as the perception of one's sense of confidence that the stimuli one receives from one's environment are structured, predictable and explicable and that one has the internal and external resources to meet these demands (Antonovsky, as cited in Klang, 1997).

Individuals with a greater sense of coherence may be better able to deal with stressful situations in positive ways. Klang (1997) goes on to propose that the way in which one copes with stressful situations depends on the nature of the circumstances, his or her perception and cognitive appraisal of the situation as well as one's previous coping resources.

Klang (1997) proposes that health-related quality of life (HRQOL) emerges out of one's adaptive process to illness which begins with the uncertainty posed by the illness and further develops with one's appraisal of this uncertainty as either a danger or an opportunity and out of this appraisal emerge coping strategies which direct this uncertainty. HRQOL is distinguished from quality of life as a whole, which also



incorporates aspects such as adequacy of housing, income and perceptions of one's immediate environment.

The concept of 'quality of life' is multidimensional as it incorporates all aspects of an individual's physical, psychological and social functioning, as seen in the multidimensional effects of Endometriosis discussed above (Forsberg, 1996). Ferrans, as cited in Forsberg (1996), proposes that there are five predominant categories of quality-of-life used in health research, namely normal life (ability to function at a similar level as a healthy person), happiness or satisfaction, achievement of personal goals, social utility (the ability to lead a socially useful life) and natural capacity (physical and mental capacity).

Aaronssen, as cited in Forsberg (1996), further suggests that health-related quality of life is comprised of four concepts, namely physical functional status, the disease symptoms and treatment as well as the side-effects of treatment, psychological status and social functioning. However, when discussing specific diseases, aspects specific to that disease across all four concepts need to be considered, for example, sexual functioning in gynaecological conditions such as Endometriosis would need to be explored.

Furthermore, Patrick and Erikson, as cited in Klang (1997), define HRQOL as the value assigned to life which is mediated or modified by one's impairments, functional status, perception and social functioning which are influenced by disease or its treatment. The inclusion of multi-factorial aspects in such a definition opens the possibility for multiple entry points in terms of possible intervention strategies.

The Quality of Life concept is also dynamic as an individual's values change throughout life. Quality of life is also a personal concept in that it incorporates an individual's perceived state of well-being, as well as one's perspectives on life, and the various roles, relationships and experiences within it (Forsberg, 1996). In the case of Endometriosis, various areas of one's quality of life are affected by the chronic condition of Endometriosis, including one's various life roles.

The potential impact of Endometriosis is far-reaching. This impact may reach to one's physical, psychological and occupational worlds and may also infiltrate into one's family life and marital relationships. Mediation with the medical profession may also reduce or compound these effects.

### **2.5.1 The impact of Endometriosis on women's lives**

It has been argued that little research has been done into the impact of symptoms of endometriosis (chronic pelvic pain, dysmenorrhoea, dyspareunia and infertility) on women's health-related quality of life (Jones, Jenkinson and Kennedy, 2004). In their study on the impact of endometriosis on women's quality of life Jones et al (2004) reported that pain was one of the largest contributors to negative health-related quality of life. Associated with this pain was decreased physical functioning, such as difficulty walking or sitting as well as reduced appetite and sleeping difficulties.

The pervasiveness of endometriosis was recognised with regards to altered role performance as a result of pain. For example, women have been found to experience

difficulty attending to household activities as well as employment obligations due to debilitating symptoms. Many women experiencing Endometriosis may find it necessary to take time off work as a result of the severe, chronic pain associated with their condition and this pain may interfere with their ability to perform certain work-related duties. This may also cause significant distress as affected women may worry about not performing at their optimum level.

On the home front, child rearing might be a difficult task to perform by women with Endometriosis due to the physical limitations imposed by, and psychological implications of, the disease. Those women who have children might find it difficult to perform different tasks associated with child rearing. For example, they might find it difficult to play with their children as a result of their pain. In terms of the marital relationship pain during or after intercourse may also be experienced by the woman, which might cause distress and a subsequent avoidance of intercourse. They may also experience guilt for not wanting to engage in intercourse with their partners as well as frustration at not being able to enjoy intercourse (Jones et al, 2004). Adding to the strain this condition frequently places on the marital relationship is distress at not being able to, or fear of not being able to, conceive. As a result women may feel inadequate and fear that their inability to conceive may further strain their relationship.

Chronic pain has been found to decrease one's energy and vitality in one's daily life and also impacts on one's social functioning, often confining one to bed thus preventing participation in social activities, often reducing one's access to social support (Jones et al, 2004).

Another area found to be severely impacted upon by endometriosis is emotional distress and frustration, and general decreased emotional well-being (Jones et al, 2004). Women with Endometriosis may feel unable to cope with their condition and experience frustration in terms of their lack of control over their symptoms and their inability to recover. The experience of helplessness has also been associated with Endometriosis (Jones et al, 2001). Lemaire (2004) argues that in their emotional response to endometriosis women may experience numerous and varied reactions including shock, denial, fear, loss anxiety and a sense of isolation. The emotional distress related to uncertainty about the condition appears to stem from the unpredictable nature of the disease (Lemaire, 2004), which also contributes to a sense of helplessness and lack of control.

The pervasive nature of endometriosis on numerous aspects of a woman's life (Denny, 2004) frequently results in difficulty in one's occupation (sometimes including workplace discrimination), marital difficulty and a sense of being alone in one's struggle against a pervasive and debilitating disease. This, in conjunction with a frequently experienced delay in diagnosis, trivialisation of one's symptoms and limited efficacy of treatment, sometimes contributes to the development of psychological depression, and sometimes even suicidality (Cox, Henderson, Andersen, Cagliarini and Ski, 2003). For some women, the inability to conceive contributes to a sense of being a failure as a woman which may further erode one's sense of worth and esteem. The chronic nature of symptoms further perpetuate anger and frustration, which may drive some women to exert themselves in other areas of their life in an attempt to maintain a sense of self-preservation and normalcy (Wang, 2004).

In addition to the above effects of Endometriosis on women's quality of life, these effects may be compounded by the perception of the medical profession as being unable to help. Affected women might also become frustrated with medical doctor's lack of knowledge of the condition. They may also feel frustrated with the amount of treatment they undergo as well as the effects of treatment.

From the discussion above it can be seen that the experience of Endometriosis is frequently a painful and frustrating one. The symptoms associated with Endometriosis are major contributors to psychosocial problems experienced by women with the condition. For example, chronic pelvic pain can result in impairment in one's ability to function socially and the arduous treatment process and possibility of infertility can result in feelings of isolation and frustration (Jones et al, 2001).

## **2.6 THEORETICAL FRAMEWORK**

Theoretical components for the various aspects of Endometriosis, and chronic illness in general, were drawn upon to understand women's lived experience of Endometriosis.

This includes illness representation theory and various psychosocial aspects related to the experience, and coping with, chronic illness.

### **2.6.1 Illness representation theory**

The ways in which a chronically ill person appraises and copes with their illness is pertinently influenced by their representation of that illness. Illness representation, a concept developed by Leventhal as cited in Heijmans, de Ridder and Bensing (1999) is defined as a person's own common sense beliefs about their illness, that is, a person's

*lived experience* of that illness, and their beliefs and expectations regarding that illness.

Illness representation is closely related to the means by which a person copes with an illness and incorporates the role of social factors in mediating how one appraises having an illness. Therefore, according to illness representation theory, individuals actively create meaning out of their illness experience and this directs the ways in which they cope with the illness (Meyer-Weitz, Reddy, Weijts, van den Borne and Kok, 1998).

The way in which one's lived experience of illness, or how one *represents* illness, emerges out of five core themes namely identity, cause, time-line, cure and consequences (Heijmans et al, 2001). Identity involves the label of the illness as well as information known about it; time-line involves the likely course and length that the illness is expected to take. Cause involves the factors resulting in the onset of the illness, and cure involves the ability for the illness to be controlled; and consequences refers to the outcomes of that illness. Kidel and Rowe-Leete (1988) argue that illness reveals vulnerability and that a predominantly negative perception of illness is directly linked with the competitive nature of our culture whereby vulnerability and weakness are seen as undermining roles and goals which are common to many work environments.

Heijmans et al (2001) further propose that a patient's social network also plays a significant role in terms of influence on the patient's beliefs about health and illness. However, the social nature of chronically ill people's health beliefs has not been adequately researched.

Leventhal, Nerenz and Steele (1984) proposed a theoretical model of illness representation to explain how individuals regulate or minimise their health-related risk. They conceptualised that this process incorporates a “self-regulating processing system” (Leventhal, Nerenz and Steele, 1984, p. 221). The four basic assumptions of their model include 1) active processing, 2) parallel processing, 3) stages in processing and 4) hierarchical processing. In terms of the first assumption (active processing) it is argued that behaviour and experiences, including health and illness experiences, are constructed by an underlying information-processing system, which combines current stimulus information as well as past memories. One’s experience of the world, and emotional reactions to it, and coping mechanism arise out of the continuous processing system which functions to organise experience. Leventhal, Nerenz and Steele (1984) propose that this system is comprised of two parallel ‘pathways’ or concurrently occurring mechanisms by which illness representations are created. The first ‘pathway’ involves the development of an objective representation of an illness and the creation of a coping plan to manage that threat, while the second pathway involves the creation of an emotional response to the threat and the development of a coping plan to manage this emotion. These two pathways are in mutual operation and interact in order to assist the individual in adapting to a specific situation.

Leventhal, Nerenz and Steele (1984) propose that there are many ways in which emotion can modify one’s response to illness. Firstly, emotions can impact on the amount of energy available for coping and secondly, emotion can also increase or decrease the intensity of symptoms and can also generate symptoms which can be confused with those of the illness. Thirdly, emotions can also impact on the sequence in which features of an

illness representation are scanned. For example, if an individual is severely depressed by the threat of an illness (for example, Endometriosis) any actual or presumed symptoms of Endometriosis can result in grave thoughts and images of the consequences of that threat, for example pain and infertility. Emotions can also impact on the individual's physiological coping with the illness in that emotional arousal may weaken the individual and can also deplete neurotransmitter and neuro-hormonal systems necessary for coping action (Leventhal, Nerenz and Steele, 1984).

This self-regulating system functions in stages. During the first stage a *representation* of the problems and emotional reactions related to it is created. In the second stage the system develops a *plan* for the execution of responses and for coping with the problems and the emotion, the coping thus being steered by the representation. During the third stage, *appraisal* occurs to determine whether the coping strategy has brought the individual closer to the goals defined in the representation. During this stage information *feeds back* to earlier stages of the process, enabling an alteration in coping strategies or the way in which the problem was represented (Leventhal, Nerenz and Steele, 1984).

Finally, the self-regulating system is hierarchically organised in that processing occurs on two levels, namely concrete and abstract. Behaviours to cope with the representations involve concrete aspects (such as pelvic pain) as well as abstract features (such as the idea that one has a gynaecological disorder) in the representation, coping and appraisal stages.

Leventhal, Nerenz and Steele (1984) propose that the definition of goals for coping and its appraisal are evaluated against aspects of illness representations, particularly in terms of identity, cause, consequence and duration aspects, discussed above. Their research into



hypertension treatment indicated that individuals attempt to integrate concrete components (such as symptoms) with abstract components (such as labels of a condition) in order to identify an illness episode. Furthermore, it is argued that individuals draw on three major sources of information in their development of illness representations. The first source is the general collection of illness information in one's culture, and involves the specific meanings embedded in the language used to describe and discuss particular illnesses. The second source involves the collection of information via communication with other people, practitioners in particular. Symptom appraisals are influenced by the sharing of information with others in the individual's social network, including family members and friends. This sharing of social communication further extends the evaluation of the cause, consequences, duration, treatment options and possible treatment outcomes. Out of this sharing the individual develops his or her own model of the illness and develops a plan of action to deal with it. The third source of information is the individual's own personal experience of an illness. During an episode of illness, information is drawn upon from all three resources to form an illness representation.

The process of formulating illness representations may also have consequences for one's relationships with others. In their research Heijmans et al (1999) argued that patients and their spouses can have divergent illness representations and this has consequences in terms of how the couple copes with the illness. For example, spouses can either minimise or maximise the seriousness of the illness in an attempt to establish a balance between their relationship and the functioning of the chronically ill spouse. Spouses that minimise might overestimate the chances for cure, thus not attributing much seriousness to the illness whilst others might exaggerate the seriousness of the illness and become

overprotective of the ill spouse. What their research indicated was that maximisation and minimisation had to do with the healthy spouse's concern regarding how the ill spouse was coping. Maximised illness representation or overprotective behaviour towards the ill spouse had negative implications for the ill spouse as it increased dependant behaviour and reduced the ill spouse's sense of competency, thus resulting in growing depression. What these results revealed is that when one spouse is chronically ill, both spouses may differ in their representations of the illness, which has specific consequences for the relationship. They also concluded that minimisation of the seriousness of the ill spouse's condition could also have a negative effect in that it gives the impression of not being taken seriously.

## **2.6.2 The experience of chronic illness**

A discussion of the effects of chronic illness is useful in understanding how women with Endometriosis develop representations of their lived experiences. Chronic illness can be understood as affecting the individual on both intrapersonal as well as interpersonal levels. While these two levels may be discussed as separate it is important to consider that they mutually influence each other. For example, one's lowered self-image as a result of one's inability to function adequately as a result of pain may impact on one's interpersonal interactions with others. Support for the understanding that chronic illness affects numerous areas of functioning is provided by Antonovsky, as cited in Klang (1997), who argues for a systems approach to health and illness. This approach incorporates the assumption that health is a dynamic entity comprised of interrelated parts. It can be argued that the complex interrelation of parts, such as physical, social and psychological factors produces the lived experience of the person living with the chronic

disease, thus perceived quality of life is mediated through these variables. This approach can be applied effectively to Endometriosis which has prominent physical features, including chronic pain and discomfort; psychological features, such as fears and frustrations regarding infertility and emotional well-being; as well as social factors, in that the experience of symptoms and appraisals of Endometriosis both impact *on* social relationships and are mediated *by* them.

Lubkin , as cited in Klang (1997) defines chronic illness as impairments in or deviations from 'normal' functioning that are characterised by permanency or non-reversible functional change. This change results in disability or necessitates long-term rehabilitation. The quantity or degree of disability depends not only on the severity of the illness but on the implications it has for the person. The World Health Organisation recognises the consequences of chronic illness as impairment in physical status, disability (in terms of physiological functioning) and handicap or disadvantage in social functioning (Klang, 1997). Chronic illness tends to impact on the social, psychological, physical and economic aspects or spheres of one's life. For example, one's physical disability may alter one's psychological status, which may impact on one's work and economic capability. Klang (1997) states that problems usually emanating from chronic physiological conditions include intrafamilial conflict, sexual stressors, conflicts of dependence versus independence, self-image modifications and economic strain.

Long-term chronic illness has been found to cause a disruption in one's sense of normalcy as patients face numerous changes in their functioning and social roles. In addition to this plans for the future are also frequently disrupted (Heijmans, De Ridder and Bensing,

1999; Gillis, 2002). Women with Endometriosis may also experience disruptions in their plans for the future as hopes for childbearing may become dashed. Social and personal relationships can also be impacted on by both the more immediate consequences of Endometriosis, such as chronic pain, as well as more indirect consequences, such as the need to fulfil role-expectations, for example, being an adequate sexual partner or fulfilling the role of motherhood.

### **2.6.2.1 Chronic illness and gender identity**

When attempting to understand the lived experience of a reproductive related chronic illness, such as Endometriosis, the inter-relationship between health and gender need to be explored. Bekker (2000) argues that the body is the site of health and illness experiences and that gender identity is also fundamentally related to the body. For example, because males and females have different bodies both sexes may experience specific illnesses in terms of their own sex, for example, prostate cancer (in males) and Endometriosis (in females). However, this direct relation is only one possible component in the complex interrelation between gender and health. Health-related differences between males and females can be explained and explored on numerous levels.

Bekker (2000, p. 18), in emphasising that the human body plays a core role in identity, proposes a “Multi-Faceted Gender and Health Model” indicating the complex relationships between biological sex differences and gender differences in health and illness experiences. On one level, as referred to above, having either a male or female body means that certain illnesses and not others can effect it, due to the exclusive occurrence of certain illness in particularly male or female bodies. On another level health

is also influenced by one's environment, either by direct influences or by particular life occurrences that may be sex-specific. On a broader level, processes of gender identity formation and sex-typing result in the creation of different social positions occupied by men and women, such as different professions, different leisure activities and roles in child care. For example, Lundberg as cited in Bekker (2000) argues that women experience higher psychophysiological arousal levels due to role conflicts experienced at work, possibly contributing to their higher incidence of psychophysiological complaints. Therefore, what is clearly seen is that gender differences play an important role in the incidence and experience of illness.

Bekker (2000) also argued that biological sex difference also plays an important role in health care in that the process of diagnosis and treatment is influenced by sex-role stereotyping. Sex differences in health are mediated by multiple factors, namely direct and indirect bodily factors, Biopsychosocial experiences in daily life, person-related factors such as coping styles and bodily experiences as well as gender bias (Bekker, 2000).

Previous research has emphasised the role of outward appearance in body experience (such as perceptions of slenderness in eating disorders) while very little research has explored *inner* bodily experience (Bekker, 2000). Outward body appearance has been researched as playing a crucial role in body esteem and body dissatisfaction, whereby the body is seen as an external, aesthetic object. The large emphasis on the body as external aesthetic object may be due to the researchers' focus or that many studies have been conducted in the field of eating disorders. It could also reflect a possible one-sidedness

within western culture whereby the external appearance of bodies receives major emphasis. Could this mean that the inner experience of one's body as dysfunctional, as in the case of potential infertility in women with Endometriosis, runs the risk of being ignored or unattended to socially in a culture whereby such experiences are not given major exposure?

Penn (2001, p. 10) argued that the social perceptions of illness often incorporate a sense of "defective[ness]" and that negative cultural metaphors exist surrounding chronic illness. It is therefore possible that the experience of having Endometriosis is characterised by a sense of 'defectiveness' in one's socially-mediated role as a woman in society. For example, Darke (1996, p. 149) emphasised that fertility is understood as "the essence of femininity in medico-moral discourses" therefore the loss of fertility or the threat thereof, as sometimes occurs in Endometriosis, could have implications for the woman's sense of fulfilling her 'feminine' role. However, in Darke's (1996) study with menopausal women she found that this was not necessarily the case, in that the participant's feminine self-image was not necessarily impacted on by the loss of fertility. However, an important distinction needs to be made between Endometriosis and menopause in that menopause is frequently experienced later in one's life and is therefore more likely to be accepted as a normal process of ageing. However, Endometriosis can be experienced by women at any child-bearing age, even in one's teenage years, therefore the threat of infertility may play a more powerful role in one's experience of this chronic illness.

Dayus, Rajacich and Carty (2001) argued that issues related to childbearing and reproduction are embedded in a complex array of feelings and that parenthood is frequently seen as a societal imperative desired by most people. In terms of the effect of the threat or experience of infertility on the couple, reproductive 'failure' infiltrates the couple's life, necessitating a redefinition of their personal life goals and identities. This difficult life experience is frequently exacerbated by the silence surrounding infertility in society, and in addition to this, many infertile couples frequently preclude themselves from outside support at this difficult time. The couple relationship may be placed under increased strain as the infertile woman may experience herself as 'damaged' or as a 'failure'. She may also experience anger, disappointment, self-doubt, hopelessness and guilt. These implications are important to consider in the South African context whereby the socialised role of woman as child-bearer is essential to her cultural identity.

Gantt (2002) also argued that chronic illness, such as Endometriosis, contributes to a sense of disrupted normalcy. In addition to normalcy in the sense of adequate social functioning in a broad sense, normalcy can also be disrupted in terms of a woman's expectations of what it means to *be a woman*, that is her sexual identity.

#### **2.6.2.2 Sociocultural meanings of chronic illness and the dysfunctional body**

Intimately involved in the process of developing one's illness representations are sociocultural meanings attributed to bodily functioning, which has implications for the meaning of illness for both sexes. It has been argued that cultural meanings of masculinity and femininity are intricately related to one's body (Bekker, 2000). Because

culture shapes the ways in which gender identity is formed and gender identity, in turn, influences bodily experiences, these bodily experiences differ across various cultures. For example, the female experience of hysterectomy could be understood as being mediated by sociocultural values attributed to the uterus, for example, as an organ symbolising womanhood, femininity and motherhood. On another level, processes of socialisation contribute to sex differences in terms of the way in which the human body is related to and interacted with.

When understanding the process in which illness representations are developed, the socio-cultural meanings associated with sexuality and fertility are especially important to consider in the South African context where most women still adhere to traditional female identities. It is essential that these factors be considered when exploring illness representations of Endometriosis and its impact on the perceived quality of life among women in this context.

### **2.6.2.3 Coping with illness**

One's ability to cope with a chronic illness such as Endometriosis also mediates one's lived experience of that illness. The individual's ability to cope with the above-mentioned implications is mediated by the biological, psychological, interpersonal and socio-cultural aspects of their life (Klang, 1997). Dimond, in Klang (1997), argued that one's social adaptation involves the balance between the demands posed by a particular situation and the individual's capacity to respond to these demands. In the case of the chronically ill individual, the demands upon their life may remain the same or be greater than those



demands before the onset of the illness, while their capacity to respond to these demands may be decreased.

The way in which an individual copes with illness influences their sense of physical, psychological and social well-being (Forsberg, 1996). The way in which one copes with a particular illness depends on the variables associated with that specific disease, as well as individual characteristics, such as the stage of life they are in at the time of being affected by the disease, as well as what social and emotional resources are available to that person. Therefore, how a person copes may be determined by the person's personality, the social context and associated socio-cultural issues.

Forsberg (1996) proposes that there are two major components to the coping process, namely the problem-focussed component and the emotion-focussed component. The problem-focussed component relates to the relationship between the person (including their physical affliction, in the case of chronic illness) and their environment, while the emotion-focussed component relates to the regulation of emotional stress brought about, for example, by the necessity to make life changes and adaptations due to the illness. In addition to this, it is accepted that individuals adopt a general approach to life, which may either facilitate or hamper their coping strategies. When meaning is found in one's daily existence, this results in a sense of coherence with life, meaning that one has confidence that the stimuli with which one is faced are manageable. For effective coping to occur demands should be seen as challenges which require engagement and a sense of confidence that one has adequate resources to manage these challenges (Forsberg, 1996).

When this process is effective it prevents a disruption to one's sense of self, as the emotional response is regulated. The impact of the stressor, such as having endometriosis, can be reduced by active engagement in goal-directed activities, for example, by becoming actively involved in health-related decision making (Forsberg, 1996). This active involvement comprises self-care when the affected individual translates information (regarding the disease) into action.

One's active involvement in coping with disease can be divided into two types of tasks, namely illness-related tasks and general adaptive tasks (Schlebusch, 1990). Illness-related tasks include dealing with the pain of illness, dealing with the hospital or clinic environment and undergoing medical procedures. General adaptive tasks include the maintenance of a desirable emotional state whilst experiencing the illness, maintaining a satisfactory sense of body image and a sense of competence in one's social relationships. In this process of coping both defence mechanisms and coping strategies can be understood as contributory processes. Schlebusch (1990) argues that it is important to consider that although defence mechanisms, such as denial, can be maladaptive, this is not necessarily so. For example, in coping with a particular illness, denial may play the part of a temporary adaptive skill as it may function to minimise one's situation thus reducing the possibility of being emotionally overwhelmed. It therefore allows the individual to access other coping resources. Many beneficial active coping skills have been identified, for example, patients may choose what topics related to their illness to think about, and to alternate intensive thoughts about the topic, to avoidance of the topic in order to moderate their emotional responses to their situation. Accurate appraisal of one's situation, and the implications of the disease on one's life is essential to mobilise

relevant resources. In addition, the provision of intellectual resources, such as information related to the disease (it's aetiology, manifestation and consequences) can alleviate stress. At the same time, patients may significantly benefit from social support, both from family and friends, as well as from other patients experiencing the same condition (Dayus, Rajacich and Carty, 2001). When considering an individual's adaptation to illness, particularly when involved in intervention procedures, it is important to note that while there may be global characteristics to the coping process it is not a *generic* process, rather, it needs to be considered from that particular individual's context and experience (Kleinman, 1988). The role played by specific individual characteristics, as well as characteristics specific to that particular disease needs to be carefully taken into account to affectively implement intervention. Without an adequate understanding of what a specific illness *means* to a particular individual his or her suffering cannot be appropriately attended to (Toombs, 1993).

The purpose of this study was to explore the effects of endometriosis on various spheres of affected women's lives as well as to develop a deeper understanding of the subjective lived experience of this chronic disease. An understanding of the complex nature of this chronic disease can be used to inform interventions developed to assist women, and medical professionals treating women, with endometriosis.

## CHAPTER THREE

### METHODOLOGY

#### 3.1 STRATEGY OF INQUIRY

A phenomenological inquiry was done into the lived experience of women with Endometriosis. This framework guided the exploration into the meaning, structure and the basis of the lived experience of living with Endometriosis. The phenomenological approach involves an exploration into how people make sense of their experience (Patton, 2002). This inquiry involves exploring and describing how people experience a particular phenomenon in terms of their perception of it, their thoughts about it, how they discuss it with others and how they make meaning out of their encounter with a phenomenon, in this case, Endometriosis. Such an enquiry necessitates in-depth interviews with people who have experienced the phenomenon directly, so as to ascertain an understanding of their 'lived experience'.

In order to explore the core of the lived experience of a phenomenon, interpretation must occur in order to see *how* the meaning of a phenomenon is constructed. This 'meaning-making' indicates the essence of lived experience. Phenomenological enquiry, therefore, focuses on what is being experienced and how people interpret this experience (Patton, 2002). The phenomenological approach assumes that the essence of an experience is shared, and that through common experience the essential understanding of that experience are mutually shared. This approach also assumes that there is commonality in human experience, therefore the 'bracketing' approach was used in order to determine these commonalities. In bracketing a phenomena, it is attended to in such a way as to attend to the phenomenon, such as

endometriosis, as it is known, and incorporating the meaning in which it is embedded (Toombs, 1993).

### **3.1.1 Participants**

In-depth interviews were conducted with six participants between July 2004 and September 2004. Participants were found by accessing a support group run by the Endometriosis Society. Most of the participants had been encouraged to join the society by a gynaecologist specialising in Endometriosis in Westville who supported the Endometriosis Society on the basis that the society provided a useful source of information and support for affected individuals. The researcher attended monthly meetings held by the support group and informed consent was attained by members of the group. It should be noted that the interviews took place over a long time span as interviews frequently needed to be rescheduled due to the adverse effects of Endometriosis experienced by the participants. For example, an interview with one particular interviewee needed to be rescheduled three times due to the physiological difficulties she was experiencing with Endometriosis. Such incidents were insightful as they gave real life insight into the various difficulties experienced by women with this condition. Such insights were further highlighted in the interviews themselves.

The sample used in this study comprised of six women between 26 and 34 years of age, all of whom were married. Two of the participants had been unable to conceive any children. Of the four participants who had been able to conceive a child, three had experienced difficulty conceiving a second child. Three participants suffered from additional chronic conditions,

including Hernia, Chronic Fatigue Syndrome and Irritable Bowel Syndrome. In terms of surgical procedures, all of the participants had undergone at least two laparoscopies up until the time of the interviews. Two of these participants had undergone three laparoscopic surgeries. One participant had undergone three laparoscopies, one laparotomy and one hysteroscopy in the space of 15 months. Only one participant had received other alternative treatments which included Reflexology, Homeopathy and Dietetic intervention. In terms of the ethnographic constitution of the sample comprised of two White, one Coloured and three Indian women.

### **3.1.2 Data collection**

The first stage of enquiry involved a key informant interview. The key informant supplies information relating to the field of enquiry but not necessarily pertaining to the objectives of the study (Gorden, 1980). In this study the key informant supplied information relating to her experiences of endometriosis in general, thus 'opening up' areas for further exploration.

Following the key informant interview, areas of exploration were identified and used as markers to further explore women's lived experience. During the interview emphasis was placed on fostering an atmosphere safe to conduct a free flowing interview. Interviews were based on guidelines to open-ended interviewing set out by Dr. Ineke Meulenberg-Buskens in the Human Sciences Research Council's Manual for the Free Attitude Interview Technique. In the course of the interviews the participants were asked to elaborate on aspects mentioned in passing that needed to be explored in depth to gain a better understanding of their experiences. Although an interview schedule was compiled, it was not used to direct the interview in a rigid, preconceived way, but rather used to assist me in the interviewing process in exploring the lived experience of

Endometriosis on both the interpersonal and intrapersonal levels. A copy of the schedule can be seen in Appendix A. Once the interviews were completed they were carefully transcribed not to lose the dynamics and meanings that emerged from the interviews.

### **3.1.3 Phenomenological Analysis**

The theoretical perspectives of phenomenology influenced my method of analysis and assisted in making sense of the data. In analysing the data using a phenomenological perspective the aim was to ascertain the meaning and essence of the lived, subjective experience of Endometriosis from the perspective of the participant (Patton, 2002; Toombs, 1993). The first step in this process involves the researcher becoming aware of their own understandings and personal bias so as not to contaminate the subject material (Patton, 2002). This involves the investigator placing aside, or at least being cognisant of his or her prejudices, judgements or bias. The maintenance of the 'phenomenological attitude' is an ongoing process throughout the analysis, in which everyday understandings and presuppositions are kept aside in order for the essence of that phenomena to be seen.

The second step in phenomenological analysis involves bracketing or, 'phenomenological reduction' (Husserl, 1969). What then transpires is the 'intentionality', that is, the conscious process of experiencing as well as the object of experience (the phenomenon) (Toombs, 1993). The essential aspects and structures in the data are then analysed. This involves an interpretation of the key statements and phrases that were used by the participants. These phrases are analysed to explore the meanings regarding what they expose about the essential recurring aspects of the

phenomenon (Patton, 2002). The next step in the analysis process incorporates the meaningful clustering of data into different groups and a simultaneous exclusion of that data which is irrelevant. Common themes are then identified and viewed from different perspectives. Following this, the common themes are then synthesised in order to develop deeper meanings of the experience. In the final phase, the meanings and the 'essences' of the experience are synthesised and integrated to generate an understanding of the lived experience of the phenomenon.

#### **3.1.4 Ethical clearance**

Ethical clearance was obtained in terms of University regulations for conducting research. In terms of further ethical considerations confidentiality was maintained and informed consent was obtained from the participants. The rationale for this research was also explained in detail to them. Participants were informed that they could withdraw at any stage of the study and for any reason should they feel this necessary.



## **CHAPTER FOUR**

### **RESULTS**

Various themes emerged from women's experience of Endometriosis. Subjective experiences appeared to be based on women's illness representations and perceived quality of life. All aspects of a woman's functioning were identified as being impacted upon, namely physical, psychological and social. The creation of illness representations appeared to emerge out of experiences within women's personal and social worlds and included, significantly, the role of the medical encounter.

#### **4.1 ILLNESS REPRESENTATION AND THE MEDICAL PROFESSION**

Understanding of Endometriosis was informed by its debilitating effects of pain and fatigue and the numerous interactions with medical practitioners. These experiences and conceptualisations played a significant role in mediating the psychosocial experience of Endometriosis. The experience of illness symptoms like pain or in some cases infertility, brought anxiety and uncertainty and prompted women to seek help from the medical profession. This process of help seeking was not always satisfactory.

A delay in diagnosis resulted in women experiencing a cocktail of emotions. Many women felt that they experienced unnecessary medical procedures by practitioners who were not specialists. For many, much time elapsed before they were correctly diagnosed by a doctor or specialist familiar with the condition. They reported feelings of frustration that their condition was not

recognised and diagnosed earlier. Many women felt as though their symptoms had been dismissed by general practitioners as being “in your head” which was sometimes socially reinforced by others who would tell them to “forget about it”.

*P: I think it was the anger at first, because we only found out, after we had been trying for two years to have a second child, and our gynae at that time kept on saying, 'It's normal to battle to have a second child-lots of couples have difficulty'. And I just felt that a lot of the time was wasted in those two years...and eventually when it was diagnosed, I was very angry with this gynae, that he had wasted so much time, and I felt if it had been addressed at that point...I wouldn't have been here ... I'm so frustrated, because I just feel they haven't spent enough time and research on this whole thing. I mean, my gynae-the first one I ha-d is a classic example-I just felt he was so condescending, he didn't take the time to find out about endometriosis...he should have referred me to somebody else...*

Women reported a sense of helplessness in the inaccessibility of specialised and experienced doctors familiar with Endometriosis. Specialised gynaecologists were seen as ‘invisible helpers’ who were stumbled upon by chance, through radio talk shows or word of mouth, rather than through formal referrals. The general lack of progress, combined with emotions of helplessness led women to doubt their doctors and the medical profession. In some cases women had spent years pursuing a diagnosis prior to being diagnosed and during those years felt that their symptoms had not been ‘taken seriously’.

The lack of recognition or acknowledgement of their condition sometimes resulted in women beginning to “*double guess*” themselves, questioning the legitimacy of their subjective experience. It is here that the role played by diagnosis became prominent. Being able to attribute a name to one’s condition appeared to empower women in dealing with Endometriosis. One participant explained that being able to attribute her experience to a clear medical causation validated her experience. Acknowledgement of pain also played a crucial role in the interpersonal success of the doctor-patient relationship. Patients who perceived their pain to be unacknowledged by their practitioners appeared to experience more emotional distress. However, when pain was openly discussed and explained in ‘medical’ terms, women felt acknowledged and heard in the medical encounter.

N: *‘Incidentally, when I had this (experimental treatment) they took my blood test before and afterwards. There’s a certain hormone in your blood...that when your Endometriosis is bad it releases this hormone into your blood and you can read it scientifically. You can say this hormone has level ‘x’, and at the end you can read this hormone level... (The doctor) said to me that my initial reading was very high. So he said to me that he understands that I must be in a lot of pain and that I must be very tired.... Which is also good for me to know because, it’s like, it’s not like it’s all in my head...it’s nice for you to know, if a doctor says to you, ‘Look, it’s a measured reading, that’s quantifiable scientifically, and yes, it’s there, and, yes, it exists, and that’s why you’re feeling the way you’re feeling.’*

What can also be seen from the above extract is that being able to explain, in medical terms, the reasons for one's pain and symptoms also facilitates communication in the doctor-patient relationship. Having a definite diagnosis also had an impact on interpersonal relationships in that it provided patients with an opportunity to attribute their symptoms to a biological cause which enabled others to better understand their condition, rather than being seen as an almost mysterious "women's disease". However, this was not always the case, as some individuals reported that upon being questioned by others on their illness, the disclosure of their condition did not necessarily elicit better understanding from others.

However, receiving the diagnosis of Endometriosis was also a frightening experience, leaving many women feeling disempowered and disillusioned as this knowledge impacted on their core identities as women. Receiving a diagnosis often meant that women would have difficulty conceiving which, for some women, shattered dreams of motherhood, an integral part of one's feminine identity.

N: *'When I was first diagnosed...I just felt like my whole world had been shattered. I was like 'What do you mean I can't have children? This is what I've wanted my whole life! What do you mean?' ...I felt very alone I think....I don't think (my husband) really understood what a frightening place I was in.'*

It also appeared that a loss of physiological functioning of one's body was accompanied by a psychological sense of loss, that part of one's being and identity that had been irrevocably lost or

damaged. Having attempted multiple surgical procedures and various inconclusive treatment procedures many women also reported loss of agency that “*nothing [they did] helps*” as well “*they would not be able to cure it*”. While some participants overtly expressed “a loss of hope” this appeared to be counteracted by a *desire* for a “*miracle cure*”.

In the absence of personal and medical control over the disease, women may seek to find alternative explanations for why such an ‘*invasion*’ was present, or not prevented, such as self-blame, or religious-cultural beliefs that one was being punished for a wrong doing in one’s spiritual life. Some spoke as though they questioned whether they somehow may have been responsible for bringing endometriosis upon themselves.

*P: It does impact on your role as a woman—especially if you’re not able to conceive...when I was trying to conceive it was like everyone else around me was falling pregnant at the drop of a hat...you just feel it’s so unfair, you know—what have I done wrong? ...And you see yourself as a failure...*

*R: So you start thinking it’s something that you’ve done-...*

*P: Exactly, what have I done? ...You know, I used to think, what have I done wrong, I mean, I’m sort of a good person, I don’t do anything negative or bad. Really, what have I done?*

One Indian women spoke of her endometriosis as something that others may perceive as a form of punishment, for a previous wrong doing in one's life.

*L: '... They just feel that you're a very unlucky person you know-that you probably did something in your past life .... so they'd say you're a bad luck.'*

A sense of blame was also alluded to in how women understood the conceptualisation of Endometriosis as a 'career women's disease'. In trying to attribute a cause or reason for their experience some women who only had one child and who wanted more children yet had not been able to conceive blamed themselves for pursuing their careers at a time when they believed they might have been more 'fertile'.

*R: 'But I think my mistake was, that before it got very severe, I should have actually had [another child]. But I guess that with our lifestyle, we want to do everything first and do that (childbearing) last. Unfortunately I got caught up in the wrong time. But there's nothing I can do ...they say it's workingwomen's' disease.'*

In discussing how their medical condition affected them, women spoke on the basis of there being a mind-body dichotomy in that they appeared to see their mind and body as completely separate entities, often describing their bodies as being 'split-off' and 'diseased entities', separate from a healthy mind, an entity one tried desperately to keep 'healthy'.

R: *'...you know, your entire body goes into a different state for a few days or about a week, completely from your normal self. And everything is completely out of your normal self.'*

M: *'No matter how much my mind is there, my body will not do it. It cannot do it'.*

Apart from this intrapersonal sense of dichotomy was the development of an interpersonal sense of being different from others. Women described Endometriosis as a condition that removed one from one's "normal" functioning, thus introducing a sense of "otherness" in relation to other people. Women felt that the condition had made them 'abnormal' which further psychologically separated them from others, including those belonging to one's social support network.

For many women the repeated medical procedures resulted in a sense of their personal space being invaded and violated. A sense of privacy also became difficult to maintain because the symptoms could sometimes not be disguised from others, as alluded to by this participant:

M: *'I think I do not have completely any more, any more pride, because I've been poked and prodded and I don't know, it's too many operations, too much, I think my privacy has completely been invaded, that's why (laughs), I don't know .... I don't feel anything is personal anymore ...I don't think anything is personal anymore. In school everybody just knew that this girl is having her period. At work we all just know when I'm sick (laughs).'*

*So there's no privacy anymore you know. It's quite public. 'She's sick. She's going through it again.'*

Having to attend numerous doctor's consultations resulted in financial resources being depleted and strained, often perpetuating psychological distress. This financial stress added to the sense of psychological distress experienced by many participants.

## 4.2 INTERPERSONAL RELATIONSHIPS

### 4.2.1 Motherhood

For many women the inability to conceive caused significant distress as it raised previously unquestioned issues regarding motherhood. Having dreamt of having children at some point in the future, many women found it difficult coming to terms with the possibility of infertility. Fertility was expressed as a key feature of 'feminine identity' and was spoken about as the "*completion of a woman's role*". In light of this the psychological devastation faced by women with Endometriosis, who may be unable to conceive children, is understood.

Some women, particularly those in the Indian culture described childbearing as ensuring a '*right of passage*' in becoming a woman and in being a respectful member of the culture. It was reported that one was considered "*unlucky*" should one be infertile, that is, "*bad luck*" to the rest of one's family members. Notions of motherhood appeared to be particularly pertinent to the Indian culture whereby women were expected to conceive within a particular time frame after being married to their husbands.



M: *'My husband and my mother in law, they all want children! And um, especially in the Indian community, it's a major thing if you can't have children.'*

Women who had one child, felt responsible to have at least one other child as a sibling for their child to ensure an '*acceptable family life*'. The prospect of being unable to produce children was seen as a frightening and life-altering experience. For women who did have children, exhaustion and fatigue impacted on their ability to fulfil their role as a mother and one participant stated that this resulted in her not being a "*good-enough mother*". Others reported that their preoccupation with their condition resulted in them feeling as though they were "*not there*" for their children, being incapacitated to cook meals for their children, not being able to assist them during exam time or being able to fetch them from school. This played a major part in the role conflict, which appeared to exist between one's function as a wife and as a mother as well as being a woman in a contemporary twenty-first century. The physical debilitation and exhaustion caused by Endometriosis impacted on a woman's ability to negotiate between her role in the family, engaging in homecare tasks, such as cooking and cleaning, child-care and being a sexual partner in the marital relationship.

Perceiving oneself as coping poorly with multiple tasks resulted in a sense of guilt and self-blame. Although it was accepted that stress negatively impacts on the Endometriosis condition, there appeared to be significant role conflict in terms of expected gender roles.

Having Endometriosis often meant a change in family life with increased concerns regarding the effects of Endometriosis on the well being of other members of the family. For example, one woman reported that her daughter became “*worried*” and “*depressed*” whenever she was taken into hospital for medical procedures and surgery. One respondent pointed to the fact that Endometriosis never singularly affects the affected person. Rather, “*it affects everybody*” within the family.

#### 4.2.2 Marital relationship

All participants reported that their condition had a significant impact on their marital relationships. Living with Endometriosis participants felt that it was necessary to alter the way in which household activities were managed in that they were frequently incapacitated to partake in these. Husbands needed to become more actively involved in activities that were previously designated to the wives, such as cooking and childcare. This frequently resulted in guilt on the woman’s part in feeling that she was not fulfilling her role in the family. One participant reported that she did not feel she was a wife at all because of this incapacitation. She reported that, particularly in the Indian culture, one was not considered a ‘true’ wife if one could not perform one’s marital duties such as childbearing and household activities.

M: ‘...for Indian girls who come into the family-being sick for 2 weeks of every month, um, my mother-in-law has to ...help with everything. Um, I’m constantly being called names...Its-to her, I’m not a wife. I’ve been told that I’m not a wife-I’m too sick all the time.... Um, [my mother-in law] is a very traditional woman, not very old, but very very

*very-she's a typical Indian...(laughs). She expects the woman-irrespective of if she's working or not to be running around after her husband, picking things up after him, pulling out his chair, taking out his shoes and leaving them for him-so that type! So now, if not even able to do normal chores, like cooking, for him. I just take money out and say, like 'babe, you have to go out and buy food for this week'. Ya, so, to her that's not acceptable. To her, you don't buy food. Indians are very sceptical about that.'*

A common theme that emerged was a sense of guilt at the changed and increased responsibilities that the husband or life partners had to take upon them, necessitated by their illness. Respondents reported guilt and frustration that their husbands frequently needed to take them for medical procedures:

*M: 'And he's constantly having to come home from work and take me for an injection, and rushing me.... After the first year of marriage every month he had to rush me off to hospital, many times at 1 or 2 in the morning for pain injections.... So he's had a really tough time as well.'*

Living in a marital relationship with Endometriosis placed much strain on a couple as many of their usual activities needed to “*be on hold*” in order for the woman to attend doctor's visits, receive emergency pain injections, attend check ups and have blood tests. In addition to daily routines being changed by the presence of symptoms, many women also expressed a decreased interest in sexual intercourse and decreased sexual enjoyment due to the pain experienced during

lovmaking. As a result some complained of a lack of intimacy in their marital relationships. Participants also expressed concern with how they were being perceived by their husbands and were doubtful of their husbands' sense of fulfilment in their marriage. For example, one participant reported that she was afraid that her husband was no longer enjoying their marriage because of her chronic condition. Associated with this fear was a sense of guilt of being responsible for their changed sexual relationship.

N: *'.... And then I think (my husband) does understand, your husband does understand, but then he starts to think, 'Well, it's been a while now that she doesn't want to do anything, and is it because of me?'*

M: *'But me being sick all the time obviously can't be the best situation for him. And he's a very reserved person. He won't come out and say, 'You know, you're sick all the time, you're bothering me' but you can sense it. You can definitely sense it. Maybe it's um, the way that I'm feeling, that, how can a man be happy with someone who is sick all the time...?'*

Another aspect for which women felt responsible was their husbands' helplessness in dealing with their condition. Dealing with severe Endometriosis meant that nothing, including pain medication at times, could help alleviate the pain and discomfort they experienced. In an effort to assist, although not directly impacting on their wives' pain, husbands helped them to cope by massaging their backs or making them tea.

M: *'Even if I wake him up in the middle of the night he can't do anything. So it's that feeling of helplessness from his side. He knows that nobody can do anything. So it frustrates him a bit. But he can't help. No matter what he does...'*

Further impacting on the marital experience of Endometriosis was the change in expectations regarding family life. Many couples experienced difficulty accepting that previous expectations regarding childbearing needed to be put on hold or completely abandoned. This placed significant strain on the marital relationship. Adding to this strain is the financial distress many women reported in having to attempt artificial fertilisation procedures. Women complained of exorbitant medical aid costs and numerous specialist consultation fees which they experienced considerable strain maintaining.

Apart from the negative effects of the disease on the marital relationship the value of partner participation and attendance was considered most beneficial for women, both during doctor's visits and support group meetings.

R: *'...no operation is going to help you as much as that-of them understanding and being with you and him coming with me all the time to the support group...You can tell him how much you want but for him to come to that meeting...and for the doctor to be there...for them to talk to you and to say 'this is what is happening to the person in your life, this is how it's affecting them' .... He really understood about it and he questioned the doctor-you know*

*he wanted to know himself. She he played a very, very big part in this group-so I'm glad about that.'*

### 4.2.3 Other Social Relationships

Affected women experienced a decreased range of social activities due to debilitating physical symptoms such as exhaustion and pain as well as recovery from surgical procedures. This led to a sense of isolation, and detachment from 'normal' people, resulting in much loneliness. Having received frequent medical interventions women also perceived others as being frustrated and irritated with them, often decreasing their interest in confiding in others regarding their experience.

*M: 'I think that as month by month by month goes by and in the beginning certain people are supportive and then afterwards they get tired-you know- "Not again..." They must think I'm such a useless person or something.'*

The perception that women with Endometriosis were a 'burden' to others was emphasised by a perception that unaffected women did not understand Endometriosis and that they were perceived to be "exaggerating" an experience commonly and universally experienced by all women:

N: *'Ya, it's almost like its something exaggerated by [affected] women. You know, every woman in the world menstruates and some women have a problem with it. Sometimes, I find, the social kind of attitude is almost: 'Ag, please, get over it! Everyone has it'*

Participants also reported that social silences regarding “*womanly issues*” also contributed to a lack of social understanding and acceptance of Endometriosis in the public. This was attributed to the fact that “*women's problems*” such as menstruation are not openly spoken about, because, and perhaps, menstruation is seen as something experienced by “*every woman*” “*since time immemorial*”. Despite menstruation being a common process experienced by women, the irregularities and pathology associated with the process were not discussed.

#### **4.2.4 Social support**

While respondents reported that family members and friends could not do very much to physically change their condition, social support was identified as essential to cope with the condition, both in the home and at work. Words of encouragement and understanding, as well as assistance with general tasks, such as providing heated water bottles and other practical activities, were identified as helpful and encouraging.

While positive aspects of support were recognised some aspects of support had a negative effect. Having someone closely assist them with practical tasks meant that women were often seen in their worst state, which sometimes resulted in an altered sense of dignity. This perceived loss of

dignity may have reinforced one's emotional state of helplessness, as aptly described by the following respondent:

M: *'You just go to the loo, and you pass out because you're too weak, and you're bleeding so heavily, and you're in so much of pain and you're so drowsy, and you pass out in the loo. It's got to be the most undignified thing ever, when your Dad has to come and take you out, and carry you out of the loo.'*

Some respondents reported feeling as though they were a burden to those who were supporting them and frequently visiting them in hospital. They perceived their friends as feeling "*obligated*" to visit them and felt guilt that they were 'impinging' on or '*interrupting their friends*' and families' "*hectic lifestyles*", and subsequently making themselves responsible for retarding their friends' own well-being.

Although respondents did feel guilt for receiving a large deal of social support whilst receiving surgical intervention, this support was, however, appreciated and often missed on return home from the hospital. Participants noted that social support largely dissipated in the periods following their return home from hospital. While social support was good directly following a medical procedure one woman stated that "*once you've been two or three days at home (your friends) don't bother to call... but you're like still sick for like six weeks.*"



## 4.2.5 Occupational functioning

### 4.2.5.1 Physical limitations on performance

The debilitating symptoms of Endometriosis had both direct and indirect effects on participants' occupational functioning and performance. In terms of direct effects participants stated that the physical symptoms sometimes resulted in decreased occupational performance and drive in that the executions of some work activities was made difficult by cramping and severe pain.

The chronicity of these symptoms reduced affected women's capacity to pursue career goals because the need for frequent surgical procedures and hospitalisations limited their scope of possible job opportunities.

M: *'... I did leave the company because of this problem. I found myself having to take too much of sick leave and...It was, uh, becoming too much. ...I couldn't keep up. I find that I can never do a really high role. I was a manageress and I was an accountant and... (now)- I've taken a step backwards. I've become an assistant to the manager from being a manageress. Um, I worked so hard so young to be in positions like that... I... had to say, "slow down girl, you're moving too fast. And your mind may be there to keep up with it but your body won't be able to". And within the last 2 years I've had 4 operations, so, there's no way I can do a high job and especially with me, I was a steady student, dux award. 'A' aggregate in matric-everything! I had everything to look forward to. And now - I get jobs. I can put out my CV immediately and get a job. But I actually pulled out. And my husband is*

*always saying I sell myself short. It's not me, I know I can do the job, it's just my body will not. Nobody's going to give you sick leave in certain positions.'*

What clearly emerged was conflict between the need and desire to achieve in one's occupation versus frustration in not being able to fulfil such aspirations due to one's bodily limitations. Such conflict resulted in the psychological necessity of striking a balance between maintaining one's sense of self-efficacy and self-confidence.

One participant who was self-employed expressed frustration that on some days she would *"have to turn a lot of customers away"* from her home-based business as a result of physical incapacitation. Associated with this were fears that one would be perceived by clients as *"lazy"* and incompetent.

#### 4.2.5.2 Relationships with colleagues

Many of the participants reported feeling understood by co-workers and one participant reported having been labelled as *"overreacting"* and *"sickly"*. Others frequently misunderstood Endometriosis as being an ordinary menstruation process and that the affected woman was simply overreacting to an experience that needs to be experienced by all women as a type of *'feminine responsibility'*.

*M: '...so many of the women they completely don't understand. I mean, in the last month or so I got a comment 'well we are women as well, so, we don't behave like that'. So to some*

women you're pretending. They can't possibly fathom something like this: 'you're pretending'. 'Why's she holding her stomach and walking?'. 'Why's she limping and walking?'. It's got so bad that I bring my hot water bottle to work to keep on my chair - so it's like- 'why's she bringing in her hot water bottle-she's acting like an old maid!' You get one or two women who are the gossiping type who go around saying, 'Look at this sickly girl!', so you get labelled as a sickly person. And that's enough - that's...I don't know...emotionally I can't cope with it sometimes. Ya, the cramps, sometimes you're in a meeting, and you have to just sometimes hold your tummy, or you have to just go to the toilet and you sit there because the bleeding is heavy, absolutely heavy- [like] you're opening a tap and sometimes you have to go and sit in the loo and my boss is looking for me (laughs).... To me, male or female, there are not a lot of people who understand. They can't possibly understand, because their wives, their girlfriends or even if it's a woman, they have their periods, so. And you're complaining about it! 'So why are you over reacting, get on with your life.'

The ability to cope in one's work situation also appeared to be influenced by type of occupation and whether that particular job was single-sex dominated or not. For example, one participant reported that working as a lawyer in a largely male-dominated company meant that she did not openly disclose her condition to colleagues for fear of not being understood or because of a need to maintain the image that she was entirely capable and not unduly influenced by 'female issues', thus maintaining respect.

### 4.3 COPING

Endometriosis had a major impact on women's psychological coping resources in that many reported experiencing some degree of 'psychological breakdown'. Women experienced a range of emotions from irritation to sadness, some to the degree of experiencing suicidal ideation and clinical depression. Having to spend days or weeks lying in bed resulted in much frustration and a sense of loneliness, as well as a sense of 'otherness' and detachment from family members and friends.

Various coping mechanisms were used by participants and these drew on various aspects, namely biological, psychological, social and spiritual. In terms of biological aspects to coping almost all participants reported that painkillers were the first line of coping with pain and other symptoms experienced with Endometriosis. However, painkillers were not always effective in reducing pain and were also associated with side effects. Women attempted other measures to 'escape' their pain, such as sleeping and exercise, but although exercise was useful in minimising pain, increasing energy and encouraging well being, in contrast, some women also identified it as counterproductive in the context of over-exertion.

Psychologically, women adopted various approaches both as individuals and as well as throughout their stages of dealing with Endometriosis. One participant used depersonalisation as a coping mechanism as she imagined herself "*mentally stepping out of the situation*", "*pretending*" that her body was not her own. This appeared to equip her with psychological distance with which to emotionally contain her psychological and physiological experiences.

The same respondent also explained that, at times, a contrary approach was also necessary which involved “acceptance” and “realistic” expectations of her condition.

*M: 'It's like you have to come to a point where you know you have this disease... You know you have it, so accept it, and that's the only way you will cope. If you tell yourself, 'No, it's going to get better. It's going to get better,' you're fooling yourself.'*

The doctor-patient relationship played a significant role in mediating the effects of endometriosis. Women appreciated a realistic and open approach taken by doctors when this was combined with compassion and a “caring” attitude. For another participant, the only means of remaining psychologically intact when “*no-one else can take the pain away*” was through sheer determination, enduring to “*bite your teeth and carry on*”.

Some women felt that certain cognitive shifts were necessary in order to cope. Rather than being overwhelmed by the negative aspects of the condition one participant reported that she was able to view the fact that she could not have a second child meant that her general cost of living would be lower and that she would be better able to afford good schooling for her one child.

All respondents raised the benefits of being informed regarding the condition and actively sought out literature to understand their experience. However, obstacles to being informed were also identified as women reported that information about what was perceived to be a ‘young’ disease

was not readily accessible. When information was found some felt that it “*makes you more depressed*” in that it reinforces the current fact that no cure is available.

Apart from finding information useful in the form of medical literature women expressed appreciation of situations whereby information regarding shared personal experience could be exchanged. Being with other affected women, for example, in the context of a support group, was greatly beneficial to all respondents. Telling one’s story with other affected individuals had a validating and supportive effect on one’s personal experience.

*P: ‘...with the support group now, if I know people that have been in for surgery, I will phone them a few days later to ask them, ‘How are you doing? How is the pain?’. That helps them...And, I think the group is good because people who are feeling depressed and stuff like that, they will phone and you will try just to encourage them and be positive...’*

Having a context in which to hear other women’s stories also enabled women to re-evaluate their own situations. For example, one participant reported that, listening to other women describe their sadness and trouble in not being able to have a child she was able to reflect on her own experience and be grateful that she had been able to conceive one child.

However, support groups were not without their own obstacles in that regular members of the support group reported that attendance was not sustained over time by many women in that women had unrealistic expectations regarding the group.

*P: '...I also think people expect miracles when they come to the group-they expect immediate answers, because when we started the group there were a lot of people that came initially, and I think they just became despondent afterwards, because there's no miracles.'*

Another important aspect of social coping with Endometriosis was the sharing of household duties with unaffected live-in partners, such as childcare and cooking. In marital relationships practical interventions such as massage was identified as useful in helping a woman to cope physically with Endometriosis. Women reported that, although husbands frequently felt disempowered in helping their wives their emotional availability was recognised as invaluable to the coping process as expressed by one woman's wishes of her husband:

*M: 'I know that we can't do anything about it but just to say 'I know what you are going through, I understand' ...that would help.'*

The effects of Endometriosis also appeared to impact on one's spiritual and religious life. Dealing with their condition some women reported a considerable impact on their spiritual faith in that there was ambivalence between a hope of healing and a sense of anger that God had not prevented them from experiencing the condition. Amidst this struggle some participants reported that spiritual practices such as praying, were effective in assisting one to cope with Endometriosis.

## CHAPTER FIVE

### DISCUSSION

Quality of life is experienced in various aspects of one's physiological, psychological and social being (Forsberg, 1996). The effects of Endometriosis permeated into various aspects of women's lives. Its pervasiveness was experienced on a personal level in that one's "*private space*" was intruded upon, both physically and in the depths of one's psychological being. In addition, these effects took hold, and had repercussions on women's social lives.

Many of these effects were closely associated with women's interactions with the medical world, during their numerous encounters with medical professionals. It was at the interface of the doctor-patient relationship where the subjective meaning of this chronic disease was first negotiated.

The physical pain, and in some instances infertility contributed to the debilitating nature of the 'unnamed' condition. These became apparent in their private and social worlds and motivated women to approach doctors for investigation. Their help seeking was also facilitated by their own failed attempts in understanding their illness experience.



## **5.1 THE MEDICAL PRACTITIONER'S ROLE IN THE MEDIATION OF THE SUBJECTIVE EXPERIENCE OF ENDOMETRIOSIS**

Riddled by anxiety and uncertainty of being faced with the unknown, women sought medical help from the “experts” in an attempt to find relief in ‘labelling’ their experience. However, many women expressed frustration in their experience what Cox et al (2003) call the ‘doctor trail’, experiencing years of discomfort before being appropriately diagnosed or referred. Previous studies have supported participants’ claims of encounters with medical practitioners who were ‘callous’ and dismissive of their illness experience. Cox et al (2003) claim that attitudinal problems are frequently found among general practitioner doctors towards ‘women’s problems’. In the Jones et al (2004) study, participants felt that they were ‘fobbed off’ by some medical practitioners who had been told that their symptoms were merely a ‘woman’s lot’ in life. The lack of acknowledgment and legitimisation of women’s experiences during this chronic illness has serious implications for women’s health related quality of life.

The narratives which occur between ‘doctor and patient’ were shown to facilitate the construction of meaning of the women’s lived experience, adaptation and coping with Endometriosis. The critical role of the medical profession in the ‘meaning-making process’ could be seen in a similar way as to Habermas’s notion, as cited in Scambler (2002), of the colonisation of the ‘lifeworld’ but in this instance, by medical power. Such a notion would emphasise that scientific or ‘expert’ knowledge is a resource that is drawn upon in the development of lay knowledge.

However, Endometriosis seems to challenge the notion of the expert culture of medicine (Scambler, 2002). Various psychosocial issues related to the experience and treatment of the condition inform the development of the lifeworld or lived experiences. Such 'lay knowledge' of lived experience is seen as extremely beneficial in informing and developing 'expert' knowledge regarding the lived experience of Endometriosis. Scambler (2002) recognises that lay experience and knowledge contribute to the development of its own credibility whereas, in the past, it was understood as a defective form of scientific knowledge. A general disappointment and resentment exists among women towards the expert medical profession for not being able to diagnose, cure and also acknowledge the symptoms of Endometriosis (Jones et al, 2004). This is suggestive of a lack of medical knowledge on Endometriosis in terms of presenting symptoms, and treatment. A general lack of understanding of the gender and social issues in which Endometriosis is embedded, was reflected in most women's experience with medical practitioners. Their gender insensitive practice was noticed in them attributing women's reports on the severity of symptoms, particularly pain, within a 'sex-stereotyped' manner. Women's major concern was that their experience was not fully understood and viewed by some medical practitioners, friends and colleagues as "*being real*" but rather "*in the head*", a feigned experience. The expressed need of women to have their 'illness' understood as real and therefore legitimate was also supported in the well-known Cornwall's studies in 1984, as cited in Scambler (2002), on health and illness. In this study a distinction was made between people's 'public' and 'private' accounts of illness. Illness as part of the public account was viewed as morally problematic because the desired condition was to be healthy. When poor health or disease was

experienced it was necessary for people to make sure that it was considered to be real and thus legitimate.

Similarly, Stein, Friedson and Svensson, as cited in Reddy et al (1998), argued that within the biomedical paradigm doctors hold the most powerful positions within the hierarchy of the medical world, due to their medical knowledge. Therefore, when a doctor provides a patient with a diagnosis or label this validates their subjective experience. Because the doctor's position within the medical hierarchy is recognised by society in general, the doctor's diagnosis and validation of the patient's subjective experience can be used as a tool in the patient's social interactions.

Rather than the woman's experience being understood as a dismissible "womanly issue" the doctor's validation, communicated to the patient, can be translated into one's social encounters. Therefore, patients can use the doctor's powerful position to legitimise their experience in the social world. This is clearly seen in the data whereby the patient's own illness experience was often questioned, whereas, when information was received from a doctor, this information was received as unquestionable and 'real'. Women used the authority of the information and the medical discourse to explain Endometriosis to others, including partners, friends and family, who in turn acknowledge the doctor's authority. This has immense implications in that, having accepted this information, 'lay people' are better able to then cope with the patient. Just as the patient was able to use their diagnosis and medical information as a framework for constructing meaning out of their experiences, similarly the community is able to use the medical authority as

a framework for their understanding of the patient. Diagnosis could also be used as a tool in one's personal relationships, for example, in marital relationships being able to explain one's decreased sexual enjoyment in terms of the condition helped to reduce doubts about one's intimate sexual relationship.

In light of the crucial role played by social support in assisting affected women to cope with Endometriosis, it seems that the effective use of a doctor's authoritative position is invaluable in securing and enhancing this social support base. Having this social support more accessible decreased the emotional distress of having one's family or community disregarding one's experience. The consequence of not being taken seriously was that women started questioning their own subjective experience and felt psychologically uncontained. However, on the other hand, a treating doctor's understanding of the multiple influences of Endometriosis on a woman's life, assist women to cope better with Endometriosis.

It should also be noted that gynaecologists may be inadequately trained in dealing with chronic gynaecological illnesses such as Endometriosis, and these specialists may, themselves feel helpless in being unable to effectively treat or "cure" patients with medication or surgical procedures. Corbin and Strauss (1988) argued that the management of chronic diseases has moved from a prominently bodily-focussed approach to one that incorporates the social dimension of diseases. They further stated that the humanistic aspect of medical treatment has become equally recognised as the biomedical aspect and has thus renewed approaches to the doctor-patient relationship. Health care intervention therefore has much to benefit from marrying

a patient-centred approach (whereby patient concerns are dealt with) with a doctor-centred approach (where the doctor provides information on the disease and diagnosis). A patient-centred and gender sensitive approach is essential in dealing with a chronic illness like Endometriosis. In order to provide such a gender sensitive approach it can be argued that the reflective practice of health care practitioners needs to be encouraged. Kleinman (1988) argues that there is a dialectic in the interaction between doctor, patient and the social world and that the occurrences within these relationships mediate the lived experience of chronic illness. He argued that patient's idioms, which are embedded in lay understandings of illness, such as reproductive-related problems being "*in your head*" inform the patient's communication with the doctor. The doctor, in turn, interprets this language based on his own social framework and their socialisation into the medical profession. These understandings are used to interpret the patient's verbalisations or complaints and this understanding is then communicated to the patient. An understanding of this meaning-making process is important considering that the doctor's response may affect the patient's experience of their symptoms, as discussed earlier. It can therefore be argued that reflective practice should be integrated into medical practice to benefit both patient and medical practitioner. In being actively reflective, doctors may become more aware of their own attitudes that are brought into the therapeutic relationship and this may mediate the experience of distress of the patient. In addition to this, literature has pointed to the important role played by communication between doctor and patient during intervention for chronic disease (Thorne, Harris, Mahoney, Con and McGuinness, 2004) in that it can either powerfully facilitate or hinder health promotion. Furthermore, empathy is recognised as a key

skill to facilitate a good doctor-patient relationship and good medical intervention (Eide et al, 2004).

Another aspect of patient-centeredness that emerged from the data was related to patient involvement in medical procedures and information dissemination and gathering. When patient involvement was translated into the treatment process this resulted in increased trust of the practitioner and a sense of active participation. For example, when treatment options were negotiated and when women were given the option of seeing photographs taken during surgery, it resulted in women being better informed which facilitated psychological coping. What can be concluded is that the efficacy of a more patient-directed approach is important to prevent the current high rate of 'doctor-shopping'.

From the data it appears that in order to achieve maximum efficacy of medical treatment a combination of both biomedical and humanistic approaches needs to be employed in the treatment of women with Endometriosis. While diagnosis provided a framework for interpreting experiences, it also inferred a deeper realisation of the pervasiveness of the condition, often resulting in much ambivalence and emotional distress. Women became affected through the realisation of the chronic nature of the condition and its impact on their gender identity, which in turn influenced their interpersonal relationships.

## 5.2 GENDER IDENTITY IN THE LIVED EXPERIENCE

Apart from perceiving themselves as being physically ‘invaded’ by Endometriosis the disease’s invasiveness was felt in one’s intimate and personal world and impacted the core of women’s being. Women enter into their various roles, such as marital or occupational, with traditional gender identities. Endometriosis was experienced as impacting on all spheres of a woman’s gendered role and challenged traditional femininity. Traditional feminine identity is understood as encompassing women’s role in motherhood as well as caregiver and home-maker (Darke, 1996). The lived experience of Endometriosis challenged this role and necessitated change to women’s gender identity. This was experienced as highly stressful and threatening. For many women with Endometriosis the prospect of infertility is immensely stressful as it sometimes translates into being a “*failure*” as a woman. The data showed that although all women from all cultural backgrounds experienced infertility as very painful, some carried a greater burden. In more traditional cultures, not being able to have children impacted negatively on extended family relationships. In some instances, women’s inability to conceive was attributed to devious past lives for which their bodily condition was a punishment. Against this onslaught, women were left helpless to defend themselves.

The ability to maintain the role as a working woman, particularly among White women, was very important in sustaining women’s sense of self. The liberation of women into contemporary feminine roles as multi-tasking career woman implies a need to negotiate multiple roles, the responsibility for which could not always be met by the women.

The fatigue and physical restraints caused by Endometriosis magnified role conflict inherent in maintaining one's role as wife, carer, homemaker and career woman. This highlights the significant strain placed on the contemporary woman who is emerging as a prominent force in the professional world whilst maintaining more traditional 'feminine' activities such as child rearing and being responsible for maintaining the well being of family members. Self-blame was evident when the effects of their condition impacted on their family, for example, when anxiety was experienced by their children when mothers needed to attend multiple medical consultations.

The extent to which women's gendered roles were embedded in socio-cultural beliefs was reflected in the language used by the respondents when they reported that, being unable to fulfil these roles they felt that they were not "*whole*" and were 'abnormal' compared to other healthy women. This notion of 'defectiveness' and abnormality is supported by Penn (2001) who argued that negative social perceptions sometimes surround chronic illness. This socially perceived sense of 'otherness' was seen to perpetuate the psychological sense of loss experienced by women with Endometriosis, in that, for many, their 'social standing' as feminine identities had been negatively impacted upon.

Not only did affected women experience loss of physiological functioning but psychological loss was also experienced regarding one's changed feminine identity associated with changes in roles as well as changes in broader areas of their life. Change was required in their marital relationships and in family and social responsibilities. Women experienced significant guilt and felt responsible for being the cause of these painful changes. Their guilt also seemed to be



extended to some extent to their husbands or life partners in that men started to question their own possible involvement in the couple's infertility. The fact that male partners were asked to engage in sperm washes in order to explore all possible reasons for a couple's inability to conceive, triggered various coping mechanisms. Men resorted to denial as they perceive the female's body as 'diseased' and therefore be subjected to medical procedures and not their own bodies. The possibility that both partners could be implicated in the inability to conceive children may have been overwhelming for some men to cope with.

Further adding to the affected woman's stress was her decreased sexual involvement in the marital relationship, which had consequences for her perceived ability to maintain her role as an adequate sexual partner. This inner conflict in needing to avoid pain versus needing to be an adequate sexual partner would sometimes impact on the intimacy experienced within the marriage. Whilst being the site of illness (Bekker, 2000) the woman's body plays a major role in mediating her gender identity, which includes her role as a sexual partner. Thus, the sense of defectiveness (Penn, 2001) related to her experience of chronic illness can be translated into her sexual relationship, further implicating her sense of self-regard. The effect of chronic illness or bodily injury has been recognised as significantly impacting on one's body image and sense of self-regard (Schlebusch, 1990). The multiple ways in which Endometriosis impacts on the marital relationship require interventions directed to both partners. This is crucial as marital support played a major role in providing psychological support to women. Husbands' involvement in interventions could also function as a tool to decrease marital distress. Women's reported symptoms of depression could be understood as a form of bereavement for lost aspects

of the self. Kleinman (1988) suggested grief work as a way to assist people in coping with experiences of both physiological and psychological loss.

### **5.3 COPING WITH THE PHYSICAL, EMOTIONAL AND SOCIAL RAMIFICATIONS OF ENDOMETRIOSIS**

The unpredictability of the pain experienced in endometriosis, in addition with helplessness, fear and anxiety contribute to a highly emotionally taxing experience for women experiencing this disease. It is acknowledged that the largely unpredictable nature of the pain significantly contributes to feelings of frustration (Lemaire, 2004). Many women reported feeling depressed at some stage in their illness experience and one participant even experienced an episode of suicidality. Despite the trying symptoms and health-related experiences encountered by women in this study many different coping mechanisms were alluded to, including those of physical, psychological and social nature.

Various psychological coping mechanisms were drawn upon, including a cognitive function of mind-body dichotomy, whereby women appeared to perceive the mind and body as completely separate entities. It can be argued that such a process relates to Schlebusch's (1990) notion of an adaptive defence mechanism whereby complete psychological disintegration is negated by separating 'healthy' parts of one's being (for example, one's mind) from less functional parts (one's diseased body). However, the data also suggests that women alternated between embedding themselves in their lived experiences, deeply contemplating their state and complete avoidance of thoughts related to their symptoms. For example, one participant reported that at

times she would read as much information as she could find pertaining to endometriosis, while at other times she would avoid all thoughts of her condition by engrossing herself in exercise.

While endometriosis frequently leaves women with a sense of helplessness, the ability to gain any form of control during the treatment phase has been identified as useful in assisting women to cope with their condition (Cox et al, 2003). Many participants reported that actively looking for information on the disease, as well as sharing this information with family and loved ones, assisted them in gaining a sense of autonomy. Lemaire (2004) argues that the perception of the complexity of the disease is reduced by gathering information about it. The process of actively seeking information, insisting on adequate referrals and insisting on partners and friends listening to their experiences, enables women to regain a sense of autonomy where much of their own sense of control and dignity had been eroded by their illness experience (Cox et al, 2003). The sharing of information regarding lived experience of endometriosis with other affected women was also effective in enabling women to reflect on their own conditions as well as share medical information.

While biological coping mechanisms, such as taking pain medication, was not always effective, the effectiveness of other forms of coping such as drawing on social support was prominent. It is widely recognised that social support can effectively reduce one's experience of stress, as well as speed one's recovery from illness (Taylor et al, 2003). This aspect will be discussed in the next section in more detail

Considering the complex nature of endometriosis and its multi-faceted manifestation in women's lives and psyches a holistic approach to coping needs to be taken. Such an approach would allow for the use of physical, psychological, spiritual and social means of coping.

## **5.4 THE MEDIATING ROLE OF SOCIAL RELATIONSHIPS AND SUPPORT IN THE LIVED EXPERIENCE**

The mediating role played by social support in women's lived experience of Endometriosis was evident in the data. It has been strongly emphasised that social support is highly effective in reducing distress, including stress related to chronic illness (Taylor, Klein, Gruenewald, Gurung and Fernandes-Taylor, 2003). As Endometriosis often resulted in decreased social interaction, the provision of social support in an accessible form became essential in assisting women to cope. This is especially so when social silence is present around "*women's issues*", leaving women feeling isolated with very few or no outlets for receiving support.

Social support enables a connection to the exterior world from which women reported feeling alienated as a result of their bodily pathology. Women reported that social support from unaffected women, friends and family members was also crucial. Not only does social support provide psychosocial benefits, but it has been shown to decrease one's susceptibility to illness but may also aid the recovery process (Taylor et al, 2003).

Taylor et al (2003) refer to Stanley Scachter's 1959 study on affiliation in relation to stress and argue that women expressed a desire to be surrounded by other women who were being exposed

to the same stress as this assisted them in coping with their situation. This notion of affiliation can be linked to Yalom's concept of universality in group psychotherapy whereby the sharing of common experiences assist one in the process of therapeutic change (Yalom, 1985).

The powerful role played by social support suggests a revisiting of the role played by support groups. Participants reported numerous advantages in belonging to a support group. Having access to other affected women enabled their experiences to be normalised through the sharing of lived experiences. Listening to other women's stories further assisted women in being able to re-evaluate their own experience and gain renewed perspectives on their condition. Having a rich access to empathic support enabled a sense of containment.

When medical practitioners attended these support groups providing talks on various aspects of the disease, this also showed benefits in that the doctor's expert medical knowledge could be used to validate experiences of women in the group. However, the doctors' presence at these meetings also assisted in improving the doctor-patient relationship. The humanistic aspects of the medical practitioner's role is developed through the narratives of women's experiences outside of the consultation room. Support groups thus serve to acknowledge the expression of women's lived experiences, or illness narratives (Kleinman, 1988). It is further possible that the doctor's involvement in support groups assists in developing empathy and genuine concern for the patient which has been identified as crucial to the effectiveness of the doctor-patient relationship in chronic illness (Kleinman, 1988). For women, being in a group with similarly affected women may give them the confidence to discuss their lived experience in the presence of the doctor, the

expert in medical knowledge, which may not always be possible during a one-on-one consultation.

Although many women reported that social support waned over time following surgical procedures practical social support activities such as assisting with household tasks, were recognised as being very helpful. In addition, mere emotional availability further assisted women in feeling heard and acknowledged. While social support helped them to renegotiate the development of a new identity, too much of it resulted in a sense of disempowerment that perpetuated emotions of helplessness. This points to the importance of acknowledging that, despite the numerous benefits of social support, it's nature is not *always* supportive (Taylor et al, 2003). Some women felt that in receiving social support they were obliged to return the favour, which was often not possible thus resulting in guilt at being unable to reciprocate the favours.

## CHAPTER SIX

### CONCLUSION

The effects of Endometriosis penetrated into all aspects of affected women's lives. This pervasiveness was evident in the reported implications of the disease on women's personal and social worlds.

The interaction with the medical profession provided a framework for the generation of meanings around Endometriosis. The doctor emerged as playing a significant yet 'invisible' role in the women's personal and social worlds as the use of their expert medical knowledge and social power enabled the validation and legitimisation of experiences in both the personal and the social world. Conversely, when gender-insensitive practice occurred, it reinforced destructive cultural notions regarding women's illness, such as being "*in the head*", thus invalidating women's experiences. The interface of the personal and medical worlds seemed to occur in the medical consultation room where women initially presented with much anxiety and apprehension with a condition that appeared to emerge from a web of 'silent' yet powerful sociocultural beliefs. The labelling and 'expert knowledge' provided by the medical world appeared to combine with 'lay' knowledge in the generation of women's subjective experiences.

Beyond the consulting room, the impact of Endometriosis continued to be felt on numerous levels. Receiving the diagnosis implicated one's traditional feminine identity and raised issues concerning one's role as a wife, a mother and a sexual partner. Furthermore, women's social and occupational functioning was frequently affected which further perpetuated psychological

distress and necessitated changes to their ordinary daily lives. Dynamic and reciprocal relationships thus exist between women's personal, medical and social worlds.

The reported aspects of the pervasiveness of this condition into women's innermost "*private space*", and, simultaneously, into the public life, gives insight into the lived experiences of women with Endometriosis and provides various 'in roads' for intervention strategies for affected women and families. For example, it is recommended that life partners be included in the decision-making and treatment process.

Furthermore, this research could be used to inform and generate future research into the invaluable role of support groups for women with Endometriosis, and possible other chronic illnesses, or for life partners living, or closely associated, with ill women. Through support groups the challenges of living with this condition could be negotiated.

The development of effective informed support groups and medical practice, needed by affected people should be encouraged. However, various issues around social support would need further exploration to ascertain the kind of social support needed and the conditions under which support groups would yield the optimal positive effects for people in need of social support.

While effective means to cope with Endometriosis, should be actively sought, it is important for such approaches to be informed by an understanding of the complex gender, social and psychological issues pertaining to the lived experiences of women with Endometriosis. For



example, in running such a support group, one would need to be aware of one's own, and participants', expectations regarding the role and function of such a group.

This phenomenological inquiry into women's lived experience and perceptions of quality of life, drew on narratives from women living with the condition and illustrated the dynamics of the meaning-making process that emerge from women's personal, social and medical worlds. While the findings of this study cannot be generalised to a wider population, it provides many insights and identifies opportunities for further research into the lived experiences of people with chronic illness, which would benefit the practice of a multi-disciplinary and holistic health care in South Africa.

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## **APPENDICES**

### **Appendix A: Interview schedule**

- Biographical information
- Understandings of Quality of Life and Perceived impact of Endometriosis on Quality of Life
- Understandings of Endometriosis as a physiological disease
- Impact of Endometriosis on the following areas of functioning: social, psychological, physical, occupational, sexual
- Impact of Endometriosis on gender identity, such as a woman's role as child-bearer
- The role played by socio-cultural factors in mediating the lived experience of Endometriosis
- Perceptions of the medical profession and treatment procedures
- The effect of, and role played by, social support in mediating the effects of Endometriosis on Quality of Life



## **Appendix B: Key informant interview**

### **“Natasha”**

R: Maybe we can start by you telling me what you understand quality of life is?

N: Um...Quality of life is a measure of life whereby you...I don't know actually!

Quality of life is your level of, uh, enjoyment, of your life, contentment with the way your life is. And I suppose happiness has got a lot to do with it as well.

Happiness comes into whether you have quality of life or not.

R: Anything else? I mean, happiness related to what?

N: Happiness within yourself as a person, it's got to do with your health, um within your family, your relationships, within your work environment. All those different factors, and I suppose your financial factors. All those things, I would imagine, come together to quantify your quality of life.

R: So to quantify, you means you will either have more of it or less of it.

N: Ya, I mean if you have a better quality of life...having more money could give you a better quality of life, or not. Or your health. Does your physical or mental health give you quality of live? And ya,

R: Okay. So it's something mental, your relationships, your body, financially...

N: Yes. Ya. It's your sense of security within your home, within your relationship with your husband, with your friend, with your child, with your family. With all those kinds of things put together.

R: Okay. SO that's how you basically understand what quality of life is?

N: Ya

R: Okay.

N: Ya

R: SO, tell me, how do you understand how Endometriosis has, if at all, impacted on your quality of life?

N: Immm. I think it has. I think you, well I hope, you get better at coping with it...I think it definite definitely does effect things like quality of like with obvious things like pain, um, at the moment, when I ovulate and when I have my period I am in a lot of pain. And it makes me irritable, it makes me crabby and I get PMS much more pronounced. Although I never really ever suffered from PMS, but I get crabby, crochety, angry and resentful. SO from that pint of view, the pain, the side-effects of pain and at the moment, when I menstruate, it seems to weigh down on my level of fatigue. And I don't know if it's M.E, chronic fatigue, or if it's just tiredness. I don't know if you can quantify it scientifically, but I'm just exhausted. So that I think it effects your quality of life, 'cos you feel like you're not being as good a mother as you should. Or as good a wife as you should, as good a homemaker as you should. Or as good a friend as you should. 'Cos you're dealing with one thing that seems to be weighing everything else down. SO from that pint of view...ya.

R: Well, you've mentioned the two things...the one thing is that its the actual physical pain of having the condition, it's so sore that you feel it makes you irritable in interacting with other people but it also you feel, your role as a mother, because you are so tired that you just can't do the stuff..

N: Ya...Umm... And you also don't do it joyfully. You know, like I'll play with Matt (Pseudonym for 2 year old son) but I'll be thinking 'I wish I could lie down for 10 minutes', or 'I wish I could just lie down on my own and get my head around this and then get up back to it', but I can't. So, ya, it does effect you in that way as well.

R: SO you say, it's the sheer fatigue of having it.

N: Ya, it IS the fatigue, it IS the pain. But One of the side effects of Endometriosis is that...intercourse is painful sometimes, when you have it badly. And that also kind of effects your relationship because then you kind of don't want to have sex because it is painful. It's not like hectically painful-but it's uncomfortable.

R: YA

N: My gynae said to me, he like asked me straight out, "Are you experiencing pain in intercourse?" and I said, I can't really call it pain, I mean I'm not like clutching at things. But it's not comfortable, you know.

R: YA

N: And he said "Natasha, (Pseudonym)That's pain", because, he said, if you're not enjoying intercourse because it's painful, that's pain! Whether you want to call it discomfort or not, that's pain!

R: YA

N: SO, ya, that kind of has a bearing on your relationship because then you're not quite as close and as intimate as you'd like to be . And then I think Ron (Pseudonym) does understand, your husband does understand, but then he starts to think, 'Well, it's been a while now that she doesn't want to do anything, and is it because of me...?'

R: Mmm

N: You know? You know what I mean, it starts going into that kind of thing as well

R: SO it effects your marital relationship as well...

N: YA, ya

R: ...Your sexual relationship, your enjoyment of it, and that obviously impacts on your intimacy-

N: Absolutely! And then you kind of fell terrible. I mean, while you're having intercourse Ron will be saying to me "Natasha, are you okay?". I'm saying no, gritting my teeth. But he knows, and he feels it. And he said "Babe, if it's uncomfortable for you just say so. We don't have to do this...don't be silly". But you kind of feel, it's kind of a responsibility, I mean you shouldn't look at it like that. But I mean it is...

R: Part of your role

N: YA, ya. SO It sometimes affects that. Um, I think there's a big culture of blame and guilt with Endometriosis, you kind of think of think you brought this down on yourself. Which is kind of a vicious cycle, which is quite difficult to come out of because you think well, like, I mean, every time I see my gynae he keeps on saying to me "Are you still working? Shouldn't you be taking some time off, just chilling out, just enjoying time with your child?" or whatever. But you can't step out of life. I mean financially I have to work but he says the stress has a negative effect on the body and he says maybe I should consider maybe taking some time off and spending time with your son and spending time going into those things that you enjoy. But practically speaking it's not always possible to do that. I can't just take time off.

R: YA. Tell me, can you tell me more about what you said-you said something about 'bringing it all down upon yourself'. How exactly...

N: There is, I mean like, Ron, I don't think he necessarily means it as a blame thing but he's like often said to me, "You know, you do this to yourself" and to an extent I do. I work late at night now, but those are terms I've had to negotiate with my job. Matt goes down to bed at 8 or 8.30. I then cook supper and whip together some fruit salad or something for breakfast and then it's 10 or 10.30. SO I'm only starting to work at 10 or 10.30, so I put in an hour's work or two hours. And then it's 12 o'clock. Ron say's "You're crazy. You're doing this to yourself, don't do it. Don't do it". But I have to do it. He says to me, like, "stuff dinner and just make toast for dinner. Whatever, But Get your work done early and go to bed. Sleep". But he doesn't understand, it's like a -you can't. Because then If I go to bed at 10

o'clock I don't feel like a good enough mother. How can I give my husband, who works like a dog, a toasted sandwich for dinner? It's not, it's my role to cook him a good meal, to cook Matt a good meal. SO it's like this constant like a tug of war

R: Ya

N: So there is definitely-cos you read, you know, even when you go to these courses for time-urgent perfectionists. And I am, I can recognise that-I think I've got older. Because I can recognise things that before would like, rile me. And now I can consciously step back and say, it's okay. It's okay. And it really-stuff that before would have upset me and I could feel it (Your blood pressure just rises, and whatever). You know, I mean think I have worked on a lot on that, but you still kind of think-there's a part of me that thinks, 'Well, it's my personality type that has brought this sickness on myself. You know, so there is that blame thing. There is that guilt thing, cos you think, maybe I am not the mother that I should be, the wife that I should be. Because I have actually brought this down on myself, because I am that kind of persona, you know? I want to be a good wife and a good mom, and all these things. And my health really come at the end of the line. You know, if I only sleep 5 hours a night it's okay. But I feel better knowing that Rob comes home to a warm meal, that Matt has had his bedtime story, and whatever. And then I've done everything I have to do in the house and then I do my work. You know what I mean? I don't want to compromise the house situation. If I need to work then I will cut down on my sleeping time to get the work done...

R: Your health will take the last priority.

N: It does, and I know it's not always right and that's why I think Ron sometimes gets very upset with me, because Ron is one of these guys who needs to sleep. So Ron goes to bed and says "Babe, I'm going to sleep. Please come to bed". And I say I can't. I can't. Every day I write a menu for Alice (Pseudonym for the day maid), for Matt's next day so she knows what to feed him for breakfast and for lunch. I need to sort that out and make a shopping list, all like healthy stuff, you



know. And Ron gets upset with me. He says, "Natasha, you need to compromise something". But I'm just-it's my health that gets compromised in the end.

R: You're saying that can be making your condition worse? In that you're trying to make everyone else happy. You're trying to do all the things that you want to as a wife, as a mother, as a working woman. And you're saying that your health takes a battering at the end of the day.

R: SO you're talking about a few things, you were talking about your role as a mother, so maybe we can talk about that as well? Has it affected you with Matt at all I mean do you feel that, whether it's the pain or the fatigue, has it affected your relationship with him at all? Does it have any impact?

N: Not really. I think I'm probably just being a bit over-maybe I am exaggerating. Um, it affects me just because I feel um, it's a coping mechanism: when you've had lots of sleep and you're well rested you feel you can cope with anything. But when you're not rested it's more difficult to cope because you've got, it's just-the hurdle is just so much greater. And I sometimes just feel like, uh, it's about, it's like a guilt thing. I know you've got to keep your body, it's one of the theories in that book, is that women who are overweight, or slightly overweight, that contributes, on average, if you look at the stats, the women who are overweight tend to have Endometriosis, whereas women who are underweight or in peak condition tend to not get Endometriosis. You know, it's just a silly stat... you know. So I'd love to go to gym in the afternoons, but I'd feel bad going. Because, I know just having a healthy lifestyle makes it better, but I can't because I don't

want him at home. It's also just tiredness, it's a coping thing. I don't want to shout at him, don't want to smack him, and sometimes I am just irritable because I am tired and I am in pain. And I just feel like I need to lie down for half an hour. But you can't lie down for half an hour, you know what mean? Um, you just need to keep on going. Or I'll come home from work so exhausted and I'll just sit down in front of a video with him. And I'm thinking, 'you know, you shouldn't be inside watching a video-you should be outside climbing trees' or riding his bike up and down, or riding his bike at the zoo. He shouldn't be sitting in front of the TV, but I'm doing it because-it's for me, not for him. It's easier for me to cope with. It's selfish.

R: SO you're saying the one thing, that seems to be quite a big thing coming up in lots of your roles, seems to be the fatigue. The fatigue seems to be quite a big thing-that you just don't have the energy. Um, what are the other kinds of symptoms that effect your functioning?

N: Tiredness and fatigue are the most predominant, as well as pain. It triggers, and goes hand-in0hand with my problem M.E. My glands come up and the sweats come up.

R: Is the pain something you will experience everyday for a full day or is every day for a smaller part of the day or...

N: It's not every day, no. Um, it's mostly when I ovulate or when I'm stressed. Then I take neurofen normally and sometimes if it's really bad I take Myprodol. And that's where I know it's quite bad now. Incidentally, when I had this Panag

treatment, they take my blood test before, and afterwards. There's a certain hormone in your blood, I don't know what it is, that when your Endometriosis is bad it releases this hormone into your blood and you can read it scientifically. You can say this hormone has level-x, and at the end you can read this hormone level. I don't know what my end result was but he said to me that my initial reading was very high. SO he said to me that he understands that I must be in a lot of pain and that I must be very tired. So he told the nurse that even though the 10 day treatment was over, whenever I want to come in I must because he understands that I must be in a lot of pain. Which is also good for me to know because, it's like, it's not like it's all in my head. Cos sometimes, it's almost-because it's a womanly thing-because it's a gynaecological thing, perception is often that it's on of these women's 'gynaecological things', 'it's all a bit in her head-it's like PMS'. You know, it's not really real., you know what I mean?

R: You mean, it's something made up?

N: Ya, it's almost like it's something exaggerated by women. You know, every woman in the world menstruates and some women have a problem with it. Sometimes, I find, the social kind of attitude is almost: "Ag, please, get over it. Everyone has it" and whatever. And it's nice for you to know, if a doctor says to you, look, it's a measured reading, that's quantifiable scientifically , and, yes, it's there, and yes. It exists, and that's why you're feeling the way you're feeling.

R: So what else gives you that kind of vibe from people in general?

N: Um... I don't know, it's just people's perception-People are understanding-people do understand. But you kind of like think, I don't know. It's just sometimes spoken about in magazines. It's spoken about. It's something that's taken seriously. It's just like in conversation: "Oh, you know (sarcastic) she's got women's problems". That kind of-

R: ... sounds like quite a disregarded kind of-

N: Ya. It's like something you don't-you don't really talk about it. It's like 'women's problems', you know.

R: You don't talk about it...you mean taboo?

N: Not taboo, it's like menstruating: you don't really talk about menstruating, you know? That kind of thing, you know? You don't talk about it. It's almost like, the perception is almost 'well, every woman in the world menstruates. For time immemorial. Since women were born, you know. So, get over it! So why is your situation different? It's not!'. You know, and I sometimes feel that is the perception. SO I sometimes think, well, I remember even before I was diagnosed with Endometriosis, since I was a child. I had chronic periods. I just thought it was normal. Because Mom had chronic periods. And when I went to the gynaecologist just before I got married, and he felt it. And that's when he told me how bad it was and he told me "You've had Endometriosis for years!". You've had Endometriosis since you were like 15 years old. And I started menstruating when I was 12. 12 or 13. I said, "You know, my Mom always had bad periods, sore periods." And I always thought, well, whatever and ya...

R: You kind of didn't question it

N: Ya, and that's why I sometimes think, you know, Mom: I'm sure she must have had it. Maybe she just didn't realise she had it. I mean, it's extremely widespread. Even my friend Carol (Pseudonym)-you know my friend, Carol?

R: Ya

N: She just says, when it gets to that time of the month she just knocks back Neurofens.

R: Really?

N: Ya. But, the perception is "Just deal with it" and you must deal with it, you know, but I sometimes...ya, it's just a coping thing. Sometimes you feel like you can't cope. Sometimes you're tired and you're sore.

R: So people in general, there hasn't been much support, really? Or understanding of it?

N: No, there has. There has. But with anything. With any chronic illness that you're gonna have for the rest of your life. When you're first diagnosed people are sympathetic. It's like death. You know, when you are in morning or something. Your friends are very understanding: they rally around you. But a month or two later, they're over it and they're getting on with their lives again. And you've got this issue to deal with. It's the same as Endometriosis. I will have Endometriosis 'til the day I die. And, for me, it's a coping mechanism that I have to deal with on a month-to-month, or sometimes a day- to- day basis. But people have forgotten about this 4 years ago.

R: ... but it's something you're still living with. Something you still have-

N: ...and still dealing with, you know? And I sometimes just wish I could-mean, my sister-in-law: they've just decided this month that she's gonna go off the pill

and try for a baby. And she fell pregnant in the first month. I don't think I'll have that. I mean, I may, but chances are, I won't. Um, and it's something that sometimes makes you resentful because I think every girl as a child dreams of having a family one day. Maybe not every girl, but I certainly did.

R: Ya

N: I dreamt of getting married and having a home, making a family and having children. And you never question that you can't. You never question. And I think, infertility is the hugest thing for me. Apart from the pain, part from sometimes a disrupted sexual relationship, but, um and the psychological thing. But, infertility is a huge issue-the biggest issue for me. And it's something that you kind of feel, you kind of take it for granted, that "of course you're going to have children if you want to!"

R: Ya

N: And then you may not. And that's, ya, also quite difficult to deal with. And people don't always understand that. You know, and it is something that you...it really, I think-having Matt was really amazing. It empowered me as a woman. I really felt so female. That my body worked, and everything worked as it was meant to: I was able to give birth, and I was able to breast-feed, and I felt so womanly, I felt so fulfilled. I felt that there was a chunk in my life that had come together and made me whole.

R: Ya

N: And ya, when you don't have that you feel like you're half a woman. (Coughs). That you're a woman without the things that make you a woman, almost.

R: And so do you feel the threat of maybe not being able to have another child?

N: It affects you. I mean, I am very grateful for what I have: I have a wonderful husband, who I love very much, and we fight sometimes, but I am very happy. Very happy. And I have a wonderful son who I love very very much and I know I must be grateful for that. And I am. I'm really, really grateful because I was told that I could not have him. I would love to have more children, probably more for him than for me, just so he can have siblings and know what it's like to have brothers and sisters-do stuff together, that companionship, which I had. And I would love for him to have that. If I don't, I think I will be very sad. But I'm very grateful that I've had at least one child. Which a lot of women don't have.

R: Mmm. SO you're saying that you're grateful for that, that you've got what you have.

N: Ya, and I think I've got a lot. I've got a lot more than a lot of women.

R: But I mean, how does the-you say that you're not sure whether you are going to be able to conceive again. Has that, in terms of you and Ron, has that impacted on your marital relationship at all?



N: Umm...I think more so for me than for him. He seems quite relaxed about it. I don't think he doubts that we can have children. I think he acknowledges that there might be a problem. That we might battle. But I don't think, because Matt happened so easily, I don't think he fully understands how difficult it could be. I mean, I've done a lot of reading and, I just want to be realistic about it. I don't want to say we will have another child if we can't. I don't want to set myself up for that kind of disappointment. So, it has, ya, I don't think he-it affects me more than him. Uh... I think if I couldn't conceive again, he would be sad, because he would love to have a bigger family, but I think that he would be okay with it.

R: Okay. So you're saying that is something in your marriage relationship, something that you have to work with. You know, the infertility side of it, the difficulty conceiving side of it. We were also talking about the sexual aspect of your relationship, that it can be quite painful and that will obviously concern Ron as well, 'cos he obviously wants you to be happy as well

N: Mmm

R: Could you tell me more about your marital relationship, about the effect it's had?

N: Umm, no...I think, at first I felt a bit unsupported, because when I was first diagnosed with it, it shattered my world, it really did. Because, for me, my career has always been secondary to my dream for a home. I've always wanted to be an attorney and a lawyer, and I love what I do-I really do. I love it. Um, but In my mind it's always secondary to being a wife, having a home, being a mother. That was always very important to me. And I kind of feel like I almost made sure I had a career, because of the situation with mom. Because I always thought, 'what if Dad had died?', and Mom had stayed behind, and Mom had no tertiary education.

How would we have lived? I don't know if we would have lived-how would we have lived? 'Cos I mean, she had no tertiary education, she didn't have a good job. She didn't work. That made me-the decision was made in my mind that I will go out and get a career and insure that I will always work, that I will always bring in some money. SO that was almost my primary motivation. I mean, I love the law. It's just always been- 'make sure you are doing something to bring you an income'. That's always been my motivation. But my primary motivation has always been to have a family-always. It's always been.

R: Ya

N: So, ya, When I first was diagnosed, Ron-I mean he's a different guy, he's just a different guy. He's not very emotional guy. It takes a lot for him to come out, for that part of him to come out. IO just felt like my whole world had been shattered. That my whole femininity had been shattered. I was like "what do you mean I can't have children? This is what I've wanted my whole life! What do you mean?". You know? I felt very alone I think, because he didn't-he saw it as a problem, and it's problem is something you solve-you go for your treatment, you know. I don't think he really understood what a frightening place I was in.

R: Mmmm.

N: And it's taken him a while to get around to that. And maybe he understood it and just didn't know how to reach me, or maybe he just didn't see it. I mean, I don't know. He is, I mean, he has been-through the years, he has definitely come to the party more. I mean, mean, it always used to make me upset-when I was first diagnosed, I mean, I remember Dad sat on the internet and got 5 or 6 internet articles on laparoscopies and Endometriosis. And he sent them to be, emailed

them to0 me, whatever. I mean, Ron didn't do anything. I mean, and then like, when it came up again this year-he all of a sudden started doing searches on the net and he started finding out more what Endometriosis actually is and all that kind of stuff. So I think he-ya! Maybe it's a little bit late-(laughs). Um, I would have appreciated it a bit more if it had been a couple of years earlier! But that's the way he is. It does have an impact.

R: Ya

N: "Cos you kind of feel like you're going through this momentous thing that is attacking you as a woman-and it is. It really- and that's why I say-the infertility thing...I mean my friend Carla (Pseudonym) it's not like that for her-because she doesn't want children.

R: But it's a factor for you-

N: It's a huge factor because I desperately want-at Christmas time I want lots of children around shouting and laughing! That's what I want, you know? So it's a huge factor for me to compromise that.

R: YA. That's something quite important to you-something that's part of you as a woman.

N: Ya, absolutely! And it also defines-well, it doesn't have to, I know it doesn't have to-but I...put it into the definition of a woman. It makes me feel like a woman to know that I can bear children and I can be a mother.

R: It's important to you.

N: So ya, it does have an impact on you. You almost feel-and I know Ron doesn't see it like that, but you kind of feel less of a woman...you're less of a woman...less of a female. So...ya, from that point of view, it does effect your relationship.

R: Okay. You were talking about your career-you're obviously working in the law, um, it's obviously quite a challenging profession-especially now, with your job also, in a new environment. You've got different pressure than before. Have you found that your Endometriosis has in any way affected your work functioning...in the work sphere, or how people have responded to you?

N: No, not the way people respond to me because it's something that no-one knows about, really. I don't discuss it at work. In my professional environment it's something that no-one knows about. Um, maybe when I have an operation in July, maybe then I will have to tell them, then it'll be something that they do know about. But I prefer not to. Especially in the legal profession, which is so male dominated-you don't want them to know about your gynaecological reasons, or whatever. You know, and if they ask me why I need to have an op, I'll just say that I need laser surgery. I won't-you know what I mean? You almost feel like it will affect the respect they had for you as a professional. So, ya, from that point of view, they don't know about it. Does it affect my work? Ya! Just tiredness and pain and your ability to cope. I think that, coupled with the M.E. that sometimes comes down on it when I am under a lot of pressure and my immune system is completely suppressed. The glandular fever comes back and then I have Endometriosis and am in a lot of pain. It's just your ability to cope. And, certainly with M.E, your short-term memory is completely bombed out-I don't know why. It's one of those things that just happens-I don't know why, you just...And you kind of stress, you know "I've studied this for so long, how can I not remember this?". SO ya, it effects our professional...ya.

R: I mean your concentration-

N: Levels of concentration have also been effected-

R: ...Or does the level of pain prevent you from working the way you used to...or doing as much...or?

N: Um, I can't work as hard-I can't push as hard. It was when I was diagnosed with M.E and it was the combination of M.E and Endometriosis. They said to me 'You'll never be able to work as you did before'. You'll never be able to go to be at 2 in the morning and wake up at 4, and go to work and just survive on 3 hours of sleep. And just live on coffee and Bioplus-and anything that will keep you awake-you'll never be able to do that again! Never again! And this woman who was a homeopath and a doctor-she was treating me for M.E, she said to me, "You will work at 85% maximum. Your maximum level will be 85%. Your output will never be 100% again. It will always be 15% less and you need to accept that and deal with it."

R: Do you find you have to take much time off work...because of the pain, or anything like that?

N: No. Not yet. It's something that-I just take painkillers and I've started drinking lots of coffee again, which is a bad thing but it will keep me awake. I've started taking supplements from Herbalife-Guarana: Guarana Thermogetics. And you mix it with water and it's just caffeine actually. It just keeps me awake.

R: And what about your social relationships in general? DO you stop going to certain functions that you used to go to because of that, or your friendships-

N: Not really. It has been curbed but that's mostly because of Ron's job and the fact that we can't really afford baby sitters. SO I don't go out much purely because-I don't always like to go out on my own, I want to go out with Ron too. And he works very long hours, so from that point of view we can't do it. And also, we don't always have a baby sitter, so it's a mission. SO-

R: So, not so much because of the Endometriosis itself-

N: It's not the Endometriosis that's making it-I mean, No. A couple of times I'm just too tired, and you feel uncomfortable and you don't really want to go out because you just want to curl up on your bed and read a book, because you're feeling sore and tired and cranky, actually. SO, ya, I don't think it has much of an effect my social relationships.

R: And your friendships, like going functions with your friends. As I say, my social life has been curbed. It definitely has been curbed, but that's I think because of the reality of our lives at the moment.

R: Ya.

N: Just because, during the week I don't go out anymore because I have to work at night. Because of Mike and because Ron's hours are very long. So, I mean, its not M.E-I mean it's not the Endometriosis that's doing that-it's circumstantial.

R: And family life? Has it impacted on...I mean doing things together...

N: Just from the point of view like...just silly things. Like me cooking a meal at night-a hot cooked meal at night. You know, like, at the moment we are eating at Nando's once a week, sometimes twice a week. It's pizza or Nando's twice a week, because I'm just too tired. It gets to seven o'clock and I'm-and Ron just doesn't understand, he says "But Natasha, your life should be so much easier now. You're working a half day now. You get home at 1.30. You're spending the

afternoon spending time with Mike-playing with him, taking him out to the shops, or taking him to see his friends. Or whatever. I mean, really, your life is a lot less stressful". And it is, but it's, I don't know, it gets to seven o'clock and I'm still tired. I'm exhausted. So ya...from that point of view I'm not really cooking. I mean I really love to cook, but I'm not cooking because I'm just too tired.

R: The fatigue...

N: And then Ron walks in at half past nine, he's had a long day, and I'm barely-when I'm extremely tired, my speech goes-I don't know if it's a neurological thing. But I start to slur and mix my words. SO Ron will walk in at 9.30 and say "Hey, babe. How's it going?". And I should jump up and say "Hey, how was your day?". And talk and just, whatever...I'm too tired to even talk. We'll say "Hi babe" "How are you?" "Fine" "Want some tea?" "Yes" "Okay" "I'm gonna go to bed" "Okay, bye.". SO there's no, like, Shhho, there's no communication. And I suppose that's a common thing (Tape stoops. Tape turned over)

R: What is your perception of the medical profession and your treatment in terms of...

N: I've had a fantastic doctor. I really have full faith in him. I've never sought a second opinion, I'm seeing the same doctor I saw before I got married and Ron and I have been married 6 years this year. He's treated me, he's given me 3 laparoscopies. SO he's amazing, he really is. He's very open to questions. The whole clinic is a fertility clinic...

R: What clinic is that again?

N: Medfem

R: Is that here?

N: It's in Sandton, opposite the MediClinic.

N: I feel really confident there, I know I'm in the best hands in Jo'Burg. One of the best in Jo'Burg. He's fantastic. He's been on Carte Blanche. He's great, so...medically, I wish there were more solutions. But if there were more solutions, I'm sure my Doctor would know about it.

R: Ya, so you kind of feel that they have done what they could although you wish there was more that they could do?

N: Ya, especially this latest Panag treatment. He's asked me to be part of it on a trial basis, and I have not paid, it hasn't cost me anything. And I do, I feel a big difference. SO it took me a couple of days. Cos he said after the first day you will walk out and feel like a new person. On the first day, like 2 hours later I felt better but I was still very tired. It took me about 3 or 4 days-I started on the Monday and on the Thursday I walked out and felt energetic! I just didn't have that fatigue-when you have that fatigue it's like having a filter on everything. It's like looking through coloured lenses-everything's a different colour.

R: Ya, sho!



N: So, and then, all of a sudden, the filter was gone and I had all of this energy which is fantastic. It's not always there and I do feel a lot better, but ya...sp I'm quite confident.

R: And you're saying it involved what light...light treatment?

N: No...Panag. It's apparently a product that has been on the market for a long time. It's apparently registered with the health council, or whatever, it's registered in the States so it's a registered product. But it's used mostly for back pain and back spasms. It's an electrode, it's a box which you plug into a plug, into electricity and you turn up the electric current. And it's a probe-

R: Like something they use in physio?

N: I've never been to physio...

R: They put, like pads...is it pads they put on you?

N: They've adapted it. Apparently the woman who originally designed the Panag treatment is a client of Dr. Van Rensburg.

R: Okay, ya...

N: And she came up to him and said, "This stuff is amazing, why don't you use it on your patients?". And he said, "I tell you what, why don't we modify it and let's try it". And what happens is you put one-it's like a little pencil about this long (indicates length) and you insert it vaginally.

R: Okay

N: Okay, how it works is you've got this probe and you put it under your tongue. And it hurts if you move your tongue, 'cos it's electricity, so you don't move your tongue! And you put it under your tongue and you lie still, for 15 minutes. And then you unplug it and then insert it vaginally. And you do that for half an hour. But that way, you can move around-you don't have that restriction. But you put it

on max so there's maximum electric current running through, and that's it. And then after half an hour you take it out and you pack it away.

R: Okay. So does it actually enter the uterus itself?

N: No, it's just like putting a tampon in. It's like a tampon.

R: Oh, is it? Okay...so it's all got to do with electricity and all that.

N: YA, and it does. It has an amazing effect. It doesn't-and how he explained it-it doesn't take it away-it alleviates the symptoms. Like with him, he said his massive, massive abscess. And he was doing surgeries and all this and he had to go to the States. SO He phoned this surgeon, and said "You need to do something about this tooth!". His mouth was like this (indicates that his mouth was heavily swollen), he was in chronic pain! And the surgeon was away, it was the Christmas weekend, and he said "Sorry, I'm going away, I'll only be able to see you on Monday, I'm sorry!". So he was going out of his tree and he put this probe right on his tooth. And for 2 or 3 weeks later, the pain was gone, the abscess was still there, but the pain was gone. And after 3 weeks after Christmas he phoned this guy and said "I need to see you" And he said "What! You haven't done anything about it yet?". He said "No. I used this thing and the pain is gone". It was still there but "I need to sort it out" then 3 weeks later they did it.

N: It's still there, I don't know how it works scientifically or medically, but the pain from the Endometriosis is much less. But it's still there but it just delays the fact that I need the op.

R: YA, okay. What else...weren't you part of a support group...wasn't there something else?

N: That as the course of time-urgent perfectionists.

R: Was it with women with Endometriosis?

N: I've done it twice-the first time was with a group, once a week between life half-past six and half past seven and we worked with one psychologist or psychiatrist-I'm not sure which one she is. I think the husband is a psychiatrist and she's a psychologist and they work together. And I did it with the husband because she was having a baby. So he ran the group. And there were about 10 of us in a group and all of them, most of the women had tried to conceive and they couldn't...they were all ages. The second time I've done it, my doctor said to me "you really needed to watch your stress levels. A lot of it is within your control so what's in your control-you need to try and learn to control it". So I went to see Mandy Wolf-she's this guy's wife, she's a psychologist. And I saw her for a nightly session after work, for an hour, for a bout 6 weeks. Just once a week. And we went through a similar programme-slightly different. They've modified it from 18 months before.

R: And did that have any effect?

N: It did. YA. Things that would stress you out before-small, small silly things, like-getting caught in a traffic jam, getting cut off by a taxi. Um, they call them 'hooks': those things that trigger a reaction. Um, ya...

R: So was it like a stress-management kind of-

N: YA, it was stress management.

R: And did you find that it did help you.

R: Ya it definitely did. Like before, if I walked in to Spar and there are like 500 people there and I would have to wait 20 minutes or a teller, it would freak me out! And you think that every second is ticking and you have so much to do and it's pouring with rain and Mike's crying and Ron's coming home and I've cooked

nothing. And now it's just like "There are 20 people in the queue and I'll just have to wait and it's okay". SO ya, it does help.

R: And is there anything else you have done that has helped you at all?

N: I think exercise definitely helps, if you can find the time to do it.

R: YA. With the pain or the stress....

N: Just your general level of health. I think you are just more...eating well, exercising more, having a healthier life, then I think your symptoms are much better. If you've got a bad lifestyle and you're not exercising well, drinking coffee and not eating fresh fruit, not eating fresh vegetables, your whole immune system is suppressed. Whereas if you are eating well, exercising, not drinking coffee and your sleeping well then your whole immune system overall is...

R: It makes it easier to cope

N: Ya, it makes it easier to cope. Ya

R: And what effect do you think social support has played in dealing with Endometriosis.

N: When you say social support do you mean support groups?

R: Well, you've spoken about the group you belonged to with people with similar difficulties but I mean friends, family, other people- does it play a role?

N: It does play a role but I kind of think-it's a self-imposed perception, but you kind of think well, 'I was diagnosed with this thing almost 6 years ago' and I made such a big thing of it 'cos it was such a big thing and six years later people- your friends, expect you to have dealt with it. It's like a death: 'Your mother's been dead for 13 years...you shouldn't be crying about it anymore. Just get over it'>. And you kind of feel their level of patience is like-you know what I mean, it's almost like...you don't want to say anything, "cos they're almost thinking "oh,

you know, this again...I actually can't hear about Endometriosis again!". You know! And I'm not-it's a self-imposed thing. I almost feel guilty...you almost don't want people to think that you've got problems, you know. You know, I've dealt with this 6 years ago. People don't want to hear about it anymore. People don't want to hear about-you know! 'You know...just get over it. Just deal with it!'"

R: SO, ya, I think we're almost out of time!

N: Yes!

R: SO...Is there any other way that you have coped with it. Anything else that you-whether it's a positive or negative coping mechanism that you use.

N: This course that I did made a very big difference, um. I think it's... within your relationship...it's so important that your partner understands what you're going through. I really do. And I must say, even after I had my laparoscopies and Ron was there next to my bed when I came out of anaesthetic...and I was just-you're like a braai chop inside. They've just lasered you to Sh\*\*. I was-I got over my caesar-and I've always said it, it's the truth-I got over my caesar so much faster than my laparoscopy. I mean a caesar- there they cut through how many layers of muscle? I was driving a week later! With the laparoscopy you battle. It is so sore!

R: With all the lasering...

N: Mmmm. I just think support is very important. Ron was very supportive, my family was very very supportive, you guys were fantastic...And that is quite-the people really close to you-not to have their sympathy-but just to have their understanding. 'Cos you do feel fragile and you do sometimes feel depressed 'cos you think, "my next door neighbour is not going through this. Why? Why am I going through this, why isn't she? Why have I been fingered out? And Is it really

because I have done this to myself? Am really so stupid as to make myself so sick?" And I do think it's an element of both. Yes, some of it you do do to yourself. You do abuse your body. But you can't tell me that Endometriosis is so widespread, it's so common, because women are all doing it to themselves? So I think it's a bit of both, I really do. SO ya, support is really important.

R: And is there anything particular about the support that is helpful? Anything that if you could ask for, you know to say "This is what really helps: whether it's having somebody to look after Mike for a while, or helping you cook. Anything particular about the social support that makes it more useful?

N: Not really, 'cos if there is too much support you almost feel disempowered. You know? But you do definitely-you do almost need to take a week off work, off everything. Because it is extremely painful and uncomfortable 'cos of all the air bubbles going under your collar bone. You know, and it's so (inaudible)...mmm...not really.

R: I mean, if you had a friend who had Endometriosis, and you having had it could think of something that really helped you or would have helped you-

N: I think, silly things like a phone call. I mean those kinds of things, you don't necessarily have to go to the effort of having a visit, but like a phone call. After I had that laparoscopy last year I was kind of disappointed with my friends. Yes, it was the third one I was having. And Ron's mother was here and there was the February heat and everything was just so hot and I was just sweating in bed and everything was just so sore. And I had a reaction to my painkillers so I was vomiting and vomiting. I was just holding my stomach and I was just puking and puking and puking and I couldn't eat anything. And I felt like I was dying. It was terrible. And...none of my friends even phoned. They kind of said "well, good luck for the op". But, I don't blame them because, in their mind, "Natasha's had 3. She'll get over it. She's had 3 already. We'll call her next week and see how it went. But...on Saturday afternoon when you feel "I can't handle it anymore!", and the nausea is just debilitating. You actually think-you kind of feel left out. You kind of feel a bit lonely. And you think, 'You know, it would have been nice if Sara had phoned, if Jasmine had phoned.' Just to say "How are you doing? How are you guys going? Can I make you some pizza tonight?. You know...

R: That you're being considered...thought about.

N: Ya...as I said I don't blame them. 'cos on their part Natasha has had 3. It's her third one. She knows what she's in for. She knows how to deal with it. It's fine. But I think, having been through this experience myself, Christine's going for a laparoscopy soon-I will definitely be phoning her a lot. Even if she gets irritated with me. Because I know what it's like to feel down like that. You do kind of feel that you need a bit of support. You don't need to be molly coddled, you just need support.

R: Ya, you don't want to be disempowered but you want to know that you're being considered.

N: Ya, that they're thinking of you.

R: They're thinking of you.

N: Ya, so that's it, really.

R: Is there anything else you want to say about what your experience has been like?



N: The biggest factor for me is like, and I've said it a couple of times, is the infertility and it's also the unknown. I mean, it's not like having cancer where you know you're gonna die because with your strain of cancer there is no cure for it. You know, with infertility, the whole thing is kind of nebulous. Some women with Endometriosis will never conceive and others do. Others flook and...you know...It's just the not knowing that's frustrating.

R: Ya

N: I don't know if I'll be able to have any other children. Then I suppose every other woman is in the same boat. Women with perfect gynaecological health they also may not conceive. So I suppose there is no certainty because it's one of those-even a man with fully functioning equipment may not be able to father a child. It just happens. So I suppose there is no certainty, but you kind of like, feel like, it's a diagnosed condition. Can't they just tell me if I can have a baby or not? You know what I mean? You think it would be such a simple thing to do. But they can't. That's kind of frustrating. Because like...we were about to start trying for a baby in January this year. And now it's almost the end of March and I mean, we can't. I just don't think, morally, it's not right to fall pregnant just as you've started a new job. Um, but then you kind of think "Stuff them! I mean, this is my family! I don't care about a company. I'm sorry. But I don't care. Um, should we really be making those compromises? I mean it may take us 8 years to conceive. Some women it's taken more than that. It's taken more than that, to fall pregnant. Shouldn't we try? I mean you don't know?

R: It's the not knowing.

N: It's the uncertainty.

R: Well, thanks, you've told me how Endometriosis has affected your quality of life. Thanks a lot for telling me everything.

N: It's a pleasure.

R: Super, ya I think it's very helpful to speak to somebody who has actually had it. What is your actual experience.

## **Appendix C: Respondent interview**

### **“Elisabeth”**

R: Maybe we can do by you explaining to me how you understand what endometriosis is – as like a physiological illness.

E: I think I understand it now, I think it's more chronic than I realised, umm, I think in the beginning when you're diagnosed, you don't really take it seriously – you think it's something that's just gonna go away – you know you have this little op and it's just gonna go away, but it doesn't. I think it's something you've gotta come to terms with. It's more of a long-term thing, it's maybe not serious like a heart condition, but it's – it's like a permanent physical disability, almost. People don't see it, but, you know, it's always there.

R: I mean, how do you understand it as like a physical disease?

E: Umm, well basically – are you talking about the medical side of it?

R: Ya.

E: Umm, well from what I've been told, from all the doctors, I understand that its, umm, it's like a reproduction of cells – not in – in your uterus – it's on the outside of your uterus and it affects your other organs – almost.

R: Ya, so it's not where it's meant to be.

E: No, no, okay.

R: And then how do you understand what quality of life is.

E: Free of pain, Ya, definitely free of pain. I suffer – that's my biggest, umm problem or worry is pain. It's horrible. I live with it all the time – some days are worse than others, but

umm, you know, they all say if you have a laparoscopy every couple of years it decreases the chance of it multiplying as much and everybody says, if you've got to have it so often, what's the point. But, I don't think they understand that even six months free of pain means so much. I lived with it for so long, until I had something, until I had the laparoscopy and to have no pain for six months and not feel that permanent irritation and... - it sounds ridiculous, but six months out of even two years is a bonus.

R: You say the laparoscopy gave you that pain free...

E: It did – it only lasts about six months, if that.

R: You said you've been twice.

E: But, it doesn't last long and for me, it takes a long time to recover because I always have an adverse effect to the anaesthetic and that sort of thing – so it takes me a long time to get over it, sometimes two months, you know, before you actually feel well.

R: Gee, it's a long time after an op hey.

E: Especially with the last one – it hit me, so hard.

R: Gee whiz.

E: And, then it's time off work and you don't want to always say – you've got to go and have these funny things done.

R: How've you been finding it's affecting your work.?

E: The only thing that really bothers me, is that I take a lot of pain killers, so – I think it affects me – I never really take time off work unless I'm actually going for the op, and once or twice I've taken time off, but I sort of just – I think you get used to the condition and you get up in the morning and go to work – you know what I mean?

R: Ya.

E: And, you can't really explain to people, like if you're feeling bad I'd like to stay at home, because people just seem to think it's something to do with your monthly's or your cycle – oh, I've got that too, what are you worried about? I think the medication affects me quite a bit.

R: The painkillers?

E: Ya.

R: How does it affect you?

E: Well, you know, when you take heavy painkillers, it never makes you feel well – it takes the pain away, but then you've got other side-effects like, maybe dizziness, or headaches, umm, sometimes you – a lot of them they say you shouldn't really drive with it, so I've gotta be careful when I take it.

R: So, it hampers other aspects of your life.

E: It does, you've gotta think, well how sore is it, should I take the painkiller or shouldn't I - this week I've taken just about every day.

R: I expect it's with a bad week.

E: Ya, it varies and it used to be worse at certain times of the month – now it just varies – it's anytime.

R: Okay, so it's not predictable when it's going to become very painful.

E: No, no.

R: So, you've talked a lot about pain and how the pain is the one thing for you, which makes you notice that your quality of life gets affected. But, how else do you understand what quality of life is?

E: Umm, I think it's also being able to enjoy life – you know sometimes you don't wanna go out and socialise, sometimes you come home and you're tired. You don't wanna do some things – some weekends, I don't wanna do anything and I think you should be because if you think you work all the time and you should be able to enjoy yourself. You don't and the times when you have the opportunity to – to have that free time to go and enjoy yourself, you don't feel like it. It also sometimes affects your relationships – I'm lucky as it hasn't really affected my marriage as such, because we, we haven't really been interested in having children, but I can imagine somebody who would – it would affect them, you know. Because it definitely does affect that side of it.

R: So, you say if that was an issue with you and your husband, then that would be something that could maybe...

E: I'm lucky, because we've sort of got an understanding, so it's fine, you know, it's not an issue at all with us.

R: So, it's something you've decided that you don't want kids, so it's something you've spoken about, so it's not – so it doesn't really but in as an issue. You said that you sometimes get quite irritable, that you get the pain and all that – has that had any impact on your relationships?

E: Sometimes, because I don't think people understand. If you say, I'm sore, just leave me alone – she's irritable again – you know you just get over it. Also, it's not a physical thing, people can't see it and so many people that don't know anything about it and when you say the word – it's quite a long word – and they – it doesn't really mean anything and when you say the word, it doesn't register anything in somebody's mind like heart disease and

sometimes the word will tell them something about it, but that means nothing to people unless you explain it.

R: Okay, I mean how do you find it – how does that impact on talking to people about it – the fact that they don't know what the thing is?

E: I think, most people unless they've had first hand experience, or they've got somebody that they know or a friend or family member, they don't grasp it. I mean I've had two ops and I've been at work and even my boss, she's a woman, and she said to me, what is it – why don't they just give you a hysterectomy? You know, as a woman, and she's an older woman, you think she would be in tune with that sort of thing, and even, you can see – it's almost like a frustration for them – what are you going on about, why don't you go and get yourself sorted out?

R: It's like a hassle for people, it almost feels like it is...

E: Ya.

R: Do you find that you have male colleagues and female colleagues?

E: Ya, I do have those – they male colleagues, they don't – I don't really seem to have a problem with them. They, they don't really get involved. The female colleagues – well most of them don't understand. They're actually very ignorant I think.

R: Do they ask you why are you going in – do you have to explain it to them – all the different stuff...

E: Well, most of the time I don't explain anything, my close friends – they'll understand, but still most of them – it's like a foreign disease to them – almost. They just see it as a like a complication with your monthly's – something like that, you know what I mean, they don't really understand. Especially when you can't explain about the physical side of it – your

cells are... - they don't understand, they can't grasp that your things are in the wrong place – you know this is where it shouldn't be, that's the reason you have pain and discomfort.

R: And, I mean, have actually tried speaking with them, your work colleagues for example?

E: A couple of my friends I have, but the people at work, I don't really get too involved with – but I've got quite a few close friends and they're actually very nice, because a lot of them have got friends with it – other friends with it or family members, so...

R: So, you kind of know of someone who has it or knows of it, and it makes it a little bit easier to get them to understand. I'm just interested in that you don't really tell your work colleagues – is it something that just isn't spoken about or something that you don't want to talk about?

E: Well, I think umm, when it's got anything to do with girl issues, you don't really want to make it public – even when I went in for my op, I didn't really tell anybody. I think maybe the ladies knew, but umm, you try and come up with another excuse, you know you're just going in for – I was lucky when I had mine done, I had a hernia op at the same time and I could say, I actually went in for in for a hernia op (laughs). So, I was lucky – it's not nice – I could see – but there's been quite a few ladies in my office that have had cysts on their ovaries and other like gynaecological problems, so in that respect, they appreciate – I'm like a supervisor there and if they come to me, they actually feel comfortable coming to me, because they know I'm also suffering with a similar sort of thing.

R: So, you can empathise with them and can be there to understand what they're going through.

E: It's true – you can only if you've had it. My boss, she's never really had any problems, she's had one child and no complications, no hassles, so she doesn't actually understand.



R: Do you find that people want to know or that people just aren't interested or are people...

E: Some of the people are – I would say, sometimes the older people – they seem to be more understanding, I think definitely, I would say, like forty onwards seem to be more sympathetic – I think it's maybe because they've experienced something similar because most of these things, not maybe my condition, but other conditions related to women things come later in life and they more...

R: They might have experienced it as well and know kind of what you're talking about and kind of understand. Do you find your friends – do you find that manage to speak to them?

E: Umm, Ya, I've got some very, very close friends and they're very understanding. In fact, one of my closest friends is the type who'll go onto the website and will give me pamphlets, and you know...

R: She'll look up information. Do you find that helps?

E: You know, it only helps so much, I think once you've read everything, you tend to like exhaust...

R: Ya, all your resources...

E: Ya, and, there's not much more you can learn. I think, I think the biggest thing is that everybody is different, not everybody experiences the same problems with this condition, so it's just dealing with it in your own way. Like, I might have pain but somebody else might have problems with conceiving, so it's two totally different things.

R: Ya, although it's the same condition, you may have experiences...

E: I mean, some people don't have any pain, some people just have maybe pain at certain times, it's so hard. Some people don't even know they've got it. They only find out when, when they come to having children.

R: Okay, it can be so varied...

E: It is.

R: In terms of what you were saying, you could become quite irritable with the pain – psychologically how has it affected you do you think?

E: I think since my last op, I never ever thought I had it as bad as I did and then it sort of hit me and I actually thought it would be like the first one – go in – it's quite easy, you have the procedure, take a week off work, a bit of pain, get over it, you go back to work and you know, but I tell you, it took a lot out of me, it really, really did. It knocked me so badly. It took me – even my family they said – I think I had the op at the end of September – in December I was still ill.

R: What were you experiencing from the op?

E: It was the pain, it just never left me. I think I had pain post-op for so, so long – just because of all the work they'd done on me. It wasn't just a matter of... - before I went in, they never, they never really, I suppose they do it so they don't put fear into you and they say it's a quick procedure, you'll be in and out in no time, but they never really tell you how bad it's gonna be, and only a week after, you know you have the op and you go home and sit at home for a week and then you have a check up and only after that week did I go back and they said they did so much work – they just couldn't believe how bad it was. And, that shocked me as well because I'd had pain for years and years and years but I'm an optimist, when it comes to pain with myself I never expect the worse, unless somebody puts it in black and white. I think, so what...

R: You'll deal with it...

E: Ya, it can't be that bad, you know, don't be ridiculous and I think it really knocked me. It did. I think I'm, like I'm over thirty now and I never really looked as my age as old, until I had this and then I think, gosh, I actually felt old, you know it makes you feel old. You know, I think and then I think there's these other people who're actually my age and they're having kids and they do all sorts of things. They feel young but its... - I don't know - I think it took it out of me, it really did, and then what was worse, was in six months it came back.

R: Was this last year?

E: Ya.

R: So, it was quite soon...

E: But by January, I had to have another procedure done, and it took so long just for that procedure to settle - six months for that, so August now was the deadline for them to see whether this other goodie worked.

R: Okay. The other procedure.

E: Ya, to see if that helped because it just came back so soon, they didn't expect it to.

R: So, it just kind of knocked you flat.

E: It did, it really did.

R: You said it made you feel almost as if you were ageing, was it because it took you so long to recover?

E: I think so, I think so - I just never expected it to be that bad. I don't know whether - I think it was a shock to my system, umm, and I don't know whether because of all of what's happened, I think your hormones take a turn for the worst. And, particularly since January I would say, with all of the things that I've had to have done, I've never been a moody person, I've never been - I've never had like erratic behaviour, never - I'm straight down the line

and I've always been very responsible, you know what I mean and even my husband just said he can't believe, it was almost like a change in character.

R: After the procedure – was it while you were recovering or since you've had Endometriosis.

E: I would say probably since the last procedure.

R: And so did you become moody and erratic?

E: I did, I did terrible. And then you know they put you onto hormone treatments and that sort of thing. They say it's not in high doses but I can't believe that it doesn't affect people and I think that everybody has different side effects – something that effects you, won't effect me. So, really, I mean I've become – I mean there's times when I battle to actually get out of bed in the morning. On the weekend, we were always very active – I'm not saying that we do sport, but we were always out and about – I was up early – 05.30, 6 O clock in the morning on the weekend, and now 0800, 0730, 0800. There's a lot of things I don't want to do anymore because they always say with other problems, if you do exercise it helps. This it doesn't. In fact, if I overdo it, if I stand for long periods, if I go out and socialise with my friends for an evening, the next morning I battle to get out of bed, I'm in agony.

R: Is it the pain?

E: Yes, the pain.

R: So, it's not so much exhaustion but just the pain.

E: Sometimes a bit of both. I got very, very tired at one time. I've never been one to sleep during the day and it got to stages where on a Saturday afternoon, I'd be physically exhausted, I couldn't even keep my eyes open and I went to sleep, even if it was just for an hour or two. But literally, I would force myself to stay awake and even my Mom would say,

why don't you go and lie down. And, there's been times when I got to work and my boss said, you look shocking, like what's wrong and I didn't even know I looked so bad.

R: So, exhaustion is another kind of symptom you've had with it as well, mood changes...

E: I've always been one – I don't go to bed early but if I go to bed at 10 or 11<sup>o</sup>Clock, I sleep right through, now I find I get tired by 8 or 9<sup>o</sup> Clock I get very tired and I sleep but by 12<sup>o</sup>Clock, I'm up and then I can't sleep and I've never ever been one like that.

R: So, it's disrupted your sleep pattern.

E: It does, especially with the pain – I can get up and if it affects your internal organs and it affects something like your bladder, it seems ridiculous, but now I have to get up in the night. And, I always had coffee before I went to bed, I mean such silly things, I used to have coffee always, have coffee all day, coffee before I go to bed, coffee at 10<sup>o</sup>Clock at night – now I've gotta think – gosh, I'm going to wake up in the morning and am not even going to be able to go to work because it's such pain.

R: With the coffee – were you taking it to keep you awake, or help you sleep or...

E: No, because I find with me, as soon as I eat or drink too much, it affects my pain.

R: So with all your organs – it gives you adhesions and things...

E: Yes, that's the thing, because it affected – that's where most of my endo is – it's around my organs, it's around the bladder and the bowel and all of that.

R: So, like digestion and that is quite painful for you.

E: Yes, Ya.

R: So, if you overdo it, and eat too much, you're really going to feel it the next day.

E: Yes, Ya.

R: And so you were saying, in your marital relationship, with you getting up in the middle of the night or feeling quite tired – has it affected your relationship with your husband at all?

E: Umm, I think maybe my moods, I wouldn't say, umm, the other side of it – the physical side of it so much, I would just say maybe the emotional side – when I'm moody – I used be so easy going but now the silliest things bother me and just irritable – you know you just snap at people, you don't mean to but you do. But sometimes you don't even realise you're doing it and you also become a bit selfish. I find I'm becoming very selfish. I'm tired and why should I have to do that. I'm sore and somebody else can do it, you know.

R: You become (illegible) for yourself – it wouldn't be a bad thing...

E: Ya, I don't know...

R: This is a personal question, some other people have raised it that intercourse can be quite a painful thing and it really makes the relationship quite difficult.

E: That's actually one of the first things I found – I'm talking years ago, when I was in my early twenties – when I went for a check-up -- that's when I was saying, there's certain things that you just don't want to do – it's an issue. My husband is very easy going, so I wouldn't say it would cause a rift, but umm, it definitely effect you. You know what I mean, they always say at our age we shouldn't say, I don't want to do it you know, it's gonna be sore. I mean, there's some times when I don't want to do it for a week because I know it's gonna be sore. If I walk around and I'm in pain for the whole week, you don't want to do it and a lot of the medication you take, it affects your libido – I know it sounds silly, but you actually don't want to.

R: I mean, you say your husband has been quite supportive. Is there anything from his point of view that helps – I mean like helping you around the house, or anything he might say to you that makes it easier?

E: Ya, sometimes I think men do sort of loose touch a bit, you've got to remind them, but we've always shared chores, so in that respect, I don't really have a problem. Sometimes I can see, there is a bit of like frustration, you know he tries not to show it, but there is. Definitely like frustration. Like he'll say, if I'm really sore and I'm moaning, he'll say – just take the day off work. And I'll say, no I can't and he'll say that if you're not going to take the day off work, just go and see a doctor. Then I'll say, what is the doctor going to do for me – nothing! I think sometimes they also get frustrated – they can't believe that there's nothing that can be done, you know what I mean and I've been through it – this huge procedure and it's also cost and I know – it's even – I mean people that can't afford it, it must be frustrating, it must be... - cos, if you're sick and I just listen to some people at work – because if you're feeling sick and you want to go to the doctor, I'll just go to the doctor and if you don't have the money to go to the doctor – what do you do – even to get a pain killer. I mean, last year, this op was a huge cost to us. I mean, a lot of the procedures the medical aid won't pay for. It seems silly, but it all adds up.

R: And, you look at the end of the day, it's becoming a frequent thing.

E: Yes, it is, I mean I use my medical aid up every single year, I flatten it – just on this. I can go for three check ups a year and it's R500 to R600 at a time and then it's your medication and umm, you know they won't put my medication or pain medication on chronic, so it's out of your pocket, so it's R200 to R300 a month.

R: A lot of money.

E: You know it's just little things like that that add up and I can just imagine somebody that's battling, it must be so hard. And, especially after all of this and you think, you've made out so much money and the pain comes back six months later and you think what a waste, why do I bother.

R: What have you done this for... and it's interesting what you say about your husband, almost like he wants to help you, he wants to find a solution...

E: And, he says to me, we don't want to have children – why don't you go to them and ask them to give you a hysterectomy. But, in some ways I think I should, maybe go to them and say, listen I want it done, but the doctor always says no, you're too young and also, I've sat and thought about it sometimes – it's such a huge decision – even if you don't want kids, it's almost like umm, it sounds silly, but you're almost giving up your womanhood – so young. You my mom had it – she had a hysterectomy when she was very young – like my age, but she'd had two children. Although I don't want kids, it's, it's – I don't know – but it's a big decision. And, I think the doctors know that sometimes people do change their mind. I'm adamant that I know, but I do know people who've changed their mind when they were 38.

R: So, you want to rather keep the option open.

E: Ya, you never know.

R: I mean, it's interesting that you brought up the fact that it's got to do with your womanhood, how do you think Endometriosis plays a role in affecting your sense of – what you say womanhood?

E: Ya, sometimes you feel a little bit, I don't know... inadequate – I don't know if that sounds right.

R: Ya, if that's how you feel, then that's something it does.



E: I think when it affects you, it's umm, I always think like, gosh, why doesn't it happen to people when you're older, why does it happen to us when you're so young. Like, maybe when you're in your fifties and you've actually enjoyed life, you know. And, I think, if I look like I've had this for so many years and it actually gets worse, it's not getting any better and so you're having more procedures done and it's actually getting worse. I thought after the first one, it would improve and then after the second one, I thought gosh, this has definitely gotta be the end of this and the doctor says no, in two years time you should come back. I think, how can I put myself through this again, it's ridiculous, it's you know....

R: A lot to go through...

E: It is.

R: I mean, in terms of feeling inadequate, what do you feel inadequate is?

E: I think, sometimes, umm, how to explain it, you know when you're young and I just feel that I've got too many problems for my age and for – you know people that have – gosh, I don't know how to explain this – almost like you have lost something. I mean, even if you can't have children because of this condition, it's almost like you have, you've lost something, you've been done out! You've sort of got a raw deal, you know. And even if, like I say, you're not going to have children, it's – it's like your quality of life is less and, I think if I wasn't married and... it could be an issue. Imagine if I wasn't married – how would you meet somebody with a condition like this. How could you explain that to them? Would somebody be prepared to put up with it.

R: I see what you're saying...

E: I was sort of fortunate, because we went through it together.

R: You're saying for someone who's maybe single, or hasn't yet met with someone to live with and spend the night with...

E: And often you think, does it really bother the other person – they say it doesn't, but does it? You never really know. They say no, it doesn't bother me and it's fine but...

R: You still worry about it.

E: You wonder if it does, you know they might think God, this woman, you know.

R: It's difficult, because you're not only thinking about how you're dealing with it, but you're thinking, I wonder what he's really thinking. I mean, do the two of you ever talk about that, does it ever come up.

E: I think just sometimes, sometimes when I'm really at a low, you know, then you tend to... - then you're at that emotional point where you're fed up with everything and you're at the lowest – then it comes out, and then you can sort of explain how you're feeling and... most of the time I just say, I'm so fed up with it.

R: Just had enough, Ya.

E: Ya, but then it's hard to explain to them.

R: So, it's hard for them to understand, although he'll try to understand.

E: He can't really. I mean even at the hospital, I think, I don't think he understood how long it took me to get over it – he tried but I don't think he could. I think the only person who understood was my mother. Even your friends – shame, you're in pain, but once you've had the op and it's a week – how are you feeling – fine you know – but its – its those two months later, after I had my op, people I hadn't seen for a couple of months said, gosh you look shocking – why are you looking like that and I'd say, I had an op recently, but that was a couple of months back, what's wrong with you – you look terrible – you've lost so much

weight and there's big bags under your eyes, and you know (laughs). I mean it was friends of my mother that said, what's wrong with your daughter – she looks shocking, you know. I never knew I looked that bad.

R: Shame, what an ordeal. And I mean, I know some people have spoken of culturally, in terms of your race, how it sometimes affects how people sometimes understand your condition. Do you find being a white, thirty year old woman, obviously working – does that have any (illegible) at all?

E: Umm, I think now, it's harder than ever, I think because of where we are, with women being in the positions they are now, you've always got to prove that you, that you can do it. I even think of me at work, I'm in a position that I've got to supervise some thirty odd staff, most of them are older than me and at least half of them are males and I can't, I can't get to work and have an ache or a pain or and also there's so many other things we've got to deal with now – like you say with culture and race – I think you've got to work so much harder to prove you can do your job and just survive in the working world.

R: It's more competitive.

E: It is, so you can't be like a weakling – so even if I'm feeling terrible, I know I've got to get out there and you know, I've got to deal with / interact with these people all day and there's some days when you go to work, when you just want to close your door and if I'm irritable, those men don't care, the fact that you're in that position and you're a woman and you're younger is hard enough for them to deal with already – they're not interested if you're had a bad night or you're sick.

R: Ya, Ya, it's already an issue enough, that you're in the position you're in.

E: And especially you know, the people we deal with now or we work with are so diverse – it's not like in the old days – you know you had like a certain type of person – mostly men you dealt with, but now it's anybody and everybody – and a lot of the cultures I don't think understand. They're still very ignorant about this sort of thing – in fact I don't think they even understand it from their own culture.

R: What culture are you talking about specifically here?

E: I mean, I've got ladies in my office, like black ladies, in fact one of my own staff, just on Friday she went in to have a procedure done, you know and she was just chatting to me and saying how she's been married for 25 years and her husband just doesn't understand about women issues. I mean, especially in the black culture, the men aren't interested – they don't really have an interest – the women are there, and although we're westernised and they've in a different environment now and they deal with all sorts of people, they don't seem to be any more educated when it comes to women. And, I think that a lot of the black ladies especially, actually appreciate being able to talk to us, because I think we are more sympathetic than the people in their lives.

R: So, it's almost like a cultural thing as well.

E: It is.

R: Maybe amongst white people it seems to be more acceptable.

E: I think with the women, they try to speak about it and they try to explain their problems but the men on their side don't have a clue really. I feel actually quite sorry for them because in their culture their men are totally oblivious to anything else.

R: So, you're saying that among whites the men are more informed or more accepting of...

E: Totally, completely different. Even, if they're not that tolerant of it, they can understand it.

R: Ya, I see what you're saying, Ya.

E: The other cultures actually don't understand it. I find the white men as opposed to the other men are completely more accepting.

R: It's interesting what you say, that culture definitely has a role to play in why it is more that way...

E: I think they interact more maybe with their wives.

R: You mean personally or...

E: Ya, I would think. You know there's some – I've just heard people chatting in general, and I listen to the men, they're not even in tune with what's happening with their own wives. You know, you ask them something just – if their wife is pregnant for example and they honestly don't have a clue. Oh, she went for a check-up for what – is she ill – I don't know. What did the doctor say – oh, he mentioned something, you know. And, I think with us, I think also the women are firmer, they insist that their husbands get involved.

R: So, it's more like a team thing.

E: Ya, when I went in to umm, I even noticed, that when I went into the doctors rooms after my procedure and that – my husband came in too, and the doctor explained to both of us – he said this is how it is and this is what I did and I noticed there were so many other women sitting there by themselves. I don't know if maybe the husbands don't come or that's just not their scene.

R: It's just not their scene. Do you find that that affects how you cope with Endometriosis – having your husband involved?

E: I think they have to be. They can't just – I don't think you can even have a relationship if they don't understand.

R: Ya, it's understanding what you're going through.

E: It is, it's like a life altering thing, it's not like you're having flu – it's not going to go away.

R: It's not going to go away.

E: Ya, it's not as serious as like a heart condition, but if your partner or your husband had a heart condition or triple bypass, or something like that you would be involved. This is the same sort of thing, it's affecting them as much as it's affecting us.

R: So, you're going through it together. In terms of the doctors, how do you understand the medical profession and the role they play in the treatment?

E: I have no faith in the doctors at all. I was passed from pillar to post for so long and all I was told was to take some antibiotics and you'll feel better. It took them about six years to diagnose me, after going backwards and forwards so many times, complaining of pain. I had all the symptoms and nobody picked it up and eventually I actually went to a woman doctor, hoping she would be more sympathetic and I found, of all the doctors that I'd been to, that she was the most unsympathetic doctor – it was literally, I've made my money, I've done the procedure and that's the end. And, she never ever told me that it would come back. She gave me the impression that was the end of it, she never had a follow-up visit, there was no interest and I literally had to, through word of mouth, oh do know somebody who is a good gynaecologist, yes – go to so and so, go to so and so and after being, after going to a couple of others and explaining what I'd had done previously, they never once said, you know what,

your symptoms are getting worse, why don't you have a laparoscopy and why don't we find out how bad it is.

R: Ya, to explore...

E: You know, there was always the excuse, there's not much we can do for you. Why don't you just have a child – it might improve, you know it was that attitude all the time and in fact I still get it now because there's days that I need a prescription for medication and my GP's know my condition and I'm not going to go the Gynae for a prescription and I'll go there and they say why don't you just have a child – you know that's the attitude. And, you know what, it makes you feel so bad, because it was only about two or three months back that I had to go in for a prescription and I was in so much pain, I said to him, I don't know what to do, I haven't been able to get an appointment with my Gynae because he's always booked up, just give me something for pain – give me an antibiotic or give me anything and he said, you know what I can give you a pain pill, but I'm really sorry, I don't know what to do for you, I don't know what to do. And, I walked out there, I was almost in tears. I said to my husband, I actually feel worse walking out than I did walking in.

R: What was it about the actual visit?

E: I don't know if it's – there's almost like a lack of interest, or there's a lack of... - it's like a condition like they can't really treat – you know, my GP is a woman and every time I go there she says, you know the clock is ticking, don't think you can come back in two years time and expect to have a child. I say, I'm not ready to have a child, I don't... Yes, but what does your husband think about it, you know. And, I think, gosh, as a woman she should be more understanding – it's not – they're so closed minded, really they are. And, I mean with all the conditions they treat now, they should be more open minded, they should suggest

alternative treatments. They should say, you know I'm a medical doctor but I've got a friend that, that is good at this, or umm, maybe that do acupuncture – I might not go for it, but as least suggest something.

R: So, it's not as if you're hitting a dead wall kind of thing... (end of first side of tape)

R: And, what do you find in terms of going to the Gynae, just in terms of making your experience of it good, whether it's an examination or explaining results, what is it about the medical profession that can make it easier for you to cope with.

E: I find, with just about all the doctors, you've actually gotta go there and ask 101 questions – you've gotta draw it out of them. They'll never sit you down and say, you know what, this is what you've got and give you a whole long spiel about what you've just been through. You've got to say, what can I do about it and what happens if I don't feel better and what is the best medication to take, and you know what I mean. I've taken medication and they've said well, why are you taking that and I've said that, at the moment it's the only thing that works. But, you shouldn't be having pain now! As I say, if you haven't had the condition, how would you know?

R: So, they don't actually know what you're going through.

E: And, I think sometimes, they're actually too busy. It's a case of, try it and if it doesn't work, come back. and they don't understand that you can't always just come back. You know, if a doctor says that to me, I'm never going to come back. Because what are they going to do for when I do come back – nothing!

R: You want some sort of guarantee that there is a plan and there is a plan B instead, so something that will be done, rather than just shutting you away.



E: Ya, it's true.

R: And, in terms of examinations or preparing you for an operation?

E: Umm, in my experiences, I just wish that they would, I suppose everyone's different, I always wish that they would let you know that it's not going to be that nice and that you are going to feel discomfort and expect to feel a fair amount of pain. You know, try and explain it, to me sometimes to go in blindly is sometimes even worse.

R: So, at least you can prepare yourself for what is coming.

E: Ya, and I always feel, the doctor could be more involved, even like post-operative, you know I find I had the op, I was as sick as anything for two or three days in hospital and I think I saw him once and he literally just popped his head in and said, oh Nurse – just give her an injection and then it was with the doctor – oh he's gone out and you have to go and see him in a weeks time. You know, during that week, I must have phoned the man five times – I couldn't believe how ill I was, I actually thought I was going to die. I couldn't even walk. I said to him, how am I going to come and visit you. I can't even get out of bed. Oh, sort of thing – you'll manage and I think, gosh, if they had told how bad it was and I could have prepared myself.

R: Ya, got ready for what was coming...

E: You know when you walk in blindly and they tell you it's going to be a half an hour procedure and you'll be in and out in two ticks, and it's nothing. In fact, they said to me that I'll be in – in the morning and I can come home, and when I got to the hospital and they said no, you're actually staying in overnight and my husband had to come home and get my clothes. You know that already put the fear of God into me. I said, what'll I do now, now I've gotta stay overnight – and I was told to go to the Day Clinic, so I went to the Day Clinic

and they said, no – we’ve got a bed upstairs for you. Now I’m terrified, so by the time I get to the operating theatre, I’m shaking like a leaf.

R: Because you don’t know what’s going on because you haven’t been told what to expect.

E: Yes, that’s the thing.

R: You’ve told me a lot about in terms of how it’s affected you at work, socially, psychologically, those kind of physical aspects and how it’s affected you – what makes you cope and what makes it harder to cope? What about, just in general, people that you’re faced with generally, every day – if there was something that you could almost request from people – you could say this really helps me to cope, even when you’re preparing for an op, or going through pain or recovering – what is it that people could do in general – whether it’s a friend or your husband?

E: I would say sometimes it’s just to give me sympathy (laughs).

R: Ya.

E: It sounds silly, but it is, it is. You know if somebody just says, shame you know – why don’t you just go and lie down. It means so much, if the person can’t do anything for you, they can just say, why don’t they say, why don’t you go and have a sleep, I’ll bring you a cup of coffee, don’t worry about doing washing or ironing – I’ll do all of that, you know – silly things, they seem to count for nothing, but I promise you it means a lot.

R: And, so I mean what role do you think social support plays?

E: Umm, are you talking in respect of educating people or...

R: Or, helping you cope – does it play a role, for example, friends, family or people checking up on you a couple of weeks after the procedure.

E: Ya, I would say you actually need people, probably more so – you know everybody rallies around you in the beginning. You know, my Mom is very understanding. She's one of those real moms you know, and she's the type, that I don't phone her for two or three days, she'll actually phone me and say, how are you, how's your Endometriosis. You know, she'll actually say that. It won't be just hello, how are you and to hear your voice to say are you fine. She actually says when last did you... and if I say I'm fine, you don't sound fine, when last did you take a pain killer. You know what I mean – my Mom's very good like that.

R: Ya, Ya – generally asking and specifically...

E: And, my Dad as well. My Mom and Dad are darlings – they are – I think because they've had conditions and my Dad's like terminally ill. He knows about pain, so in fact when I had my op, he would actually come and sit with me, you know because my husband had to go back to work, he couldn't really take time off and such silly things. My folks would actually bring me lunch and you know.

R: So, it's the small things that really make you feel important.

E: Yes, it's the small things – I don't think I could have gotten through it, if it wasn't for things like that.

R: So, it's something that you would tell other people.

E: I tell you that you need support straight after, also physically, but I would say just emotionally afterwards because I think it's traumatic, it's – everything, the operation, the – just everything – the shock to your system – your whole being. I know that some people have operations all the time, but I'm one who's never really had a lot of operations, so to me, it's a big deal and for me to go into hospital is a big deal. You know, for my Dad – he might

go in every second month, so for him, he's gotten over that but for me it's an issue, you know and you need to have people that can understand.

R: So, that's actually quite important.

E: You can't have a person that says, oh how are you feeling – lets go out. Oh, come on man, what's wrong with you, you know.

R: The last thing you need is a pub.

E: I actually don't wanna come out. You don't need people around that are umm, going to sympathise so much, that it actually gets you down, but I think you just need somebody that understands, but in the same token says, well when you're feeling better, why don't we go for a cup of coffee or, you know.

R: So, it's almost like someone empathising with you and actually saying we understand what you're going through and supporting you. Is there anything else – I think it's time for you to go out and get to your dinner party – I mean, you told me quite a lot about all the areas that I would have liked to ask about, but is there anything in particular that you want to say that I haven't asked or we haven't spoken about?

E: Umm, ..... gosh, not really – I think, umm, maybe to people that are, that have just been diagnosed, I think they need to educate themselves, and maybe, not only to help them with the support side of it – if they want to join a support group, but sometimes, just to – you know people talk and they say, which doctors are the nicest, who've you been to see, how did they treat you, you know word of mouth, and you know a doctor might be a good doctor, but you can come out of there feeling so bad.

R: He might be good at what he's doing, but in terms of his acting...

E: That's the thing – I mean, I've been to supposedly, the best Gynaes and I've come out of there and have felt helpless and they've done nothing for me and then, you walk in there and everything's cold – there's no – you're just a number, and you know what, when you're feeling really rotten and you've got pain and you're irritable, and you're sort of at the end of your tether, there's nothing worse than walking into a doctors room and they can't wait to get you out and just pay your money when you leave, you know. You've gotta find a doctor that works for you.

R: So, actually you're having a relationship.

E: I think so – look everybody feels differently about doctors, but that counts for so much. It really does.

R: Well thank you very much.

## **Appendix D: Respondent interview**

### **“Renee”**

Romy: Maybe what we can do is to start by you telling me what you understand what Endometriosis is as a physiological condition.

Renee: Initially it's something that you don't understand when you go to the doctor, because some of them, they don't really explain to you what it is. They will just tell you that you have a certain thing. You go and read about it. So when you do happen to read about it, you realize that a lot of the things is true about you. It makes you very depressed. It makes you, what can I say – well at this moment, I'm fed up. I just wanna get away from it. I just want everything to be sorted out and what have you. It's been a strain for everybody I feel – my family and most especially my husband who attends to the financial side of it. I mean there's nothing much you can do about it. You try different things. You go to different people and they give you a different story. You get so fed up. That's the only thing I can say about it. I'm just hoping that this is the last. I don't think I'm going for another op. I've been through this year so far. It does make you feel very, very bad and I was quite like quite upset when I went for my first one, because I'd been to a doctor who didn't really have the skill to do this thing. He ended up operating me and when I came home, within a month it was back. The pain was back, and the irritation was back and what have you. And I just wanted to get it sorted out. So that was it.

Romy: What do you understand as quality of life?

Renee: Well, it does change it, I would say, because I can't do what I used to. I just want to sit and relax. You're just wanted to be on the move all the time, and when it comes to work now, especially at that time of the month, I like to stay at home. I wouldn't be going to work at all, because I can't walk, I can't do anything. It plays a very big difference in your health. It means you have to cut down and you hope that it will change after the last op.

Romy: If you would say that you have quality of life – what would quality of life itself mean to you.

Renee: You mean before I was diagnosed....

Romy: Or even not even thinking of Endometriosis.

Renee: Ok, I would be more carefree. I wouldn't have to think that it's that time of the month for me. I can't go anywhere, I can't do anything, I will be at home. Just go – if you're a female, not worry about it, about that time of the month.

Romy: So quality of life is having the freedom to do what you want to do.

Renee: You don't have to worry about this thing all the time, about going somewhere. You know I have to go to work today – am I going to manage.

Romy: So it's the freedom to do what you want to do and not having your life restricted. And what else does quality of life mean to you?

Renee: As long as everybody is happy. You know what I mean because it's frustrating for everybody. Because it means that my husband, he will have to be there all the time. He's more worried about me now, going for all this – appointments and going for group work and whatever. So if it means time away from the family to go and do all these things now and when you go for the op you go two, three weeks where you can't do anything. You can't do anything! So it makes a very big difference.

Romy: It restricts you quite a bit.

Renee: Ya, it does.

Romy: But in terms of your husband – you talk about what he does for you. Do you find it has any affect on your marital relationship?

Renee: Oh, he's a very caring husband. He does everything for you. He's the one, with this last operation, I didn't want to go for it. In the doctor's rooms I told him I'm not going to the doctor, I'm not going. He's the one who changed my mind. You have to go and otherwise I would never have went. So he's very supportive and I think he's actually made me a bit stronger, very much stronger.

Romy: All right, he strengthened you.

Renee: He did.

Romy: And generally, socially with your family and friends – what kind of impact....

Renee: To be honest with you, when you tell somebody this is what you have, they do not know what it is. They say oh, we've never heard of this thing and what is it. To explain to them it's very, very impossible. They have no idea but on the other hand, even though they don't know much about it, they helped me a lot. They have.

Romy: People obviously knowing what you're going through helps and helps you to cope with it.

Renee: It does, because you don't have to tell them that you know that this is what it means. Ok, I will tell you with the Indian community, you're afraid to tell people this is what is wrong with you. You know what I'm trying to say now and say for example now, OK you have my child now and you didn't have the next one in a couple of years and now what happened! Everyone wants to know what is wrong with you. What can be the problem.



Why aren't you having more children. But now they don't realize that you have this disease and this is what's causing it. Now how do you explain to them this is what it is. It's impossible.

Romy: Even if you say this is because of a disease and what kind of response do you get?

Renee: Most of them don't know what it is. If you do try to explain to them, it's impossible for them to get the problem of it.

Romy: OK, to actually understand how it would affect you.

Renee: Ya, you try to explain to them, but it's very, very hard. Ya!

Romy: So, it makes it a bit difficult. And you're saying sometimes when you know it's that time of the month – you know you get a bit irritable. What affect does that have on your relationships with your friends, your husband, your family or your daughter?

Renee: To be honest to you – I think when I found out, I had had it for quite a while and at the beginning when I was first diagnosed, I used to be a bit irritable, and you know, and I couldn't do much. But as time is going now, I've been covering myself – I've been able to control myself. I have been. Because no matter how much of medication you've gotta have, no matter who is going to try to help you – there's no way that the pain's going to stop – there's no way! You will just have to bite onto your teeth and carry on until it subsides on its own. So, I mean, I've been very, very patient and I've just held it, you know and I haven't complained and done anything out of ordinary.

Romy: So, it's the kind of way you will approach it

Renee: So for the past few months I would say that, compared to what it was, it has increased to the time I was first diagnosed with it until I went for the last operation. I felt that

every month it was actually getting more and more severe. And now, I mean – only now will I know the difference with this last op now – I will know the difference!

Romy: So now you're waiting to see that hopefully the most recent one will have helped in some way.

Renee: Ya, I will.

Romy: So now you've mentioned a lot about the pain and about irritability. Are there any other symptoms that affect you?

Renee: Um, there's a lot to be honest with you. Now for example, the last time when I did get sick, just before I went for the operation, I actually went into kind of hysterical state because of the bleeding and then my husband had to rush me to (name of hospital) where they had to sedate me because of the pain. And obviously it does have a problem with your sexual life as well. And, on top of that, I fault that – you know your entire body goes into a different state for a few days or about a week, completely from your normal self. And everything is completely out of your normal self.

Romy: You said you went hysterical – what do you mean?

Renee: To be honest with you I was actually talking to myself, because there was no control over it. I couldn't do anything, I couldn't sit, I couldn't stand – that's how bad it was. I didn't realize until I had the second op that it had got severe in the uterus. It wasn't just starting off. And, I thought because I just got diagnosed, that it was just starting off and it would be just gone away. Not realizing, that you know what, it was actually quite intense – it was bad and I just had to take pills.

Romy: So it affects quite a lot of areas.

Renee: It does make a big difference.

Romy: How does it affect you at work?

Renee: Well at work now, as I told you, I have to take off every month at that time of the month now to be at home and I was lucky that where I'm working, that people are not so strict with it, you know. So I have to be at home during that time. There's nothing I can do about it.

Romy: How do people respond to you at work?

Renee: You know, I did have a problem, because I didn't have to explain myself, being the only female person working there. So nobody really asked me what is wrong with you. I never really had a problem – OK, they're concerned about my welfare, but nobody actually came out and asked me anything.

Romy: So, you haven't had to explain to them.

Renee: That's about it.

Romy: So, does anyone at work know?

Renee: No, I haven't really told them exactly what it is. You know it's just guys. To explain to them is just so like impossible.

Romy: Ya, so does it affect you, not being able to tell them in any way.

Renee: Not really – you know I just go to work to do my job and then I'm back at home. So at least if I could have another female there and if you've got time on hand, then you tend just to talk about anything. But, it's not like that. I'm fine with that.

Romy: So, in terms of your functioning at work, does Endometriosis affect how you work at all?

Renee: Not really but because of this thing now, I have to swap and change things to be able to go to work on certain days, you know stuff like that now. And with this op and

everything, and because I'm the only one that does a certain thing now, I will have to swap it around stay at home on a certain day and to be able to go work on another day. You know it has to work around the people at work, what I've got at work. With the ops – you know what ever it is. So it does make a difference.

Romy: And, when you're at work and you're having the pain, does it influence your ability to work at all?

Renee: Oh, yes it does, because it's too, too – I mean the pain is too much, because you won't be able to do anything at that moment in time. I mean, even to wake up and to walk to the toilet is too much. That's how it is.

Romy: So, work is also affected – it's your ability to work...

Renee: I mean even to wake up in the morning and to go to work – it's a problem. But hopefully I won't be feeling this pain.

Romy: So, that's the affect on your work. You were saying that you almost became hysterical at the one point and sometimes get irritable. Are there any other like psychological influences that it has had on you?

Renee: Not really hey, because I feel it's been for so long now, it really doesn't worry me anymore. The only thing at this moment, I really feel that the amount of time and money that we've put into this thing - because if you really think of it, if you go back and you look at all the bills it's caused - you know the hospital bills are rolling in at this moment now – it's absolutely stressful, it's too much to be honest with you. Mentally they don't even understand. They don't even want to bother about it. You will have to somehow – you think this is the last time and you will try and scrape up that little from somewhere just to get it sorted out and that's it.

Romy: So obviously you are quite disappointed when you save up for it and it comes back.

Renee: Yes, what do you do? That's the thing now that I'm so irritated about because the first time that I went it was my fault that I had not known much about and I just went to a normal Gynae – it was he that discovered – let me take you to theatre and find out what is wrong with you. He did take me and this is what will happen and before I could go back for my second appointment with him, I said let me get a second opinion. And, I just think to myself, initially, and I was very disappointed initially, when he did find out, why didn't he refer me to a specialist at this stage. You know it's so frustrating to think I had to go three times when I could have done it two times. It's very irritating and disappointing.

Romy: So to actually find a specialist that deals with Endometriosis a lot, to know what it's about, you're saying it's actually difficult to diagnose it...

Renee: Yes, according even to (name of doctor), he tells us that there's no way of diagnosing it until you go and have the lap done and he says that there's no way that any doctor can tell you that you have it just like that. You can give all your symptoms, but you cannot confirm until you go in and check.

Romy: You've actually got to see it...

Renee: Yes, to be sure of it and what happened to me was – I had to go to the doctor and I'd been complaining to the doctor for close to four years, of all my symptoms and he said don't worry, maybe it's just your normal monthly period – you know things like that and then one day I listened to the radio and (name of doctor) was on (name of radio station) and he was doing a section on this here, on Endometriosis and it was that time that I think the lady from Jo'burg came and did a seminar on Endometriosis at (name of hospital) and he said that if you have similar symptoms – you know you can come in and have a check up for this. So, I did

make an appointment and he said, let's see what happens – let's go in and check.. That's what happened – he did diagnose it. But he always tells us – you know he talks – he's so disappointed that other doctors don't refer you to a specialist. He knows about it, because apparently if you really don't know and you go and do the wrong thing, it's worse.

Romy: So you've really got to know what you're dealing with!

Renee: Yes. So your best bet is that you must talk with this doctor. Have you ever made an appointment?

Romy: With (name of doctor) – yes, I have spoken with him. He's very knowledgeable. Ya.

Renee: I've actually got that thing that he wrote in some book and what the (name of medical aid) magazine or whatever, on Endometriosis, written by him.

Romy: So, he's actually quite a specialist – super. So, you're talking about going from one gynae to the other – I mean what effect does the medical profession play in helping you to cope with Endometriosis?

Renee: I was (illegible) with them, I was actually just going to give up and not bother about it, because when I went to the first one and I didn't get any results, I said to myself, you know I'm wasting my time going the medical route. I was just gonna leave it at this time. I mean, so many people, more especially my mother – she was the one who forced me to go and get a second opinion – just check it out, and because of her, I said just let me go and do it. But, I'd had up to I don't know where – because you know jumping from here to there. And, to have it for so many years, and they did not try to do something to find out what's wrong with you – just giving you pain killers and what have you. How long can you carry on like that?

Romy: Ya, before you find out what's really wrong.

Renee: Exactly and then it's worse if you have go and listen to a programme and diagnose yourself and go to him and tell him, this is what I think I have. Now, how come he can't pick this up, being a gynaecologist – how can this possibly have continued for four and a half years without picking up what is wrong with you. It's very, very frustrating - because, being a doctor obviously, you must know something about what is wrong. Ya, and if somebody has to come and tell him, you know can you test me for this, can you do it for me and I actually had to go and tell the doctor. I watched the programme and this is what I have. Then he said, OK lets go to theatre and check it up. To make it worse now, why I was irritated with him was when with the first doctor was that he had started this treatment on me in theatre, without even telling me. It's called local injections which they give you, so they tell me, to try and suppress it – not to try and remove it, but just to suppress it. How long will you be able to suppress it for? He wanted me to go onto the treatment for six months and these injections are about R2 500 each a month. So, without asking a patient now, can you afford it – how can you just start a treatment like that!

Romy: And, if you can't actually afford it...

Renee: Ya, so you do get a bit fed up.

Romy: So, you're saying that basically having a voice in the whole process and being involved in the decision that's going to be made, being told what's going to happen – it has an affect on you.

Renee: Exactly, because if you know what you're coming against now, then you know what – this is what is going to happen to me and obviously I will have to look to further medication and further operations – this is the cost it's going to be – and you know for yourself this is what I can afford, this is what I can do and this is what my body can take. You can't be

taking it all the time and you say to yourself that I'll be OK but two months down the line you have work on another thing, on another thing and then so on...

Romy: So, if you could ask the medical profession from their point of view for something they could do which could help you – what would it be?

Renee: They shouldn't really try anything, if the doctor is not knowing that field. Do not try it. Don't make the patient your experiment. If you don't know it, then refer them to a specialist who's dealing with this thing – then you know at least, I'm going to get a lot of support from this person, because they know about the disease. You know what I'm saying. And, that's the only thing.

Romy: In terms of dealing with you and your consultations, booking you for operations, speaking to you after the operation – is there anything you want to comment on that?

Renee: The doctor has explained every single thing to us, everything, to be honest with you, before you go into theatre, he tells you that this is what could happen or I would need to use a certain thing – do you agree or disagree to it? (Name of doctor) has done that to me and that is what I was happy about – you know he just didn't take things onto his own hand and just use stuff. I was happy about it and in the long run, I knew I was going on – and he gives you alternatives – do you want to do this or that – whatever the case may be. – so you are happy with it.

Romy: So he keeps you aware....

Renee: And, the first thing he tells you, the day you are diagnosed with it – please do me a favour and join the Endometriosis society. That's the first thing he told me that day and also said, please try and get some kind of literature. Read it, get to know it, and then you'll be happy. He always emphasised read and learn about it.



Romy: Tell me, apart from your treatments, how have you coped with it?

Renee: Oh, I would say that towards the ending now, I have been a bit frustrated and I just wanted to go and get help, but because of everybody else, I just held it and just came to doing whatever the doctors have said but I just hope that at the end of this now, I just want to get back to normal. You know, I'm not worried about having more children, (illegible), that's not worrying me anymore but it was when I went for the second op, but you know he told me about these things. After that I said to myself, as long as I'm cured, or should I say, have some control over it, I'm happy. You know what I'm saying, as long as I have some control, I'm not getting and it's not getting worse.

Romy: Just to keep it under control.

Renee: Yes, that right.

Romy: And, in your daily life, what kind of things help you cope with the pain or irritability or cramps? What do you do to help yourself?

Renee: I try not to think of it as most as possible – I try as most as possible. And I try, just to walk around, even when I came out of hospital, even though I had pain and what have you – I just didn't sit back. And, you know I feel sick that day, and I would like to lie down and you know I walked around and did everything as normal. I feel that's what made me not sick – to be able to move around and just to be with everybody down here, not being upstairs on your own, thinking of it all the time, that sort of stuff.

Romy: So, distracting yourself.

Renee: Ya, yes.

Romy: So, you found that that helped you.

Renee: I felt like that, like two times now. When I went for the first one, the second one in August, I um, said to myself – you know when I went into theatre, I said to my husband, you know this is the last one – because my body couldn't take any more and because my mind couldn't take it any more. I said this is it now. He said we'll see what happens. I guess, the whole thing is, as long as you have your family and they understand what it is, and they're trying to help you. That's most important I think. No medication, no operation is going to help you as much as that – of them understanding and being with you and him coming with me all the time to the support group. So, you understand more about it you know.

Romy: So, you're talking about your husband and family – what kind of things can family members do, can your husband do to help you feel better or help you to cope?

Renee: The only thing I was happy about was that he had come with me, you know he could see that there were so many other ladies out there and their story or whatever their case might be. I could tell him that you know my body is paining and this is wrong with me and I'm feeling so terrible and he's going to say you know what, take it easy, have a rest or whatever. You can tell him how much you want, but for him to come to that meeting now and for the doctor to be there or the (illegible) to be there, you know what, for them to talk to you and to say this is what is happening to the person in your life – this is how it's affecting them (illegible), just take it easy, don't stress, don't think about it. That's there approach because they know what's going on inside you. So, I'm glad he came with me. He really understood about it and he questioned the doctor – you know he wanted to know himself. So, he played a very, very big part in this group – so I'm glad about that.

Romy: And the rest of your family – what things are helpful?

Renee: Oh, I will say that they're very concerned, but uh, I mean there's nothing that they can do as such, there's nothing. And, I will say, as I told you, my mother insisted that I get a second opinion – so I will say, if it wasn't for her, I would still be stuck with the first doctor that I went to. So, it was because of her now, and her, you know pushing me or whatever you call it, that I said, let me go and get the second opinion.

Romy: So that helped. You're talking about a few things that affected you generally – what about in terms of your identity as a woman – in terms of your womanhood?

Renee: OK, uh, let me tell you alright. To be honest with you, my daughter - I had a very big ..... (illegible) and against my parents wishes and what have you. And, now I'm ever so happy that I did. Imagine now if I had waited - I said to myself, let me wait another 10 years to settle myself and what have you and look at today what has happened. What would have been my situation – I would have been very, very disappointed that I couldn't have children. I think that every female wants to have a baby one day – maybe one or two as the case may be, I would have been very disappointed had I just left it. So in present conditions I would say...

Romy: So actually having a child and being able to – that has an affect in your role as a woman!

Renee: Yes.

Romy: And now you're saying with your difficulty conceiving – does that impact on that all?

Renee: Well, I've been trying for the past about four, say four and a half years and nothing has come of it and umm, I mean I said to myself, I'll go for this one or two times you know – for these ops and whatever. From there the doctor ~~has~~ told me – he says you know what,

there is a very big chance that I might be able to have a baby but only time will tell. If it doesn't happen, I'm not uhh..., well I would be a bit depressed, but I'm quite happy about it – if it's just one, then it's fine. There's other alternatives if you think about it, so I mean I was a bit upset but there's nothing I can do about it now – it's gone a bit too far now.

Romy: So, it's something that you've tried to deal with.

Renee: Ya.

Romy: What other aspects in terms of identity or how you see yourself as a person – has it had any affect?

Renee: Well not really – it's internally, so you can't really explain to every single person, you what this is what's wrong with me. I would say, except for changing a few things with me, itself, it doesn't there are big changes at all in my life – to do with this but I had to learn about it to understand it. That's all of it. I hope it's helping you.

Romy: Ya, definitely. It is, definitely it is.

Renee: You can explain until you're blue in the face but it's just that people don't understand, because you see when I tell people that this is what is wrong, they tell me you know, how come 20 or 30 years ago, people didn't complain about this. It didn't affect anybody – it's something so new. It's just that people might have had it, but they never had a check up to see what's wrong with them and what their condition was. So, it's not something new, it's just that people weren't made aware of it. You see now, if things are written and you know people go out and look for information, then they will be (illegible). I've been to the library and it's a bit difficult to get information. I mean with the doctors help or whatever, we have learned a bit about it.

Romy: And is there anything that you could ask anybody, in terms of something to help you to cope – what would it be?

Renee: What would it be? Well, to be honest with you, I would say that we belong to this Endometriosis society – I would feel very happy, I would say, if more doctors put some time into it. You know, and most of them refer – they don't come to the hospital – they should encourage the people to come and have spend one hour or whatever is there problem – you learn so much from it. I guess a lot of doctors – they do not belong to a certain hospital – they (don't like ..... ??? illegible - ? right words) to see about the patients going and getting further information. So if you have it and I talk to you, you're going to tell me so many different things about it, so I will understand more. Whenever I'm speaking in my language, you will understand it because the doctor's terms are so high – whatever it is – whatever the case may be. I would feel that it's so good just to go and spend an hour or whatever the case may be – it makes such a big difference.

Romy: So, it's definitely something you should keep up.

Renee: Ya, and it should go, that's what I think, it really should go. I mean its up to the doctors, because they are diagnosing the patients – its for them to tell, you know, this is where it is – please come, sit down, listen to them. It's for the group also, to get good speakers – you know for us to enjoy the topic, to want to come again.

Romy: To keep you interested – Ya, you're right. Is there anything else you want to tell me which I haven't asked or anything?

Renee: That's about it – you should know what else you would like to know by now. Some things are off limits – don't ask me anything about it.

Romy: I was just wondering, in terms of your relationship with your daughter – does it have any affect in terms of your role as a mother?

Renee: Not really – I've tried to do everything with her or whatever the case may be. She understands that I'm not well and this is what is wrong with me and I go for these ops and whatever. But otherwise no. I mean you have to explain to them, you can't entertain (???) her because I'm sick. You see 12 year olds are very intelligent. You can't just beat around the bush and tell them nothing. It's good for them to know because I have read somewhere that apparently it can be hereditary. So, I mean it's nice to be aware of it all the time, because as time goes, and she grows up, I wouldn't want her to go through the same pain as me – because you don't know how long I have had it, but I didn't really bother about it. For me now, I would be very conscious about it – but it's her time to come and the slightest thing that I know – if there's any symptoms I have, obviously I'm going to try and sort it out as soon as possible.

Romy: Definitely, check that out.

Renee: I guess at that time, my parents didn't understand all that as well. So you know, they were not aware of it. I guess, before I did get married, I did have this thing, it did start – I never thought of it as ... - maybe it was just the beginning of it. But I never thought of it. But now it's the basic for me (words missed – illegible).

Romy: You were telling me that your husband has managed to help and support you – in terms of him – the affect it has on you or how he understands Endometriosis.

Renee: He's got a very good understanding of it. The other thing is – he's also a.. – he's a paramedic and works for the provincial hospital and so he goes and talks to the doctors there in the maternity section, or whatever. That's how we got more information – he's been

talking to the doctors and a few friends of mine who are nurses – I've been asking them about it. So he actually went out of his way and got more information about it. So, he's helped a lot.

Romy: In terms of the affect it might have had on him, in terms of seeing you go through the pain, having procedures.

Renee: Oh, I'd say it was a very big strain on him – it was because everything in that two or three weeks – everything had to revolve around me. You know – going for visits to the doctor, going for blood tests, check ups – whatever it could be. Everything else had to be on hold. This was most important. You know when it comes to work – you know what it is to work for the government – so he actually go to them and ask for days off – family responsibility leave and you know all these things. I'm glad it got to the attention of his officer in charge and she had some understanding. She had some understanding. She wasn't very hard on him, so I would say, you know, it did take a toll on him. And, now he says to me all the time – as long as it's sorted out, that he doesn't care the amount of money it will take, or whatever, as long as it is OK. That's his last word on it.

Romy: You've told me a lot about all the different areas of your life and looking at quality of life and all the different things it might mean – psychologically, physically, socially – all those sort of things that have an affect on you and how you've coped with it – what has worked and what hasn't. So definitely you've been very helpful.

Renee: Well, I'm glad that there's something that's written about it. Hopefully when you do finish it, you will let us read what you have done.

Romy: I would like definitely to do something – maybe a feed back session or something.

Renee: Something – I'm sure you would have more understanding of it, now that you've done it. It would help a lot and as I've said, I hope that this is the end of it. If it's not, then I would say that this was my last. I don't think I would go for any more treatment or operations. This would be it. I guess, you know, everybody will tell me – you know what – you get some people who say it's in your head – just don't think about it – forget about it. But you have to go through it to understand it. That's why I was so disappointed when the doctors said there's nothing wrong, nothing wrong – to hear that every time you go, every time you have a pain and you go to him and say this is it...

Romy: And you know that something's not right.

Renee: Exactly, that something's not right and for him to keep on telling you that nothing's wrong – there must be something wrong you in your head for them not to find out what is wrong with you.

Romy: You start double guessing yourself.

Renee: Exactly, you do. I mean how many times are you going to tell your husband, you know I'm not well tonight – there's something wrong with me today. How much are they going to be able to take – I've got a very niggly wife. She's always sick. I forgot to say that when you go for these meetings, that a lot of them go with their husbands. Maybe they're understanding and that's the best.

Romy: I was very impressed by that.

Renee: You get a lot of them, where they actually tell you to go by yourself, you can come and tell me what is wrong. And with the doctor for that matter, you go yourself and you come and tell him what's wrong. Now how do you come and tell him this is what is wrong with me. Ya, it's good for them to be there, to see the whole thing and the only good thing



was when I went to the doctor and he had to take me to theatre, he had taken photographs of each and every specimen that he had done and this last time I went for it – I went especially to have that spray gel used – I know (name of doctor) spoke to you about it. It's mostly used when you have severe Endometriosis and after everything is cleared off, he uses the spray gel to actually separate everything, because apparently when you do have it, all your organs seem to get stuck, so what had happened to me was it was very, very bad. So when he had separated everything, he had to use the spray gel. He had shown photographs of him spraying it onto different parts of me. He says actually it's a very good thing and hopefully it did work. That was my last option – to use that thing.

Romy: Hold thumbs.

Renee: Ya, that's the most important thing. But it really takes a toll, it does.

Romy: It's not an easy thing to live with.

Renee: Ok fine – if you have cancer or whatever you might have – you go and have your treatment – you go all the time just to have a check up, it's OK, it might come back or it might not come back. Now this time he says I gonna do the operation, I'm gonna remove it and this will guarantee that it's gonna stay away. Now in two years time you'll have to come back and have it done again. Now it's something that's chronic all the time now. It's not as if it's something that's uncomfortable – sweep it all off and that's it. You know it's something that will be fine for now. How many more years and more am I going to go through this thing now. Every two years to go to the theatre, have the thing removed and start all over again. So, it's not something once off and that's it.

Romy: It's very chronic.

Renee: So, my other alternative is - if I'm still suffering with it in a month or two and if I definitely know that I'm definitely not going to have any more children, my other alternative is I will have to have everything removed – that is my last alternative. But, I've actually psyched myself up for it

Romy: Prepared yourself!

Renee: So, I would say that if it comes to that and I have to go back and he tells me, I would be prepared – I've actually said to myself that's the worse thing that can happen. But – what is worse than that now. It's the worse thing.

Romy: So, you've prepared yourself for that...

Renee: Ya, I have. My other alternative is – I've actually looked around, I've said to myself, I don't have another child, I'd probably have to adopt one – another child– that's fine, I don't mind. As long as I can feed my family – that's my most important thing. But I think my mistake was, that before it got very severe, I should have actually had another one. But, I guess that with our lifestyle, we want to do everything first and do that last time. Unfortunately I got caught up at the wrong time. But, there's nothing I can do. That's about it. They say it's working women disease.

Romy: That's the one argument.

Renee: Serious, but I don't think so – I've seen people who are very young with it, who've just left school or something.

Romy: That's the thing. They have theories, which explain all the cases.

Renee: So, I guess it's just you're unlucky – you are the person that's unlucky to end up with it. Maybe one in every twenty ladies – whatever the case may be. You are the unfortunate

one. So, it's something that your body – I mean that you can't do something about. It's there – you will have to treat yourself and that's it. That's it.

Romy: Well, thank you Renee.

Renee: Well, as long as you have the information or whatever you want.

Romy: Thank you.

Renee: It's just that this is it.

Romy: I hope so too, for your sake.

## **Appendix E: Respondent interview**

### **“Patricia”**

R: Maybe we can start by you telling me how you understand what quality of life is?

P: Quality of life – hmmm... - I understand what it means, but it's so hard to put into words (laughs) – well, I suppose your everyday functioning - the quality of functioning... Ya.

R: So, functioning as...

P: As a person – be it at home or at work, different aspects of your life.

R: Okay, so it's different parts of who you are...

P: Yes, Ya.

R: Whether it's working, at home, being a wife, a mom...

P: Yes.

R: Okay, so it's different of who you are. Okay and, obviously physically as well.

P: Physically, emotionally, socially, Ya.

R: So, it's all those different aspects. But then, how do you understand how Endometriosis has impacted on those areas of your life?

P: Mmmm, it does affect you, ummm, because of the various emotions that it evokes in you and also physically, ummm – you know – experiencing pain and things like that. So, with the pain, it's a physical aspect and then also socially you feel miserable and you don't want to have people around you and things like that. And, especially if you haven't accepted it, and you're battling to come to terms with it, it's really affects you emotionally, Ya.

R: I mean how so, how do you feel?

P: Okay, I think for me, ummm – I think it was the anger at first, because we only found out, after we had been trying for two years to have a second child and our Gynae at that time kept on saying, it's normal to battle to have a second child – lots of couples have difficulty and I just felt that a lot of time was wasted in those two years, ummm and when eventually it was diagnosed, I was very angry with this Gynae, you know, that he had wasted so much time and I felt if it had addressed at that point, you know, it wouldn't have been (illegible) here – so those were my initial feelings of anger, and then when I had my various treatments – laparoscopic surgery and all of that, medication... - you battle with feelings of hope, you know – am I going to be pregnant this month and the depression when you finally have your period. You know, so you become quite miserable.

R: So, it's a mixture of feelings – the anger, sadness and ...

P: The disappointment and then you feel so helpless at the end of the day, that you just say oh well, just bugger this now, I've lost hope. Because, if especially if you've been for all the surgery and you've been on this medication, ummm, and then you just find it's not working, you know, and you have to keep on going back for the surgery every time.

R: It's having to go back and back – so it's the medical procedures as well which can be quite daunting maybe?

P: Quite daunting – especially if you're going to go through it for the first time, and if you don't have a Gynae who explains the whole procedure to you properly – you know you're at a loss, you don't even understand the terminology and things like that properly, and then the people that you don't work with, don't know about this, about Endometriosis and you have to keep on explaining to everybody what it means, and what it entails and things like that. So, it's explaining to everybody and so the whole

world here knows that I've got Endometriosis – because I'm very open about it. Ummm, and I share my experiences here with the ladies at the office – because I get a lot of support from them. You know, so for me I find that a lot of people don't want to talk about it, they keep it a secret thing, but I feel that the more you talk about it, the more support you're going to get from people.

R: So, you find in your work situation here, that people are quite understanding about it.

P: Very understanding, very supportive – when I've had to go for my surgery, I've had no problem taking off from the office, people phone me in hospital to find out how I'm doing and things like that, so Ya, I've had a lot of support – but I think it's because I'm so open about it. Even when I went in, in July, (name of doctor) – now I always have to memorise the terminology for all this scopy, dopy – all this (laughs), because the hysteroscopy that he did – and I came back and told the ladies, you know that I'm going in for this procedure and for the life of me, I can't pronounce this word, and I had to write it down and so everybody knows exactly what I went in for and I explained the whole thing to them in detail, so you know it's kind of a big joke, but I found I get my support from the ladies here at the office.

R: So, from actually telling people about it, that's how....

P: Definitely, if you're open about it and you also hear, people can refer you to another Gynae, or something that they've heard about - something that you can try, you know.

R: So, you're saying that the ladies here are quite supportive – are there men here?

P: Well, it's all social workers on this floor – we only have two male social workers – so, no, I don't tell them anything...

R: Just the ladies...

P: Just the ladies, I think that would be too much – if I had to share things like that with them. Now, I would come back from my surgery and show the ladies my, stitching and things like that, but I wouldn't share it with the men – with old guys too, they're not even young guys. They would come in bad – it's just their personalities.

R: At work the people have obviously been quite nice to you, but you say that some people don't tell people – why do you think that is – why some people wouldn't say?

P: I feel that some people, I don't know if they think it's a private thing – or something private, Ya, it's a big secret – that kind of thing. I think it also stems – I think it's a cultural thing – ummm – the specific person I'm referring to is an Indian lady, and in the Indian culture, ummm, the fact that you're having difficulty in conceiving, or having Endometriosis – it's like a big thing, you know, and for her it's a private thing and she doesn't share it with anybody and it was only after I had shared the fact that I've got Endometriosis, that she opened up to me, but nobody else knows that she's got Endometriosis.

R: OK, so you would say that it's a cultural thing.

P: It's a cultural thing – I would say that it's a cultural thing, Ya.

R: And, with you – do you find there's been any cultural... – I mean, has it impacted on you in terms of your culture?

P: No, it hasn't – in fact, I haven't met any coloured ladies so far, that's got Endometriosis (laughs).

R: Okay, so you haven't met any other...

P: No, I have not – not in Durban, I think because there are so few coloured people here, but I'm from the Cape and I've heard it's quite common – in fact I share it with my sister now, and I phone her and her boss's sister also suffers from Endometriosis – so, I think it's because there's hardly any coloured people in Durban. You know, if I

had to go share it with people in Wentworth or Sydenham, they'd probably tell me, Ya, I've heard about somebody or something like that, but I think culturally, I think we're very much open about things like that, Ya.

R: Do you feel that in your culture, you're more open, I mean you were saying compared to your friend who's an Indian.

P: Definitely, definitely, definitely – you know I'm open about the fact that we're having difficulty in having a second child – I mean, when I – my son was three years old when I went off the pill – now I'm trying for the second one – now the whole world knew that Patricia is off the pill and she's going to start trying for a second one, everyone knew that – ummm – yet with my sister in law that's Indian (I'm married to an Indian guy), ummm, that's why I can speak with experience, she didn't tell anybody now that she's trying to have a second one, you know, and it's only after I shared with her the fact that I'm having difficulty in conceiving, that she also shared the fact that she's also having difficulty in conceiving and then I referred her to my previous Gynae and that's when she eventually went on the medication and when she eventually fell pregnant. But, it definitely is a cultural thing, and there's a lot of pressure from the Indian community, on women, ummm – if you can't conceive, it's a very big thing – there's a lot of pressure on women to have babies. When's the next one coming, you mustn't have such a big gap – yet when I shared with my Mom, she's telling me, you know it's just one of those things – if you can't have another one, it's just one of those things.

R: So, it's more acceptable?

P: It's very much more acceptable, Ya, Ya – yet with the Indian community they won't... - I get very irritated – people ask me – so when the second – the next one coming? So, you have to explain to everybody, sorry I'm having difficulty, I've got



Endometriosis – especially with the older folk, you know I can't be blasé about the whole thing as with my colleagues, you know – it would be nice to say we have just decided to have one child – it's so expensive having two children, you know – stories like that. But, there's a lot of pressure and I've experienced the pressure - so, when are you having the second one, you mustn't have such a big gap between your two children and things like that.

R: So, it's that pressure...

P: Ya, even from my in-laws – they know about my Endometriosis, but there's still that pressure, you know – when are you going back to the Gynae, what's happening? You know – things like that and yet you know with the ladies at the office, they would say, maybe it's a good thing that you've been unable to have a second one – look at the cost of living, it's so high – at least with that one, it's the only one and you'll be able to give that one a good education, everything in life, and all of that. Ya...

R: So, you find that they almost think it's a positive aspect of ...

P: Ya, definitely, definitely.

R: So you're saying that with the in-laws giving you a lot of pressure – how do you cope with the pressure?

P: I get very irritated – I get so frustrated, ummm, I actually get angry sometimes, you know, ummm, and I just feel, really now – they know about the Endometriosis, and that I've been for the surgeries, and all of that, ummm, but I maintain my cool, I'm a very tolerant person, so I will just say, ummm, ooh no, when God is ready, or you it's not up to me to decide – you know – God is the one that decides – my son now, he would say – Mummy – how come I'm an only child, how come I don't have a brother or sister like everybody else – at school, at Sunday School or at Church and I would say (name of child) we don't decide – you know how many children we should have – I think God

decides. He says but why is God taking so long to decide. You know, with my son I felt very helpless when it came to those kind of questions – why don't I have a brother or sister, Mummy and would be all excited when he meets somebody who's got lots of siblings – that child's so lucky Mummy – he's got a brother or sister and a cousin and all of that. And, I think from age five or seven or six and a half, (name of child) was very much wanting to have a brother or sister, but I think it's now also – he's OK with it now, he's OK with it and people make you feel guilty, and people make you feel guilty – they say shame, the child must be so lonely, you must make a plan to get a brother or sister for him but, I think (name of child) is quite – he's a typical only child, you know play's for hours by himself, he can amuse himself, keep himself busy and things like that – so, he's Okay, he's fine.

R: So, although there was pressure from other people, also from him for a while...

P: My husband's been very supportive as well about the Endometriosis, ummm, and I think with both of us, (name of child) was three when we started trying, and (name of child) is now seven and a half and I think, only up to last year, towards September when I went to see (name of doctor) was when we accepted – look it might not happen and we both now accepted it and look I'm OK with it that we might not have a second child. We even told (name of doctor) because he was telling us, look you might have to consider going for GIFT or IVF and my husband said, you know what doctor, we've decided that we're not going to go for all that – because there's no guarantee – we're going to spend all that money and there's no guarantee that I will conceive, so we've accepted that we might only just have the one child, but that's fine. But, it took a long time to get to that point – I must say that it's been a process – it's been a process because I'm the one that went for the laparoscopic surgeries and for the hormone tablets. You know the first Gynae said, you know we don't have to see your husband

for any tests, because he's got a child, he's made a child, so there's nothing wrong with him. And, I just felt this so unfair you know and we went to (name of doctor) and he told my husband that he needs to go for sperm wash and things like that – and my husband just refused. He said, no, no, no – he's not gonna go. I just think that he felt that it was an insult kind of thing to him, you know. He's a male and this kind of male thing. So, when he said he's not gonna go for that, I said I'm not going for anything anymore. Really, I've been for everything possible and then the problem could be with you, and not me (laughs).

R: So, the blame is full on him.

P: Yes, definitely, but I tell you, it's been a process. I think the first three years that we were trying to conceive a second one – I think the first three years were the worst because, you're so helpful now, your period is late, you know – ooh, my period is late – I started to count – I'd mark my period was on this day and then I'd count and it's now the 28<sup>th</sup> day – ooh gosh maybe, it's late now and then by the 30<sup>th</sup> day, you know, it comes. Then when I used to get my period, I used to get so depressed, I'd go straight to the shop, to the mall and I would go and buy clothes. I promise you, I'd feel depressed and I'd go and try on all the clothes in all the shops (laughs).

R: So, it was something, which helped you.

P: Yes, yes and then you're dealing with the pain and all like that. That was the worst – I suffered with terrible pain.

R: So, it was the pain and difficult

P: Yes, the two difficulty things...

R: ...the physical aspects. And, how else do you understand Endometriosis as a physiological...

P: Physiological...

R: I mean, how do you understand what it is:

P: You mean what it is all about – I know about the medical terms and the condition and the fact that there is really no explanation really as to how it occurs – there's so many reasons given. So, ummm, Ya, but I know the medical terms – you know (name of doctor) has explained it to me and I've read us so much of Endometriosis and things like that. I understand the condition very well.

R: So about the lining...

P: Yes, the lining of the womb and that you know when you have your period, the lining sheds and things like that. Well, I know all this terminology (laughs).

R: So, tell me, how do you – obviously there's pain and difficulty in conceiving, have there been any other physical....

P: No, I suffer with migraines – when I get my period, it's severe migraine – and I know I get it a week before my period starts – so I know it's that horrible migraine here – that tension and I'm very stressed – anything can set me off, I'm in a bad mood – ooh, I'm the worst person then, I feel very sorry for my husband (laughs) – that is just a few days before my period, but once I get it, I'm fine, my mood is Okay, but then I suffer with severe pain on these two days – there's heavy bleeding and clotting, severe backache. At the office I'm very moody and the ladies know it, especially before I get my period and I undergo a personality change. I become – I'm very tolerant – but that is the time – I... - the other day I said I went mad, I went off my head (laughs). Normally I would have kept quiet for something that irritated me and I don't have any tolerance then for nonsense, and I just express my opinion. I even took the files and I through them on the floor and I kicked the files and I was shouting at somebody and it's not me – it's just not me.

R: Like a total personality change...

P: Ya, and there were people in the office when I took the files – and I was tearing papers...

R: So, you really, really were ...

P: Ya, a tantrum – a tantrum. The people in my office were shocked, they really just couldn't believe it and they all just left my office and when I sat down, I started laughing and I said, God in Heaven what happened to me (laughs) and I phoned my colleague and said, you know what, I went off my head – but the very next day my period started so it's like a real – I become a very ugly person then.

R: Intolerant...

P: Ya, very moody and I mustn't go near my mother-in-law when I get my period because she just irritates me. Especially when they come with things like, (name of son) needs a sibling, I tell you I can bit off her head then, but other than that, for the other three weeks of the month, I'm very good – tolerant and patient and you couldn't find a better person.

R: Mostly at work or do you find that at home as well?

P: At home as well – at home as well – I've got no patience – anything irritates me. You know normally I would tolerate my son's toys all over the house, but I would get irritated and I would shout. You know, anything – the dishes that are dirty, it's – they're waiting for me – anything just irritates me and all I want to do is to just be left alone. You know, I just want to sleep and I just don't want to hear anything.

R: And tell me – you've told me about your home and work – how's it affected your marital relationship?

P: My marriage – ummm, I've got a very good marriage, very strong and I've got a very good husband, very supportive, the only things - were the blame – I was very patient, I said I'll go for all the treatment and all that – my husband used to come with

me to the Gynae and things like that, be very supportive, but up to last year when I said that I'm not going to go for anything further unless you go for your sperm wash – so he didn't go, but I haven't been back for surgery after this thing with the hysteroscopy I had the end of July. But, marriage wise – I would say quite a bit of stress, tension within the marriage, ummm, especially now when it gets to the period – my husband says, did you get your period, did you get your period, because he knows it's due, then if I say yes, he says no, aah – you know like that. For maybe a year or two, but now he's okay, it gets to be okay, but it took a long time to get to that level – it took a long time, Ya.

R: So any other affects in terms of your relationship with him?

P: No, No.

R: And sexually, because I know when someone has difficulties in that area...

P: Yes, no – I never experienced pain with sex, nothing like that – the only thing was that I was not sticking to my timetable. Especially now when I'm ovulating, I'm telling him you have to be ready (laughs) – so it's putting a lot of pressure on him, and towards the end I expected him to know now I'm ovulating and then when it's 14<sup>th</sup> day now – I always find on the 14<sup>th</sup> day, it's the most fertile day of my cycle – he's either working late or he's so exhausted, that I just feel why must I make the effort now to tell you it's the 14<sup>th</sup> day. So, the next now day, I'll tell him, it was very nice of you, it was the 14<sup>th</sup> day and you slept. So, he says why didn't you tell me. So, I said why must I always initiate really, Ya.

R: So, you get tired of being the one...

P: You get tired, yes, yes – but I know for at least two years, I would tell him I'm ovulating, get ready now, it's not just for – it's procreation, you know like that – there

was a lot of pressure (laughs) – and the girls would actually laugh at it all and I come and share everything with them, everything.

R: You'd tell them all.

P: I'd tell them everything, shame. But, we have a very good sex life – it's very natural, ummm, my husband's got a very high sex drive (laughs), but I've now stopped counting my days, so if it happens, it happens. But, it took about three years before I could say now okay, finish and klaar, let it be now, let it be – but it took – I think it's worse for people that don't have a child. It places a lot of strain on the marriage, because you know, I know of couples that actually divorce, because the woman has actually tried everything – even in our group – this lady she's actually left the group now, but she and her husband went through a divorce because she went for the GIFT three times, and it failed and at the end she just said she couldn't take the stress anymore and they've since divorced and also left the group as well. I know it places a lot of strain on the marriage – umm, especially if you don't have a child. And, you know since I started going to the group, I actually feel, I'm so blessed to have the one, because a lot of them don't even have one child, umm, and I feel that they're so obsessed with wanting to have a child, you know all we ever talk about is children, children – which doctor is coming to talk about fertility, you know what's new and things like that. I actually feel that do I need to be here – is there need for me to be here because all they talk about is wanting to have babies, and that's actually been – that's been positive in the fact that it made me accept the fact that I've got one, it's a blessing, umm, you know and that helped me.

R: So, being with other people that had (fertility?) problems, and comparing this with yourself helped you?

P: Definitely, definitely, because when we found that we started the group, most of us were in our mid-thirties – most of us – and when they shared their experiences, they tried everything – they'd spent thousands upon thousands, on IVF and GIFT and things like that, umm, and I just thought sure – what am I doing here, you know and that's really helped. That's the one positive aspect of listening to other people's experiences and things like that.

R: How could Endometriosis impact on your role as a woman?

P: It does, it does impact on your role as a woman and I think, especially in the marriage – especially if you're not able to conceive – you feel you're such a failure. You feel so helpless, so helpless, and especially you know with the pressure from family and especially if you don't have a child, people wonder why isn't she having – why have they been married for so long and there's no child and things like that. So, you feel the constant – it's like all eyes are on you – you know and I know for me, when I was trying to conceive, it was like everyone else around me was just falling pregnant at the drop of a hat – and we deal with teenagers, all these problematic children, and fourteen or fifteen, at the drop of a hat they're pregnant – you know so you just feel it's so unfair, you know – what have I done wrong – things like that, umm, and you see yourself as a failure.

R: So, you start thinking it's something that you've done – something that you're responsible for.

P: Exactly, what have I done – I would say – you know I used to think, what have I done wrong, I mean, I'm sort of a good person, I don't do anything negative or bad, I'm in a helping profession, umm, even with my own family members, I would help them and you know – help financially and materially – my family, my husband's family. Really, what have I done, and yet there's people that don't live positive lives, and yet



they're just having babies one after the other (laughs) and it's just so unfair, just so unfair (laughs).

R: Sure, you see that all time?

P: And, I think the worse is when people fall pregnant and they don't want to tell you that they're pregnant – because they feel – they think you're going to take it so... - you're going to feel so bad, you're going to feel so disappointed, and I know I must be honest when this one worker fell pregnant, we were both trying and she after, after a year now, she fell pregnant with her third one and she didn't want to tell me – she didn't know what my reaction would be – she actually went to my supervisor and told her that she don't know how to tell me and just recently as well, somebody from our probation unit also fell pregnant and I felt I should congratulate her, I went to her and I was touching her tummy and things like that and she said, you know what, I didn't know how to tell you – I didn't want to tell you. I said, no – I'm fine, but it took me a long time to get there. I must say that initially I was like envious and jealous and didn't know to control my facial reactions but everybody's now so positive and happy for that person – you also to have to act like you're happy, but inside you, you say - oh shucks (laughs) and for me, I had planned everything to a T– I'm a very organised person – my life is very organised and I wanted a four year gap between my two children, I was only going to have two and I was going to have a spring baby. So, I went off the pill, everything to prepare my body, went onto my folic acids and I wanted to conceive in January now to have to have my baby in September and it never happened and it's now four and a half years later and it hasn't happened (laughs). I even went to the Gynae and you know checked my calendar and you know the thirteenth and the fourteenth day is my most fertile, and eating all the (foods?) now that are supposed to make you fertile (laughs) – just giving me a (illegible)...

R: Preparing yourself – you like to think that you’ve done everything that you could have done and how else do you think it affects your role as a woman and your identity as a woman?

P: I think you lose your loss of self esteem, you know, umm, Ya, self esteem – you feel a failure and also once you go onto the medication, some women tend to put on weight and things like that, umm, so it’s also that, you know you’re physically putting on weight, I know I was very conscious of all of that. But, I was lucky I didn’t put on weight, but I know I had mood swings and things like that.

R: So, it’s all those sort of things. The putting on weight – what affect does that have on you?

P: Well, especially, you know I’m very – I like to groom myself nicely and things like that. I like nice clothes and now I was scared - ooh golly – I’m very conscious about my cellulite.

R: Okay.

P: (Laughs) – and it made the cellulite worse, you know and people started calling me JLO – you know they said I’m getting a bum – you’ve got a bum. I was very conscious about those things, you know.

R: Your body image.

P: I think, only now I’ve lost the cellulite – the extra that I put on during that time. I think also, you know, you’re not able to be as physically active as you want to be, you know especially with the pain, you know stuff like that – sports – if you’re a sports woman it affects you in that way. I know that one of the ladies in the group – she’s very much a sports woman – it has affected her in that she bleeds right through the month – non-stop bleeding, so she’s not able to do any sports or things like – so it also affects you in that way.

R: So, it limits the sort of things that you want to do yourself.

P: Yes, definitely.

R: ... that you want to enjoy. Tell me, what about socially – with your friends and has it impacted on you at all.

P: It has, because especially when you get your period and things like that, you're feeling depressed, you don't want to be with people, umm, at home as well you don't want people coming home and visiting – so my husband says let me go and pick my mother in law up (my mother) up to come and spend the day with us. You know, oh God why do you want them to come now because I just want to curl up and just sleep the day away – you know you don't want people visiting, you don't want to go and visit people, you don't want to go and walk in the mall because you know you've got a heavy period – it's uncomfortable, you're miserable, there's the pain – umm – so it affects you socially as well. People think you just a party (pooper?) kind of thing, you're so miserable because you're suffering with the pain and things that you only want to go home and also because you think, am I bleeding right through my pants – because it happens with the heavy clotting that you spot and it stains your clothes and things like that. So also when I'm walking in the mall, that I tell my husband – just walk behind me – do I have any blood on my jeans or things like that.

R: Just to check!

P: To check – so it also affects him that way.

R: Tell me how do you understand medically - the medical professions role in dealing with Endometriosis – are you happy, frustrated – what do you find?

P: I'm so frustrated, because I just feel they haven't spent enough time and research on this whole thing. I mean – my Gynae – the first one I had is a classic example – really – to tell you, after two years – no, it's normal, just be patient – it takes a while to fall

pregnant, and when I used to suffer pain, and yet a lot of women suffer pain and I found out that it's not normal – it's the bodies way of telling you there's something wrong. I just felt he was so condescending, he didn't take the time to find out about Endometriosis as such – umm and I think he was just out to protect his own interest. He didn't want to lose a patient – he should have referred me to somebody else – a specialist or somebody like that – I find a lot of Gynaes are not clued up on Endometriosis – you know.

R: So, it's the lack of knowledge...

P: The lack of knowledge and yet there's so many women who're suffering with it – you know surely by now, they should realise that there's so many women with this problem – we should spend some money on research of this. Even in the newspapers and things like that, there's very little material on it - like now with HIV / AIDS and with cancer – you know – everybody knows what it is, but with Endometriosis you have to explain to everybody what it's all about.

R: In terms of treatment procedures – how do you feel – is there anything that happens during treatment procedures itself, that affects how you cope with it?

P: The pain afterwards is quite severe, after the laparoscopic surgeries and they don't tell you that the pain is going to be that severe. Umm, they don't really tell you what the procedure entails, you know they should spend more time explaining what they're going to do – how they do it – what they're looking for and things like that – umm – you just get going to theatre – you come out and that's it. They say we've removed most of the Endometriosis, lets put onto some medication and that's it. And, I think (name of doctor) was the first Gynae that really – he showed me pictures and said this is what it looked like – this is what we use to remove the Endometriosis and things like that. I think it's because he takes the time to – you know –he's done research and he

knows what he's talking about. Umm, but I think that Gynaes really need to go back to Varsity or medical school.

R: In terms of – you say that to cope with it better, it would help to know more what was happening with the procedure and what to expect...

P: What to expect because you tell people that I'm going in – I'm having a laparoscopic procedure and they want to know what it is – I didn't know the first time what it meant – you know how do they do it, where do they cut you, how do they do it – nothing – what do they use – umm, I mean with the first Gynae, when I went in and just before they gave me the anaesthetic, I heard him saying, just bring me the dye – so I thought what do they mean to do with the dye – but apparently they put inside to show up better on the screen where the Endometriosis is and (name of doctor) explained that to me. But, it would really help you to cope, because now it's the fear – the fear of the unknown – you know what do they do, how do they do it, umm things like that. You know, with my last procedure, (name of doctor) got a surgeon to come and assist because I had this nodule – because of where the nodule was situated – and he explained to me why he had to get the surgeon in, to assist – you know – and I felt at ease. Also, when I saw the photos and things like that – I felt so much better.

R: So, when you actually see what's being done – when you watch on a screen – does that help you at all or was it too much for you?

P: That doesn't really help you but when they show you the photo's, and things like that, Ya.

R: It's actually to have knowledge about what's happening...

P: You know – Gynaes should be more open with you, don't just use the terminology and expect us to understand what you're talking about. You know, explain it to us – (name of doctor) will show me his diagrams and say that this is where the nodule is,

you know, and he'll point – he'll show me on the body where it is. You know that has really helped me, it also helps you to gain confidence in your doctor, you know as to what's happening with you.

R: And, I suppose having that confidence helps you to cope...

P: Ya, definitely, definitely, definitely because you wonder, does this man know what he's talking about, you know – I mean now I realise that the first Gynae really didn't have a clue about Endometriosis – really, he didn't have a clue and really he was just trying – taking his chances with me – he kept on bluffing me – but really he wasn't treating me the way it was supposed to have been done but because (name of doctor) has got so much of knowledge on it, you know he explained the terminology, he explained the procedure and really I feel so much better – I think that's also helped me to cope with the condition.

R: Is there anything else that would help you to cope – what do find helps you to cope. I mean, you said it took you a long time to get to the point where you are now, what did you kind of go through at that time – what worked, what didn't?

P: I think what helps is the support of people who are suffering from the same condition and that have been through it and they can tell you exactly – If you say that I'm suffering from this pain, I've been to the Surgery – they can tell you, it's normal – they can tell you how it's supposed to be. Like there's this lady at the office who's got Endometriosis, when I went in for my first procedure – I told her and she told me exactly what to expect and that helped me and you know, it also prepares you, for the surgery and things like that. So, I think it's the support of people experiencing the same problems, also if your Gynae is knowledgeable and knows what he's talking about and is an expert in that field – that also helps you to cope and I the support of your family and friends and your husband.

R: In your marriage – what would help you to cope?

P: I think in the marriage, umm, I think it would be not for the husband to pressurise you – putting the ball totally in your court, it's like you've got the condition – you deal with it and accept it as our problem, you know – it's part of our marriage, it's part of your condition, you go for the surgery and things like that.

R: Sharing...

P: Sharing it, Ya, sharing it.

R: Friends – how could they help?

P: Friends are being supportive, umm, Ya and also but you can't expect them to read up on it – but if they also read up on the condition and because now when you're telling about it – it's like you have to explain for them to be enlightened, because if they had an understanding about it, they could be supportive and you don't know what you're talking about but if you're talking to people who don't know – it's like you're explaining – you're giving them a lecture now – you know on Endometriosis.

R: You're giving the support...

P: The support, Ya definitely, definitely. Also, with the support group now, if I know people that have been in for surgery, I will phone them a few days later to ask them – how are you doing, how's the pain – that helps them – that helps them. And, I think the group is good because people who are feeling depressed and stuff like that – they will phone and you will try just to encourage them and be positive, Ya.

R: So, having that support network helps...

P: The support network – it helps, it helps, Ya. But, I know with the group, it's difficult, you know with the last group we only had five ladies and three husbands that came along – so to get people to come to the groups is a problem – I don't know what one can do to motivate them.

R: Trying to get people to come...

P: But, I also think people expect miracles when they come to the group – they expect immediate answers, because when we started the group, there were a lot of people that came initially, and I think they just became so despondent afterwards, because there's no miracles.

R: They have expectations...

P: They have expectations, Ya.

R: Is there anything else you would want to say or anything that you feel is important for people to know about Endometriosis.

P: Get a second opinion – very important – I just felt so much of time went by – with this Gynae telling me, no – there's nothing wrong, it's normal to have pain, it's normal to wait or to try to struggle to conceive. Go for a second opinion immediately. You know that would help you, don't be scared to look for support or just talk about it, you know it's not a secret to share it with other people. I feel that the more you share, the more support you're going to get from people. Ya, because I tell you on this floor, everybody knows what Endometriosis is – everybody knows...

R: It helps you because you're not explaining, as you said, to everyone what it is...

P: Yes, because you're not suffering all by yourself, you're not – people look at you when you're in pain and they're wondering what's wrong with you – you know they don't know what's wrong you – they're assuming what a miserable person, anti-social but I mean, if they understood they would know – she's having a bad day or something. If I take off – if I have my period and I get severe cramps – and I phone in and tell my supervisor, I'm suffering with severe cramps, it's fine with them – I put in my leave form and I put there – menstrual cramps – it's acceptable because they know about the condition – so that helps . You need to be open about it.



R: Are there any downsides about being open about it?

P: Umm – no, I don't think there's any downsides, but what I've learned was for anybody, if they're wanting to have a child – don't tell the whole world – because now, everybody's waiting. Umm, are you pregnant this month – so when – any news yet? And, that was my mistake, because I told everybody, I'm off the pill now, I'm on my folics, umm – that's the type of person I am – just very open – what's there to hide about it – and because of that, now everybody was – even the ladies in the Typing Pool, and Admin Section – so, not pregnant yet and every month you have to come up with an excuse. So, that is my advice to everybody – if you're wanting to have a baby – don't tell anybody (laughs) – don't share with too many people – just the one's close to you.

R: You've told me a lot about physically, emotionally, socially, about how it affects you and the good points about what can be done and what would make it easier...

P: I think spiritually – sorry, I forgot to mention that, I was very upset with God, umm, you know with the first one – I conceived within two months of marriage – you know and I just, I mean I go to Church, I'm committed – I'm a committed Christian and I just question God, you know why is this happening. You know, you go for prayer for healing, umm, and my husband said – lets go to the Dome (the Christian Centre) – they're having a crusade and you'll go and if they ask if anyone has any illness, put up your hand or whatever, you pray and then the next month, you know you're expecting a period – you know I was very off God.

R: Last hope!

P: Last hope, but umm it also took a long time for me to accept – oh okay, if it isn't God's will – that's helped me to deal with it – maybe he's got a plan (laughs).

R: You say that on the one hand it helps you but on the other hand you feel resentful...

P: Ya, very resentful, Ya, definitely.

R: And, I mean, people from your Church – do you find that they help at all – do you feel you can speak with them?

P: Ya, but not just everybody – I tell friends but because we're all the same age and we all had our first babies together, we all sit in the Mothers Room and then, umm, they all now have their second lot now and I'm still with my first one now, who's a big seven and a half and then you know, we all tried for the second one at the same time, so then they fell pregnant and their children are three and four and so, I couldn't now – they said what's happening, and I said there's still time – there still time, but eventually now I had to tell them, look I've got Endometriosis and explain it to them, and so now they that I've got Endometriosis and might not conceive and they said no – they're actually quite supportive about it. But, I think once people know you've got Endometriosis and you explain – you know don't beat around the bush – ooh no, I'm not interested now, I think maybe later – just tell them, look I've got Endometriosis, difficulty in conceiving – finish and klaar – they won't ask you again.

R: It helps, just using that – it helps...

P: Because, otherwise they're going to ask you every month – when's the baby coming – no news, no news and so now everybody knows I've got Endometriosis – umm and that's it – don't ask me anything (laughs).

R: Okay, so that helps you.

P: Ya, it does help, it does help.

R: Anyway, thanks so much.

P: No problem.

R: You've given me a lot of aspects – I think that's very helpful. Ya, very helpful.

P: I think you'll pick up – I think the worst thing is people who don't have a child – for them it's worst. You know there's a lot of pressure on the marriage.

R: To have a child.

P: Mmmm, a lot of tension, I think if there's one, it's still okay – the family can say it's okay – the husband can say, I've got one – it's still okay. But, let there not be a single child, it's you know, quite bad and I think that goes across cultures. Really it does, it does.

R: So, whether or not you have a child can also impact on it.

P: Definitely, the pressure is much greater then and it places a lot of strain on the marriage.

R: Okay, thanks Patricia.

P: That's no problem.

## Appendix F: Respondent interview

### “Louise”

R: Maybe we can start by you telling me how you understand what quality of life means?

L: It kind of taking care of yourself and accepting every day as it comes.

R: So the acceptance of life and taking care of yourself, okay. And, what does this mean to you having the quality of life?

L: I don't actually know what to say (laughs). .....To be positive which I'm not (laughs) and you know to take each thing as it comes – which I am not. You know the little things really get to me and I don't know.

R: And, so you're saying that for you, it's definitely something like psychological.

L: Ya, oh ya..

R: ...and attitude and emotions that you're feeling. Okay, I'd like to get to that a little bit later as well. I think that (illegible) an important part of quality of life. What other aspects do you think are involved in quality of life?

L: Oh, being happy, being positive...

(Terrible background noise – laughing and shouting – distracting interview)

R: As I was saying, how do you think Endometriosis impacts on your quality of life?

L: Well, umm, it's affected me a hell of a lot, I mean – I'm unable to exercise like I used to, as I'm always in aches and pains. I used to be a very fit person and it's really affected me.

R: So it's your physical fitness – it's the pain that's actually prevents you from keeping fit.

L: Ya.

R: Okay, so it's your physical life. How do you understand Endometriosis as a physiological thing, as a physical condition – I mean do you understand what it is?

L: Ya, I do understand what it is.

R: So you say, it's had its toll on you.

L: Physiologically, ya.

R: How else has it influenced your life?

L: Well, I'm very emotional and I've been affected with depression as well and it's affected my family a hell of a lot. I spend most of my time in hospital, getting admitted and stuff.

R: Are the admissions for Endometriosis?

L: Ya. 99 % of the time, ya.

R: And, you've had quite a few of those?

L: Ooh, yes – I'm always bleeding continuously and they've tried to you know, help with that, and recently I've been admitted like seven times because of the bleeding, in two months – that's like almost every week I've been in hospital. So it's affected my family, it's life, and the kids you know. I'm not sure if to send them off to school because I don't have in-laws, I don't have parents, you know I don't have family that's close by that could come and help in the morning.

R: Is it that both you and your husband don't have parents. So, it's difficult not having the extra support.

L: It is.

R: And, how's it affected your family life – what kind of things have changed?

L: Well, I'm always irritated, shouting at the kids, you know, always in and out of hospital and not being here for them when I should, and when my son's writing exams, I'm not here

you know. It's important for me to be here to see that his meals are provided and he's studying, and stuff like that.

R: So, you feel in terms of your role in the family, you can't even help with things you want to do.

L: Definitely, ya.

R: All right. I mean, that your role as a woman in the family, is obviously quite an important one. How else is your role changed as a woman. Well (laughs), my relationship with my husband is very good, but you know, in terms of having sex and stuff it's really bad because I'm bleeding like – two months continuously, and obviously.... you know, ya, it's sad. I mean he understands, he's very understanding. He's always been supportive and stuff but I feel sh\*\*- I really feel lousy, ya.

R: But how... - what does it do to your relationship with your husband?

L: Well, like I said, he's very understanding and supportive. I mean it's okay, but I know he's worried as well and very concerned.....

R: Well how does that affect the two of you and how you get along?

L: Ummm... and also the medication I'm on, is like, you know – the side affects – hypertension and loss of memory, you know – and I've been on tons of it, so (laughs) but I don't know if I'm using that as an excuse, but you get short tempered and you're irritable. Like I said, he's understanding, so he just accepts (laughs) what comes his way.

R: You actually find that that's been quite a strength for you.

L: Ya, oh definitely.

R: All right. You started saying earlier, emotionally, that you've been depressed – is that related to the Endometriosis, I mean how did that happen?

L: It is, I mean I'm bleeding all the time and I feel so, you know, unable to do things and always want to lie in bed and want to take pain killers, and .... it's really depressing – taking the medication and I never used to like taking medication and I never used to take even an injection, but now I like actually just go to the doctors, sometimes on a Sunday morning or Sunday evening, just for injection for the pain.

R: So it's the pain and the bleeding that you've mentioned are quite big factors, is there anything else physical which you've been experiencing, you know the physical symptoms that affect you.

L: Well, you know lower back pain and pain running down the legs – it's really painful.

R: And, obviously the medication that you take as well has its side effects...

L: Oh, ya, its got its side effects and most of the time, the pain killers just make me drowsy, but the pain is still there – the pain just didn't go away, no matter what – you either sleep, take a strong medication and sleep, then... the pain will go away.

R: But, I mean, you've spoken about your role about a woman in the house – do you have your own children?

L: Yes, I've got two – my daughter is eleven and my son seventeen.

R: Okay – I mean, how's it affected your relationship with them – or has it even?

L: Well my daughter is very umm.... sensitive and really very caring and she's really – you know when I'm in hospital, she's worried, she's depressed and when I go for my ops and stuff, she's like – you know – it affects her.

R: Okay, she's very worried about you.... Has anything helped you to cope with that at all?

L: Not really, nothing. Because you know at the end of the day, it's going to keep coming back and there's more and more to come, so it's really frustrating you know. It just goes on –

it's a chronic problem, it's like – you know it's not going to go away and there's always something (illegible) coming. Like I've been for an op now and I know it didn't do much good, because from the photo's that the doctor took during the op, it shows that I may have damaged one of my ovaries – so there's like another forthcoming operation, and I expect my family to know what is going on, especially my kids, so you know they don't just think that Mommy's sleeping and she's lazy and she doesn't want to be with us you know.

R: So, you explained to them what the conditions about.

L: Uhuh.

R: And did that help at all – how did they respond to you explaining to them?

L: I mean they understand and (furniture being scraped over the floor and lots of extra noise) and they try and be helpful around the house and while I'm in bed.

R: So, you explained to them why this (illegible – too much noise) and the kind of (illegible) you're going to be given – treatment – okay, so you have explained that to them.

L: Ya, I have.

R: And with your family in general – your in-laws are staying – is that your sister in law?

L: She's my nephew's wife.

R: Your nephew's wife.

L: My sister's daughter in law.

R: Your sister's daughter in law. I mean with are you also...

L: Yes, we talk about it quite often, they all know about it. It's actually like it affects the whole family, everybody, because each time you get hospitalised, they're there to visit and they see you going through this pain, and especially if you're close you know with relatives,



they go through it as well. It's like cancer, that affects everybody, you know. I know it's getting that bad, you know amongst women.

R: And, I mean, are you working at the moment – I mean I know you work from home, but...

L: I've also got a casual job at Gateway, which has been affected because I work on weekends, and because every time I'm hospitalised, I have to stay away, you know.

R: So that does affect your attendance at work and to go there, and with the ops that's difficult. And then, those who're responsible at work, do you explain to them what it is you're going for?

L: I did more or less, you know I've got a male boss, so... I have explained to him, but he doesn't know much about Endometriosis, so just probably thinks there's just cysts (laughs) and you know...

R: So, you're not sure if he totally understands the reason why you're actually going – okay, all right and is there anyone else you work with at Gateway?

L: Where my husband works as well – part-time...

R: And here, do you work here.?

L: No, I work alone.

R: You work alone – okay. And, with your clients?

L: Well, I've got two clients that's suffering from it – actually one is going to have her uterus removed this month, and when we're talking, we you know, like I just said, I've just been for an op and that's how we became, you know, that we know that each other have got it.

R: So, you realised that there were other people as well, that were suffering from it, okay.

But, I mean how have you felt – has that made any difference?

L: It did, it made a big difference, cos they understand exactly what you are going through. They are having the same medication, so it feels very good you know, talking to somebody who you can relate to you know and who can relate to you.

R: I suppose that (illegible) will probably find that as well – when you find people that know what you're talking about.

L: Ya, that's true.

R: So you find that when your clients and people actually have it as well, it actually helps you out quite a bit as well. Okay. And, in terms of your work functioning, has it had any affect on your ability to work.

L: Ya, because of your pain and the cramps, you can't stand for long – especially if you've got like a hair colour to do or a perm to do – it's like – you don't want to stand and you're like irritated and I mean, if you're in that way, you obviously cannot attend to people, you know. So I turn a lot of customers away and my clients away and... they come tomorrow and they've been here the next day, and you're still not well, so...

R: So then, how does that make you feel?

L: Very depressed.

R: So it's a restriction...

L: Ya, that I'm unable to do my job, and you know.... they probably just think that this person is lazy and you know...but like some of the women will understand, but kids you know...

R: So, some people just don't really know what it is – then you don't get the kind of understanding that you'd like to have.

L: Yes.

R: And socially, with your friends and that, how has that been?

L: ..... Well they, they're very concerned – I still go out and we still meet and we still have our chats and stuff but umm, it affects them as well because they have to come to hospital and see you – they feel obligated you know. They say I have to come and see you and stuff. I feel lousy that you know I have to keep going into hospital and it's like you....

R: Like you?

L: Like I said now, you're in hospital and they have to come and see you, you know – like I'm putting pressure on them you know and today, everybody's lifestyle is so hectic and... and they have to make time to come – because I know my friends always do that.

R: Okay.

L: They're always there, ya – like if I'm admitted four times in a month, they're there the whole four times – every day.

R: So you have had some support from your friends.

L: Ya, I do.

R: But I mean, what do you think helps from their support, what is it that helps you?

L: Well, you talk about it and you feel a bit better, and I don't know...

R: It sounds like you're saying that people are there and they're saying it (illegible)

R: Have you received any help for depression?

L: No, not recently because medical aid is exhausted.

R: Okay, all right. So, you say your medical aid is also taking quite a toll.

L: It has, because every time you get admitted, you have to pay a certain portion – medical aid doesn't cover everything. I mean you're paying these bills and your medical aid is exhausted and you cannot even go to the GP if you've got a flu, because you've got to pay like R150 bucks and that's excluding medication, and you're off work 90 % of the time, so how on earth are you going to pay these bills.

R: So, it's kind of like a cycle.

L: And you know most of the women are having the same problem – I have some women who call me at home – because of me being on the committee and everything and they're having the same problems – they're just paying bills, medical aid bills.

R: So, it's quite a financial strain?

L: Yep.

R: So, that would affect your family as well.

L: I can show you quite a few bills, like R2000, R5000 – we just put it on our monthly budget – because I mean, we cannot afford that money, you know.

R: I suppose the procedures themselves are quite costly?

L: Absolutely – I've already used like R58 000 from the medical aid for this year.

R: Just on procedures and doctors bills?

L: Ya, ya.

R: And then you've mentioned financially and psychologically – the affect it's having on you. What about being an Indian woman – does that have any affect – are there any cultural factors?

L: If I didn't have kids, ya, but luckily I've got my kids, so – it would have had an affect if I didn't have kids.

R: How so – what kind of affect would it have had?

L: Well, they say its umm, how can I explain it, they just feel that you're a very unlucky person you know – that you probably did something in your past life and therefore you.... – they don't understand that it's a type of sickness and you know. So they'd say you're a bad luck.

R: And at the moment, are you wanting more children?

L: No, my family is complete.

R: Okay. So you feel content with the children side of things.

L: Yes.

R: And I mean you saying that it doesn't pay much of a role to have the children, but what about generally – are there any cultural factors that impact on how you've coped with Endometriosis?

L: No.

R: In terms of support from your community or things like, that.

L: No, nothing.

R: You haven't really found anything.... all right. You were telling me about your role as being a mother, inside the home and your ability to do activities around the home and (illegible) your children, lunch for school, things like that gets quite affected. I mean, what about your identity as a woman – I mean I know being a mother is part of that – are there any other aspects that you'd like to share?

L: ..... No, nothing, can't think.

R: Can't think – it's more that sort of thing that seems to.... and so you're saying that at the moment, you've obviously been to a lot of doctors and how do you understand how the role of the medical profession has been in your experience of Endometriosis.

L: Well they cannot find a cure and I hope that they will do more research you know, because its about time we found what's causing it and what can cure it. Well they just do what they have to and you know, because it just keeps coming back and they cannot find why or what causes it so – so it really p..... you off when you have to go back and each consult with the Gynae is like about R450.

R: So each time you have to go back to find out what's going to happen, it costs more which obviously adds to the frustration as well.

L: And now more or less you have an idea what they are going to say you, what medication they're gonna put you on and sometimes now when I get sick, I just go myself and get the medication.

R: So you kind of know what's going to be all right. Okay. And I mean what do you feel - is there anything that you feel the medical profession could do that would make your experience of them any better, whether they way they deal with you in examinations or anything – anything that you can say.

L: No, just to find a cure I think, you know.

R: Okay.

L: To try and save your ovaries at least, and your uterus you know, to avoid going for those ops – I wish they could just find a way you know and say lets just do this laser and it's not going to come back. It just goes from one thing to another.

R: Okay. And, I mean, is there anything that the doctors, anything that makes you find it harder to cope with, either how they interact with you or .....

L: Well, my doctor's very understanding – he's really sweet – I don't find any problems with him, not really.

R: So there's nothing you would want to have done differently.

L: No.

R: Not really, okay.

L: Only if they could chide(?) us a little less (laughs)

R: So you tell me, you've been battling to be positive like you say taking one day at a time – how have you coped – you've managed this far, what have you done to manage?

L: I think my husband helped me a lot to cope because sometimes I just break down and cry and cry and cry and I spoke to you once – that made a bit of a difference, ya – I don't know, I have no idea how I've coped, really.

R: Okay, so you say that definitely the one thing that does play a role is other people – you say someone close to you like your husband, someone you can just tell how you're feeling and like you were saying, just let go, just listen to you and with yourself, is there anything you do to manage pain or...

L: I don't think anything I can do can help, because I've tried everything, lying down, reading, meditating – nothing helps. Nothing, I've tried so much.

R: Mostly it's the pain and the heavy periods that has been the most crippling aspect of it.

L: Continuously – thirty days in the month, not even clots in (illegible), you know, terrible.

R: There hasn't been any cessation to that – it's just carried on...

L: Carrying on – I've been for a procedure and it's – still nothing much...

R: I mean what are the options that you kind of look at – what are the options you’ve been given?

L: Well, my doctor doesn’t really tell me what’s up you know next – he just wants me to take – he knows it affects me and its bothering me but I know eventually that I’m going to have to have my uterus removed, because I have done research and stuff and know it keeps coming back, and umm, I know I’m gonna have to lose my one ovary, cos my last procedure, he showed me photos and my ovaries were like stuck to the uterus and covered, totally covered, so the procedures that he did, he got to one ovary and helped loosen it and get it free from Endometriosis and lasered them, whatever – but the other one was unreachable, because it was covered with a vein and arteries running from my leg, so he couldn’t get to it at all. If he had to, he would have had to do the bikini cut because I just had a small cut done on both sides of the ovary, so according to him that is why I still have a hell of a lot of pain - is because of that ovary being stuck to the uterus.

R: So that’s causing the pain – so that operation would hopefully alleviate it – if you were to have it done, all right.

L: But that would have its side effects you know.

R: Like what?

L: Probably I’d have to go on hormone treatment and stuff, you know. The doctor wouldn’t tell you that, until you get to that stage you know. But I’ve done research and stuff.

R: So when you say that you’ve done your own research, that at least shows that’s one way of coping – that you try and get information as much as you can, okay, so you’ve been trying to research, get information, look for new developments that have been happening, that helps you to cope, helps you to feel...



L: I think it just makes you more depressed (laughs) – because you know, I mean, you know there's no cure for it, you know it's going to come back, that it keeps growing back – it's gives you peace of mind that you know what's happening, but it keeps you so depressed, you know.

R: And what helps you cope with the depression when you feel like that?

L: I think just talking to my husband.

R: Okay and spending some time with him – it sounds as if you've got a very good relationship....

L: Oh ya, absolutely – you can depend on him quite a bit.

R: It's obviously something you're quite thankful for – I can see it on your face. Is there anything else you want to ask me, to say to me that I haven't asked you – that is for you significant that I haven't asked you about having Endometriosis.

L: No, not really. Nothing that I can think of.

R: You say that support from other people is quite important – is there anything that you can tell that maybe your family or your husband does or could do that could make your experience of it any better?

L: I think he does everything.

R: What?

L: Just being there, being there for the kids, you know when I'm not well. He does everything that's possible I think.

R: So helping around the house, looking after the kids and your daily sort of things, being there for you emotionally, okay. And with your friends, what would help you cope?

L: Well I think they're doing everything as well, like being there at hospitals and... but then when you come home they're like you know, once you've been two or three days at home, they don't bother to call, you know, but you're like still sick for like six weeks.

R: Okay so kind of like you should be better by now, but you're still feeling it.

L: It takes a hell of a lot to get back to normal, you know, to be yourself, like running and walking and everything.

R: All right, so the recovery is quite painful as well. Is there nothing else that you would like to say?

L: I just hope that the medical aids wouldn't stop paying for Endometriosis treatment because that's my worry that they're not gonna cover patients with Endometriosis because it's quite expensive – the treatment and stuff.

R: Ya, it's something that shouldn't be stopped. Okay. Well you certainly helped me quite a bit just understand a little bit more – because it's important to understand just how you've experienced it, because each individual experiences it differently and disease means different things to different people.

L: It's irritating because you take so much of medication and the pain wouldn't go away you know. You get up at 2 am and the last thing you wanna do is to swallow a tablet. You know and even if you do, I mean the tablet will just make you drowsy but the pain wouldn't go away.

R: Okay, so it's quite frustrating. Okay. So you've told me that like physically, psychologically, socially – your family life, your role as a mother – the kind of effect it's had on you – has been very helpful and I'm hoping that this information from a few participants

will help us to get more information out there in terms of what people are experiencing and what can be done to make their experiences better.

## **Appendix G: Respondent interview**

### **“Margaret”**

R: Maybe you can start by telling me what you understand what quality of life is?

M: Quality of life? My life, or life in general?

R: I think life in general.

M: OK, um, I would think, living life to the fullest, being able to do anything. To me, having a quality of life is being able to have a family, children of your own, to be able to do whatever you want, especially when it comes to work as well, to do your best without having to be sick all the time. I guess it's every aspect of your life...to do things normally, like a normal person. So, to me, a person without any illnesses has no reason to be living without quality of life!

R: So illness and health comes into it?

M: Ya, very much so! Cos when you're normal you can do anything you want to when you want to. Nothing holding you back. Especially for me, I'm absolutely sporty person. I absolutely love going out and doing things, playing sport. But then you get 12 or 14 days a month when you have to be in bed and I can't do anything. That frustrates me more than anything, more than the pain, the fact that I can't move, that I can't do things.

R: Ya, you're restricted in doing the things that you want to do.

M: Ya, you're very restricted. Especially at work I can't go for any promotions or things very readily. I always have to think about 'Am I going to be able to do this job, bearing in mind this illness?'

R: Ya, okay

M: So, A good quality of life is being able to get what you want, to strive for it and be able to do it. You know, physically and emotionally.

R: So it's a physical thing-

M: Ya-emotionally it's there! I wanna do everything. I've got the spirit to everything, but it's my body that's not keeping up to it!

R: So, it gives you a limitation?

M: Ya, on everything!

R: So you're saying quality of life has to work...it has to do with work, the physical, the emotional...your sports, your leisure, your family. Your identity-you're saying having a family, so...being a mom-

M: Being a Mom-very important! Ya, I never really thought about it much before being diagnosed, but now that I'm having all these problems, I just (laughs)...Knowing that you can't, or it's very...there's a very slight chance you can be a mother, that makes it really difficult, you know?

R: ya

M: It makes you think about it all the time. Cos, prior to this, prior to being married, I never really gave it so much thought, like, 'I'm gonna be married, I'm going to have so many of kids and name them this!' No, I never really thought about it, no.

R When were you diagnosed?

M: Well, I've been suffering with horrible pains for ages, I think since the age of 15, and I'm 26 now. So that's eleven years. But I've only been diagnosed by a doctor, medically, since I've got married, um, which was 3 years ago.

R: Okay

M: They had to take me into theatre to cut, to do a laparoscopy and then...but I was passed from doctor to doctor. Nobody knew. And nobody was brave enough to say "It

could be this and I want to do something about it", because I wasn't married as yet, and he didn't want to be too intrusive.

R: Okay, alright. So they didn't want to investigate by having a laparoscopy.

M: Ya, especially for unmarried women, it's a...having all those procedures, it's not very...it's very intrusive. It's not just going through your stomach, it's, it's at the bottom as well, it's ya... (laughs)

R: Ya, some of the procedures are quite something to go through.

M: Uh hum

R: But then, I mean, if that's how you understand what quality of life is, then how do you think Endometriosis has affected those areas?

M: Okay, as I was saying, in my case, I can't keep up with the training programmes. Because, I go to gym, and for 2 weeks of the month I cannot go at all, and ya, that completely (laughs) - I can't be as active as I want to...I can't join um a group of friends whenever. If people pick up the phone and say, "let's go out", I have to, with me; I have to be..."only on specific days I can go out with you guys". Um, for jobs, I'm like so qualified and I've got all this experience but I'm so sceptical about actually putting in my application for a higher post, because I'm always thinking "am I going to be able to do this with my Endometriosis? I'm going to have to go for an operation every 3 months." Or every now and then, you can't have a high post and, you know, and take off from work. And it's frustrating for my husband as well. It's frustrating for my marriage as well. It's a problem for my marriage; it's a problem for me, personally. So it's completely taking away the quality of my life, so I'm just hanging in there! (laughs).

R: How long has it been that you've been trying to conceive?

M: Been trying? Um, well, ever since we got married and we started seeing this Gynae and he initially said that we might have problems conceiving. So we decided immediately

that we're going to try-we won't think about it but we're going to try immediately, 'cos we don't want to leave it, because I think 4 months into marriage I had my first laparoscopy. So we immediately we had to start trying. And we said, once we have the baby, you know, we can, from there we can go on and try enjoy being married. But uh, it didn't work that way! (laughs)...it's 3 years later.

R: So that was in 2001 that you got married

M: The first laparoscopy was in 2002, ok...

R: So you say it's caused problems for you marriage...how so?

M: My husband and my mother in law, they all want children! And um, especially in the Indian community, it's a major thing if you can't have children. But besides not having children...I'm living with my in laws (laughs). We lived 2 years on our own and then in our circumstance we couldn't afford to rent somewhere else and pay the bond, so we actually take care of his parents. So um, we had to move in, because we're paying the bond. Look, it's our house, so we moved into our house with them. (laughs). So, for Indian girls who come into the family-being sick for 2 weeks of every month um, my mother-in-law has to do stuff for us for those two weeks...she has to help with everything. Um, I'm constantly being called names and, um, you know. Its, to her, I'm not a wife. I've been told that I'm not a wife-I'm too sick all the time. And ya, so...and my husband is very close to his mother...so her view is very important to him-as much as mines is - his mother is his life! (laughs). That not being able to have kids...the tension between his mother and I-because she's obviously seeing me as a sickly person...and ya, as well as not being able to have children for her, so it's huge tension.

R: Ya, so you say, for her that's not being a wife? So, what is being a wife then?

M: (Laughs)

R: You say, being healthy...

M: Ya, well...being able to do things all the time for your husband. Um, she's a very traditional woman, not very old, she's about (discloses age), but very very very-she's a typical Indian... (laughs) She expects the woman-irrespective of if she is working or not-to be running around after her husband, picking things up after him, pulling out his chair, taking out his shoes and leaving them for him-so that type! So now, I'm not even able to do normal chores, like cooking, for him, I just take money out and say, like "babe, you have to go out and buy food for this week. Ya so, to her that's not acceptable. To her you don't buy food. Indians are very sceptical about that.

R: So in terms of being a wife, she feels that you're not fulfilling your roles. In terms of household chores-

M: Ya, so she tries to like step in and then we have lots of tension and my husband feels like he's being pulled in a tug of war! (Laughs). And this is in addition to normal mother-in-law and daughter-in-law problems, now, to be sick in the house is not...

R: ...being there in the house with you as well-

M: Ya, constantly tormenting me! (laughs)

R: Mmm, ya, you say they call you names and things, is that when you're sick.

M: Well, I've heard and I just ignore. And ya, we've had quite a few arguments as well on the subject and it comes up, that I'm lazy. And I'm not a lazy person! (laughs). I'm quite active.

R: But, in those 2 weeks or so there's nothing much that you can do.

M: I can't. No matter how much my mind is there, my body will not do it. It cannot do it.

R: You say the fighting with her, when it happens...does she understand what the condition is about...or? Do you try to explain?

M: Well, I think she understands, but...culture plays a very big role in this whole thing, so, to her, a wife is a certain thing and she's not someone to understand very quickly so...



R: Ok, so even, you have explained to her, has your husband explained-

M: Ya! She knows! She knows because when I had a laparotomy, that's the one where they cut you across your tummy, I was in horrible pain. And that was the month we moved into, uh, with them. And she had to take care of me. so she, more than anybody, she had to bath me and things like that, she knew the type of pain - the extent of the condition. So, you'd expect another woman, especially a mother, to understand.

R: Okay, so that must make it quite difficult to cope with...sho!

So you're saying living with you in-laws plays quite a big role with your husband, as it is, let alone being ill. Um, but, in terms of your relationship with him? You're saying you can't see it as separate from his relationship with his mom, you say they're quite close, quite a cultural thing too, but in terms of your relationship with him, how has that been going?

M: Uh, it...it's been going okay-we have our ups and downs, it's still-we're fairly newly married-it's more or less 3 years now, so the, in-laws pay a major part in our marriage. But me being sick all the time obviously can't be the best situation for him. And he's a very reserved person. He won't come out and say " You know, you're sick all the time, you're bothering me" but you can sense it, you can definitely sense it. Maybe it's um, the way that I'm feeling, that, how can a man be happy with someone who is sick all the time? So, it's maybe something in my mind, but you can definitely sense something there.

R: All right, so it sounds to me like you feel he might get frustrated and that you feel bad about it. That you feel "well, how can he be happy if this is happening?". Do you feel like that?

M: Ya, I do feel like that, I mean how can you be happy like that all the time? Well, with the situation of the in-laws separate - having a wife who is sick all the time, I mean, how many people can be happy with that? And he's constantly having to come home from

work and take me for an injection, and rushing me... After the first year of marriage, every month he had to rush me off to hospital, many times at 1 or 2 in the morning for pain injections. And those are the type of injections you can't take at a GP, I mean no GP's are open at that time of the night! So, he's had a really tough time as well.

R: Ya, okay.

M: And he's not the type of person who will discuss it openly. He won't ever show his emotions. He's very reserved. So, I've gotta try (laughs) assume what he's thinking! And I get all sorts of thoughts in my head, you know.

R: So you're not feeding them back, so you don't know what he's thinking-sort of imagining what he's feeling? So I mean, maybe we could come to that later, I mean, do you feel that it would help you cope...I mean...does he understand your condition...?

M: He understands...right at the beginning he used to say, if he could take some of the pain away, but then now, it's become like so routine that he doesn't talk about it anymore. I mean, he just, it's like, when I'm having a terrible terrible cramp, he wouldn't...previously he used to come and wake up and rub my back. But then he's come to this conclusion, which is fairly true: no amount of massaging or anything - it's not going to do anything. You have to take very strong medication or an injection and just sleep it off. Cos whatever he does it's not gonna help. So...for him...um...if he wakes up in the middle of the night, he's not going to do anything. It's not going to help in any way. And I have this habit of calling my mother. I think if I just talk about it, shout about it or just scream-tell somebody I'm in pain, it kind of helps rather than just sitting there and holding myself.

R: Ya

M: Ya, so ya, he gets annoyed because I'm always phoning my mother. He says "she can't do anything. You know she can't do anything. I can't do anything. Nobody can do anything". Ya so...

R: Okay. SO the fact that you talk to someone about it, at least tell someone what you're going through, it helps.

M: Ya, for me it helps. But for him, I think it annoys him. Because he knows that nobody can do anything. So he doesn't understand that the mere fact that I'm saying it out aloud and somebody else knows what I'm going through.

R: ...that that can actually be helpful. So it's not just the fact that it's your mom that you're calling

M: no. no.

R: Anybody! Even if I wake him up in the middle of the night he can't do anything. So it's that feeling of helplessness from his side. He knows that nobody can do anything. So it frustrates him a bit. But he can't help. No matter what he does. The only thing he can do is rush me to the hospital or rush me to the doctor.

R: Okay, so it's limited in terms of things he feels he can do.

M: Ya, he feels quite helpless.

R: Okay. Is there any other way in your marital relationship that it has affected you?

M: Not being able to fall pregnant. We've been trying to for three and a half years. And we've been told that no matter how much we try on our own it's not going to work. And it wouldn't have worked. So this trying for the last couple of years is pointless. So this has been...this has happened in the last week, so. Really, both of us are really...depressed about that. That we've been trying we've been seeing so many different doctors and we've been trying and they tell us no matter how much we did try it wasn't going to help

anyway. Because the condition is quite severe. So, all the assisted reproductive procedures are going to help. Nothing else.

R: Okay. SO those are the ones you've just started?

M: I haven't started actually. We're waiting for test results to come so they can tell us to go for GIFT or In Vitro.

R: Ok, so you're waiting...

M Ya, we're waiting for the doctor to get back to us. We will know on Wednesday which way we're going. It's definitely something cos they're rushing it (laughs). We're not sure yet which of the two.

R: Ok, so you're waiting for that...anything else in terms of your marital relationship that you feel has changed, like leisure, or quality time together? Anything like that?

M: Um, well that's basically everything. My husband is pretty sporty himself and he's pretty active. So he works a lot of over time. So he gets really little time at home. So I'm quite often alone in pain. Very much alone. So on the nights when I'm screaming in pain, I'm alone with my mother-in-law in the next room and she couldn't care less cos she doesn't speak to me in this point. Ya so, it's that feeling of loneliness on my side. In a normal relationship if you're alone you can get up and go and do stuff. But I'm stuck in bed alone with nobody. Because he's at work. And when he does have time off, I try not to restrict him to the bedroom by saying stay with me I am not well. I try and allow him to do stuff, things he would normally do so that's like further separating us, cos he's like off playing sports and things. And I've completely...I've allowed him to. Because I don't want him sitting there and baby-sitting me, you know? And I am restricted in bed for those two weeks, so...

R: So it's quite ambiguous-you want him to be able to do what he wants-

M: And at the same time I'm lonely, I need somebody there, but, you can never restrict another person like that, I mean. It's not like something every six months or something. It's every month. You can't expect him to sit with you day and night with you in bed. It's not right. I wouldn't want someone to do that to me.

R: Mmm, okay. So you feel responsible for some of his well being as well?

M: ya!

R: So you've told me about your husband and about work...what about friends, and your own relationships with friends, how has it impacted on that?

M: Uh...I don't have much friends (laughs). To me I don't have much - because it's so limited ...that I have 2 weeks in a month that I can completely enjoy myself. I try to spend as much time with my parents and my husband. Or if I want to do some stuff I try and go out with him. Because I know that I restrict him - I put a restriction on our relationship for those 2 weeks. So for whatever time I am okay and I am able to do stuff I try and do as much with him as possible. And ya, with my type of job and my very stressful life (Laughs), I try and do stuff for myself. I go to gym on my own. I go running - I just started long-distance running. I don't go and waiting around for other people - and I know I keep coming back to culture (laughs) but, Indian girls-after a certain age nobody wants to do anything. And I'm not that type of a person. I know about - I wanna make the most out of life as I can, so, instead of sitting around and waiting for someone to go out with I go running, or I'll go play some sport, so I don't particularly make much friends, cos not many people wanna do all these things (laughs).

R: So you're saying that in the Indian community, women older than what - 20 something? - will generally calm down doing that sort of thing-

M: Ya! They're with their family, their kids and stuff. And you know, Indians are mothers very early in life, so, being with their families and husbands and things-so...to me it

doesn't make sense. Most of the friends I have are from work, because I spend so much of time here at work anyway, so, ya...

R: Ya, so how is that for you? You talk about yourself as being different from other Indian women yet at the same, being affected by your condition, but how is it for you that other women are having families and staying at home. I mean it sounds like you enjoy being able to go running, and...how is that for you?

M: Well, you mean not being like other girls?

R: Or not, like for example, if you're having difficulty conceiving and there are other women your age conceiving, what is that like for you?

M: It's actually the most terrible thing! Especially here at work where I was in this team and people, girls, 29 or 30 years, are falling pregnant one after the other. I mean, at about one time there were about 6 people pregnant at the same time in our department. And one after the other-and all unplanned pregnancies. It just happened! And here I am spending all this money trying everything to fall pregnant, going on this fertility drug and nothing! Absolutely nothing! And people without even thinking about it, and then...ya. I know there was this one girl who wanted and she couldn't afford it. She's already got 2 boys, and my heart just fell when she was so unhappy when she found out she was pregnant. I can't imagine what that's like...because I would give anything. in fact, actually this GIFT procedure is fifteen to twenty thousand rand cash - medical aid doesn't cover it. And with the injections I have to go for treatment beforehand, so, it's gonna come to about twenty to thirty thousand rand. So ya, I'm always spending money trying to fall pregnant - everything I save goes into this. And ya, its so hard when you see other people without unplanned pregnancies or without even thinking, just, like my sister decided that she wants to have another baby after 10 years, and just like that she fell pregnant! And I've been trying and trying and nothing...

R: It must be difficult seeing people being able to so easily and yet you're trying so hard.

M: Yes, definitely.

R: Well, what work do you do here?

M: I'm assistant to the financial manager-senior bookkeeper kind of job.

R: Ok, so it's quite pressured work from the sounds of things?

M: Mmm.

R: I mean, do you work in a team quite a bit?

M: No. No more. Um. I did leave the company because of this problem. I found myself having to take too much of sick leave and I had to go and have 2 operations while I was here and it was too much for the job I was doing, when I was just an ordinary bookkeeper. It was, uh, becoming too much. So I left and, ya, I completed some of my studies and I started temping again. And then I became an accountant in City Hospital (laughs). And that was even worse because (laughs) this was an 8 to 10 o'clock in the night job. And, ya, it was terrible, especially with my condition-I couldn't keep up. I find that I can never do a really high role. I was. I was a manageress and I was an accountant and...I mean the salary is higher but the actual role itself - I've taken a step backwards. I've become an assistant to the manager from being an accountant and a manageress. Um, I worked so hard so young to be in positions like that, cos at, I think it was 24 or 23, I was a manageress! Ya, and I did actually...

R: Back off a bit?

M: Ya, I had to say "slow down girl, you're moving too fast. And your mind may be there to keep up with it but your body won't be able to". And within the last 2 years I've had 4 operations, so, there's no way I can do a high job and especially with me, I was a steady student, dux award. 'A' aggregate in matric-everything! I had everything to look forward to. And now - I get jobs. I can put out my CV immediately and get a job. But I actually

pulled out. And my husband is always saying I sell myself short. It's not me, I know I can do the job, it's just my body will not. Nobody's going to give you sick leave in certain positions.

R: So you say it's something...you've backed off from getting the job because you feel, physically, you wouldn't be able to cope?

M: Ya. And I'd rather not try and put myself in that position again. Cos I've been in higher posts. And so I decided to come back here (Laughs). I've only been back since January. I decided to come back here because the environment is more laid back and you can earn a higher salary in a lower post, than in other companies.

R: And I mean, do you feel that actually, in terms of the work that you do, how has it impacted on the work that you do? You've told me that you have to have time off for your ops and to have all those things done. And when you're actually at work when you're having all the cramps...

M: YA (laughs). Uh, okay, there are so many aspects to this, because, so many of the women the completely don't understand. I mean, in the last month or so I got a comment "well we are women as well, so, we don't behave like that". So to some women you're pretending. They can't possibly fathom something like this. "you're pretending". "Why's she holding her stomach and walking?", "Why's she limping and walking", it's got so bad that I bring my hot water bottle to work to keep on my chair - so it's like-why's she bringing in her hot water bottle-she's acting like an old maid! You get one or two women who are the gossiping type who go around saying "Look at this sickly girl!" so you get labelled as a sickly person. And that's enough - that's...I don't know...emotionally I can't cope with it sometimes. Ya, the cramps, sometimes you're in a meeting, and you have to just sometimes hold your tummy, or you have to just go to the toilet and you sit there because the bleeding is heavy, absolutely heavy, you're opening a tap and sometimes you



have to go and sit in the loo and my boss is looking for me (laughs), and I'm lucky now, this time around, I've got a female boss. Prior to this, I've always had male bosses and trying to explain to them is not the easiest thing. To me, male or female, there are not a lot of people who understand. They can't possibly understand, because their wives, their girlfriends or even if it's a women, they have their periods, so. And you're complaining about it!

R: Oh, well everyone has their periods!

M: So why are you over reacting, get on with your life.

R: Ya, some people don't understand the extent of the pain you're going through or what exactly what the condition's about. There's a lot of people that still need to be educated.

M: I'm all for telling people. I'm all for publishing whatever has to happen. I'd like to tell as many people as possible, this is a condition out there and people are really suffering, and the emotional stress of people commenting all the time doesn't help. It doesn't help at all. Because then you get a headache and you take something for your head and take something for your tummy.

R: You said that sometimes you just feel you can't take it anymore and the emotional stress. What is that about. Tell me about the emotional side of things.

M: It's since, I don't know sometimes, in fact last month, I told someone that I can't handle it any more, the comments or the pain. You just start crying at any time. Even if you've taken a painkiller, and the pain is numb, just you know, why do you have to go through this, and now another month, and when is it going to get better. And you know in the back of your mind, it's now going to get better. The doctors tell you, it's not going to get any better, it's only going to get worse. So just pray that some brilliant person will invent something. It doesn't seem to help you out, but it's not going to get better. Sometimes what I do, is that I act that it's not my life. I'm watching it happening to

somebody else. That's the only thing which helps me to cope, just step out of the situation. Just let my mind go. Every time you think about it and you start feeling sorry for yourself, the only thing you do is to cry, because you feel like just escaping sometimes.

R: Is that for you, your way of escaping, thinking it's happening to someone else.

M: Like when I'm in, when I'm having those horrible pains, or when I'm going for an operation, I just imagine it's not me (laughs), it's happening to someone else.

R: How else do you cope with that emotionally?

M: How else! I don't know. That's my main thing, the only thing so far that's helped me all these years, being a Christian – I don't know if I had been in one of those other Indian religions or something, how I would have coped. But, being a Christian has completely helped me in ways which I can't even tell you. I've seen miracles happening in my body, times where I just couldn't manage. I thought I was just going to pass out with pain. And, just pray, and just concentrate on God and know that God controls everything. To know that he can help you through this. I think that is the only only thing which has been helping me to get through. There were times, and I know this is really stupid thinking, but there are times when I was ready to say, I can't take it anymore, I wanna to end my life. In fact, I was very young, only 15 – I started menstruating at only 13 (laughs), the day before my 13<sup>th</sup> birthday and I've never had a non-painful period, never and then from about 15 it started getting really bad. So the thing is, I've been through lots of pain and also support from all my family. I think, the main support from is from the people who've been with me, like my Mom and Dad. They've been with me throughout. You just go to the loo, and you pass out because you're too weak, and you're bleeding so heavily, and you're in so much of pain and you're so drowsy, and you pass out in the loo. It's got to be the most undignified thing ever, when your Dad has to come and take you out, and carry you out of the loo.

R: It's like your self pride as well.

M: I think I do not have completely any more, any more pride, because I've been poked and prodded and I don't know, it's too many operations, too much, I think my privacy has completely been invaded, that's why why (laughs), I don't know.

R: It's almost like your personal space has been invaded.

M: Completely, I don't feel anything is personal anymore. In school everybody just knew that this girl is having her period. At work we all just know when I'm sick (laughs). So there's no privacy anymore you know. It's quite public. She's sick, she's going through it again.

R: Ya, so it's something that's hard to hide from other people, even if you wanted to do, you can't.

M: Emotionally prayer is the only thing.

R: You say that that has been helping you, but it's quite severe when you say that you used to have thoughts of ending your life.

M: And the only thing is that I'm a Christian, and I know that there's greater things, greater reasons for my life and thinking that one day I'll be a testimony to someone else.

Ya, it keeps me going. That's the only thing, Ya.

R: It gives you a meaning for what you're going through.

M: Very early in life - I think I was very young when I latched onto God with all my life, because I needed it, I think I was so desperate then and I think that's what's been keeping me...

R: What's been keeping you going.

M: And now just a step to the loo and I say a prayer, or something like that - God please help me. Like this morning I was cramping, and no-one's there to help me, the only thing you can do is to grab hold of my Bible or something and just pray. Prayer is the only

thing, there's nothing, nothing else. You've been told there's nothing that can be done, so there's only God.

R: You've told me quite a bit about the doctors, and you're saying that on the one hand that the procedures are quite invasive, and you have go through a lot of them, and it's your own body space that's being invaded and it sounds as if you're saying and the doctors are saying that there is nothing that they can do, it's going to get worse. So it sounds as if there is a lot of negativity.

M: I don't think it's negativity, I think it's being realistic. In the beginning, I wasn't realistic. It was like, one operation, I'll be fine and then two operations, no I'll be fine after that one, and then the big one came, and then within November to January this year, I've had two (laughs) – not even three months apart, two months apart – end of January to beginning of January. It's like to have to come to a point where you know you have this disease, or whatever it is. You know you have it, so accept it and that's the only way you will cope. If you tell yourself, no it's going to get better, it's going to get better, you're fooling yourself. So if you accept the fact that's its lifelong and I think when doctors who deal specifically with Endometriosis (name of doctor), he sits you down and says, listen. He's not being negative – I don't think so. He's actually trying to bring to reality.

R: Reality about it.

M: Exactly, because with that severe pain, he's not one to say take an injection, it's going to be fine, because it's not going to be fine. Because, I've experienced 10 years of experience now, I know it's not going to be fine. Its nothing but being more realistic, but the positive part come with me believing in God and I believe that miracles do happen. So, the doctors or anyone can say anything, and the pain can be getting worse, and I know just before I got married, it was really bad and I feel that it's going back to those stages again, after all the operations and things! I think I've gone nowhere. The only thing I

keep thinking is that God will get me out of this somehow. And Ya, that's reality. It's not being negative.

R: It's almost as if the doctor is being realistic, up front with you, direct with you.

M: It's actually much more. It's actually helped me to cope in the last couple of months. Prior to this I used to think it's going to be fine, it's going to be fine. It's not fine and after you've had this procedure and you've taken this medication and it's not fine. What are you left with. Are the doctors lying to you. Then you get the doctors being up front with you and you know what to expect and at the moment I'm prepared for anything.

R: You feel that being up front and realistic about it has helped you. What else do you think doctors could do to help people cope with Endometriosis – I mean in terms of the medical profession.

M: Mmmm...

R: What do you find makes it easier or worse?

M: I'm not really sure..... being up front is definitely a plus, ummm some of the doctors in the earlier days were too afraid to take you into theatre to check what was happening. I don't know. I've been admitted so many times and they've done countless scans and they've told you, we don't know why you are suffering. There's nothing wrong with you – because an external scan can't reveal anything. It can give you ideas what's inside, but can never reveal it completely... So maybe, if someone is complaining of pain, don't treat them as if they don't know what they are talking about. If you suspect it, take them into theatre immediately. Don't leave it for so many years. Because after so many years of pain, and I've been passed from one doctor to another, and to finally tell you, you've got severe Endometriosis at this stage. What if it could have helped, you know, what if I could have ... I don't know. I'm just saying we don't know. Maybe it wouldn't have helped at all if they had diagnosed it much earlier. But what if?

R: What if? But then you're saying that because Endometriosis is a condition that people are learning more now how to deal with. It's almost as a fairly young kind of disease, in that obviously it's been around for a long time but are you saying that because doctors don't know about it so much, or are you saying that doctors are reluctant to do procedures.

M: To me I think that they were reluctant because they didn't know that much about it, now I'm not sure. Now, I'm not sure – there are specialised doctors, but I don't know about other doctors at the moment. I don't know how they are at the moment. I know initially they were really reluctant with me. I was *au fait* – if you want to take me into theatre, take me in, but I don't want to suffer any more. But I kept on having doctor after doctor tell me, there's nothing wrong. We don't know why you're suffering with pain. Like with having to take two boxes of painkillers, in one week of your period, something's obviously wrong. If you're telling the doctor, this is what I'm taking for my pain and I'm still not getting relief – obviously you know – check her out. Take her into theatre, she's not imagining it.

R: So you're saying that physically things alerted you to the fact that something was wrong. You're saying, that on the one hand it was the pain you were going through. What else happened to you? What other physical signs did you get?

M: The reason I knew I had – I had pain now before I even knew that I had Endometriosis, but a lot of women obviously when they're trying to fall pregnant, but mine was never like that. Mine was never like that – terrible, terrible pain. I used to work part-time. I had to stay home the whole day. I had to just crouch in the corner, every time the boss wasn't looking. I used to just hold myself and cry my eyes out, because of the pain. This was from when I was very young – I was still in school – I think because of the excessive bleeding as well. That can't be normal.

R: Heavy periods, Ya!

M: I used to be quite protected and changing constantly through the day, but still somehow I used to mess my clothes – I used to be wearing a blazer on the hottest days.

R: Shame, Ya.

M: Terrible. I was such a straight A student – I can't miss school because of my periods. I used to be absent quite often.

R: Is there anything else? Do you get hot flushes, obviously the cramps you're getting, fatigue, anything like that, any other symptoms that I'll name for you.

M: When you get your very severe cramps, you do get like hot and feverish. Sometimes it's really bad, and your lower back pain. Ya, you get hot and you want to take everything off. It's a tough world. Until we get some form of relief and I think with me, I'm more prone to take the quickest relief – an injection or anything – because I know what's in store if I don't take that, I know what's going to happen. It just gets worse and worse and worse and you almost get paralysed and you can't move with the pain.

R: You spoke of being a Christian and your beliefs are helping you to pray, injections, talking to you – some people will obviously listen. What else for you - I mean if you could tell people what you could do to cope, or is there something that other people could do to help you to cope? What would that be?

M: You are starting a pain in your tummy and your back, but your head gets sore, your muscles tense up all over your body. So much of side effects to your medications – my husband knows that and then he like gives me a massage – that helps – physically that helps. Emotionally, I don't know. I think that as month by month by month goes by and in the beginning certain people are supportive and then afterwards they get tired you know – not again... So, just if people don't act like – oh, not again. People should think, that it's the person. Imagine, if you're thinking, oh there she goes again, imagine what she's

going through, having to feel that pain, month after month. Rather than you just being annoyed because I'm sick month after month. Just think she's the one going through it month after month.

R: She's actually experiencing it first hand.

M: Exactly. So, don't be annoyed. Be supportive or just stay away. That's a good thing – if you've got anything negative to say or to think, rather stay far away than come to ask questions. And that's another thing, when you're having severe cramps, you don't want people coming and asking you questions and pestering you and things.

R: You don't want to explain about it.

M: Exactly.

R: You mention people to be supportive – what would supportive be? Could you define it and give people almost like a list of things – what would that be?

M: (Laughs) When I'm at work – its like I can't walk to get a cup of tea, so if you have a friend there to help you, who knows there are certain days you can't manage. Sometimes I just go without eating or anything, because I can't manage to go up the stairs. I can't manage to walk even to the lift. The only thing I want to do is to walk to the loo and back and that's even a mission for me, so just someone offering me a cup of tea, or something you know, so instead of going without or struggling to do it yourself. Ya, things like that. At the moment I've got pretty supportive people with me at the moment. Like the one girl, out of the blue the one month, she buys me that little heater pad and says try this out the next time you're in pain. Ya, our secretary, our PA – she normally asks me if I'm OK, if I need anything. All those little things help, and especially if you've got a supportive boss – like my boss is really supportive. She tells me that if I need to put my head down, put your head down. If you need to go home, go home. If you're tired, don't come into work. But I'm the type of person who likes success, so for me to not come to work



because I've got my period, I know if I stay away this week, then I'll have to stay away next month and the month after. So I make sure I push myself and come to work and everything and because I'm doing all that, she shows her appreciation, she tells me and buys me chocolates. There's also good things, like I told you with my husband, it goes through my mind – they don't come out and tell you, listen we're annoyed with you, listen you're sick again, but it's in your head, you're feeling it. You feel as if these people have all these thoughts about you and you feel as if everyone knows and that everyone's frustrated with you. So when my boss had just heard that I have to go through the GIFT procedure, she comes in and tells me, that although it's going to be a hectic time for us, we'll manage, don't worry and somehow we'll cope. She says that if I can relieve any stress and I know you must be stressed about the procedure and how you are going to cope with your work and things – so don't worry, we'll manage. There's so many things going through your mind, so if someone says it's OK. Like sometimes my husband tells me, when I have to ask him are you frustrated and he says it's not your fault. But he could say that I know what you're going through or something like that – just before telling you that I understand. I know that we can't do anything about it but just to say I know what you are going through, I understand.

R: Just to say I accept it.

M: Ya, that would help.

R: So social support seems to play quite a big role.

M: It does help, although you can't take away the pain, but somehow emotionally it helps. It relieves you of those thoughts that are going through your head of what's he thinking or what's she feeling? They must think I'm such a useless person or something. But if they tell you straight out, we have faith in your ability but we understand that you can't cope at

this point, but the other three weeks of the month, you more than make up for it. Ya, that helps that so much.

R: That's quite a lot about work and at home – what people can do there. But in terms of the medical profession – can they give you that type of support or do you feel that they haven't been that good. I mean, obviously I am not going to mention this to any of the doctors – this is confidential, but have they or have they not helped.

M: Well I used to go to (doctors name) who passed me onto my present doctor (doctors name) and he had this way of making you feel absolutely comfortable with yourself. You are comfortable with everything – he's a more loving, more caring doctor, so you're happy to talk to him and to discuss your pain. But with (doctors name), it's more technical – I don't know you get this from other people. I've spoken to other people about him – he's very reserved. Very little emotion comes through. Everything's technical and lecture type like you know. You don't get that emotional support from him.

R: That would help things?

M: Ya, a different approach to things, cos we know I'm in this pain, but to be more gentle. I don't know how to say it, but, Ya, more emotional support.

R: And in terms of having procedures done is there anything that they could do?

M: What I do know, um, my first two procedures were done by (doctors name), and he's very good, but I suffered with a lot of pain. But the two procedures that (doctors name) did for me – somehow, I don't know what he does, but you tend to heal much quicker – he probably cuts you or puts the incision in places where movement doesn't hurt as much. Look it's very painful – it has to be, but not as much. So, whatever he's doing, he is doing is right.

R: So, that helps you....

M: So, if that I know that I have to go for that operation and things, and I'm fine to do it, because I know that within a couple of days I'll be fine. I'll heal quickly. But somehow I don't know what he does, but you heal much faster.

R: So it's his technique...

M: But then again I went for a hysteroscopy with him and bled for 30 days. That was done in his Surgery. I don't feel that things done in his surgery are the thing – I'd prefer him to take me to theatre.

R: It's better to go into hospital to have it done...

M: Ya, doing it in his surgery, I don't know – I don't feel the same cos... I just don't. Maybe it's particular just to me. I'm very queasy. You can poke me, cut me, do whatever you want to me, I just don't want to see it. When they force you, when they're doing a hysteroscopy to look at the screen – full camera view inside of you. It somehow emotionally makes you feel more pain. I prefer not looking. I don't care what you have to do to sort it out – I don't want to see it. I hate looking. I don't want to see what they're doing inside, because with the pain that I already have, it just somehow intensifies it when you can see it – emotionally maybe. It's all in my head, but the fact that you can see it happening makes it so much worse. Maybe it's just me... I don't know.

R: But, it's good to know...

M: I don't like looking.

R: I know your lunch break is probably coming to end now, but tell me is there anything else that you want to say, anything that I haven't asked you that you want to say something about.

M: No, not really. If you want any more information you're welcome...

R: I'll come to you. You've told me quite a lot about your condition and how it affects your relationship with your husband and your family and how culture plays an important

part and what helps you to cope and what hasn't helped you to cope. Those are all important things because obviously the more people who understand impact on all these other things that affect you. It gives you more ways to come in and tackle the problem, rather than just physically. You know how else can you come in and try to help things.

M: Just now we're going through a really emotional stage where we're being told that we need to fall pregnant pretty quickly. All these procedures and things, and I can't believe it's come to this stage. I think at least we're getting there you know, but actually now I have go for a programme for fertility and these are expensive things, and chances of success are so minimal, and you're paying so much each time. So, it's like a new phase, and I know we're in for so much of disappointment, but also there's this very small chance that it could work. So that's the only thing that keeps me going...

R: The chance that it keeps you wanting to give it a try...

M: Otherwise why put yourself through all this.

R: So that's the next step...

M: The pain has gotten really bad, sharp...

R: I wish you all the best – it's on Wednesday that you find out...

M: I'm actually going to (doctors name) – he's the fertility specialist – so, he's going to tell us. We went for lots of blood tests. We're just waiting for the test results and then from there, take the next step. I don't think it's not a good time of the year to be going for any procedures, because it's year-end for us in October and I write my final exam for my B Com in October.

R: So, you're studying as well.

M: Ya, I had to leave Varsity full time because it was getting too much and I did it part-time and ya, if my exam was ever scheduled for a day when I had my period, I had to not turn up for the exam. I had to give writing so many papers because of my period.

R: Because of that – that's awful.

M: So my studies have dragged for somebody who's taken a Dux award at school, to be finishing a degree nine years later – it's not too impressive, but for me it's a major achievement, considering what I've been through.

R: So, you write your exams in October.

M: I think this whole thing is scheduled to go through in October, so....

R: Well at least you're doing things to manage your stress as well, because obviously stress can make it worse. If you can keep any eye on that.

M: Running helps, very aggressive gym helps.

R: So you're been doing that. Well thanks very much. I appreciate your time – especially your lunch break.