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The Endometriosis Stories: A Narrative Analysis

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ABSTRACT

Endometriosis is a chronic and, complex gynaecological condition. The range of symptoms, issues related to diagnosis, varieties of treatment, differing theories of etiology, all contribute to its complexity. The principal symptoms associated with the condition are pelvic pain and heavy menstrual flow. Many women with endometriosis also experience fertility difficulties. As a chronic illness, particularly one strongly associated with pain, endometriosis can be constructed as leading to physical and psychosocial distress. Further, many women have experienced many years of unexplained symptoms or have received unsatisfactory explanations for these symptoms, such as 'it's part of being a woman' or 'it's all in your head'. My own personal experience of having endometriosis together with listening to many other women's stories over the years about their endometriosis experiences, stimulated my interest to learn more and, thus, the endometriosis experience became my PhD research topic. To date, little research has been conducted on the psychosocial side of the endometriosis story. I considered it was time to privilege the women's stories and let their voices be heard. I hoped to add to the biomedical story which was dominating what was disseminated about endometriosis.

The research is based on the objectives of examining women's experiences of endometriosis with respect to their identity and to learn how the women made sense of events, particularly unexplained symptoms. Relating the condition to what health psychology has to say about illness, I could understand how women may experience the condition as a disruption to their lives. But how did they experience this disruption? How did they feel about themselves? In other words, was this disruption constructed as a challenge to their identities and, if so, in what ways and what did they do about it? To answer these questions I decided that some form of narrative analysis would enable me to find answers or, at least, be able to find a way in to these issues.

I interviewed twelve women in the Manawatu region of New Zealand who had been diagnosed with endometriosis no less than two years earlier.

My research is underpinned by social constructionist epistemology. After several attempts to use some forms of narrative analysis which I decided were not appropriate for my study, I developed a form of narrative analysis comprising graduated levels of explanation and meaning. The first level involved writing individual stories from each woman's accounts. From these stories I was able to gain an overall impression of what their stories were about and what each woman was trying to express to me at that time. The next level related to the identification of narrative themes and from these I analysed the way identity was expressed. The third level of meaning involved an analysis of the process of construction of the women's narratives as well as the content. Narrative devices, such as imagery and metaphor, for example, were identified. I noted where the women seemed to be drawing upon their personal narratives as well as the cultural narratives to construct their endometriosis stories.

Identity was analysed in the narrative themes concerning fertility issues, relationships, occupations, and self-concept, both physical and psychological. Some of the women constructed their stories as, what I have termed, a victim, while others assumed, what I have termed, the role of controller. Diagnosis was constructed as an important reference point for the women and was reflected in the way they talked about their sense of identity and how it was either reconstructed or maintained over time. Making sense of events in their endometriosis experiences focussed strongly on how the women understood unexplained symptoms. Such perceptions were termed as a 'normalising' story or, as a 'resisting' story. The often long period of time prior to diagnosis was expressed as a time of physical and psychological distress. Once the women had made sense of their symptoms they were able to take control of their bodies, rather than allowing the endometriosis to control them.

Overall, the findings from my research have contributed to a greater understanding of endometriosis from the women's perspectives. By adding research like this to the biomedical account of the condition, we are contributing to a growing, collective endometriosis narrative. Such a narrative comprises the biomedical story, personal accounts from individual women, together with a growing range of research analysing the psychosocial experience.

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This thesis is dedicated to the memory of

Joan Robin Moultrie

a founding member of the NZ Endometriosis Foundation

4 June 1943 - 29 September 1998

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Chapter One

The Nature of Endometriosis

I must say that the experience (endometriosis) has been the most challenging physically, mentally, emotionally, and spiritually that I have been through. It is stressful in every way... (Woman with endometriosis, 2000)

What is it about the experience of endometriosis that leads women to express such strong sentiments? The above quotation from one woman encapsulates well what many other women also say about living with this condition and I have heard similar views expressed time and again. As I describe in this chapter, my interest was stimulated to find out more about women's endometriosis experiences. I wanted to listen to their stories, analyse them and gain a better understanding of such experiences.

In this chapter, I outline how I came to select endometriosis as my PhD research topic and briefly mention my choice of narrative analysis. In the following section, I then set out what is known about endometriosis, portraying mostly a biomedical account of a perplexing, gynaecological disease. I then present the limited literature pertaining to the psychosocial issues which can arise from having endometriosis, examining both the quantitative and the qualitative research. I note that, to date, little formal research has been conducted and published in the area of psychosocial issues related to endometriosis. Consequently, much of what I have learned has been through more informal publications and conversations with endometriosis sufferers. Finally, I introduce the present study in brief, overview terms.

Why Study Endometriosis?

Over several years, I had learned a lot about the distress and difficulties which women with endometriosis experience with this condition. As I have endometriosis, and my eldest sister once suffered from it, I also had my own personal experience upon which to draw. I read many magazine articles and books and, spoke to a wide variety of women about their experiences of endometriosis. As a member of the New Zealand Endometriosis Foundation, I attended support group meetings, seminars and conferences and, during these events, heard many stories. Many of these stories were filled with despair, frustration, depression and anger about the women's endometriosis experiences. After reading and listening to many such accounts, my interest in researching the psychosocial aspects of this condition was fostered. However, most of the published work in this area was confined to a chapter or two in the few books written about endometriosis. To date, very little work on the psychological, or psychosocial issues surrounding endometriosis has been published in journals. In order to seek more information, I joined an endometriosis website and read through literally hundreds of communications across the site as women poured out their endometriosis stories, asked questions, shared ideas on conservative, radical and alternative treatment therapies, as well as giving to one another the support they seemed to so desperately need. I say 'desperately' as some women spoke of severe depression, thoughts of suicide, being isolated in their suffering and many others gave accounts of being dismissed and not believed by their doctors. After two or three weeks of reading these messages across the web, I unsubscribed. I could no longer deal with reading up to 130 messages a day!

My consequent concern with the apparent distress and difficulties associated with living with this gynaecological condition, was the catalyst in formulating my ideas for a PhD research topic. My broad objective was to learn more about

the condition by analysing women's stories of endometriosis. I knew about the common and not so common symptoms. I had gleaned a reasonable idea of how many of the women suffered physically and I also knew that some women did not, in fact, experience physical distress. What were the implications for their lives of having a disorder which might lead to infertility? Did their symptoms somehow stop them leading the sort of life they wanted to live? What was it like to go for years without being diagnosed? How did other people relate to their condition? Although, at one level, I had learned some of the answers to these questions, I also wanted to know if, and how, women's experiences of endometriosis affected their identity. I decided that narrative inquiry would be an appropriate entry into learning more about women's endometriosis stories. Not only would narrative inquiry enable me to examine the ways a woman's sense of identity may be challenged, but it would also allow me to learn about the way she made sense of her experiences across time. I envisaged that my research could enrich and widen the knowledge we already had and, hopefully, reach both lay people and medical people alike, in an effort to broaden their understandings of this gynaecological problem.

The following section sets out what is known about the condition, but it presents a fragmented picture, portraying mostly a biomedical account of a perplexing disease. Even this biomedical information is incomplete as we learn that medical researchers are still seeking answers to basic questions such as etiology, prognoses and cures. This section is therefore presented both as a summary of medical facts and figures and an examination of the work that has been carried out on the psychosocial side.

What is Endometriosis?

Endometriosis is a very perplexing condition. The many symptoms, effects, diagnostic issues and varieties of treatment, together with conflicting opinions

of etiology, all contribute to its enormous complexity. Despite intensive research over the past few years, endometriosis remains a baffling and elusive disorder. At present, the incidence, etiology and pathogenesis remain speculative.

The first known report on endometriosis was in 1860 and, until 1920, little research was published on this condition (Barbieri, 1995). A chronic, non life-threatening gynaecological disease, endometriosis is characterised by the development of endometrial tissue outside the lining of the uterus. The most common location is in the pelvis, mostly on the ovaries, but can also be found in the fallopian tubes, the uterosacral ligaments, the outer surface of the uterus and in the recto-vaginal pouch (Moghissi, 1995). Other, more rare, sites include the diaphragm (Redwine, 1994), bowel, bladder, cervix, vagina (Buttram, 1978; Moghissi, 1995), umbilicus, bronchi, lungs and kidneys (Moghissi, 1995). (Polan, 1995) describes endometriosis as 'A continuum of changes that begins at the cellular level and is fully exposed as a debilitating, painful disease' (p.ix).

The true incidence of endometriosis is unknown, but has been reported as anywhere between 1-53 % of the female population (Berger, 1995). Rare cases have also been reported in males (Schrodt, Alcorn & Ibanez, 1980, cited in Franklin & Grunert, 1995). Diagnostic problems, coupled with the sometimes asymptomatic nature of the condition, seem to be the main reasons why actual frequency has not been determined. Accordingly, while there is no definitive, non-invasive test for diagnosing endometriosis, incidence rates will remain unknown (Berger, 1995).

Until recent years endometriosis was known as the career woman's disease, as it was associated with delayed childbearing in women from a higher socioeconomic class. It was also believed that it only affected white women.

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However, differences in social class prevalence tended to reflect the differential diagnosis for lower social classes and black women, who were once diagnosed as having pelvic inflammatory disease (Ballweg, 1996; Low & Edelmann, 1991). While endometriosis is considered to be a common problem in women from all age groups (Ballweg, 1996; Weinstein, 1987), although it is rare prior to puberty and after menopause.

Endometriosis is one of the most common causes of pelvic pain and infertility (Berger & Nezhat, 1995) pelvic pain, specifically dysmenorrhoea, or menstrual pain, being the most commonly reported symptom (Ballweg, 1995). Other pain symptoms include dyspareunia, or painful intercourse, lower abdominal pain, lower back pain, bowel and ovulation pain (NZ Endometriosis Foundation Inc, 1995). Other symptoms commonly include heavy menstrual flow, fatigue, bowel problems and muscular aches (Ballweg, 1995). Conversely, endometriosis can be asymptomatic (Berger & Nezhat, 1995) which is a further contributing factor to the undetermined prevalence of the condition. Some researchers, for example, have found little relationship between the severity of pain and the stage or site of the dyspareunia and dysmenorrhoea and the degree of endometriosis (Fedele, Parazzini, Bianchi, & al, 1995). (Perper, Nezhat, Goldstein, Nezhat, & Nezhat, 1995), on the other hand, found that the intensity of dysmenorrhoea was related to the number of endometrial implants, while (Fedele, Bianchi, Bocciolone, & al, 1992) found that severe pelvic pain does seem to be associated more strongly with advanced stages of endometriosis than earlier stages.

A consensus has not been reached as to the etiology of endometriosis. Theories include retrograde menstruation, where menstrual tissue migrates through the fallopian tubes, implants and grows in the abdomen (Sampson, 1927, cited in (Ramey & Archer, 1993); a congenital birth defect (Redwine, 1994); autoimmune

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disease or suppressed immune system (Hill, 1992); and the relationship between peritoneal fluid and the growth of ectopic endometrial tissue (Ramey & Archer, 1993). Perper, Breitkopf, Breitstein, Cody, & Manowitz, (1993) has also found a correlation between high alcohol consumption and gynaecological problems of endometriosis. Additionally, endometriosis appears to coexist with other health-related problems, including irritable bowel syndrome and fibromyalgia (Ballweg, 1995). A large research project, the Oxford Endometriosis Gene Study (Oxegene), is presently being conducted at Oxford University, England, looking at possible genetic links (Oxegene, 1999, September).

The Endometriosis Association's (1999) survey of over 4000 endometriosis patients in the United States and Canada, shows that endometriosis is associated with a higher incidence of some forms of cancer, specifically ovarian cancer, melanoma and breast cancer. They note that these findings parallel other research, including a study of 20,686 cases in the Swedish registry which found an increased risk of ovarian cancer, breast cancer and non-Hodgkin's lymphoma in women with endometriosis. The USA results show that among the women with endometriosis, there was: a 9.8% incidence of melanoma, compared with 0.01% of the general population; a 26.9% incidence of breast cancer, compared with 0.1% of the general population; and an 8.5% incidence of ovarian cancer, compared with 0.04% in the general population.

The diagnostic process can be of potentially long duration, owing to the uncertainty and ambiguity of the condition. As the symptoms of endometriosis are similar to other disorders, they are sometimes differentially diagnosed as abdominal complaints such as inflammatory bowel disease, ruptured appendix or diverticulitis (Shah, Tager, & Feller, 1995). Further, as Robert Israel, M.D., chief of gynaecology at the University of Southern California School of

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Medicine, (cited in Cool, 2000) expresses: "There isn't just one symptom everybody gets that jumps out, bites you, and shouts, 'This is endometriosis!'" While laparoscopy, a surgical intervention, is the sole definitive diagnostic technique presently available for endometriosis (Moghissi, 1995), medical professionals may be reluctant to submit a woman to surgery if they consider the symptoms may have a different cause. These difficulties may result in several years duration from the onset of symptoms until diagnosis.

There are further salient factors which can contribute to either a lengthy delay in diagnosis or non-diagnosis. Women are sometimes informed by their practitioners that their condition is psychosomatic, which Ballweg (1995) considers to be just one of the misconceptions surrounding endometriosis. For others, non-diagnosis can carry the implicit message that their symptoms have a psychological origin. Women who are told by their mothers or their general practitioners that to experience menstrual pain is normal, may tolerate prolonged discomfort and delay seeking further help. Also many women believe their problems are normal, having grown accustomed to severe symptoms from an early age, thus leading, in some cases, to several years before consulting a physician. Cool (2000) notes that in a 1998 study of 4000 women conducted by the Endometriosis Association in the USA, less than 25% suspected endometriosis before it was diagnosed, while 60% normalised their symptoms. Sixty-one percent of the women studied said the first doctor they consulted informed them nothing was wrong and nearly 50% of them had to see a doctor five or more times before receiving a correct diagnosis. Sixty percent of the women thought their problems (symptoms) were normal. However, on a more positive note, there appears to be a positive change in the attitudes of gynaecologists and doctors to women with endometriosis. Such changes in attitudes may see reduced diagnostic times and, accordingly, reduced suffering for women with endometriosis symptoms. The

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asymptomatic nature of endometriosis may mean the condition goes undiagnosed or perhaps later discovered when a woman is being treated for problems related to other organs. For example, she may present with bowel problems and then learn, after surgical intervention, she has endometriosis. In some cases, the disease may only be detected if a woman is undergoing a hysterectomy or an autopsy is being performed. In other cases, a woman experiencing fertility difficulties may undergo investigations, including a laparoscopy, which shows she has endometriosis.

The endometriosis diagnosis provides, not only validation of symptoms, but also confirmation of organic pathology. It then forms a base from which to initiate treatment choices. As long as the condition remains undiagnosed, a woman is excluded from suitable treatment. Even if she does not choose to have surgical or medical intervention, there are alternative ways that can be helpful in managing symptoms, and these avenues are not always open to an undiagnosed woman. Those who remain undiagnosed, and who are experiencing chronic pain and other symptoms, may be at risk of both physical and psychological distress.

There is no definitive cure for endometriosis. Medical or surgical treatment, or a combination of both, are the principal approaches to management of the condition. Conservative surgery involves the removal of endometrial implants, scar tissue and adhesions, either by laparoscopy or laparotomy. With radical surgery, the uterus, or uterus and ovaries, are removed. Hormone therapy is used in medical treatment to prevent ovulation and menstruation, with the aim of reducing endometrial deposits. The oral contraceptive pill may be prescribed to reduce pain during menstruation and suppress ovulation (NZ Endometriosis Foundation Inc, 1996). Alternative therapies which may be sought include homeopathy, osteopathy, herbalism, naturopathy, diet,

nutrition and vitamin supplement programmes (Ballweg, 1988; Weinstein, 1987). In a recent Endometriosis Association survey of 2300 women who had tried natural remedies, 40-60% reported that supplements, acupuncture or herbs alleviated their pain and other symptoms (Cool, 2000). Along with good nutrition, regular gentle exercise is also recommended (Fromer, 1998).

As Buttram (1995) discusses, there are several, salient factors to be considered, both by the woman and the practitioner, when choosing treatment. Surgery and medical suppression both have significant drawbacks. Surgery can lead to post-operative adhesions, causing infertility, endometriotic deposits may not all be removed in case a vital organ is harmed, microscopic implants are not attended to, health risks and pain may be great, and the operation can be very expensive. Medical treatment may not always be an effective measure due to the possible recurrence of endometriosis after discontinuation of drugs, dense adhesions not being affected and, sometimes, intolerable and possibly harmful side effects to the woman. However, Buttram (1995) considers a combined medical and surgical treatment the best approach to eradicating adhesions and improving chances of pregnancy for otherwise infertile women.

Weinstein (1987) notes that the treatment phase can be very stressful for most women, often characterised by disruption and confusion. Women may feel overwhelmed and helpless as they try to choose appropriate treatment and learn more about their condition. Even after treatment, symptoms may return which may necessitate the woman having to make further treatment decisions. Berger (1995) points out that 'Without understanding the cause of endometriosis, we can neither prevent nor cure the disease; management is the best option we can offer at present' (p.288).

In summary, the prominent features related to endometriosis are the often distressing physical symptoms, particularly pelvic pain and heavy menstrual flow. Fertility difficulties are also related to the condition which, in turn, can be a source of emotional distress. The diagnostic process can be of long duration. The etiology is unknown, the course of the disease is uncertain and there is no known cure. However, endometriosis, in many cases, can be effectively managed, particularly where good nutrition and gentle exercise complement an individually planned therapeutic regime.

Psychosocial Issues

As a chronic illness, endometriosis is typically associated with psychological issues, particularly those related to the experience of pain. There are also other factors of psychosocial importance, such as self-image, ability to work, involvement in leisure activities and relationships. The following research highlights the psychological aspects and psychosocial concerns relating to the experience of endometriosis.

The quantitative research conducted on psychological aspects of endometriosis has tended to focus on the psychological profiles of women experiencing chronic pelvic pain. The psychological profiles largely contain measures of psychological constructs such as depression, anxiety, neuroticism and hypochondriasis. There is sufficient evidence to support the idea that women suffering from chronic pelvic pain may also experience consequent adverse psychological symptoms. Chronic pelvic pain groups of different pathologies have tended to show elevated levels of psychological abnormalities including mild depression (Low, Edelmann, & Sutton, 1993; Renaer, Vertommen, Nijs, Wagemans, & Van Hemelrijck, 1979; Waller & Shaw, 1995), hypochondriasis and hysteria (Renaer et al., 1979), anxiety and neuroticism (Low, Edelmann, & Sutton, 1994). These findings lend support to Pearce and Beard's (1984) review

of studies relating to women with pelvic pain, which revealed that most of these women had abnormal psychological profiles, as measured by the Minnesota Multiphasic Personality Inventory (MMPI). These 'abnormal' psychological profiles indicate that the women in these studies had higher levels of the psychological 'abnormalities' noted above, than women without pelvic pain. Gath et al's (1987) community survey of 521 women, also found that psychiatric morbidity and neuroticism was significantly associated with a wide range of gynaecological symptoms with neuroticism being strongly related to dysmenorrhoea.

However, we have to be careful in interpreting the results of these studies. Are the so-called abnormal psychological profiles the result of having chronic pelvic pain and, in this case, endometriosis? Or, does the co-existence of these psychological abnormalities suggest that they may be attributes of women with endometriosis? The following studies exemplify both possibilities.

The preliminary findings of a 1987 study of 16 women with endometriosis suggest a relationship between endometriosis and mood disorders, in particular, bipolar disorder (Lewis, Comite, Mallouh, Zadunaisky, & al, 1987). Twelve of the subjects met the DSM-III criteria for a mood disorder (seven for bipolar mood disorder, mixed; three for bipolar disorder, manic; and two for major depression); two had symptoms of mood disorder which were not sufficient for a diagnosis; and two had no evidence of mood disorder. The authors also noted that abnormal levels of the same hormones have been implicated in both endometriosis and mood disorders. All of the women with 'well documented bipolar or major depressive disorders' (p.1589) reported experiencing their first episodes before receiving a diagnosis of endometriosis. This study suggest that endometriosis and mood disorders, particularly bipolar disorder, may be closely related. I note that there was a small sample of

subjects and there was no comparison group. Further, the women were already known to have endometriosis by the researchers as they were being treated for endometriosis at a women's clinic at a university hospital. I believe that knowing the women had endometriosis could bias the findings.

Walker, Katon, Jones and Russo (1989) followed up Lewis et al's (1987) study in order to compare findings. Sixty-nine women, selected from laparoscopy schedules and whose laparoscopic results were not known by the psychiatric interviewers, comprised the sample. Fourteen of the women were found to have endometriosis. Unlike Lewis et al's study, Walker et al's study contained a comparison group, and the endometriosis group were unknown to the researcher. Contrary to the findings of Lewis et al, they did not find a link between affective disorder and endometriosis. They suggested that Lewis et al's findings may have been biased as they knew the women had endometriosis. They went on to note that Lewis et al's sample was not a heterogeneous mix of subjects and may have contained an over representation of patients with psychiatric illness as they stemmed from a university clinic. The latter many not necessarily be true. Just because the women were attending a university clinic for endometriosis treatment, should not suggest they may contain a higher representation of patients with psychiatric illness than a group derived from a more heterogeneous source. However, the rationale behind Walker et al's assertion derives from their citing of other studies, such as Gath et al (1987), that psychopathology, most commonly affective illness, were significantly related to a broad range of gynaecological symptoms. Thus, they argue, if the women in Lewis et al's study had gynaecological symptoms, they may have had higher than normal rates of psychopathology. However, it is not clear, in fact, whether these women did have gynaecological symptoms. Accordingly, the results of Lewis et al's (1987) study are equivocal.

Waller and Shaw (1995), on the other hand, suggest that the distress resulting from chronic pain may be the pathway which leads to psychological abnormalities. They conducted measures on four groups of women. The control group ($n = 38$) were patients admitted for sterilization and found to have a normal pelvis. Group 2 ($n = 31$) were women having fertility difficulties and found to have minimal or mild endometriosis. Group 3 ($n = 18$) consisted of women with minimal or mild endometriosis complaining of one or more of the following: dysmenorrhea, dyspareunia, or pelvic pain. Group 4 ($n = 30$) were patients with pelvic pain symptoms and who had no obvious pathology at laparoscopy. In their study, the group of women with asymptomatic endometriosis and fertility difficulties did not show any psychological abnormality on measures of anxiety and depression. The women in the pain groups, 3 and 4, had higher mean scores on the Beck Depression Inventory than Groups 1 and 2. No significant differences were found between the groups for the Speilberger State or Trait Anxiety scales. The authors conclude that it does not seem certain psychological features make some women more vulnerable to developing endometriosis. Rather, they suggest, it is the substantial distress experienced by women with chronic pain which leads to any abnormalities in psychological functioning.

While Waller & Shaw's study did not indicate psychological abnormalities arising from the group of women complaining of infertility, Low, Edelmann and Sutton (1993) found that the women with endometriosis showed elevated levels on anxiety scores when compared to normative data on general medical and surgical patients. Low et al's study consisted of 95 women attending a gynaecological clinic; each woman being interviewed two weeks prior to undergoing a laparoscopy. They were psychologically evaluated using six questionnaires, Eyesenck Personality Questionnaire, Beck Depression Inventory, General Health Questionnaire, State-Trait Anxiety Inventory, the

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Golombok Rust Inventory of Marital State and the Short-Form McGill Pain Questionnaire. Relatively mild levels of depression were observed in both groups, that is the endometriosis group, and the group who had gynaecological problems other than endometriosis. However, the endometriosis group had higher scores on psychoticism and both state and trait anxiety. The authors suggest that the raised state anxiety for the endometriosis group may be attributable to the greater risk of infertility and the uncertain prognosis of endometriosis yet these factors cannot account for the elevated dispositional anxiety scores. They conclude by acknowledging the possibility of anxiety being a vulnerability factor, which means that such women are more prone to endometriosis.

Pre- and post-treatment studies of chronic pelvic pain have found that a reduction of, or an end to, pain is associated with a significant reduction in depression scores (Low et al., 1994), or a return to normal levels on measures of neuroticism (Sternbach & Timmermans, 1975). The authors conclude that anxiety and depression is a consequence of experiencing chronic pain, as opposed to an antecedent. The negative effects of chronic pain can also impact adversely on marital and family functioning (Weinstein, 1987).

What does this research show us? While some of these studies suggest that psychological effects derive from the woman's experience of chronic pelvic pain, there are some findings which point to the possibility of psychological abnormalities co-existing with, or perhaps functioning as triggers to the development of endometriosis. I conclude that it is difficult to draw a strong conclusion from these findings. As not all of this research focuses solely upon endometriosis but is generally concerned with pelvic pain, we cannot draw conclusions with respect to women with endometriosis.

Grace (1995) conducted a combined qualitative and quantitative study of New Zealand women with pelvic pain, many of whom had been diagnosed with endometriosis. She identified the following issues: a long wait before being referred to a gynaecologist, a continuing lack of diagnosis, communication problems with doctors, inadequate explanations, belief that the doctor has indicated that there is nothing wrong, or that the woman is 'neurotic', unsatisfactory explanations, loss of confidence and disillusionment with the medical profession's ability to assist. With respect to medical encounters Grace concluded 'It is clear from the results of this research that the doctor's dismissal of an absence of a physiologically-based diagnosis as "psychological" or "neurotic" is highly problematic in many ways' (p.48). She found that women from a lower income group were more likely to experience the above problems than those from a higher income group. Grace concluded that a lack of diagnosis is not always a clinical problem, rather, a sociological one. Although socio-economic status has not been considered in my study, I consider that these findings are important to bear in mind when drawing conclusions about the implications and possible reasons for diagnostic delays.

With endometriosis the pain is not always confined to the pelvic region but may also be manifested in other sites and cause further problems. For example, endometriotic implants can cause severe pain during penile penetration. Painful intercourse can lead to relationship difficulties, characterised by a breakdown in communication, a loss of intimacy, erosion of romance, distress and, for single women, avoidance of new relationships. An adolescent may learn from an early painful sexual experience that this is the norm, resulting in adverse effects on sexual development and body image (Weinstein, 1987). Not all women experience pain and not all adverse psychological effects necessarily derive from pain. Infertility, for example, is another symptom which may leave a woman feeling powerless, depressed and a failure as a woman (Weinstein,

1987). Therefore, while the foregoing research has established the presence of psychological distress related to the endometriosis experience, the nature of the relationship is still unclear. For example, some studies have shown that women with endometriosis may experience depression. Is the disease itself causing depression, or is it because the woman has a chronic condition with no cure? Hormonal influences, for example, whether through natural occurrence or through medication, may also lead to mood change (Low & Edelmann, 1991). Perhaps it is because the woman is infertile, or she is no longer able to work full-time.

A recent study by Redman (2002) comprised a group of 167 Australian women with endometriosis. They completed a questionnaire containing questions of length of time from commencement of symptoms to diagnosis and number of treatment procedures; a depression scale, a measure of dispositional optimism and questions from published scales to measure feelings of helplessness. As Redman points out, endometriosis sufferers do not necessarily experience pain or fertility problems. Thus she focussed her study on issues related to lengthy delays in diagnosis and multiple treatment procedures. Drawing upon Seligman's (1975, cited in Redman, 2002) theory of helplessness and his theory of explanatory style (1990, cited in Redman, 2002) she hypothesised that endometriosis sufferers with a positive explanatory style would be less likely to generalise feelings of helplessness due to personal factors and thus be less likely to become depressed, while those women with a negative style may become depressed. Her results showed that '56% of the women were depressed, compared to 11% of the normal Australian female population; 45% of heart attack victims; 42% of hospitalised cancer patients; and 40% of recent stroke survivors, people with multiple sclerosis and Parkinsons disease' (p.13). I do not know if the latter groups were mixed, or only female. While her analysis was not able to identify a relationship between either diagnostic delays

or multiple treatment procedures and depression, she did find that dispositional optimism was found to be a moderating factor between delays in diagnosis and depression, with low optimism related to higher depression scores. Redman suggests a woman's level of optimism may fall because she is depressed. She notes that women with endometriosis experience more than seven different procedures on average and 61% try some form of natural therapy, as well as medical and surgical treatments. Redman suggests that because they are taking control of their treatment, as opposed to leaving it to medical professionals, this could be a reason for this factor not leading to helplessness and depression. She also notes that many of the women did not consult a doctor at an early stage, with 70% suffering symptoms for over a year before seeking medical advice, and over 27% waiting longer than five years. She suggests that increased education about endometriosis may help improve this situation. Redman's result of high numbers of women experiencing depression is an important finding. I consider this study is an important step forward in endometriosis research. It is not just focussed upon pelvic pain; it also looks at other issues directly relevant to the women with endometriosis, namely delays in diagnosis and multiple treatment procedures.

To date, little in the way of qualitative work has been published relating to endometriosis. However, many individuals' accounts have been published in popular magazines, across the Internet and in a few books. The following examines some of these.

Weinstein's (1987) book, 'Living with Endometriosis' gives information and advice to women with endometriosis and I selected it to exemplify the few books on endometriosis published for this purpose. Weinstein discusses treatment and the experience of living with continuing symptoms. Her examination is highlighted by extracts from several case histories of women

with endometriosis. She notes how treatment can be characterised by disruption and disorder and conceptualises it as having five stages: the initial disruption, the dilemma of which treatment to undertake, living with treatments, waiting and worrying as the results of treatment are monitored and, lastly, persistence and recurrence: the treatment carousel. The latter refers to those women for whom treatment has not been successful and find themselves repeating the above, their day to day life and long-term plans being turned into a treatment carousel. Weinstein points out that the decision as to which treatment to choose can be difficult and very trying for most women, thus treatment can be a disruptive, confusing and stressful time. Weinstein goes on to highlight the troubles often experienced when living with continuing symptoms associated with endometriosis - pain, infertility and sexual difficulties. She explains the issues related to the pain cycle, such as anxiety, stress, depression, loss of control, loss of self-esteem, social withdrawal, invalidism, hopelessness and helplessness and how these issues can develop into a pain lifestyle. With respect to infertility, she acknowledges that the associated emotional reactions are highly complex and beyond the scope of her book. However, she points out that infertility can be conceptualised as a crisis, and be potentially devastating for some couples often leading to social withdrawal, alienation and isolation.

Weinstein notes that chronic conditions can take their toll on sexual relationships, often indirectly. For example, pain and fatigue can diminish sexual interest or bring discomfort during intercourse. For some women this situation can be even worse with the common endometriosis symptom of dyspareunia - pain with intercourse, 'caused by trauma to endometriotic implants during penile penetration' (p.177). Dyspareunia can ruin relationships along with a woman's self-image and self-esteem. 'Seldom, however, are couples able to maintain affection and intimacy when sexual

difficulties are not eliminated or relieved' (p.177). From the case studies, Weinstein examined a variety of responses to dyspareunia, from women and men. For example, a woman may suffer silently, 'grinning and bearing it' as they are trying hard to conceive and/or she does not want to deprive her partner of sexual satisfaction. A woman may anticipate the pain which will, in turn, inhibit sexual arousal, preventing lubrication and, thus, exacerbating the pain and leading to avoidance of intercourse. A man may misunderstand his partner's pain, may be protective and thus avoid intercourse, or he may feel guilty, rejected, frustrated and may become impotent. The brief examination of these issues is complemented by a helpful discussion on ways to eliminate or diminish sexual difficulties.

The vast number of reports received by the Endometriosis Foundation also attest to women experiencing depression, nervous breakdowns, not being understood, feelings of helplessness and isolation, reduced job performance and high rates of absenteeism (Ballweg, 1995). Mary Lou Ballweg is the founder and president of the Endometriosis Association in the USA. She discusses findings from the focus groups conducted by the Endometriosis Association (Ballweg, 1992) relating to the patient's perspective of endometriosis. Firstly, the women were asked to draw their endometriosis as a person and typically portrayed it as 'a sinister man or a devil type of monster'. Their drawings were interpreted as a 'sadistic and controlling force that enjoys causing pain' (p.747). Ballweg goes on to present some of the women's accounts and I quote extracts from these stories:

I was continually curious why women didn't talk about periods - since they were so incredibly painful and disruptive. ... I assumed all women were sick several days previous to their period, experienced terrible cramps, aching, and nausea, to the extent that I did. ... I spent the entire summer in bed with extreme migraines and bleeding everyday. (Peg)

After 9 years of treatment ... I was a mental wreck. I am very fortunate because I found a doctor who was always ready to listen to my ideas and feelings. ... I made my own decision to have a hysterectomy. The mental anguish I went through to reach that decision was one of the hardest things I have ever done in my life. (Debbie, 29 years old, no children)

The chronicity of illness is devastating, especially if no one is able to tell you that what you feel indeed does exist. It is incredibly miserable when you start to believe that they are right, and you are wrong. It affects every waking moment. ... After 5 years of hell, I am just beginning to see a light at the end of the darkest medical tunnel, filled with self-doubt and frustration. (Linda)

I started my periods when I was 9 years old. ... I can only remember having two or three periods that were pain-free at the first. I can remember sitting at my desk in the fifth grade with a terrible ache in my lower back. My parents never told me much about my periods except that it was the "woman's curse". The pain steadily got worse over the years. ... Sometimes the depression and the "poor little me" syndrome still sets in. ... You cannot believe some of the responses I have gotten from friends and family on the subject of hysterectomy. They really think I should endure anything to keep being a "full woman". (Shari)

These stories are very similar to the many I have read over the Internet and which have been communicated to me personally. Within these stories one can hear the frustration, sometimes depression and distress of the women. Further, issues of identity are also expressed, for example, 'self-doubt', 'poor little me' and being a 'full woman'.

Women may also experience several losses and crises associated with this chronic condition such as loss of reproductive organs and childbearing ability, infertility (Weinstein, 1987), or even just the long-term loss of energy associated with fatigue. As noted earlier, the diagnostic process and treatment may be characterised by stress and confusion, all impacting on psychological well-being. In their review of quantitative studies of the psychosocial aspects of

endometriosis, Low and Edelmann (1991) concluded that it was an under-researched area and, to date, little work has been carried out in this realm. As evidenced in the few studies cited earlier, women's experiences of the condition are often decontextualised, which, according to Mishler (1986a), leads to a distortion of meaning. Some of the quantitative research has fragmented the experience of endometriosis to merely causal relationships, yet endometriosis is a complex condition; a condition which is experienced over a long course of time and which is imbued with broad and deep psychological issues. Different research, and specifically involving contextualised analysis, could shed light on the extent and range of suffering involved in this puzzling, gynaecological condition.

While I acknowledge the studies which indicate the possibility of certain psychological 'abnormalities' which may co-exist with endometriosis, I want to know more and develop a greater understanding of how going through the experience of endometriosis may have its own psychological implications. I believe what we also need to address is *how the woman experiences the condition* and how *she* makes sense of any changes to her psychological and social well-being. This provides a different angle to the psychological question; an angle which privileges the women's storying of their experiences.

To date, the issues surrounding endometriosis which fall outside the medical realm have received little attention. However, through my personal communication with other 'beginning' researchers like myself, I have learned there are a few endometriosis studies in progress informed by psychological, sociological, nursing and anthropological disciplines. This research will, no doubt, add valuable information and promote a better understanding about endometriosis.

Summary

Endometriosis is an enigmatic condition reflected in the range of questions relating to its etiology, its prognosis and so forth, remaining unanswered. Many women endure difficult symptoms which can distress them physically and psychologically. Diagnostic delays are very common, resulting in further concerns for women and, while the present treatment can definitely alleviate the symptoms, it cannot cure the disease. Research has established that there are real concerns of a psychosocial nature for many women with this condition. Both the medicalised view and the psychological view have afforded a limited understanding of endometriosis. While case studies and popular accounts may bring us closer to understanding women's psychosocial experiences, there are other issues such as the challenge to a woman's identity which are barely touched upon. Accordingly, I believe much more work could be carried out in this area by a range of researchers from a variety of disciplines.

The Present Study

The foregoing section established that there are psychological issues associated with the experience of endometriosis. One can understand that the management of this condition is a long term activity. It is not just a physical concern with managing pain or heavy periods; women also need to find ways of dealing with the psychological side. The case studies, which have been presented in a range of, mostly, lay publications, have yielded some good experiential accounts of the condition.

However, I wanted to know more than this. I wanted to learn more about how women talk about their experiences and in what sort of ways they present themselves in relation to these experiences. For example, some women may present themselves as a victim of the condition, while others may characterise endometriosis as a challenge and something to be overcome. What sort of

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stories are women telling? Within these stories, we can learn and understand something of the women's representations of endometriosis and the ways they talk about it affecting their identity, or sense of self. From a constructionist perspective we view everyone reconstructing their identities in the light of ongoing experiences. I wanted to know how the women reconstructed their identities in the face of the disruption, that is endometriosis, or could some women maintain a strong sense of their identities? How do they understand the variety of experiences they might have of endometriosis? At the start of the study, I already knew that many women talked of suffering years of debilitating symptoms, which they had been told were a normal part of a woman's life. I wondered how they made sense of such a situation. If a woman is experiencing severe pain and 'floods' when she is menstruating, how does she understand her experiences if she has been told it is normal? How do women construct the process of diagnosis? What meanings, if any, does endometriosis hold for them?

Across these issues of meanings and identity, also runs the aspect of time. The women's range of experiences with endometriosis may stretch across many years and so I wanted to learn how their sense of self and the way they make sense of their experiences may shift and change. While my interview with each woman is but one small space of time, an individual can talk about their experiences across time. Throughout the storying of her experiences we can listen to the process of how she talks about the past, makes sense of things that happened in the past, make connections to what is happening now, as well as reflecting upon what the future may hold.

In order to gain a deeper understanding of the condition, I chose narrative inquiry as my research methodology. Narrative analysis, as explained in Chapter Four, enables examination of how people construct their identities,

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particularly, in this case, when their identity may be challenged in the face of chronic illness. People's stories are a construction of their life experiences; a representation of their 'realities'. Listening to and examining stories facilitates an understanding of human experiences.

The selection of narrative inquiry for this study, requires the choice of an underlying philosophical perspective. My study is informed by a realist ontology and a social constructionist epistemology and the following chapter examines these perspectives.

Chapter Two

Ontological and Epistemological Perspectives

My research is underpinned by a critical realist, ontological perspective and a social constructionist epistemological perspective. This philosophical position relates to my understanding that the physical aspects of endometriosis are grounded in a realist ontology, yet the features associated with how individuals make meaning from the condition, are socially constructed. In other words, endometriosis has certain observable features which relate to the presence of endometrial cells situated outside the uterus, and the associated symptoms, such as pelvic pain, are socially agreed upon. It is difficult to discuss ontological and epistemological issues without reference to each other and, while I attempt to present my position on each separately, I acknowledge that there are overlaps in each section. I outline the assumptions upon which realism and social constructionism rest, following which, I discuss how narrative inquiry is an appropriate methodology as it relates to these perspectives.

Realist Ontology

My stance on ontology is that of a critical realist. Critical realism assumes the existence of an objective reality we can only understand imperfectly. The realist ontological position relates to the way I perceive the world. Essentially, this position argues that there are ‘things’ out there, independent of whether we see or experience them, or not. This world has existed before human beings but, it is through engagement with the world, that human beings are conscious

of it and make sense of it. It only becomes a world of meaning when 'meaning-making beings make sense of it' (Crotty, 1998, p.10). This contrasts sharply with the relativist view that the external world is not accessible to us and, accordingly, there are no universal truths, only multiple realities. However, the process of human endeavour to know and understand reality is fallible, thus, according to Guba & Lincoln (1994), any claims about reality must be examined most critically. Many writers have expounded on the nature of reality often with disparate views, even within the narrower confines of the ontological perspectives of realism and relativism. I have chosen to draw strongly upon John Searle's (1995) writing on the ontology of objects, social facts and social institutions. Searle explains the rather complex domain of reality in simple terms and has been instrumental in informing my understanding of the realist ontological perspective. While I essentially paraphrase Searle's explanation, it is also a statement of my position as a subscriber to realist ontology. Following this section, I move to the area of narrative ontology, the threads of which I pick up and follow through in the narrative analysis chapter.

The physical world is comprised of physical particles in 'fields of force' (Searle, 1995; p.7), some of which are organised into systems such as rivers and mountains. The nervous system has evolved a certain type of cellular structure, and a feature of higher-level nervous systems such as the human brain, is its ability to engender and support consciousness. The human ability to represent objects and situations in the world, apart from itself, Searle terms 'intentionality' and intentionality springs from consciousness (p.6).

The next step is understanding how social facts can be accounted for within this ontology. Much of our world view relies on our concept of objectivity and the degree of contrast between the objective and the subjective. While, of course, there is an objective/ subjective distinction in an epistemological sense, there is

a related ontological sense. For example, the sensation of pain, in the ontological sense, is subjective, as its means of existence depends upon being felt by people. On the other hand, damaged nerves, which may be the cause of the pain, are ontologically objective. Like rivers and mountains, their existence is ‘independent of any perceiver or any mental state’ (Searle, 1995; p. 8). In other words, mountains, rivers and damaged nerves exist independently of our representation of them and independently of whether or not we see them.

When we look at the specific features of the world, we find that there is a distinction between ‘intrinsic’ features of nature and those which exist ‘relative to the intentionality of observers, viewers, users etc’ (Searle, 1995; p.9). I have an object in my room which is made of wood fibres and metallic molecules and these are its intrinsic features. However, when I describe the object as a table, I define a feature of the object which is observer or user relative. It is a table because that is the purpose people have assigned to it and/or the object was made for that purpose. The observer-relative features do not add new material objects to reality, but, according to Searle, ‘can add epistemically objective *features* (*italics in original*) to reality where the features in question exist relative to observers and users’ (p.10). The feature, of the object, which I call ‘the table’, is ontologically subjective.

In summary, the existence of a physical object does not depend on people’s perceptions of or attitudes towards it. It has intrinsic features, for example, a certain mass and chemical composition. Other features which exist, do so relative to the intentionality of observers or users, such as the object is a table. These observer relative features are ontologically subjective.

I now relate these ontological issues to endometriosis. Endometriosis, as physical matter, is composed of biological material which is able to be observed

during, for example, a laparoscopic procedure, having the intrinsic features of endometrial cells growing outside the uterus. It exists independently of people observing it or not and so is ontologically objective. On the other hand, endometriosis is also ontologically subjective, as it is a term which describes a condition, or a collection of bodily disturbances, commonly experienced by women with endometrial cells growing outside their uterus. It is thus a social construction; its subjective features are socially agreed upon by a group of people. This is discussed further in the following epistemology section. While the physical nature of endometriosis is ontologically objective, the meaning attached to its physical nature is socially constructed. I contend, therefore, that endometriosis can be understood as a set of bodily disturbances, or symptoms, for example, pelvic pain at the time of menstruation, which will often co-exist with endometrial cells growing outside the uterus. The endometrial cells can grow outside the uterus without the symptoms and, conversely, the symptoms can exist without the endometrial cells. In this case, the symptoms may be assigned or related to another 'condition', which is also socially constructed.

I turn now to narrative ontology, the central premise of which is the storied nature of human experience. Stories imbue people's thinking and their actions and, according to Murray (1997) 'guide our interpretation of reality' (p.2). Stories help us to describe and explain events as we strive to make sense of our world. Further, the narrative view is also predicated on the belief that those features which make up human experience, including our emotions, our sense of self, our thinking, and time, are constructed by narrative. People's stories do not reflect or constitute reality; they are an individual representation of reality, socially constructed and can furnish a variety of meanings and interpretations. We cannot aspire to stories being a revelation of truths. Rather, we need to reflect upon the meanings of stories as being a version of events from the teller, and a possibly alternative version from the reader's interpretation.

In Polkinghorne's (1988) discussion on human experience as narrative (*Narrative Knowing and the Human Sciences*) he states that human existence is made up of different orders of reality: material reality, organic reality and meaning. Linguistic forms are important for human existence as they organise information from our physical and cultural spheres and change it into the meanings that constitute human knowledge, thus enabling people to make sense of the world. Language is thus paramount as a mode of creating the realm of meaning, as an order of reality. To relate this discussion back to endometriosis, we coordinate the information we have about the physical nature and setting of endometrial tissue with the information we have about the bodily disturbances, or symptoms, which women with this physical phenomenon talk about. We blend the realms of matter, life and meaning and construct the condition we term 'endometriosis'.

To summarise, there is a world of real objects which are there for people to describe, interact with and ascribe meaning to. There is no absolute truth about the world, nor is everything in the world purely relative. We can aspire to reach an approximation of understanding of reality, which necessitates critical examination before generalisations can be claimed. It is the meanings which people attribute to objects which help build up knowledge of the world, but these meanings are dependent on human beings' constructions, not solely on the object itself. The meanings ascribed to physical objects constitute a socially shared reality; a reality which can change as new information comes to hand, as ideas change and a new construction emerges. Linguistic forms are paramount in the creation of meaning. Accordingly, within psychology, narrative ontology is a way of explaining how psychological phenomena or concepts are composed narratively as well as how people interpret their worlds. It is a representation of human experience. The epistemological turn

this discussion has taken now leads on to the following section on social construction of meaning which further explores these issues.

Social Constructionist Epistemology

The limits of my language mean the limits of my world.

(Wittgenstein, 1922; cited in Partington, 1996, p.740)

The diverse array of meanings associated with social constructionism reflect the wide range of backgrounds, agendas and routes various authors have taken to arrive at the social constructionist door. Therefore, the social constructionist 'beginner' needs to, firstly, tease out those threads of social constructionism which seem inappropriate to his/her work, or too radical for his/her understanding and, secondly, focus upon the common assumptions shared by other constructionists. The following outlines those assumptions, which I endorse, and also takes a brief critical look at other important factors which are sometimes underplayed by some streams of social constructionist psychology.

Social constructionism disputes the traditional ways in which knowledge has been gained. It challenges the idea that knowledge is derived from the generation and testing of hypotheses and from observation (Gergen, 1985). Ideally, it offers, instead, a process of understanding the world which is sensitive to historical, cultural and social change. The philosophical perspective which underpins social constructionism is concerned with the ways people "interpret or construct the social and psychological world in specific linguistic, social, and historical contexts" (Schwandt, 1997, p.19). Hence, social constructionism has a focus on social processes and interaction and how people share an understanding of life events, and how they describe and explain the world in which they live (Gergen, 1985; Schwandt, 1997). In the constructionist view, all knowledge, and thus all meaningful reality, is constructed through the participation of people within their world, created and communicated within

a social context (Crotty, 1998); the process of understanding being created by 'an active, cooperative enterprise of persons in relationship' (Gergen, 1985; p.267). Therefore, before the existence of human beings, the world was without meaning. It may have had seas, mountains, trees and sun, but they were meaningless. Human beings interpret the objects within the world and construct meaning about them in relationship with other people. In other words, it is a social process of engaging with the world.

Social constructionism encourages us to challenge the way we look at the world, to consider other perspectives and not attempt to form truths about a so-called 'objective' reality. One perspective is not necessarily privileged over another. The construction of our understandings, constitute shared meanings; meanings which are not necessarily maintained over time. Rather, they are open to changing perspectives and the fostering of new understandings as developed within social interactions and changing cultural and historical contexts. Such understandings are also mediated by language and thus language plays a significant role in shaping reality. Gergen (1985) takes this further by arguing that talk is virtually all there is. His position is grounded in discourse and social processes which is a different perspective from social constructionist psychology which is concerned with issues of power and subjectivity and based on the work of Foucault. Danziger (1997) describes these two threads of social constructionist psychology as a 'light' and, the latter, a 'dark' version. While I acknowledge the significant roles which language plays in constituting our realities, it is also carried out within social interactions and in particular contexts. The latter issue of particular contexts is, I believe, significant to the way we construct and understand our worlds. Along with cultural, political and historical contexts, matters specific to the individual are also important. For example, Cromby and Nightingale (1999) draw attention to, among other issues, the issue of embodiment. They argue that social

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constructionism is dismissive of the individual's body and downplays its 'functional, physiological, hormonal, anatomical and phenomenological aspects' (p.10). I am not going to discuss these issues further but I do believe, as a social constructionist, it is important to be cognisant of the various aspects of both our environments and our persons that may impinge upon the way we understand our world.

One group of people may attribute different meanings to an object from those constructed by another group, and this is well illustrated when we examine and find differences between many cross-cultural meanings and understandings. With respect to illness, for example, understandings and etiologies can vary widely across cultures. In New Zealand, a person diagnosed with schizophrenia in the European culture, may be viewed by Maori as having symptoms related to spiritual malaise. Thus, I believe that health professionals need to be aware of such perceptual differences among cultures. A Maori person with those symptoms and who subscribes to Maori explanation and understandings of illness and health, is not going to relate well to the Pakeha health system of hospitalisation and medication. However, differences in meanings not only vary cross culturally, they can vary across perspectives within the same culture. The collection of the signs of bodily disturbances which has come to be understood by medical professionals as endometriosis can also be construed as some other condition. Diagnosis disparities, while construed as misdiagnosis by some individuals, can merely be reflecting the differing perspectives from which the symptoms are being diagnosed. A range of symptoms that are associated with endometriosis also meet the DSM-IV (Kaplan, Sadock, & Grebb, 1994) diagnostic criteria for somatization disorder, pain disorder associated with psychological factors, and pain disorder associated with both psychological factors and a general medical condition. One diagnosis assigns the symptoms to a physical condition, while the other

attributes them to a psychiatric disorder. Perhaps a health professional working from a spiritual perspective, may see these symptoms as springing from a sense of spiritual impoverishment. Historically, when little was known about endometriosis, these symptoms were attributed to various conditions, or not given a diagnosis, while other cultures no doubt have other explanations or diagnoses for the same symptoms. Further, it has been documented (Ballweg, 1995) that, until recently, black American women (presenting with symptoms of endometriosis) tended to be diagnosed with pelvic inflammatory disease (PID), reflecting differences in diagnosis within individual practitioners themselves, suggesting a social bias in the ways in which diagnosis was being conducted. As Ballweg interprets, this practice of differential diagnosis was based on an assumption that black women were sexually promiscuous, a contributing factor in contracting PID. Thus, 'statistics' indicated that PID was common among black women but not endometriosis. These figures also reinforced a 'truth' that black women did not get endometriosis. This is a good example of how diagnosis is a social construction and, in this case, based upon socially agreed assumptions about the sexual practices and health of black women. As Ballweg rightly points out, 'the numbers, now in the guise of science and separated from their human element, could not so easily be accused of racism (p.422)!'

Social construction of meanings is a linguistic process. People's accounts of the world occur within common systems of understanding, normally oral or written language. The emphasis, within social constructionism, is the meaning attributed to objects and concepts, as constructed by linguistic and other social procedures. Based on the social constructionist perspective, within research, knowledge derives from both the researcher and the researched. Consequently, the role of language is elemental in the production of knowledge and the representation of experience.

However, as discussed earlier, knowledge can be conceptualised as being culturally shaped and the product of activity and purpose. The ways we talk, learn about and come to understand the world can vary historically and cross-culturally. Further, as Cromby & Nightingale (1999) note, people actively search facets of their world in certain ways for certain purposes and, accordingly, construct knowledge which they then adopt as 'truth' about the world. Hence, different activities may yield different 'truths'. Therefore, I believe, the way people construct knowledge goes hand in hand with how they make sense of their experiences and the world about them. From this, they develop their individual beliefs, attitudes and practises. I refer back to the example of the differential diagnosis of black women to reinforce this idea.

Reconciling a Social Constructionist Epistemology with a Realist Ontology

Although social constructionism is presented as an epistemology and, as Danziger (1997) notes, began as a critique of objectivism, it does address the nature of reality. The ontological issue, however, is somewhat contentious. The various authors who have expounded their understandings of the social constructionist orientation such as Gergen, (1985) and Harre, (1987), while sharing a common epistemological philosophy, do not necessarily subscribe to the same ontological perspective. For example, Gergen, like many social constructionists, rejects scientific realism and adheres to a more cognitive relativism, that is, they challenge the idea of an objective reality where theories refer to real features of the world. Rather, they argue that there are no universal truths and believe that there are multiple, socially constructed realities. According to Guba and Lincoln (1994), such constructions are also liable to consistent revision when alternative constructions emerge during debate. Constructionists view knowledge and truth as the result of perspective;

they are created and can be expressed in a number of symbolic and linguistic ways (Schwandt, 1994). Gergen (1985) in his well-known work 'The Social Constructionist Movement in Modern Psychology' stresses the idea that reality, and therefore, knowledge is a product of social exchange.

The way I understand the nature of endometriosis, is that from an ontological perspective, it has certain intrinsic features, existing independent of people's observation of them, or not. However, the bodily disturbances, or symptoms, which are associated with them, are subjective features which are drawn from social agreement. The term 'endometriosis' is a social construction, describing a set of ontologically subjective symptoms co-existing with a physical, ontologically objective set of features. In other words, through language, people construct and derive shared meanings and understandings of a certain collection of 'symptoms'. The endometriosis condition would not exist without its physical features, but its physical entity can stand alone without the subjective features. This is the way I understand the reconciliation between the realist ontology and the social constructionist epistemology. I acknowledge that there is a difficulty in subscribing to one theoretical perspective. This is where a sense of blending perspectives can be appropriate. While I subscribe to the social constructionist viewpoint, I also accept that there is a physical reality out there, independent of whether I see it or not. However, it is the socially shared meanings which we assign to this reality, which construct the world in a certain way for certain groups of people.

In summary, although some forms of constructionism espouse a relativist ontology, I, like many qualitative researchers, share a realist ontology. I give credence to the existence of objects, events, people, meanings, and so forth in the environment as standing alone, as it were, from people's experience of them. However, the way I come to understand and make sense of the world

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is through the interaction of people with the objects in their environment. Theories and models are created by people; they are socially constructed. There is no one correct interpretation of the world and, as Crotty (1998) points out, social constructionism stresses the influence of our culture as it shapes the way we look at things and so providing a distinct picture of the world. In another time and in another place, the view may well be very different. I maintain that the conjoint realist ontology and social constructionist epistemology provide a tenable philosophical perspective to underpin the narrative inquiry approach to my study.

Language operates to create a social reality through the procedure of social reciprocity and the construction of shared meanings. People's stories are a version of events, a representation of reality, so we are thus able to reflect upon the meanings they construct from their world. While researchers, therefore, only have access to people's limited representations of experience, they can access the meanings people make of their experiences through language. These linguistic forms organise information from the physical, social and cultural world into meanings which constitute human knowledge. An entry into the linguistic forms is through narrative analysis. The following two chapters now discuss the nature of stories and narrative analysis, thus providing a strong rationale for using narrative for the study of women's experiences of endometriosis.

Chapter Three

Narrative Theory: The Nature of Stories

Narrative theory is an extensive area that has been contributed to by philosophers and researchers from a variety of disciplines. It is also a difficult domain to summarise succinctly. What I present is my understanding of what constitutes and is fundamental to the nature of narrative and, furthermore, what is relevant to my study.

Some writers, depending upon their particular purposes, choose to use the terms 'story' and 'narrative' separately (Cohan & Shires, 1988; Connnelly & Clandinin, 1990) while others (Coffey & Atkinson, 1996; Murray, 1999; Sarbin, 1986) use them synonymously. When I discuss the nature of my research inquiry, I use the term 'narrative', such as in 'narrative analysis'. However, I do use the terms 'story' and 'narrative' synonymously throughout the rest of the study as I believe it is too difficult to keep the terms separate; for example, people tell stories, people draw on cultural narratives, we have storied accounts of our experiences, we narrate the events of our lives, we use stories to teach others.

Stories are ubiquitous. We all tell stories; they are a part of our everyday lives. People, across cultures, can think, talk and write in a storied way. Stories are so firmly entrenched in human life that we become familiar with their form in early childhood. According to Polkinghorne (1988), a child of three or four is capable of thinking and talking in a storied way. And, there is a long historical background to storytelling. Since early times, stories have been used as an

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effective means to communicate ideas and express feelings. We can appreciate the enduring nature, together with the variety and contrast, of the narrative form. The paintings by early cave dwellers told stories of their daily lives, while the oral traditions of story-telling, passing down myths and legends to succeeding generations are still evidenced today. There are a wide range of media through which stories are communicated. Ballet, art and music exemplify the more artistic mode, while the power of fables, proverbs and parables have been used to communicate moral and religious messages. Novels, plays, documentaries, biographies and so forth, brought to us through books, newspapers, the Internet, the theatre, television and film, all demonstrate the assortment of the narrative form.

As Polkinghorne's (1995) notes:

A storied narrative is the linguistic form that preserves the complexity of human action with its interrelationship of temporal sequence, human motivation, chance happenings, and changing interpersonal and environmental contexts (p.7).

This chapter now goes on to examine the nature of narrative; its structure, devices and functions, including the functions of illness narratives. The functions are discussed with respect to how narrative operates at the personal, interpersonal and socio-cultural levels of people's lives. One of the functions of narrative is its representation of time and, thus, narrative is also characterised by its temporal structure. Accordingly, time is discussed briefly under structure and is expanded upon under functions. To exemplify points, the discussion is related to chronic illness in order to orient the reader towards the later analysis of the chronic condition of endometriosis.

Stories are Structured

Stories have common structural features which include plots or narrative themes, characters who take on roles, defining moments and, sometimes epiphanies, subsuming elements and a temporal framework.

Narratives contain plots, or themes, which characterise the experiences or events being related. For example, in the endometriosis stories, one woman's story may be mostly about how endometriosis has threatened her fertility while, for another, the narrative centres around her relationships. The plot, also known as the story-line, is the thread which weaves its way around events, characters and places and holds the story together (Polkinghorne, 1988; Sarbin, 1986). The integrative process of plotting, or emplotment, is explained in the section relating to 'narrative devices'.

Along with the plot, the story must also contain characters or roles. When people tell stories about themselves, they construct themselves in a certain way. For example, they may portray themselves as a victim or a hero. At the same time, they tell their stories identifying with the one or more roles they relate to in their lives, such as a parent, a partner, child, career person and so forth. With respect to illness narratives, a person also portrays him or herself in a particular way, as they express their illness experiences to a particular audience. An individual may construct themselves in one way to their GP and, in a different way to their employer. They may feel they need to really impress upon their GP how poorly they have been feeling lately, in an effort to convince their doctor that they want their symptoms taken seriously. On the other hand, they may not want their employer to be alarmed about their health and not consider them for promotion. They may choose, therefore, to present themselves as a stoic figure who can overcome any minor health setbacks.

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Stories may also have defining moments and epiphanies. I consider an epiphany encapsulates the ‘light-bulb’ experience where an individual suddenly understands something of great significance to him/herself. It is a point where their understandings may change and meanings for them have altered. For example, in the endometriosis story, the point of diagnosis can be a time when a woman may realise her symptoms are real and are not psychosomatic. Such a realisation may lead to a deep sense of a shift in her self-concept. On a less dramatic level, the defining moment in the narrative may be an event chosen to illustrate experiences and, while it may contain an epiphany-like experience, it may be representative of other, similar experiences. For example, a woman with endometriosis may have experienced several embarrassing incidents with respect to heavy menstrual bleeding. One day, an incident may occur where it seems like ‘the straw that broke the camel’s back’. She may have reached the point where she thought, ‘I’ve had enough’ and feel motivated to take a particular course of action. On the other hand, the incident may be one chosen to exemplify her embarrassing ‘flooding’ experiences as she relates her endometriosis story to others.

The traditional narrative is characterised by a three-part representation of time, that is, a beginning, a middle and an end. Within this temporal framework, there is an assumption that all stories have endings. However, within the chronic illness story, a woman, for example, may be in the middle of telling her story and the ending is yet to occur. She may talk about how she first experienced physical signs that something may be wrong with her body, go on to describe how she consulted her GP, how she was diagnosed, how she experienced this procedure and how she presently manages her condition. However she is unable to say what the final outcome was as she is still experiencing the chronic illness. All she can do is imagine outcomes. She can imagine herself getting worse; she can imagine herself receiving treatment

which effectively manages her condition, or whatever. Imagining possible and alternative outcomes has been termed as 'subjunctivising reality' (Bruner, 1986); that is, what is being discussed is expressed in hypothetical terms. On the other hand, one could also take the view that a person with a chronic illness is experiencing an ending, albeit one for now, that is, for that particular story. The ending could, for example, be feeling hopeless. For many women with endometriosis, once they are no longer menstruating (or passed through the socially constructed 'menopause') the endometrial cells outside the uterus no longer grow and cause pain. The 'symptoms' disappear, the endometriosis is gone and that can be the ending of that story. For other women, the ending of their particular story may relate to the fact that they adopted a child; travelled overseas and rebuilt their lives; took up a new career; left their relationship, or whatever. The endings are whatever the person chooses them to be.

How time is encapsulated and expressed in the narrative mode is examined under the third section relating to narrative functions. However, in order for a story to be structured well and to function efficiently, narrative devices are necessary. The following now briefly discusses these devices.

Stories have Narrative Devices

Narrative devices organise and shape the events, characters and settings into a coherent story. Firstly I discuss emplotment, which is the principal organising component which shapes the story. I then move on to a brief discussion concerning imagery and metaphor. They are devices which enrich and bring colour to the narrative, helping convey to the reader events which may otherwise be difficult to understand.

Emplotment

Emplotment is a narrative device, or 'tool', which Polkinghorne (1995) describes as a central organising element. Ricoeur (1991, in Valdes, 1991) notes that 'a story is made out of events, to the extent that plot makes events into a story' (p.106). (*emphasis in the original*) When events are selected for inclusion in the story, they do not necessarily form a chronological sequence, rather 'the plot construes significant wholes out of scattered events...eliciting a pattern from a succession' (Ricoeur, 1991, in Valdes, 1991; p.106). Polkinghorne (1988) argues that: 'Without the recognition of significance given by the plot, each event would appear as discontinuous and separate, and its meaning would be limited to its categorical identification or its spatiotemporal location' (p.19). Without a theme, or plot, events would be devoid of significance and meaning. Polkinghorne (1988) describes plots as 'meaning expressions' which create meaning 'through temporal sequence and progression' (p.160) and, through the integrative process of plotting, or emplotment, the meaning events have held for someone can be conveyed.

An event is not only an occurrence, but also something which adds to the advancement of the story and, the narrated story is more than an episodic succession of events; the actual narration organises them into a coherent whole. Several plots can produce a meaningful combination for the same events and, as Polkinghorne (1988) notes, different plots can alter the meaning of certain events as their roles are interpreted differently with respect to their uses in different plots. Therefore, we can then see how the meaning of events can alter, depending upon who is telling the story. Not only can the story change by the telling of different authors, but it can also differ in the telling by the same author. This can occur merely because a story can change inherently in the telling, or it can occur because an individual decides to re-author a different story from the same events. Re-authoring a different story reflects the differing

contexts in which the story may be constructed. The construction of a story is never done in isolation. It is a social construction; done with a particular audience, either present, or in mind, so the type of story told depends greatly upon the audience.

Imagery and Metaphor

Imagery and metaphor are frequently used by people to aid the telling of their stories. They are a useful way of illustrating a point, or conveying a sense of the experience that the narrator went through. If I wanted to tell someone how severe and harrowing a pain was that I had been experiencing, I would need to employ a sense of imagery. '*An incredible pain shot through my leg. It felt like I had been seared by a red hot poker*'. This communicates a good sense of what the pain was like and likely to be understood by another person. However, if I said I had experienced a bad pain going up my leg, my experience of it would not be very well conveyed to the listener. The essence of metaphor, has been described by Lakoff and Johnson (1980) as 'understanding and experiencing one kind of thing in terms of another' (p.5) and can convey complex experiences.

The battle metaphor is frequently used in illness stories. In the endometriosis story, for example, the endometriosis may be depicted as an enemy to be battled against and overcome. Employing a metaphor not only communicates how an individual experienced an event, but also connects to the reader or listener as to how that person makes meaning of events. In the battle metaphor, we can understand how the individual has externalised the condition, such as endometriosis, as an invader. Other people, may conceptualise their illness in quite a different way and, possibly, this may have some bearing upon how they manage the condition.

Stories have Functions

Stories are a key medium through which people participate in the world. They have utility, serving a variety of functions at the personal, interpersonal and socio-cultural levels of people's lives. According to Bruner (1990) stories form an 'organizing principle' by which 'people organize their experience in, knowledge about, and transactions with the social world' (p.35). The first part of this section addresses the temporal nature of the narrative, the second part discusses the various levels of people's lives at which stories function and the third part focuses on the function of illness narratives.

'Story Time' - Time and Stories are Interwoven

As people carry out their daily activities, they experience their lives in relation to time; we do certain things at certain times, we do or do not have time for something, we remember the time when we experienced a certain event, we look forward to the time when we can do something. We live in chronological time; our lives are temporally ordered. However, time is changeable. As is often said, time does not stand still, and the way we experience time, changes. So, as the present becomes the past and the future becomes the present, we can also have differing perceptions of time. It goes quickly or it can drag by. On some occasions, we experience time as a 'concordant whole' while, at others, time is experienced as discordant, such as when our thoughts of the past and the future influence our experience of the present (Richardson, 1990, p.124). The changing relationship, perception and experience we have of time is thus difficult to capture. The French philosopher, Paul Ricoeur, has written in depth on the nature of time and its relationship to the narrative in his three volume work *Time and Narrative* ((Ricoeur, 1984; Ricoeur, 1985; Ricoeur, 1988)). According to Ricoeur (1984) stories express and give shape to our experience of time.

'The world unfolded by every narrative work is always a temporal world...time becomes human time to the extent that it is organized after the manner of a narrative; narrative, in turn, is meaningful to the extent that it portrays the features of temporal existence' (1984; p.3).

Chronological time, however, is different from story time. Chronological time relates to the episodic succession of events as they occur. When events are recounted episodically, they form a chronicle. It is when they are narrated in story time, or non-chronological time, that time is captured and meaning is expressed. Stories thus express and give shape to our experience of time (Ricoeur, 1984). Stories recount events as they relate to one another, not necessarily in the order in which they occur. The difference between the temporal order and that of the narration is an anachrony (Cohan & Shires, 1988; Genette, 1980 cited in (Toolan, 1988). As events are moved back and forth in story time to collapse the linear nature of time, 'analepses' or flashbacks in time and 'prolepses' or flashforwards in time are used (Cohan & Shires, 1988). For example, the prolepsis, or flashforward device, can briefly transport the reader into the future. The following prolepsis example is an excerpt from Joanna Trollope's (1986) novel *The Taverners' Place*:

'On their behalf she had already interviewed Cook and explained about the wholesome simplicity necessary for children's food, an explanation which accounted for the dreaded trays of unadorned mutton chops and tapioca pudding cooking beneath its slimy skin, that were to ruin lunch time on the top floor for the next three years'. (p.196).

Time is structured as past-present-future and thus informs the 'temporal orientation taken in various lines of narrative and narratively oriented work' (Connelly & Clandinin, 1990). For example, the significance of past events, what is happening in the present and how the participant feels about the

present, together with future prospects, can all be discussed and examined in an interview. The chronic nature and uncertain future of the endometriosis experience indicates a time-line conceptualisation. For example, we can learn about the women's understandings of their symptoms and how they coped with them prior to diagnosis. The diagnostic process serves as a reference point with its potential for various changes for the women, such as, changes in attitude towards their symptoms, changes in symptom management and so forth. We can learn further about prospective issues and how diagnosis may have influenced the future for these women.

Another important feature of narrative is the way people locate their self-concept in time. To use the example of chronic illness, Charmaz (1991) notes that people may link their self-concept to the past, present or future. For example, an individual who is dissatisfied with her present self due to the limitations of her chronic illness, may link her self-concept to the past which she perceives to have been a time of achievement and vitality. On the other hand, a person who perceives his future to be uncertain and, somewhat bleak, may choose to construct a valued self in the present, thus anchoring his self-concept to the present. Chronic illness can be a disruptive force in people's lives and trigger them to construct themselves in relation to time. 'A once certain self-concept can become elusive and may shift and change through time, like a kaleidoscope that recombines and restructures pieces of the past, present, and future. New events result in recombining past, present, and projected future selves in different, shifting ways' (Charmaz, 1991; p.229).

Stories are a process by which we organise our experience of time and so furnish it with meaning. They also enable people to construct and locate their self-concept within a particular time-frame, depending upon the way they respond to and perceive the events of their lives. A story is not just a

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chronological recitation of successive events; it is a vehicle for expressing the experience of time and this is achieved through a non-chronological dimension. Seemingly, scattered events, can be configured into a coherent story.

Functioning at the Personal, Interpersonal and Socio-cultural Levels

Personal level - personal story and identity

The creation of our identities is a process founded in the way we make meaning of our lives, the integration of our past life with what we hope for in the future, thus providing a functional identity for the present. The multitude of events and information which are experienced day to day, need organisation so that people can gain a sense of coherence and understanding of what is happening in their lives. At a personal level, stories enable people to make sense of and bring meaning to their worlds. The literary theorist, Roland Barthes (Barthes, 1982), asserted that at the individual level, people have their own life story which enables them to understand what they are and where they are going. However, the terms 'personal story' or 'life story' can mean different things to different people. For me, the personal story is best expressed by Polkinghorne's discussion on, what he calls 'self-stories' (Polkinghorne, 1996, p.300). Polkinghorne says that these personal stories start from the individual's birth, through to their present life and on into the rest of their lives. They include emotions, thoughts, values, bodily feelings, chance events, directed activities and other people's actions. The main character is the person's own self, while other significant people such as family and friends have supporting roles. A 'life plot' (Polkinghorne, 1996; p.300) configures the events and actions of the individual into a life story. The life plot may contain a story line of the person constructing themselves in a particular way, for example, as a victim. Accordingly, the personal story, is the story that is instrumental in shaping the individual's identity.

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The personal narrative is in flux as it is revised to integrate the events which can disrupt our lives. Major life events, in particular, such as developmental milestones, illness, success or misfortune, often precipitate a change in our stories. The individual's sense of identity may be challenged, calling for a different story line, or plot, to make sense of the life changes he or she is experiencing. The ongoing attempt at integrating changing life circumstances and new experiences into one's personal story also means the revision of one's identity.

By telling and retelling the stories of life experiences, people come to create their identities. The stories people tell about their lives reflect an understanding of who they are, where they have been and where they are going. We cannot, however, answer the question 'who am I?' until we can articulate our life experiences. As people's narratives bring meaning to their lives, providing context and significance to life events, so they integrate their sense of identities. Just as our life stories evolve and change as they unfold over time, so do our identities. We are in the middle of our stories; stories which we have constructed from early childhood and which also contain how we imagine our futures to be. McAdams (1993) believes that stories which provide identity at one stage of development need to be revised as people reach the next developmental stage. The stories which we construct during our young adult years may no longer be applicable as we reach mid-life, and the mid-life identity may no longer be functional for our old age. There are a multitude of factors which can disrupt our life stories and which can impact upon our sense of identity. The projected image of our future selves may be shattered, thus a reassessment and reconstruction of one's identity is needed. To some extent, some people struggle with this crisis and may deny the impact such experiences are having, or will have, upon

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their lives and their identities. New identities may be thrust upon us, for example, a partner dies and we become a widow(er) or we are made redundant and become an unemployed person. The way people accept or do not accept these new roles and changed aspects of their identities affect the way they think about their future. Some people need counselling to help them move through these major life transitions. With help, for example, they can move on from the role of victim to what Polkinghorne terms 'purposive agent' (1996; p.303). They take charge of their lives once more, becoming actively engaged in setting goals, making choices and so forth, to make that shift away from the victim role.

Through narrative construction, we not only create our identities, but we also communicate our sense of personal identity to others (Kerby, 1991, Polkinghorne, 1988). In order to validate our claim to a particular identity, we need to tell other people stories which reflect our asserted identity (Baumeister & Newman, 1994). If a person wished to be accepted as an able student, they may relate various episodes which support this identity claim, such as the long hours they work, and the excellent grades they have received. People can integrate their lives to secure a particular identity, or even a number of identities, such as able student, good mother, charity worker and sportswoman. Wicklund and Gollwitzer (1982; cited in Baumeister & Newman, 1994) note that people usually seek social validation before they can feel secure in their desired identities. Perhaps a better way of expressing this would be to say that our identity constitutes various roles and the way we describe ourselves within those roles, such as the 'able student', 'hopeless mother', 'hard-working father' and so forth. People can also assume identities which reflect the narratives they have adopted which, in contrast to the above desired identities, constitute negative self views. It seems likely that we have a

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strong need to communicate our identities when we seek affirmation of our self views, whether they be positive or negative or, more likely, when we feel insecure in our claims. Thus, a woman who thinks of herself as a bad mother, may need to tell others about this in the hopes that the listener will dispute that view and point out the positive side of her parenting.

As Murray (1999) observes, stories are shaped by the social context within which they are framed. People are able to make sense of everyday events and assign them a meaningful place within their lives. Stories can characterise a person's existence as being individual and different from other people's. At the personal level, the narrative functions to shape identity, enable the individual to make sense of their life experiences and, in the case of illness, help the person to reorganise or reconstruct their personal identity.

The concept of identity is further discussed within the section relating to the function of illness narratives. Here I expand on these ideas and show how they relate to the illness narrative, thus providing a foundation from which to build my later rationale for employing narrative analysis to examine women's endometriosis experiences.

People's experiences are bound to other life events and are assessed accordingly in relation to the 'larger whole' (Richardson, 1990). It is through stories that people create, validate and reconstruct their sense of identity and this is strengthened in the social realm when we talk about ourselves to others.

Interpersonal level

Socially, or interpersonally, stories enable people to express their feelings and communicate ideas as they provide a way of ‘knowing’ and a way of ‘telling’ about the social world. People are therefore able to learn and understand about other individuals’ lives. Making sense of other people’s behaviour by way of being able to take their standpoint is a ‘capability grounded in narrative’ (Richardson, 1990; p.127). Thus, for example, through biographical accounts, we are able to understand the lives of those who lived in the past and generations are linked into a ‘communally shared world of experience’ (p.127). Stories are embedded in social interaction, sustaining a way of teaching and a way of learning.

Aristotle, (cited in Thompson, 1981) believed that every well-told story teaches something, while disclosing universal features of human experiences. Through the skill of good story-telling, either in oral or written form, an audience’s attention can be captured. Narratives not only have the power to entertain, but important ideas and information can also be imparted through the use of analogies and storied examples. Many of us can recall a childhood teacher who could weave a little magic and mystery into the classroom lesson by telling a good story. It was from those ‘good stories’ we remembered and learned the lesson. Relating a story about an event, provides the listener with the social context in which it was situated, establishes possible connections between related events, while also helping the individual to make sense of what happened. The social process of relating and listening to stories is a powerful tool in communicating information and understanding our own and other people’s experiences.

The shared activity of creating a story is another aspect of the

interpersonal nature of the narrative. This collaboration is the task of the narrator and the listener; the writer and the reader. The situation or context within which the narrative is constructed, has a strong bearing on how the nature of the narrative is constructed. The interaction, in particular, between the narrator and listener determines what story is told and, as Hyden (1997) notes, we 'produce new narratives in new contexts' (p.52). The story a person tells to their partner may well communicate a different sense, or they may present a different 'self' from when talking about the same events to their employer. Such aspects are discussed further in the section 'The Narrative Interview' in the following chapter on narrative analysis.

In the process of narrating their experiences, people make sense of their life events. It is important to emphasise that what people communicate about an experience is its meaning. People construct personal meaning from an experience and what is conveyed to others is its sense, while the lived experience remains private (Ricoeur, 1991 in Valdes, 1991).

At an interpersonal level, stories help people to convey knowledge and understanding of their world and life experiences. People make meaningful sense of their lives and express the meaning of their experiences through stories to others.

Socio-cultural level

Narratives, in general, are created within the wider socio-cultural context (Murray, 1999), and inform about the values and beliefs of people's cultures. These socio-cultural (or cultural) stories provide a store of meanings for people to live by (Richardson, 1990), and impart the values of their culture (Polkinghorne, 1988) such as promoting moral and

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religious messages, and equipping people with positive role models. Richardson (1990) maintains that the cultural story is told from the viewpoint of 'the ruling interests and the normative order' (p.128) thus helping maintain the status quo. In this regard, the cultural narrative may favour the interests of one group over another. However, for the purposes of this study, I would present the cultural narrative in a broader context. The cultural narrative can inform about all areas of people's lives, not just those that relate to values and meanings. I would term the stories relating to illness as 'cultural' stories. For example, when I was young, I grew up with the story about doctors being experts. If you had something bothering you physically, you went to the doctor and he (as most of the GPs were men then) would diagnose the complaint, offer advice and perhaps some medication. Often, further information about the condition relating to its possible cause and prognosis was not offered, and the doctor's word was considered sacrosanct. Nowadays, that story has been challenged and, while may still guide some people, many other people no longer 'believe' totally in this story. Further, the information we have about illness, whether in general or in a particular condition, I would suggest, is contained within a cultural narrative. A visual or auditory hallucination may be considered a spiritual event to a Maori person in New Zealand while, to Pakeha New Zealanders, it is more likely to be viewed as stemming from a psychological disorder. Both meanings belong to cultural stories about hallucinations and come from different cultures. Neither are 'right' or 'wrong' but reflect a difference in understandings and meanings from that particular culture.

I borrow the next example from Abma's (1998) study on 'Storytelling as Inquiry in a Mental Hospital'. Abma found, what she termed, a 'standard story', or what I would term a cultural story, operating about psychiatric

patients being depicted as weak, dependent and passive characters, while their mental health workers were depicted as people with authority, expertise and power to make changes and solve conflicts. Accordingly, these stories were informing the way people were working in their professional practice. Abma recognised that the 'standard story' was 'so self-evident that its claim to validity denies the need for justification or proof' (p.825). Hence, many of our decisions, attitudes and behaviour are shaped by the potent messages contained within these narratives and, at times, are not necessarily afforded much thought. This is 'just the way things are', and this is 'what we do' in this particular situation. What may appear to be simply a standard cultural practice, is actually part of a wider story prescribing the acceptable behaviours, for example, of that culture. However, while cultural narratives can be powerful influences on the way people live their lives, they can also change and evolve over time to reflect the changes in events and opinions of the culture.

The chronic illness stories can also be reshaped to reflect the experiences of those with the illness. What do people know about endometriosis, apart, for example, from heavy, painful periods? I would argue that the common story told about endometriosis, by medical professionals, is symptom riddled, lacking context and personal meanings. This 'biomedical' account is therefore misleading as it leaves gaps in the story. In this study, the women's accounts, as related to me, go some way to providing the context of their daily lives, that is, a sense of the passing of time through their endometriosis experiences, as well as the personal and social spheres of their lives. The chronic illness story performs an important function of conveying the individual's sense of self, her identity and how she makes sense of her experiences.

Functions of Illness Narratives

As discussed earlier, storying one's experiences, enables the individual to make meaningful sense of their lives. For the individual who has an illness, an illness narrative enables him or her to make sense of their symptoms. An illness narrative is also a means of expressing the sense of the illness experiences to others. As a person responds in her individual way to the meanings of illness, through narrative she can continually revise her personal life and construct her identity. Additionally, the individual illness narratives contribute to a growing 'collective' illness narrative.

Making sense of symptoms

Storying their experiences enables people to integrate the various events of their illness into a unified whole. From this process, they can draw meaning from their experiences as they reflect upon their lives. The retrospective aspect of telling stories helps people to piece together events and better understand their situation. For example, Murray (1999) in his discussion of 'the storied nature of health and illness' discusses the case of a woman diagnosed with lupus. In her story, diagnosis was a turning point and she recounted her life with respect to the diagnosis. The diagnosis enabled her to story her life, connecting various earlier experiences with her current condition, as well as her future prospects. As she drew meaning from past events, she concluded that her condition was stress-induced. Although, as Murray notes, her prognosis was uncertain, and so her story was not complete, her life had been transformed by the diagnosis. People with a chronic illness, like the woman with lupus, can imagine possible outcomes. 'Subjunctivizing reality' (Bruner, 1986) allows people to imagine alternative outcomes when storying their illness experiences. They can imagine, for example, the illness totally incapacitating them or, on the other hand, they can hypothesise a future

where they have been given a new form of treatment which has relieved their suffering.

Before a person receives a diagnosis of their condition, they try to make sense of their symptoms. Are they normal and can they perhaps be related to something innocuous? According to Hyden (1997), the illness narrative can be a vehicle for examining possible explanations for the illness and for even finding a way of relating to the illness. After thinking about possible explanations for their symptoms, the individual may decide that they are not normal. However, the testing of explanations is not something which is carried out in isolation from the surrounding world. The symptoms and the person's individual context are related to a shared cultural context (Garro, 1994; Good & Good, 1994) and meanings are informed by the personal and the cultural store of illness narratives available to the individual. Early (1984, cited in Hyden, 1997) considers that an important facet of the illness narrative is that it looks at the practical ways of relating to illness. Once an individual is diagnosed, they are then able to relate not just their symptoms, but the condition with a name, to shared cultural knowledge about the illness. And, according to Early, the common-sense explanations which are linked to cultural knowledge enable the individual to assess treatment options and to make sense of their illness experience.

Relapses, remissions and other changes in a condition, reflect a fluctuating course which so often characterises chronic illness. Correspondingly, the meanings people give to illness can change over time and the way people experience their illness can also shift. The temporal nature of chronic illness thus lends itself to a variety of stories. While the stories may shift and change, rather than perplex and confuse, they can provide differing

perspectives of the illness, all of which add richness and detail to that particular cultural store of information about that illness, also known as a collective narrative. The term 'collective narrative' contains the idea that a range of people can contribute a collection of meanings and essence of experiences to a shared narrative. The perspective from which the story is told influences the story and, in chronic illness, its possible outcomes. Hyden (1997) points out that the narrative can be told from an illness perspective and the healthy perspective. People can also swing between these two perspectives when talking about their illness. Hyden believes that 'The choice of perspective and formulation of the narrator's voice can also be seen as the narrator's struggle to define how his/her illness narrative is to end' (p.62). Following on from this viewpoint, I believe that the health of the audience, or researcher, also affects the type of story being told. Talking about their illness to a well researcher, may pressure the individual to present a convincing account, in order to show that they really have suffered and their symptoms are definitely not related to malingering. On the other hand, talking about one's illness to someone who has experienced similar symptoms, may relieve that pressure to be convincing, and may pave the way for that person to be more forthcoming about their experiences.

Hyden (1997) argues that the illness narrative can also be conceptualised as a testing of our basic moral premises. People seek to find reasons for their illness. Perhaps it has a genetic origin and is no fault of their own. Or, perhaps it is due to their lifestyle, something that the individual did or did not do which has led to the illness. Hyden exemplifies his point by drawing upon the story of a former psychiatric patient (cited in Hyden, 1997) who had been hospitalised for long-term depression and who had made several suicide attempts. For this man, it was important he

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ascertained whether he was personally responsible for his suffering or whether there were causes beyond his control. He examined his situation from different perspectives: as an inherited condition; as the result of his very high expectations of himself; or as the result of trying to live up to his mother's high expectations of him concerning his academic career and social success. Hyden suggested this ongoing dialogue between himself and other people was to do with his moral responsibility for his depression and suicidal behaviour. This moral testing is concerned, therefore, with seeking a framework within which the illness can be discussed.

People seek to find meanings for their symptoms and reasons for their illness. Their stories of illness assimilate the cultural, illness narratives into their lives. People may also examine their past life experiences to test the idea of moral responsibility for their suffering.

Expressing the illness experience

The narrative provides a vehicle for the individual to articulate their experience of illness (Hyden, 1997) particularly their experience of related suffering. While the nature of symptoms and their consequences are expressed, they are also positioned within a temporal framework and transformed into a coherent whole. Various related events are woven into the story, giving shape and meaning to the person's experiences.

The traditional nature of the medical consultation does not encourage people to 'story' their experiences. Rather, there is a tendency to give a biomedical chronicle of events. The onset, duration, severity of symptoms, together with other health-related issues are given and these medical accounts enable and encourage the physician, as Frank (1995)

argues, to become the spokesperson for the disease. This 'disease model' results in the physician concentrating on the physiological facets of the disease and often neglecting the emotional and psychological aspects (Morse & Johnson, 1991a). However, through the storying of their experiences, the individual assumes a central role in the narrative, as opposed to the more peripheral position they may occupy in the traditional medical account. The leading role in the biomedical account is often claimed by the disease itself with the story line plotting its way around symptoms and treatment. In a parallel narrative, there can be the physician taking centre stage as he or she takes responsibility for the 'case', seeks cures, is challenged, experiences successes and failures and so forth.

When people are able to articulate illness experiences in a storied way, they are enabled to find their voice and reclaim their stories of their illness. It is their story, not just a decontextualised, biomedical account of that particular illness. Their stories communicate the personal, and social, contextual setting of their illness, providing the details of their everyday lives and how they affect and are affected by illness. Psychiatrists and writers, Oliver Sacks (1985) and Robert Coles (1989), for example, have documented case studies of patients and demonstrated the importance of people's personal stories of their mental illness. Sacks (1985) talks of how, in the 19th century, neurologists and psychiatrists wrote case histories which were 'richly human clinical tales' (p.x) and believes we should recapture that lost tradition. 'We must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease - in relation to the physical' (p.x). Stories are representations of human experience, reflecting some of what people have endured in their illness experience.

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Integral to stories is the concept of time. Particularly for those people who are suffering from a chronic illness, or who are in the midst of their illness, the narrative provides a temporal location for the individual. This sense of being positioned in time enables the communication of the condition retrospectively, of the present, and how the individual envisages the future, in light of their illness. Through narrative, an individual can reconstruct their past, so that it has purpose or meaning for the present (Williams, 1984). As he or she gathers new experiences, past experiences can be reinterpreted in light of the new and, as Good and Good (1994) assert, each story told offers an alternative understanding of the illness and a possible different outlook for the future. Diagnosis is commonly a reference point in the 'time-line' of people's illnesses and, the ways in which diagnosis can change, or even transform a person's life, can be understood well in narrative expression. The events leading up to diagnosis, the process itself and the life afterwards can be brought together coherently, thus making sense of the past and bringing meaning to the future.

Reconstruction of identity and revision of personal life

The western world's strong expectations for individuals to realise their potential is a powerful, cultural message. According to Kleinman (1988), this message urges people to 'be all that you can be'. To strive to meet personal goals relating to careers and family, in particular, is a worthy quest if we are to make something of ourselves in life, to foster success, happiness and the treasured goal of many, wealth... or so the cultural story goes. However, when a person's health is compromised, there arises a potential threat to the achievement of such goals and, consequently, to the individual's sense of identity. As Kerby (1991) once said: 'Both self-understanding and self-identity are linked with the coherence of our lives

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as reflected in our personal narratives' (p.8). The following examines the link between identity and the illness narrative.

The diagnosis of chronic illness can be perceived, according to Radley (1994) as a critical moment in a person's life and a biological disruption (Bury, 1982). The course of that person's life has been disrupted and, depending on the type of illness, various aspects of that person's identity may be revised and the way in which a person defines him/herself, may change. This may be in terms of their career, their role as a parent, a partner and, for many people, all of these roles. Changes to the way people perceive themselves are also experienced in the course of chronic illness. Issues of self-esteem, confidence and physical appearance are areas where an individual may sense a change in self-perception. These changes in a person's life can also be conceptualised as a loss of self (Charmaz, 1983) which mark a subsequent reconstruction of the life story and revision of identity. In narrative terms, therefore, illness jeopardises the individual's personal life narrative.

The illness narrative is the story about the disruption brought to our lives, through illness and it is the story we share with others 'from whom we seek understanding and aid' (Brock, 1995, p.152). Storying their experiences enables people to integrate the various events of their illness into a unified whole and, as they draw meaning from their experiences, such meaning is consequently reflected in a reconstruction of their personal story. This narrative reconstruction, Radley (1993) notes, helps people to make sense of their lives as they continue to experience their chronic illness. Polkinghorne (1996) argues that to understand a person's identity, which he conceptualises as a process (Polkinghorne, 1991), one needs to know their self-narrative. The personal story, or self-narrative, expresses one's existence as a 'single unfolding and developing story'

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(Polkinghorne, 1988). In his essay on narrative and self-concept, Polkinghorne (1991) points out that people come to know themselves by drawing upon a plot which integrates their past experiences with future actions. It is when this 'operating plot' (p.149) begins to break down, that the individual's identity starts to disintegrate. Severe life stresses and major developmental events, such as illness, reaching old age and so forth can strain the plot that has previously functioned to unify life events. So, with the experience of chronic illness, an individual is faced with a plot that no longer holds together his or her experiences and provides an integrated sense of self. In order to bring coherence back into one's life, the plot needs to be revised.

The revised plot, or story line, enables the individual to configure and bring meaning to important life events. A woman faced with a chronic illness, for example, may find that she can no longer work full-time, may need help with household tasks and may need to change some of her plans for the future. Her previous identity has changed. The independent, committed career woman, who enjoyed gardening and going tramping may have changed into a person who has reduced duties at work, has become more dependent upon others and no longer able to do the physical activities she once enjoyed. Her previous 'plot' no longer integrates her change in health and its consequence or, as Mathieson and Stam (1995) notes, the meanings the individual has formerly founded her life upon, may no longer be available when she is faced with illness. And, it is this realisation that can lead to a perceived threat to one's identity. Plots, however, are not plucked from the air. According to Polkinghorne (1991) they are usually adapted from plots from literature and oral stories within one's culture and are used to integrate the events of people's lives. The woman with the chronic illness may select a story line which

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corresponds to her current state of health; perhaps one that speaks of the reduced expectations and abilities of a person with her condition which permits her to rely more upon others, seek alternative leisure activities and re-frame her future. In response to their changed circumstances, people do not necessarily start living by a plot which ensures a positive outlook to their lives. For example, the woman above may feel that she has been punished for past actions, that she is no longer a worthy person as she cannot continue in her high-powered career, and that she is a failure as she has to depend on other people to help her cope with her illness. So, in her way, albeit negative, she is still making sense of life events by emplotting them into a narrative which discloses her revised identity. It is her choice to decide what events contribute to her narrative. Another story could be told by omitting some events and including others.

A good example of narrative reconstruction is illustrated in Brock and Kleiber's (1994) study of how athletes with career-ending injuries talk about the loss of their identity as active athletes. The injury stories had themes of threats to the athletes' self-esteem and identity. The injuries that were dramatic and highly visible were more 'acceptable' to the athlete and to other people, particularly the coaches, than those athletes whose injuries were not visible and more subtle. For example, a torn eyelid is a highly visible, certain injury which leads to intervention and is recognised by others. A more subtle injury which may reflect the stress of practice is not always given credibility by significant others. When the athlete experiences doubt from other people, such as coaches and physicians, their commitment to the sport is held in question and their personal identity is threatened. Where the athletes were able to convince other people that their injury was directly caused by the sport and it was visible,

they were able to maintain their identities as athletes as well as their relationships to significant others in the sporting world.

Donald Polkinghorne (1988) captures the essence of narrative identity reconstruction well when he says:

'...we achieve our personal identities and self-concept through the use of the narrative configuration, and make our existence into a whole by understanding it as an expression of a single unfolding and developing story. We are in the middle of our stories and cannot be sure how they will end; we are constantly having to revise the plot as new events are added to our lives. Self, then, is not a static thing nor a substance, but a configuring of personal events into a historical unity which includes not only what one has been but also anticipations of what one will be'. (p.150).

The narrative organises the temporal features of people's experiences and so can accommodate the variety of perspectives that can be viewed over a period of time. Differing versions of the illness story may be told as the person adjusts to their changing sense of self. Just as the story must 'fit the audience if it is to be heard' (Charmaz, 1999), it must also fit the narrator if it is to make sense of and bring together past events and what is hoped for in the future. The chronically ill person may need to revise their story several times before they clearly express their experiences, bringing order and meaning to these experiences and thus articulating their newly shaped identity.

Adding to the growing collective narrative

Individual illness narratives can be transformed into a collective experience (Hyden, 1997) which I term the collective narrative. The accumulation of a range of stories, or case studies can facilitate the building up of a store of rich knowledge about an illness. As noted earlier,

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much of what is already written and understood about endometriosis is the biomedical side and, qualitative studies such as the present, enable the integration of the individual, social and political contexts. Listening to people's stories is an excellent way of redressing the imbalance, and is particularly fruitful when learning about a previously marginalised condition. Endometriosis illustrates this point well. It is a disorder experienced by women and it has a strong relationship with menstruation; both of these factors having been given lower priority, traditionally, in research. Moloney (1995) notes that traditionally, male-centred models have been used to focus on women's illnesses, which have perpetuated a stereotype of women being weak. The narrative approach is one way of giving voice to women's meaning of experiences and providing them with the chance to portray their strengths.

The collective illness narrative positions individual experiences within a social and political context. From the narrative, one can learn, for example, about doctor/patient interactions, the wider, social implications of having this particular illness as well as the suffering and so forth which may be experienced at the individual level.

Illness narratives enable individuals to express their illness experiences, make sense of their symptoms and experiences, construct their identity, revise their personal life, while also adding to the collective store of information relating to their particular condition. The collective illness narrative, in turn, is enriched by the individual's perspective, with the individual at the centre of the story, adding to the knowledge already gained from the biomedical perspective. A collective experience is transformed from individual experiences which, in turn, can convey the social and political context of the illness.

Summary

Narrative theory is informed by a wide range of ideas from a variety of disciplines. What I have presented are the central ideas which underlie the nature of narrative and which are relevant to my study. Basically, stories have the common structural features of a temporal framework, roles, themes, defining moments and subjunctivising elements. They also use the narrative devices of emplotment to integrate the story's events into the plot, and imagery and metaphor to illustrate a sense of the experience and how people make sense of events. Stories have utility, serving a range of functions at the personal, interpersonal and cultural levels of people's lives. The construction of identity is a fundamental role of narrative and is carried out at all these levels. Stories are the process by which we organise and construct meaning from our experience of time.

Chapter Four

Narrative Analysis

Narrative analysis is based on an ontology of the storied nature of human existence. The narrative approach, in psychology, is based on the premise that people's experiences and behaviour are meaningful and so, to understand ourselves and others, we need to examine the 'meaning systems' that make up our worlds (Polkinghorne, 1988; p.1). Language is a principal way in which experiences are made meaningful. Through the linguistic medium people make sense of themselves and their worlds and, are continually engaged in the process of creating themselves. People think about what is happening in their lives and are thus 'reflectively conscious' of themselves (Crossley, 2000; p.12). To do this, a person needs to see and experience themselves in the past tense as well as being able to imagine themselves in the future. The temporal nature of being reflectively conscious is linked to narrative and thus, the concept of self is tied up with language and narrative. Sarbin (1986) has argued that human psychology has a basic narrative structure and has proposed the idea that people think, perceive, interact and make choices according to narrative structures. People grow up with cultural stories which can be strongly influential on guiding their perceptions and their actions. In narrative analysis, therefore, the approach is focussed on examining the language and stories which people use to represent their selves.

Accounts of people's lives can be found in diaries, journals, autobiographies, biographies, memoirs, as well as interviews, and these linguistic representations provide the narrative material for the narrative researcher. Narrative interviews, as joint constructions, extend the researcher's role to

being part of that narrative construction which creates a shared understanding and meaning of the participant's life experiences. In narrative analysis, there is a strong emphasis on connected knowing, where the collaborative research relationship is characterised by both researchers' and participants' voices being heard within an empathic atmosphere (Connelly & Clandinin, 1990). How the researcher chooses to represent his or her interpretations of the data, depends on whether it is a single interview or case study, or whether there are a number of interviews. For example, the researcher may decide to construct separate narratives from each interview or, may present findings and interpretations as a whole. In this case, narrative themes may be generated across the interviews and these are discussed in a general sense, yet exemplified by extracts from the individual interviews. In order to reach the stage of being able to understand the meanings and complexities of the interviews, the researcher must maintain a close connection to the data. In other words, he or she must listen to the tapes, read the transcripts, listen to the tapes again and re-read the transcripts several times. Throughout this process, making notes on ideas, queries, themes and so forth are a continual practice.

Stories can be used in an organised way as a form of psychological inquiry, namely narrative inquiry, or narrative analysis. Scholars such as Bruner, (1990), Ricoeur (1981) and Polkinghorne (Polkinghorne, 1988; Polkinghorne, 1991; Polkinghorne, 1995; 1996) have theorised and written extensively on the nature of narrative and their theses have been instrumental in the formulation of narrative inquiry as a research tool. Ricoeur's theories relating to time and narrative, the role of plot and the function of narrative have made important theoretical and philosophical contributions to the current understandings of narrative inquiry, while Bruner and Polkinghorne have further addressed its ontological and epistemological assumptions.

Explanations of the narrative interview, further discussion of emplotment and an outline of the analysis used in this study, are presented in this chapter to provide a foundation for the presentation of my narrative process, which follows in Chapter Five. I note that some of this discussion may seem to be repeating some of what I have already discussed in Chapter Three with respect to narrative theory. However, while we have the theory and the nature of stories, I believe it is important to show the elements of this theory is carried through to narrative analysis. In other words, while Chapter Three is mostly related to the nature of stories from the standpoint of the narrator, the present chapter is concerned with the nature of the analysis of other people's stories. Hence, I have been a little repetitive.

The Narrative Interview

Interviewing for qualitative research can take varying forms. While the narrative interview is very similar to an open-ended, fairly informal qualitative interview, the main point of departure is concerned with the significance of telling stories. However, many of the following comments about the 'narrative' interview, can also apply to any qualitative interview. Riessman (1993) notes that narrative interviewers can give explicit instructions to participants that a story is required, and explaining to them how the story might be structured. However, as Riessman also expressed, my preference is for a less structured approach.

Like any good qualitative interview, the narrative interview should enable the participant to narrate the stories of her experiences within an atmosphere of rapport, respect and empathy. An important feature of the interview is the recognition that it is jointly constructed by the participant and the interviewer. The interview can be conceptualised as a 'guided conversation' (Rubin &

Rubin, 1995). The interviewer can prepare a few topics or questions he or she would like covered, however, it is important that questions are not fired at the participants, one after the another. The interview should flow as smoothly and naturally as possible, with the interviewer being encouraging, showing empathy, asking clarifying questions and, where appropriate, sharing experiences.

While the interviewer should convey a reasonable level of knowledge of the area being researched, I believe a balance needs to be struck between coming across as an 'expert' academic, and an interested party, gathering information. The researcher should continually bear in mind that the interview is a collaborative process; the participant is competent and is an expert in her own right, with respect to her own experiences. This differs markedly from the mainstream tradition of the interview relationship where there is an imbalance of power. The participant should feel respected and her experiences and opinions valued. If there is an obvious feeling of a hierarchical relationship between the researcher and the participant, then the participant may be more guarded and less likely to tell stories of her experiences. Riessman (1993) goes so far as to say that if researchers can give up control over the research process and consider the interviews as conversations, 'almost any question can generate a narrative' (p.56). The participants need to be empowered to have some control of the process and be encouraged to speak in their own voice (Mishler, 1986b).

In Bar-On's (1996) chapter on ethical issues in interviews and analysis, he says that he always assumes 'that there is some value in the interviewing process also for the interviewee' (p.10). I believe this is a valid point. It is easy for a researcher to be so focussed upon his or her research agenda and to overlook the issue of what the participant may gain from the interview. McAdams

(1993) comments that people often say to him, after an interview, that they found the process of relating their story to be 'profoundly enlightening' (p.253). While they may bring to the interview their understandings of their experiences, it is in the process of narrating them, that they may construct further meanings and thus a sense of enlightenment may be experienced.

In the research context of an interview, the researcher needs to be aware that what the person is telling them can be strongly influenced by what they think the researcher wants to hear, how much they believe the researcher understands what they are talking about, what they hope the researcher can do with the information, the status of the interviewee in relation to the interviewer and what type of story they want to tell. For example, do they want to present as a victim, as a survivor, a hero or whatever? The story they may recount to a close friend may be quite a different story from what is told to the researcher. The questions, answers and prompts, which characterise a conversation and an interview, play significant roles in narrative production.

Interviewing an ill person is quite different from interviewing a well person. The health status of the researcher, Radley and Billig (1996) alerts us, is often ignored in illness research. If the researcher is feeling fit and well, it is possible that a different type of conversation may evolve, than if the researcher is feeling unwell. Certainly, if the researcher shares the same condition as the person researched, one could expect a different interview again. The interviewer could find it easier to be empathic, to show understanding and ask appropriate questions. However, there is also a danger of the researcher slanting and colouring his or her questions because of his or her personal involvement in the condition. Further, a sick person may feel he or she must justify his or her illness in an attempt to avoid being thought of as a malingeringer, particularly if the researcher is a picture of health. The research interview, like any

qualitative interview, can be regarded as a linguistic event where meanings are contextually grounded and co-constructed (Schwandt, 1997).

Emplotment

The following draws heavily upon the work of Donald Polkinghorne whose ideas have broadly shaped my understanding of the nature of narrative.

Within the analysis process of narrative inquiry, Polkinghorne (1995) terms the emplotment process 'narrative configuration' and describes it as the central organising element and a primary analytic tool. In the analysis of accounts, the narrative researcher engages in an interactive activity of selecting a plot which may explain events. If the plot seems inappropriate in displaying a connection between events, the configuration process of moving back and forth between alternative plot structures and the set of events, enables the researcher to construct the plot according to the principle of 'best fit' (p.19). This dialectic procedure, Polkinghorne explains, occurs 'between the events themselves and a theme which discloses their significance and allows them to be grasped together as parts of one story' (p.20) and, further, plot construction can lead ultimately to the creation of distinctive and innovative configurations. As events are identified and selected according to the significance they hold in relation to the outcome of the story, a significant, coherent whole is organised from the individual elements. This 'coherent whole' in narrative inquiry, becomes the 'narrative', and it is the process of emplotment which brings order and meaning to the narrative. Narrative analysis can provide explanations of human behaviour which, according to Polkinghorne (1988) are retrospective. It 'explains by clarifying the significance of events that have occurred on the basis of the outcome that has followed' (p.21). We can thus make meaning of why a person acted in a particular way by understanding and identifying the relevant preceding events.

A narrative researcher may bring his or her own store of stories or narrative plots which he or she brings to the inquiry. Different researchers have attempted to systematise descriptive categories of plots through which narrative analysis can be carried out. Northrop Fry (cited in Ricoeur, 1981, and Polkinghorne, 1988) has proposed four basic types of emplotment which shape people's experiences: the romantic, where facets of life are configured as a mission towards a desired goal; the comic, in which progress towards a particular goal comes about by the means of evolution or revolution; the tragic, where the person is somehow thwarted from some desired end, and the ironic, in which the person is overwhelmed by events. In a similar vein, social psychologists, Kenneth and Mary Gergen (1986) have concluded that there are only three basic narrative forms: the progressive narrative where progress is made towards a desired endpoint; the regressive narrative where progress towards a goal is hindered; and the stability narrative where there is no change. Plots are built up by employing the three narrative forms in different ways. For example, in the comedy plot, a regressive narrative is characterised by the protagonist experiencing problems and moving away from happiness, the desired end goal, but is then followed by a progressive movement where the person experiences a move towards their goal of happiness. However, within narrative inquiry, it must be remembered that we are working within the human domain of meaning where categorising does not yield the same power of explanation as it does for the natural and biological sciences. 'To know ... that a story is "tragic" does not provide its particular and essential meaning' and, further, plots are not always employed according to their 'exemplar type' (Polkinghorne, 1988; p.167) but are often modified. I consider that it is not always appropriate to use a limited set of narrative plots and agree with Polkinghorne when he says that there is no one system of categories to describe plots. If a researcher uses a narrow set of plots, there is the danger of forcing

the data to fit the plot. The researcher may become blinkered, only looking for data which exemplify these plots and missing other levels of explanation for data that does not conform.

There are often similarities among narratives as they derive from a cultural store of stories. For example, as I have noted elsewhere, many of us have grown up with a cultural story relating to the medical profession. This is what I term 'the doctors are experts story'. The doctors are somewhat deified as their word is treated as gospel. They know all about illness and disease; one does not challenge what the doctor has said and one accepts and follows the doctor's counsel. Now, if a woman consults a doctor with 'symptoms' of painful, heavy periods, she may accept his or her word that they are just normal and part of being a woman. She may struggle on with distressing symptoms for some time before seeking further help. And the story goes on... The point I am trying to make here is that one might well expect to hear similar stories from other women who have shared similar experiences upon consulting a doctor. If the women draw upon the cultural story about doctors, they are then informed by that story as to what, if any, action they will then take.

Plots are expressions of meaning created through a temporal sequence into a narrative form. We engage in the process of emplotment without paying it much attention as it is so much part of our everyday lives. When we read or listen to narrative experiences, we comprehend these stories through the same linguistic processes we use in constructing our own stories. The way an individual organises events into the plot, points to the significance these events hold for that person. Thus, narrative meaning is more than just the events; it is the significance the events hold for the individual with respect to a particular theme. For example, a woman relating a story about her experience of endometriosis may be talking about what she did when she became aware of

'symptoms'. She may discuss how she felt when she consulted a doctor and was told it was all in her head. The placement of that event within the narrative, the representation and the interpretation of the experience, collectively indicate the significance it held for her. Accordingly, plots can serve as a first level of explanation, where events begin to take on meaning (Polkinghorne, 1988).

As a researcher, I believe that in order to develop a good understanding of a person's account of their experiences, one can construct a narrative from his or her account. This construction can be the initial stage of any form of narrative analysis, of which there are several. The way the researcher constructs the narrative, is not only his or her interpretation of events , but is also the way for the researcher to create meaning from the person's experiences. As noted earlier, the way we listen to or read about experiences is a similar process to the way we narrate our own experiences. Therefore, if we are going to analyse and interpret other people's stories, it makes sense that, as researchers, we can narrate them ourselves. It is in this process, which involves emplotting the events, that we develop our first level of explanation, as asserted by Polkinghorne. The events within that person's story take on some meaning for us and this is the initial stage of explanation. From here, we can delve further into the significance of these events and construct our interpretation. Referring back to my example of a woman's story of her dismissive treatment by a doctor, we can initially say that this was a significant event for that woman. That is the first level of explanation. From there, we can say *why* we think that. We can move on to interpret *how* we think that event was significant, for example, the woman did not seek further help from anyone for three more years and, during that time she suffered further physical distress. She thought that her symptoms were psychological, and came to construct herself as a weak person with low self-esteem.

Configuring the data into a coherent narrative is one way of analysing and presenting the data. For example, the researcher may decide it is appropriate for the objectives of their particular research project, to write individual narratives of each participant's experiences, similar to case studies. A commentary or discussion chapter could follow which would discuss both the general and the particular aspects of people's experiences. There is also the possibility of writing one, or more narratives, which explain and interpret the participants' experiences by plot types. These could be similar to Gergen & Gergen's (1986) narrative plots. However, for the purposes of my study, these are not appropriate options. I could not see how deciding whether the plot was romantic or tragic, or whether the woman had reached some particular life goal was going to address my research objectives. I initially looked at using Gergen & Gergen's approach, however, had great difficulty in deciding what was the so-called end goal of the women's story. I could see how a story of a person's experiences of going to university, or looking for a partner, a job, planning an overseas trip, or whatever, had quite clear end goals (a degree, a partner, a job and so forth). It was certainly not clear in my study what was each woman's end goal in the narrating of her experiences of having endometriosis.

Rather than focussing on what plot type each woman's account might exemplify, I believe that, initially, the focus should lie in identifying what each woman is trying to express. What is each woman saying to me? From there, narrative themes can emerge. For example, are these stories about suffering, the experience of infertility, about finding meaning in one's illness experience, and so forth? This method facilitates a degree of freedom and perhaps a broader approach to interpretation. Within these particular narrative themes, there may be individual stories and these can be explained within the wider theme. This technique, I would argue, encompasses the general as well as the individual aspects of the participant's stories. However, this technique is not

purely thematic analysis and thus goes further than a discussion of themes. At this secondary level of meaning, searching for narrative themes is a process where I am interpreting what the participant is trying to convey to me, as the researcher.

The third level of interpretation and explanation involves the analysis of both the content *and* the process of the women's accounts. I am specifically addressing the research objectives and, to do this, I examine the ways the woman links events and *how* she talks of making sense of her experiences. Throughout this process, I note the use of any narrative devices such as 'defining moments' and imagery. I examine the temporal aspects of her story, for example, does she use subjunctivising elements as she considers her future. Perhaps she shows instances of making retrospective sense of her past in view of her present understandings of her condition.

The process of analysis used for this study is explained in the following Method chapter.

Why use Narrative Analysis for this Study?

As stories are an effective form of communication, they are a useful tool for research within the social sciences. They can encompass the general and the particular aspects of human experience, enabling the depth and detail of a situation to be retained. Richardson (1990) notes that narrative inquiry naturalises some of the research process as it is similar to the way people question their own experiences and make meaning from their own lives.

People often do not know why they do certain things and so find it difficult to express themselves. Stiles (1990) notes that stories can convey points which are

beyond the teller's ability to explain. For example, a researcher may want to know why the research participant took a certain action. The participant may have difficulty in giving a simple answer and thus may start telling a story surrounding the events which led up to that action. Accordingly, during the narration of this story, the narrator is emplotting events together, in a particular way, and during this process starts to make meaning from them. In other words, a story is constructed, with certain events given significance and which lead to the denouement of that particular story. The listener and the narrator are both able to draw meaning from the story. Similarly, stories can provide the context and fill in the frame of reference when the speaker or listener do not understand the underlying reasons for certain events.

With respect to identity, when people tell stories about themselves and their experiences, they present a particular view and reveal themselves to be a certain sort of person. Narrative analysis provides a good vehicle for accessing the presentation of identity.

The configuration process connects salient events and thus provides an account of why or how these events may have occurred. Narrative, therefore, is a way of creating meaning and gaining access to how other people construct meaning. The meaningfulness of people's experiences is captured and, accordingly, facilitates the process of describing and examining human behaviour. As with other forms of qualitative research, narrative analysis reports on context which, in turn, builds up an understanding of connection between events and, at a more functional level, narrative analysis helps answer why a particular outcome has come about. The temporal nature of stories enables a researcher to learn about the individual's past, present and some perspective on their future. It is a way of encompassing human experience. The chronic nature of endometriosis characterises the condition along a time line and so we would

therefore expect women to feel and, possibly, act differently at various stages. Narrative analysis gives entry into the women's experience of endometriosis over time.

In Chapter Three, I discussed the functions of illness narratives and such functions provide further sound reasoning for using narrative analysis for learning about women's endometriosis experiences. To recap, illness narratives perform the following functions for the narrator :

- making sense of symptoms
- a means of expressing the illness experience
- enabling reconstruction of identity and revision of personal life
- adding to the collective illness narrative.

There has been a growing recognition that the stories people tell about their illnesses serve important functions and this has led to a greater interest in and credence given to what people are saying. I agree with Morse and Johnson (1991b) when they note that people have always been expressive about their illnesses but what is changing now is that more credibility is being given to their stories. 'We are hearing the same stories but with new ears and with new research methods and we are gaining new insights' (p.341).

The nature of narrative inquiry enables the women to tell their stories, in their own way, and for me, the researcher, to gain access to the way they understand, make sense of and represent their experiences. Narrative analysis enables me to learn about the way women talk about their identities. They talk in various ways about their selves, and the way they talk about their selves can be shown to shift or alter as they talk about the various stages of their experiences.

Summary

Stories can be used as a form of inquiry and this is the work of narrative analysis. Narrative analysis is based on an ontology of the storied nature of human existence, namely narrative ontology, for example, as discussed in **Narrative Theory**, identity is constructed through narrative. The role of the researcher is to describe, interpret and explain the data which are linguistic representations such as biographies and interviews. There is an emphasis on connected knowing and collaborative research, which is underpinned by a social constructionist epistemology. Narrative reasoning is employed to explain why an individual acted in the way he or she did and emplotment is a narrative device used to organise the narrative data to shape a coherent story for narrative analysis.

There are a variety of methods used by narrative researchers to analyse and present their data. While the use of narrative plots, such as those developed by Gergen & Gergen (1986) may be useful for certain types of studies, researchers should be cautious in employing a restricted set of narrative plots. Data may be manipulated to fit the plot and the distinctiveness of people's experiences can be missed. There are pitfalls in attempting to develop a single framework in which to locate each account. A researcher may only select information to fit that particular structure and possibly omit other material which may characterise the idiosyncratic nature of people's experiences.

The use of narrative plots may be useful at a first level of explanation as, at this level, events start to take on meaning. My preferred method is to discern what the participants are trying to express through their stories and, from there, identify narrative themes. These themes serve the purpose of generally describing, explaining and interpreting data as well as encompassing the unique and more individual characteristics. From this secondary level of

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interpretation of meaning, the researcher can then move on to examine the process as well as the content of the accounts. Being aware of the use of narrative devices enables insight into the way the participant constructs her understandings.

Narrative analysis provides a sound entry into learning about women's experiences of endometriosis as it enables the examination of the way their identity can be reconstructed over time, and the opportunity to learn about the meanings women draw from their experiences.

Chapter Five

Method

Chapter Overview

This chapter details the research procedure, reflexivity issues, my role as researcher, interview conduct, interview follow-up and issues of validity, reliability and generalisability. The next section is a presentation of the participants in the form of individual vignettes and this is followed by the analysis process. The analysis process reports on the procedure followed from when I first started analysing the data, right back in the early stage of interviewing the participants. It outlines how I struggled to find an appropriate way to analyse and present my findings after trying different forms of narrative analysis.

Procedure

I decided to interview up to fifteen women who had been diagnosed with endometriosis at least two years prior to the interview. Initially, I was unsure how many women I should interview. There was no correct number and fifteen seemed a reasonable goal. The best I could strive for was to interview sufficient to reflect a range of experiences. While we cannot expect to 'generalise' results of a qualitative study to the wider population in the same way as we do in quantitative research, we do expect people in similar situations to make connections to these experiences. Owing to personal circumstances, I was only able to interview women within the Manawatu area, and not travel long distances. The interview was planned to be semi-structured, with a few

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areas I wanted to ask each woman about. I also wanted the interview to be conducted in an open and conversational way, expecting the interviews to take from one to one and a half hours.

Firstly, an ethics proposal was presented to and approved by the Massey University Human Ethics Committee. The specific areas covered by the proposal related to the procedure for recruiting participants and obtaining informed consent, what would be involved in the interview process and how I would handle the tapes and transcripts. It was also noted, in relation to any potential harm to participants, that some women may experience some discomfort or distress when discussing their experiences and how I would handle this possibility. While this can be a normal reaction when discussing the effects of a chronic health condition, it is no less important because of its normality. On the other hand, it was noted that the chance to talk about one's experiences can have benefits. Cultural concerns were addressed noting the recognition of seeking cultural advice where and if necessary.

Participants were recruited through the New Zealand Endometriosis Foundation Inc, Manawatu Branch after consultation with two of their senior committee members. I had the full support of the Foundation who were able to assist in the recruitment of participants by including my information sheet (Appendix 1) with their quarterly newsletter, they were able to limit my request for participants to the Manawatu region.

The criteria for inclusion in the study was that the woman needed to have received a diagnosis of endometriosis and had been diagnosed for no less than two years. The reasons for these stipulations were firstly, I needed to know that the woman I was interviewing definitely had endometriosis and, secondly, that she had experienced a reasonable period of time since diagnosis to give a

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sense of her experiences over time, that is, before and after diagnosis. As I was wanting to learn about their experiences, I recognised the importance of being able to gain an understanding of how their understandings and experiences might have shifted over time. For reasons of convenience, only those women who were in the Manawatu area were given this information sheet, together with a return slip (Appendix 2) to indicate their interest in participating in the study, and a return addressed and stamped envelope. The Foundation wrote a paragraph in their newsletter introducing me and brief details of my study.

Fourteen replies were received indicating interest in participation. On receipt of these replies, I contacted each woman by telephone and answered any queries about the study. One woman shifted from the area and was subsequently unable to participate, while a second woman did not meet the criteria for the study. Twelve women were willing to participate. A time was made to meet together for an interview and this was confirmed in writing (Appendix 3). No women withdrew from the study at any stage.

Before moving on to how the interviews were conducted, I firstly discuss reflexivity and my role as researcher.

Reflexivity

The researcher is part of the constructionist research process, bringing along his or her own values, prior experiences and theoretical assumptions. It is therefore important for me, as the researcher to reflect upon how these issues might affect the research procedure and how they may help shape the way I interpret the material.

The researcher is part of the social phenomenon he or she is trying to examine (Schwandt, 1997). The reflexive process enables the researcher to reflect critically on how his or her personal and theoretical assumptions influence the research procedure. Steier (1991) talks of this process as a 'reflexive loop' (p.163) as it includes the researcher who, at the same time, is an active observer. Being reflexive is also a way of addressing the validity issue within social science research. Reflexive validity relates to how a theory or the researcher's line of thought is changed by the data. Underlying this is the concept that 'interpretation is in a dialectical relationship with observation' (Stiles, 1993). One would therefore expect that new ideas would evolve from an emerging theory as new information and data is brought forth, examined and analysed by different people.

While researchers bring personal values and life experiences to their projects, which in turn help fashion the way they interpret their material, reflexivity illuminates the context in which their methods have been constructed. This is an opportunity for the researcher to explain 'their position and socio-historical location' with respect to the phenomena being researched (Murray & Chamberlain, 1999). A reflexive account of the researcher's personal standpoint, and any ways the study may have created a shift in thinking, provides a useful tool for the researcher and the reader. The researcher addresses subjective issues while the reader can learn how the researcher's experiences may have influenced findings and consequent construction of interpretations (Owens & Payne, 1999).

The presence of the researcher and his or her role as an academic, psychologist and the various other roles a researcher can embody, also needs to be acknowledged. In the following section, I present my story about my endometriosis experience and acknowledge the various roles I play in my life

and a little of my background. In the analysis, I comment upon the shifts in thinking I experienced throughout the research process. These shifts in thinking can emerge from events occurring contemporaneously with the study, such as a worsening of my own endometriosis symptoms, surgery and so forth. Or, they can result from the reflexive process I went through as I listened to and analysed the women's accounts. Throughout the research process, I have adopted a position of self-awareness, noting down thoughts and episodes as they occur which relate to the way they interact with the study.

My Role as Researcher

My role as researcher does not stand alone. I bring to the research process all the other roles I assume in my daily life, such as PhD student, mother, partner, woman with endometriosis. These roles are shaped by the historical, social and cultural aspects of my life which I will now briefly present.

At the time of writing, I am 49 years old, separated with two young sons. I am of European descent, raised in an average, middle-class home in Auckland, the youngest of four children. After leaving secondary school, I trained, then worked as a secretary for a number of years. When I was nearly 30, I was diagnosed with endometriosis, when I was undergoing fertility investigations. As it seemed I was not going to have children, I decided I would focus on changing careers. I began extramural studies with a long-term goal of becoming a counsellor. Since 1986, I have been studying, culminating in PhD studies together with the final stages of my clinical psychology training. During these years, I have re-married and had two children. With respect to my endometriosis, I have undergone several laparoscopies and have found effective ways of managing the discomfort and pain. I have been fortunate not to have endured severe pain, but consider the years of infertility, which I

associate with the endometriosis, as a time of grief and emotional suffering. I feel that this distress, while long passed, has left its mark. However, I see this in a positive light. I am able to empathise with other people's struggles with fertility issues, particularly women with endometriosis. Similar to many people who go through a long period of some form of suffering, I believe I have gained much strength, knowledge and understanding from the experience.

I bring to this research personal knowledge and experience of endometriosis and an understanding of the suffering which can be experienced through infertility, all of which has enabled me to be empathic towards the women in the study. However, I acknowledge that when one has had personal involvement in the topic being researched, there is the real possibility that the interview and/ or analytic process may be coloured by one's personal bias. For example, when listening to a woman talking about her fertility difficulties, I could easily assume that she has suffered as I did, that she has been grief-stricken and felt less than a woman for not being able to bear children. I could continue a line of questioning, or keep seeking confirmatory statements in her account to support this idea. However, being aware of this potential bias, I ensured that I listened well and kept in mind that other people perceive and make meaning of their experiences in their own individual ways and do not necessarily share my responses to similar situations.

Within narrative inquiry, or qualitative analysis generally, it is evident that a researcher cannot expect to interpret the data in exactly the same way as would another researcher. However, we need to remain cognisant of the fact that our personal experiences and biases have the potential of shaping the analysis.

Interview Conduct

I stress the importance of the relationship between the interviewer and participant being founded on trust, empathy and respect for each other's knowledge of what is being researched. Such a relationship facilitates the co-construction of a narrative which has negotiated meanings to experiences and explanations for events. The participants are able to voice their perceptions of their experiences, while I also recognise that the women in my study are the experts at making sense of their own worlds. My subjective knowledge, grounded in personal knowledge of endometriosis and self-reflection, has helped me to connect to the experiences of my participants. Through conversational turn-taking and sharing of endometriosis stories, we were able to build up further knowledge of the endometriosis experience. The conversation and the relationship between the interviewer and the participant within narrative inquiry reflect the claim Morawski (1990) makes that language and social relations are pivotal to the creation of knowledge.

Listening to the women's accounts is an empathic way of entering their worlds. According to Moloney (1995) 'storytelling can be thought of as a way of caring: caring for the individual who is telling the story providing her with a vehicle for looking over her life, and caring for the listener who gains from the wisdom of the storyteller's experiences' (p.108). Sharing experiences and stories can be empowering. The knowledge and meaning created from relating their experiences can, for many people, result in a positive and fruitful exercise.

Riessman (1993) notes five levels of representation in the researcher process; attending to experience, telling about experience, transcribing experience, analysing experience and reading experience. And, it is with the latter level, the reader, that we are aware that another interpretation is being made out of events. From the original events, through the whole process of interview, to

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the transcription, analysis and the reader's interpretation, the knowledge imparted may not be complete. While I have been aware, therefore, that the representation of the women's experiences may be partial, I have been strongly committed to doing what I can to best represent their experiences. This commitment is grounded in the ideals of empathy, careful listening and questioning within the interview and reflecting back to the participant to gain a stronger sense of collaboration in building up our understandings of events.

At the interview, a consent form (Appendix 4) was given to the participant for her to read and sign. Before recording the interview, ten to fifteen minutes were spent on building rapport and informing the woman how the interview would proceed. I reiterated the confidentiality of the study, the use of pseudonyms and their right to withdraw from the study at any time. However, three of the women who did work with the NZ Endometriosis Foundation were not concerned with confidentiality and two, in particular, wanted to discuss the Foundation's work and have it acknowledged in this study. Accordingly, Judith is easily identifiable and I have not used any very personal or intimate extracts from her transcript. During the period over which the first three women were interviewed, I was pregnant with my second child. The first woman, Hannah, was single, in her late thirties and was keen one day to have children. I checked with her first whether she felt comfortable about being interviewed by a pregnant woman and she was quite agreeable.

Ten of the interviews took place in the woman's home and two interviews were conducted at their place of work. Each woman was asked if she would like to be interviewed at home and, if that was not convenient or satisfactory, at her place of work, or at my office at Massey University. The interviews took place mainly during the day, when the woman was at home on her own. Two were carried out in the evening while family were home, but this did not pose any

problem with respect to interruptions, privacy and so forth. Each interview took approximately one hour, terminating when each of us felt we had said all we had wanted. The time spent building rapport, both on the initial telephone conversation and at the beginning of our interview, proved invaluable. The interviews were often very conversational, open and friendly. There was sometimes a mutual sharing of experiences which facilitated and maintained the rapport. After the interview, several minutes were spent winding down the discussion. I found that the women liked to chat on a bit about various issues, not always related to their endometriosis, and it proved a comfortable way to finish our time together.

While I strove to keep the interview in a relaxed and conversational style, allowing, where possible, to let the woman relate her story, I also had a few particular areas or questions to ask of each participant. However, I only raised these questions if she did not bring them up herself. I started the interview by asking the woman if she could tell me about when she first became aware of 'symptoms' of endometriosis, even though she may not have been aware of their link to endometriosis. I asked about what she did, for example, did she talk to her mother, her doctor? Was she referred to a gynaecologist? What did she think was going on? In other words, how did she make sense of these symptoms? I wanted to know about the process of diagnosis and how she felt about not being diagnosed, being diagnosed and how she felt after diagnosis. On reflection, did she think that having endometriosis affected any areas of her life? How did she feel about the future? What did she plan or expect for the future in connection with endometriosis? I asked one woman whether she felt anything positive had been gained from the experience, while some women volunteered this information. However, I omitted to ask this question of the other women. At the time of asking Tess whether she had gained anything positive from the experience, I wondered whether I was putting ideas into her

mind, a thought that often occurred to me throughout the general process of interviewing. On reflection, I consider I should have asked each woman. After all, Tess's response was spontaneous. She definitely found nothing positive had been gained from the experience. It was not a considered response yet, it seemed to spring from the heart, so to speak. I was not putting 'ideas' into her mind.

The following reports on some of the issues I encountered while interviewing. However, before reporting on specific interviews I would like to continue the above discussion relating to 'putting ideas into a participant's mind'. As noted, I was very aware or reflexive about some of my questions and comments throughout the interviews. Was I suggesting to a woman how she might have been expected to feel in a certain situation? I tried very hard not to do this. Where possible, I would phrase the question in such a way which suggests some people may feel this or experience that in a particular situation while others may not, or they may experience something different. What was her experience? As can be expected, at times, a question, or comment 'popped' out, just as it would under the normal circumstances of a relaxed conversation. And, this situation, of course, is one drawback from using a relaxed, conversational style. However, as I interviewed more women, I became more and more cognisant of this issue and was more careful in framing my questions and responses.

Only one interview took a while to get started. Ann seemed mildly anxious when I arrived at her home to interview her. She made us coffee and we sat down and chatted for a while. I spent some time trying to put her at her ease, talking of other things besides the forthcoming interview. She inquired about my personal experience of endometriosis, so I told her my story. She seemed concerned, however, that she was not prepared for the interview. I reassured

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her that she was not expected to prepare for the interview, preferring her to talk about her experiences in a natural way, rather than having a rehearsed effect. After about 30-40 minutes, we were ready to turn on the tape-recorder and start our interview. At this time, I was nearly 8 months pregnant and my sore back was still bothering me. Ann made sure I was comfortably seated and I felt very at ease with someone who understood the discomforts of advanced pregnancy and appreciated her consideration.

When I interviewed Zoe, I had developed a mild migraine and was feeling very tired. I was reluctant to postpone the interview, so continued. I believe that the interview went well and Zoe talked freely about her endometriosis experiences. However, I need to admit to feeling relieved when it was over for, at times, I felt it was an effort to think clearly due to my tiredness and slight nausea. As I thought the interview progressed well, I do not think, on reflection, that it would have been entirely different if I had been feeling well. On the other hand, I decided that it was inadvisable to conduct any further interviews when feeling unwell as, with another participant who perhaps was reserved or anxious, I may not have had the same ability to develop rapport.

My interview with Diana got off to an unfortunate start. Before I had left home, I had followed my normal procedure of checking the microphone first. All was well. When I arrived at Diana's home, she showed me where to plug the tape recorder in and, as usual, I re-tested the equipment by saying a few words. It was not working. Despite my best efforts, I could not detect the problem. I felt a little flustered and rather unprofessional. I explained to Diana that it had been working fine earlier that evening. She offered the use of her cassette player which we duly used. Although it proved to record quite adequately, we were both aware of having to speak close to its built-in microphone, compared to the normal external microphone which can be placed discreetly on a table and

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picks up sound from a reasonably large area of the room. I later discovered that the battery had fallen out of the microphone into the carry bag in my car. Although Diana seemed to be a very pleasant person, I did not feel very relaxed at this interview, partly due to the tape recorder hiccoughs and partly due to Diana having a tendency to answer the questions fairly briefly. I found I was asking a lot of questions, when, to date, I had been used to other participants giving much longer, storied accounts of their experiences. The interview seemed to reflect the traditional interviewer/interviewee relationship, where Diana just answered my questions and awaited the next one. Compared to other interviews, this was a relatively short, and often stilted one and perhaps reflected an insufficient lack of rapport being built up earlier in the evening. Interestingly, this was the only interview where I was not offered a coffee or tea and, I realised, that this missing routine left me feeling less relaxed than usual. It seems that offering and accepting a coffee, is an important ritual in creating a relaxed ambience, and signifying approval and acceptance on the part of both people. Certainly, this is my perception of it and recognise that others may not share my view. However, the way I made meaning of this event, was that Diana perceived me as someone who was there on business and not for fraternising.

I interviewed Judith in her home in the country. The day we spoke, her husband was due to go away for a month to help with some building for their daughter and family. Judith had been unwell and was worried about her failing health. I became concerned that I was being intrusive and perhaps taking time away from her and her husband before he left for his work. However, Judith was reassuring and told me she felt it important to share her story. While I spoke with Judith, I felt sadness and a great empathy with her. I was shocked to learn of her death some few weeks after the event, thus missing the funeral. A year later, when I started analysing her transcript, I

found it a very sad process and many tears were shed for Judith. I was very grateful Judith shared her story and, as a colleague of hers said to me, 'she said, if my story can help other women, it will have all been worth while'.

Interview Follow-Up

One tape was transcribed by myself, while the others were transcribed by a friend in the psychology department, and by a secretarial acquaintance. The importance of confidentiality was discussed with each woman and discussion took place on ways of keeping the tapes and transcripts secure and where they were going to transcribe them. After transcription, a copy of the transcript, together with a covering letter (Appendix 5) was sent to the participant. This gave each woman the opportunity to make any additions, deletions or alterations. Overall, there were only a few minor changes made. Ann, however, expressed reluctance in continuing with the study. In her letter to me she commented that she felt she had not 'focussed correctly on the issue of the endometriosis'. She went on to say 'I find the way I have rambled about searching for where the endo has affected my life an embarrassment and would like the whole tape to be deleted'. I rang Ann to discuss her feelings and reassured her that I felt she had focussed very well on her endometriosis experiences. I knew she had felt nervous when we first met, so I had spent half an hour chatting to her before I turned the tape recorder on. I have also found it a common experience for participants to feel a bit embarrassed about the way they have expressed themselves on reading their transcripts. I explained to Ann, and to other participants, where necessary, that the transcript always reads like that. We always speak differently from the way we write. 'Ums and ah's and repetitions, searching for words, and so forth, reflect the way we speak normally, but we do not normally write this way. Ann felt reassured, asked for

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one small deletion to be made concerning an irrelevant topic, and said she would be happy to stay in the study.

I re-interviewed Hannah, the first participant, as she had not fully met the criteria for the study. At the time of the first interview, her time since diagnosis had been less than two years. I was very reluctant to lose her participation, so decided to follow up with a further interview, 12 months later. As Hannah was involved with the Endometriosis Foundation, I had several conversations with her over the course of my study. I also made telephone contact with nearly all the other participants, mainly to let them know I was still working on the study and to learn how they were getting on. Each woman seemed to enjoy the opportunity for another chat and brought me up to date with what had been happening in their lives. In one instance, it gave me the opportunity to clarify some confusion I was experiencing while working on one woman's transcript.

Issues of Validity, Reliability and Generalisability

The issues of validity, reliability and generalisability constitute a contentious area within qualitative research. There are differing views held and some researchers, such as Mishler (1990) and Blumenfeld-Jones (1995) have suggested new terms and definitions which show a concerted attempt to bring a sense of credibility to the qualitative field. I present my position which I consider appropriate for narrative research.

Validity

Narrative research does not provide certainty or an actual 'truth', rather an appearance of truth or reality, that is, 'verisimilitude'. Trying to validate stories for consistency or stability, is opposed to the idea of narrative truth as stories and, as Sandelowski (1991) argues, narratives are positioned in a 'hermeneutic

circle of (re)interpretation' and can change from telling to telling. Further, the attempt to 'validate' stories is contrary to the tenets of social constructionism, whereby it is claimed that language socially constructs a representation of reality. As this research is underpinned by a social constructionist epistemology it cannot be evaluated for validity in the usual positivist way.

The original concept of 'validity', like 'cause', has been redefined by formal science and narrowed down to being established by measuring instruments and tests (Polkinghorne, 1988). Such procedures are based on the experimental model (Mishler, 1990), while, in narrative research, the term 'valid' reclaims its usual meaning of supportable and well-grounded, and so conclusions reached reflect those that are well-grounded in the narratives. Evidence is provided by the narrative analyst to support such conclusions by drawing upon examples from the transcripts. Blumenfeld-Jones' (1995) distinction between the terms 'truth' and 'fidelity', I believe, is a useful aid if one is evaluating narrative inquiry. He argues that 'truth' can be conceived as being what actually happened in a particular situation, while 'fidelity' relates to what it means to the person relating the story. He says:

'(fidelity)...becomes an obligation towards preserving the bonds between the teller and receiver by honoring the self-report of the teller and the obligation of the original teller to be as honest as possible in the telling' (p.28).

However, in evaluating the degree of fidelity in a narrative analysis, certain factors need to be considered. The narrative researcher must be faithful to the person's account as well as toward what he or she cannot communicate about contextual matters. Not only has the research participant certain reasons for relating their experiences, but the researcher also brings his or her own set of intentions to the analysis. As noted earlier, working through the reflexive

process, is a way of dealing with the validity issue. Reflexive validity addresses the way the researcher's thinking or a theory can be changed by the data and, therefore, it is to be anticipated that new ideas and theories will evolve when interpreted by different people and as new data is added.

As Blumenfeld-Jones (1995) points out, there must be a perception of believability to the narrative analysis with the reader feeling a sense of congruence or resonance with their own experience in similar situations. This resonance ties in with Ricoeur's (1984) idea of the 'pre-narrative quality of experience' (p.74) which provides a contextual backdrop. The following quote from Ricoeur (1984) explains this concept.

'A judge undertakes to understand a course of actions, a character, by unravelling the tangle of plots the subject is caught up in. The accent here is on "being entangled"...a verb whose passive voice emphasizes that the story "happens to" seminar before anyone tells it. The entanglement seems more like the "prehistory" of the told story, whose beginning has to be chosen by the narrator. This "prehistory" of the story is what binds it to a larger whole and gives it a "background". This background is made up of the "living imbrication" of every lived story with every other such story. Told stories therefore have to "emerge"...from this background. With this emergence also emerges the implied subject. We may thus say, "the story stands for the person"... The principal consequence of this existential analysis of human beings as "entangled in stories" is that narrating is a secondary process, that of "the story's becoming known"...Telling, following, understanding stories is simply the "continuation" of these untold stories.' (p.75).

The narrative analyst is trying to convey to the reader what the experiences of life have been like for the participant. The reader, through his or her own life experience and their own store of cultural stories, should be able to say 'yes, I can see how this situation came about', rather than 'that just does not make sense; a person in that situation just wouldn't do that and I can't accept that explanation of events'. We cannot expect to provide a 'truth' or any certainty

within narrative research. The narrative is a construction, by the individual, of their 'reality'.

Reliability

Reliability, in narrative studies, like validity, draws on its ordinary, day to day meaning, not that defined by formal science for use in quantitative research. Reliability refers to the dependability of the data. There are no formal indicators of reliability, rather narrative research relies upon care being taken with the interview process, transcription of the tapes and the researcher presenting a thorough description of the interview process (Polkinghorne, 1988). In the analysis of the interviews, I referred both to the transcripts and the tapes. This procedure enables a richer understanding of the interview, whereby the tapes allowed me to recall the contextual setting of the interview, which are not always clear from just reading the transcripts. By repeated listening to the tapes, I was able to clear up evident uncertainties of the transcriber in the transcript. I also referred the accounts back to the women giving them the opportunity to correct any errors.

Generalisability

The concept 'generalisability' bears a similar set of arguments as those applied to the concepts of validity and reliability. It is a term which belongs in quantitative studies and is not necessarily appropriate for use in qualitative research. In narrative inquiry, the narrative does not present generalisable laws that allow us to anticipate the same events occurring whenever the original conditions are repeated.

However what we can expect in a qualitative study is for people who have shared similar experiences to experience a sense of connection with the findings. For example, within the endometriosis stories, we can learn how

some women constructed their experiences as being a time of great stress and feelings of despair and frustration. Other women may talk about how they experienced difficult symptoms and how they considered these impacted upon their intimate relationships. In the analysis, these constructions may be interpreted in terms of the women's identities. Accordingly, women with endometriosis could read such an analysis and make connections with it. So, in terms of making a generalisation from the analysis, we cannot say all women in this situation will feel and respond in the same way. What we can say is that there may be more than one way that a person will construct their experience and, here are some of them.

It can also position the decision points at which a different event could have led to a different ending (Polkinghorne, 1988). At best, a consensus seems to have emerged among many qualitative researchers where generalisability is best conceptualised as a fit between the situation under inquiry and other situations to which one might be concerned with 'applying the concepts and conclusions of that study' (Schofield, 1990). I agree with the approach that the researcher should present a detailed description of the process and the setting so that other people, such as the reader and other researchers, can ascertain its possible relevance or use to other circumstances and settings (Zyzanski, McWhinney, Blake, Crabtree, & Miller, 1992).

I consider that the collective narrative, as a store of knowledge of endometriosis, enables us to build up our understandings of the condition. We may be able to say, for example, that when women experience distressing symptoms of severe pain and heavy menstrual flows, they may also experience a disruption to their work life and their intimate relationships, and so forth.

In summary, narrative inquiry cannot be judged on issues of validity, reliability and generalisability, in the same way as assigned to quantitative research. These concepts are related to quantitative studies.

The Participants

I now present a vignette of each woman which have been set out in the order in which I conducted the interviews. These vignettes help orient the reader and, can be referred back to when the women's excerpts are quoted in the analysis.

I would note here that I also wrote more in depth 'stories' of each woman's experiences in order to orient me in my analysis. It was a lengthy process which involved several weeks' work. However, although these stories do not appear in the analysis itself, I have included one in the Appendix (6) as an example of the time and effort spent doing this 'unseen' part of the analysis.

Hannah

I interviewed Hannah on two occasions. When I first interviewed her, she had not been diagnosed two or more years previously, only one year. There was a misunderstanding about this criterion for the study. However, we went ahead with the interview and I interviewed her again 18 months later. In this way, I was able to get a longer period of time since diagnosis.

Hannah was 38 at the time of the first interview, a single woman, living on her own. The eldest of five children, Hannah was raised in the country and did her secondary schooling at a boarding school. She trained as a secretary and, after returning from overseas, went on to do administrative work. She was working

currently in a part-time, administration position, often working voluntarily longer hours than the organisation was able to pay her.

Hannah expressed as a warm, caring and intelligent woman who was very accommodating in talking to me about her experiences, both at the two interviews, and time to time on the phone. Her long history of severe endometriosis symptoms had resulted in a woman who felt grief, despair and misery. However, her understanding and experience of the condition also enabled her to be of great support to other endometriosis sufferers. She was very happy to tell her story as she was concerned that more information, about how endometriosis can affect a woman, was disseminated as widely as possible.

Tess

Tess, was a vivacious, confident woman in her late forties. She was separated, lived alone and had four grown up children. She was one of two children. Before she married, she spent some time travelling overseas, preferring to do this than tertiary studies. At the time of talking to Tess, she was doing some tertiary study and part-time work. The morning I interviewed her, she was feeling the effects of a late night, but was still happy to sit down and talk to me about her experiences.

Tess's story is of much suffering and humiliation. To her, endometriosis was a nasty, invasive condition. She felt abnormal due to her menstrual difficulties, yet despite her efforts, seemed to find little control over her symptoms. The often, long periods of debilitation associated with endometriosis and possibly related ill health, left Tess in despair. She found nothing positive to relate about her experience with endometriosis. Fortunately, her health had since improved greatly and she commented that her life was just beginning.

Ann

Ann was a 49 year old, married woman with three adult children and impressed as a very warm, caring person. The youngest of two, she was raised in the country, leaving school after the 5th form. She talked of having a stressful home life when she was younger, her father being quite stern and her mother rather anxious.

Ann was very forthcoming and shared quite intimate details very readily. However, at times she had trouble expressing herself and came across as nervous, slightly anxious and hesitant. Despite her mild anxiety, the interview did, in fact, feel comfortable. I did not feel her difficulty in articulating her experiences detracted from the interview but I did feel concern for her feelings. At one stage of the interview, I found it difficult conveying to her what I wanted to know. I am unsure whether it was my lack of articulation or her inability to grasp my meaning. On listening to the tape later, I realised that my difficulty was overcome by rephrasing the question. (Note: I discussed this particular issue in the Research Process chapter).

Ann was an active person, whose activity had declined over the years due to her endometriosis. Ann's story is characterised by years of pain relating to endometriosis, fatigue and a life shadowed by these symptoms. Although, she was learning to manage her condition and thus her life better, she was angry and resentful at the lack of understanding and often dismissive treatment she has experienced over the years. She also described herself as having been meek and unassertive, but was learning to become more assertive and take control of her situation.

Vicky

Vicky came across as a very expressive and outgoing person. She was 31, had been married for 5 years and had no children. She was the middle child of three, born in England and emigrated to New Zealand when she was a young teenager. She left school after the 6th form.

Vicky's endometriosis story is wrapped up in fertility difficulties. For the past few years, Vicky and her partner had been trying to conceive, and her childless state had left her very sad and bitter. However, from what she said, the cause of her infertility may have been related to a problem with her ovaries and may not have been anything to do with endometriosis. During the interview, her focus was almost entirely on trying to conceive. She commented that endometriosis had affected her life '10%' because of having to plan around her bleeding and pain, but the infertility had been affecting her life 80%.

Joy

Joy was in her mid-thirties, single and living with her parents. She had one older brother. She worked as a midwife, having trained as a nurse in NZ and later doing her midwifery training in England. She was presently studying towards a midwifery diploma at University.

Joy made me feel very welcome and was very supportive of my research. She was very open about her experiences and expressed herself well. She was obviously a very intelligent woman who, despite the almost crippling symptoms she had suffered throughout the years, managed to live quite a full life. In some respects, she denied that endometriosis had affected or spoiled her life in any way, yet her description of her symptoms seemed to belie this claim. Her oft-used expression 'plodding on' seemed to exemplify her way of coping with her health problems. Joy had the unfortunate experience of suffering from

co-existing health problems which compounded the effects of endometriosis.

Zoe

A 28 year old, vivacious and intelligent person, Zoe was, like all the participants, most happy to talk about her experiences. She was single and flatting with some other people. Zoe worked in the medical field and held a responsible position at the hospital. She had a younger brother, was raised in NZ and her parents took them travelling overseas for two years when they were young.

Zoe's experiences of endometriosis were characterised by intermittent severe pain and fainting episodes. She had a miscarriage while overseas and was left feeling a great sense of loss and depression. She was concerned that the endometriosis was affecting her fertility and ability to carry a child. Although she had experienced unpleasant, often severe symptoms, her fertility appeared to be the main focus of her concerns. At the time of meeting her, Zoe was working through her issues with a counsellor.

Jacky

Jacky was 39 years old, married and had no children. As one of five children, she was raised in a rural town. Jacky trained to do secretarial work, spent some time travelling overseas and seemed to lead a fairly full life, playing netball and enjoying sewing and knitting. Her husband was self-employed, working from home and was doing tertiary studies.

We settled easily into the interview and she talked openly about her life. A few minutes into the interview, she told me how she lost a baby while 6 months

pregnant the previous year, owing to toxæmia. The great sadness and grief Jacky felt following this loss was very evident. At that time, my son Benjamin was 6 months old. I felt very connected to her sadness, from the point of view of someone who had long experienced infertility and who could only imagine how tragic it would be to lose a child. We wept as she talked about the death of her daughter and so we turned off the tape-recorder for a short time.

I felt, through her story, Jacky had taught me much. Her retrospective examination of her endometriosis experiences reshaped her ideas of why she was now experiencing fertility difficulties and, in this way, showed how she made connections between events and helped her to make sense of her present infertility.

Diana

Diana, was a 32 year old woman, married for the second time, with a child from each marriage. She was the eldest of three in her family. She was brought up in various parts of New Zealand owing to her father's job which necessitated them to move. She was employed as a nurse.

Diana's symptoms of endometriosis started after the birth of her daughter, nine years earlier. Although she sought medical advice at that stage, it was another 3 or 4 years before she was diagnosed with endometriosis. The pain had been mostly manageable with painkillers. However, she had found that the associated fatigue made doing any extra night duties at the hospital difficult. She believed that the extended hours upset her cycle and so declined extra night duties if her period was imminent. At the time of diagnosis, Diana's specialist told her a hysterectomy was the only option and gave her little information about endometriosis. He did tell her that she would be unable to have any more children because of the condition. Diana was unhappy with his

dismissive attitude and finally found support and information at the Endometriosis Foundation. She later changed to a different gynaecologist with whom she was very pleased.

Diana's positive attitude appeared to have helped her to get on with her life and enable her to cope with her endometriosis. However, she seemed rather sad at the fact she was unlikely to have any more children and that the option had been taken away from her. I told Diana a little of my own experiences and how, despite thinking that endometriosis was preventing me from ever conceiving, I did in fact go on to have two children. I also encouraged her to seek more information relating to this issue.

Amelia

Amelia was an outgoing, intelligent woman who relaxed easily into the mode of the interview. She was adopted and one of three children. She was married, with two children, one of whom was also adopted. She had an academic position at the university and, like many working mothers of young children, was leading a very busy, somewhat tiring life. The interview was held in her office at lunchtime, so we were somewhat limited with our time. However, as Amelia talked very willingly and rather fast, we certainly covered a lot of ground in the hour or so we had together.

Amelia's symptoms of endometriosis did not fully emerge until she was in her early 30's. She sought medical advice when she failed to conceive at the age of 30 but, owing to lack of endometriosis related symptoms, a diagnosis of endometriosis was initially ruled out. However, it was not until the onset of severe pain after her progesterone levels were boosted in order to improve her chances of fertility, that she underwent a laparoscopy and endometriosis was diagnosed.

After two miscarriages, Amelia and her partner adopted a child and then later conceived another child. The way endometriosis had affected her life she related to often severe pain, fatigue, tearfulness and infertility. At the time of interviewing her, Amelia was enjoying a respite from symptoms following the conception and birth of her daughter. Her baby was 15 months old, but she was expecting the symptoms to build up again and expressed fear of their recurrence. Amelia was making efforts to improve her health in order to manage the endometriosis and be healthy for her children's sake.

Val

Val was a confident, articulate and strong looking woman. One of two children, she was raised in Australia, and later moved to New Zealand with her husband. Through choice, they were childless. Val was presently unemployed, though had been working in the medical field in Australia.

She was very relaxed and most willing to talk about her experiences. She was also very supportive of the study and expressed encouragement. She talked widely and at length about her endometriosis experiences and a good rapport quickly developed between us.

Val had experienced irregular, painful, heavy periods from when she started menstruating at 11. She sought medical advice at 17 and told everything was fine and, when she was 26 had her first laparoscopy. During those years, she had used the contraceptive pill, on and off, to ease some of the symptoms she experienced with her periods. When she was 34, she underwent surgery for a complex cyst on her left ovary, which subsequently burst as she was opened up. No diagnosis of endometriosis was made at this stage which, in retrospect, Val found very surprising. When she was 39, Val had had enough of her menstrual problems and chose to have a hysterectomy. While she was

undergoing this surgery it was found that she had widespread endometriosis. To Val's dismay, some of the symptoms had since returned, such as pain on intercourse and constipation. However, she felt psychologically more stable and commented she wished she had been able to have a hysterectomy when she was much younger.

Val said she felt angry that she had to put up with her symptoms for those many long years, even though she had always tried to just accept them as normal and just get on with her life. She expressed her extreme dissatisfaction with some of the experiences she had had with the medical profession but was very pleased with her present general practitioner and gynaecologist. Val was making a concerted effort to lead a healthy lifestyle in an attempt to minimise and manage her symptoms.

Judith

Judith, 55, was one of 5 children, two of whom died when young. Judith was married, with three grown up children and one grandchild. She had a long career of nursing and was a founding member of the Endometriosis Foundation in Palmerston North. She dedicated several years of effort to the Foundation in an effort to help other women with endometriosis.

Judith was very pleased I was doing my PhD research on endometriosis and wanted to help. Judith was an articulate, intelligent and caring woman who had worked very hard, despite often severe pain, all her married life.

As a teenager, Judith sometimes experienced painful periods, but it was not until she went off the contraceptive pill in her early thirties that she started experiencing severe period pain which, though managed with medication for a couple of years, progressively got worse. At one stage, she suffered such

severe abdominal pain, she went to accident and emergency and was admitted to hospital. She was told she probably had an infection and was given four hourly morphine to manage the pain. Finally, her gynaecologist suggested a laparoscopy and possible hysterectomy and readmitted her not long later. By this stage, Judith had worked out she had endometriosis and her self-diagnosis was confirmed by the gynaecologist. The very widespread endometriosis had caused her organs to adhere to one another, necessitating a five hour operation in order to remove her uterus. Judith's troubles did not end there. She developed three post-operative pulmonary emboli involving both lungs, which left her in severe pain and feeling exhausted for a long period of time.

Judith's years of, often debilitating symptoms, culminated in her developing a large malignant cyst on her remaining half ovary. This was subsequently removed but burst during surgery. Judith expressed her fear of this happening as she knew that malignant cells could be dispersed. She underwent chemotherapy treatment and, at the time of our interview, had recently been advised that her CO125 level, a tumour marker, was elevated, suggesting that the cancer was still present. She was due to have a scan a couple of days after our talk. Judith was experiencing intermittent pain but said, otherwise, she felt quite well.

As she talked about her life with endometriosis, Judith came across as a strong, positive person who just got on with her life. The endometriosis certainly took a tremendous toll on her health. She was very concerned about the familial link of cancer and endometriosis within her family and was worried about her daughters. She was also concerned about not being around for her family should she die within the next couple of years.

Judith died in September 1998, not long after the interview took place.

Jay

Jay was a 42 year old married woman with two children. She was one of two children, educated at a private school and trained as a teacher. Jay was a founding member of the Endometriosis Foundation and was currently working for the Foundation as an educator. This position involved teaching secondary school girls about menstruation and the symptoms of endometriosis and widened to her developing a teaching package which she was marketing overseas.

An articulate, expressive and vivacious person, Jay was very open about her experiences of endometriosis. Like the other two women who were involved with the Foundation, Hannah and Judith, she was unconcerned about her identity being kept confidential. I had already met Jay on previous occasions and so we had already developed a good rapport together prior to the interview.

The initial experiences of endometriosis for Jay, were quite different from the other women I interviewed. When she was 8 months pregnant, Jay was hospitalised owing to a spinal injury. While in hospital, she fell on her stomach and then went into labour. It was discovered, at a later stage, that her uterus had ruptured during the fall, causing a spill of endometrium into the pelvic cavity. This initiated an advanced stage of endometriosis, resulting in severe pain with the resumption of menstruation 12 months after the birth. However, a diagnosis of endometriosis was not actually made at this stage.

Jay's story revolves around the three years it took for her to receive a diagnosis of endometriosis and the horrors she experienced, both physically and psychologically, during that time. Much of this suffering need not have

occurred if she had not been misdiagnosed. If she had been diagnosed with endometriosis at an early stage, she could have received the urgent treatment she so desperately needed. Her severe pain, diminished self-esteem and inability to cope led to most areas of her life being affected adversely.

Jay looks back on those years with 'horror', yet does feel she has become a better person for her experiences. She talks of having a 'passion' to help other women and had spent 13 years helping build up the Endometriosis Foundation, supporting, educating and empowering women with endometriosis as well as educating the wider community about the condition.

The Process of Analysis

Narrative research is based on specific, theoretical assumptions, yet does not have a clear cut, prescriptive way of conducting the analysis. I therefore formulated my own form of analysis from which to interpret and present the data. In this sense, it is liberating to develop one's own style of analysis which is sufficiently sensitive to address the research objectives. On the other hand, it is no easy task to construct an appropriate form of analysis as the evolving style needs 'testing' and, for me, this proved to be a lengthy and difficult process. Over a two year period, I tried out several ways of analysing the women's accounts. I was dissatisfied with these various ways and, at times, became very frustrated and disheartened about my work. However, I was not prepared to settle for just any approach and was determined to find a way of analysing the women's narratives which I found acceptable. Eventually a suitable process slowly evolved.

The process of analysis started when I was interviewing the participants. Even at that early stage, I was formulating ideas and making assumptions. For

example, when I was interviewing Vicky, I found I was trying to understand her infertility and endometriosis connection. While she seemed to blame the endometriosis for her infertility, she also mentioned she had another condition which she had been told was the cause of her infertility. I found myself assuming she blamed the endometriosis but, on later analysis, I was able to look at this issue from another perspective. At the time of our interview, my baby son was 3 ½ months old. Having experienced my own long-standing fertility problems, I could relate to her sadness and strived to show my empathy, rather than sympathy. However, I sensed that her childlessness was such a painful issue to her and we could not do more than acknowledge my experience. This story exemplifies the reflexive process, the way I make meaning from someone else's account, the way I understand *she* has made meaning from her experiences and how, right from the interview stage, the process of analysis has begun.

I listened to each woman's tape while reading the accompanying manuscript and was able to fill in a few gaps left by the typist. Any ideas and thoughts I had about the women's accounts were noted down in a folder which was divided into various sections which, later, helped shape the analysis.

Firstly, I wrote the brief vignettes and then I wrote the longer narratives of each woman. These narratives were the origins of a former plan of presenting twelve individual narratives to be followed by a commentary chapter discussing what had been learned from these women. While I eventually gave away this idea, writing the individual narratives proved to be an integral part of the present analysis. I was able to develop a sense of the individual experiences before moving on to another level of understanding. Throughout my attempts to find an appropriate way of analysing the narratives from a narrative perspective, I kept uppermost in my mind the research objectives. I

was wanting to examine how women spoke of their endometriosis experiences in relationship to their sense of selves and how they made sense of their experiences. The various ways I tried did not seem appropriate in addressing these objectives. This was a very time-consuming and frustrating experience. However, it also proved to be a valuable process as I developed a good understanding of the women's experiences. I had been extremely thorough in my endeavour to develop an appropriate form of analysis, rather than just adopting one form and making it suit my data.

I move now to the process of my analysis, which explains how I went about using the framework I discussed in Chapter Four. The process involves three levels of meaning. The first level relates to a basic understanding of the woman's story and this is derived from the researcher's construction of a narrative from the account. The second level is concerned with narrative themes where I interpret what the woman is attempting to convey to me. The third level is a deeper level of interpretation where I examine and analyse the content and the process of the woman's story by also taking into account the temporal aspects and the use of narrative devices.

First Level of Meaning - Narrative Construction

I wrote a narrative from each woman's account. This stage took some time as I carefully considered what they said. I listened to their taped interviews, while following the transcripts. I read and re-read the transcripts and listened again to the interviews. I then related each woman's story as though I was writing about each of them for a magazine. Throughout this thorough process, I derived the first level of meaning from each woman's account. The first level of meaning is a basic understanding of the woman's story. Writing a story, so to speak, describes and goes some way to explaining their experiences. This story, while basically descriptive and content-based, is also a primary level of

explanation and interpretation. However, it is more than a chronology, rather it is more akin to a short story written about one of these women and her experiences for a woman's magazine. While the stories are not presented in the final analysis, they do constitute an integral part of the analytical process. An example of one of the constructed stories is contained in Appendix (6). The first level of meaning contained within these constructed stories leads into the second level of meaning, of establishing what the stories are attempting to convey.

Second Level of Meaning - Narrative Themes

What is each woman trying to tell me? What is her story about when she talks about her experiences of endometriosis? For example, is it a story of how she endured much suffering, or is it about how she could not conceive? Perhaps she expressed great dissatisfaction with her medical practitioner. While this level of meaning is still descriptive and content-based, there is a secondary level of explanation and interpretation. It is my interpretation of what she is trying to impart to me.

Initially I believed this procedure to be straight forward. After all, I was only deciding what the plot was. However, this was not so. While some stories' storylines, or plots, were self-evident, other stories' storylines were not. In some stories, there were competing storylines. Hannah's story provides a good example. Firstly, the story seemed about the physical suffering she experienced from having severe pain and heavy menstruation. After further re-reading of her two transcripts, I became aware of another storyline about how she had suffered psychologically from other people trivialising her symptoms and how she made sense of having severe menstrual problems. She came to believe that her symptoms were psychosomatic. Further, my first interview with her also contained her fears of not getting married and having a family. The second

interview realised the latter fear as she had undergone a hysterectomy and, at that time, she had not met a prospective partner. Her sense of identity had been strongly challenged. In stories such as Hannah's, I accordingly acknowledged the various narrative themes and accommodated them in the analysis.

To reach the point where I could say what the plot, or storyline, was for each account, required several careful readings of the transcripts, listening to the tapes as well as constantly making notes as ideas come to mind, throughout the whole process. I would then try and stand back from my ideas and say 'if someone else were reading this woman's story, would they agree that it is a story about not being able to have a child and the associated feelings of sadness and despair' (or whatever)? By going back and forth to the transcripts, tapes and my notes and by moving in and out of a sense of immersion to one of observation, I was able to develop a sound sense of what the women were trying to convey, as well as decide what the storyline was about. For some stories, there was no difficulty in achieving this goal. For others, I needed to leave their accounts, go on to another task and return at a later date. Putting some distance, so to speak, between the transcript and myself for a while proved helpful. Sometimes the ideas would start flowing when I had stopped poring over the written work and I was out walking.

Accordingly, what started out as a seemingly simple exercise, that is, 'what is this story about?', turned into a lengthy undertaking as I struggled to understand what each woman was attempting to convey. This level of meaning, therefore, is more abstract than the first level of narrative construction, as it interprets how the participant has constructed and expressed her experience of endometriosis. Identifying what each story is about, or its narrative theme, establishes a foundation for a deeper level of understanding.

Third Level of Interpretation and Explanation

Where there are descriptive accounts at this level, it is characterised by a finer, or deeper level of explanation and interpretation. I am analysing both the content and the process of the narrative. Thus, I am not only concerned with *what* each woman has told me, but *how* she tells the story. For example, how is she presenting herself in this story? How are other people presented? At this level, I am addressing the research objectives with respect to their identities, or sense of self, together with learning about how they make sense of their experiences. The various narrative functions and narrative devices enable this level of meaning to be grasped. With respect to narrative functions, for example, the ways the women make connections between events and establish a sense of coherence within their stories, enable me, as the researcher, to gain an understanding of how they have constructed their experiences. At the level of the individual woman, I draw out meanings from her experiences, make retrospective sense of events in light of new information, and then understand how she may have experienced endometriosis across time. At the level of the researcher, I interpret what she is saying and how she is saying it.

The use of narrative devices such as imagery and 'defining moments' give clues as to how the women understand or perceive their endometriosis experiences. While I described and interpreted the women's accounts, I was therefore noting the use of such narrative devices. I also kept in mind the temporality of the story, examining how the women related events from one period of time and how they talked about them in another time-frame. For example, do they use subjunctivising elements, imagining possible outcomes for themselves in relation to their endometriosis?

To examine the research objectives, I made notes from the transcripts where they pertained to identity and to where they related to making sense of experiences. Once again this was not a clear cut procedure as, in many

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respects, these objectives are closely bound. For example, if a woman was talking to me about how she felt about herself, within that construction was a process of making sense of experiences before she could express identity-related issues. To resolve this difficulty, I decided to draw out identity related notes and include the construction of meanings where applicable. After all, making sense of things is a narrative function, both for the individual relating her story and for me, as the researcher. I could not discuss identity, or any other topic for that matter, without talking about the construction of meaning. For the section on making sense of events, I focussed on how the women made sense of undiagnosed symptoms, prior to diagnosis, and how they made sense of events after the diagnosis, in light of this new information.

Throughout the process of gathering up information and ideas on the presentation of self, I kept asking the questions: Why is she telling me this information? How does she present her 'self'? What are the things she is saying which express her identity? What roles does she talk about? How does she present the other 'characters' in her story? How does this shift over time? While I went through this process, I became more and more aware of the huge realm which constitutes identity. I understood that identity was not only conveyed with respect to how a woman 'felt' about herself, but also the way in which she constructed herself in relationship to other people and other things. Once my awareness of this area was greatly expanded, I was then able to decide how I was going to 'contain' identity, so to speak, for the purposes of my analysis. I distinguished the essential ways in which the women expressed their sense of self throughout their stories. I leave presentation of these narrative, identity themes for the analysis chapter relating to identity.

At this stage, I was also trying to understand how the women made sense of and drew meaning from their experiences. For example, how did they

understand the nature of severe menstrual pain, or painful intercourse, prior to being diagnosed? What sense did they make of being told there was nothing wrong with them? How did they reconcile the often, conflicting views of the medical practitioner, with their own?

Collating the above notes was the principal groundwork for me to start interpreting and explaining the women's constructions of themselves and their experiences. I conceptualised my research objectives, relating to identity and making meaning from events, as constructing a deeper understanding of women's experiences of endometriosis. The identity issues could illuminate how women constructed themselves in relation to the condition, while finding out how they made sense of endometriosis-related events. This process could also enlighten me how they came to understand, for example, undiagnosed bodily signs, often over a long period of time.

The analytical process I developed for this study sets out the various steps to take in order to be able to, firstly, describe, and secondly, at a deeper level of meaning, explain and interpret the various ways the women have talked about their experiences. The actual process, the narrative structure and so forth, is crucial to understanding the whole story. I am therefore concerned with both what is said and how it is said. Accordingly, my analysis is not solely an interpretation of narratives, such as an individual's personal narrative, or the cultural narratives upon which they might draw. It is also a process of looking at the ways individuals construct their stories, make connections between and meaning from events. Just as the women, as a matter of course, employ 'narrative devices' to construct their stories, as the researcher, I also use the same devices to analyse their stories.

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This process of analysis has provided an appropriate way of learning about how women construct their identities, as portrayed in the way they speak about themselves, and also the way they make sense of and draw meaning from their endometriosis experiences.

The process of analysis brought me to a point where I had two chapters of findings, one related to identity and the other related to making sense of events.

The following chapter discusses my findings on identity.

Chapter Six

Identity

The story is one's identity, a story created, told, revised and retold throughout life. We know or discover ourselves and reveal ourselves to others, by the stories we tell. (Lieblich, Tuval-Mashiach, & Zilber, 1998, p.7)

On becoming ill, people may experience a sense of disruption to their lives. Physically, they may become unable to carry out their normal daily activities and, as a result of their reduced activity, may feel different about themselves. When the illness is a short-lived event, such feelings may be confined to those of frustration and helplessness. However, when the condition is chronic, then the individual may well experience a threat to their identity. The personal story they have constructed about themselves is challenged and there is a need to revise the story and, thus, reconstruct their identity. While endometriosis may not always be conceptualised as an illness, it is a chronic condition which can threaten a woman's physical and psychosocial well-being. It therefore has the potential of challenging her identity, or sense of self. I use these terms interchangeably throughout this chapter.

Charmaz (1999) argues that analysing people's stories about illness teaches us about suffering and, in turn, how it affects the self, or identity. However, when we think about the term 'suffering' in the context of illness, we tend to think of pain and discomfort. While endometriosis is, indeed, commonly accompanied by pain and discomfort, suffering is certainly not confined to the physical domain. In many ways, it is the suffering that the women construct from the

psychosocial realm which constitutes the strongest challenge to their identities. This chapter examines the way women express their sense of identity, through narrative, and how they may reconstruct their identities in response to experiencing endometriosis. As Charmaz also notes, a story provides a way of coming to terms with an altered existence. Accordingly, through listening to and analysing the women's stories, we can learn much about how they construct their sense of self and reconstruct their identity in the process of experiencing endometriosis.

It is in the social linguistic process of talking and telling stories about their lives that people construct their identities and the roles related to these identities. The narratives about our identities are ongoing and open-ended, needing frequent revision as we strive to make sense of all the events which go on in our lives. Mathieson and Stam (1995) refer to this 'biographical work' as a 'stable requirement of identity' as we express these life events in a coherent story (p. 299). One's sense of self is shaped by the meanings we attribute to the events of our lives, and is also a temporal process which can be understood through narrative.

In this chapter I describe and analyse the way the women have expressed their sense of identity and the roles they have constructed throughout their experiences of endometriosis. The aim, here, has been to exemplify the way a woman's sense of identity can be challenged and, through the process of narrating her experiences, how she may re-construct her identity. Through the narrative mode, we are able to shape our identities and realise our existence as 'an expression of a single unfolding and developing story' (Polkinghorne, 1995).

We understand and, thus, construct a sense of ourselves, in relationship to other people. These meanings are produced through 'cultural meaning systems such as language (and narratives)' (Crossley, 2000) and one of the features of making meaning is the experience of time. Crossley also notes that narrative approaches to the study of self and identity emphasise the 'inextricable interconnection between "self" and "social structures"' and particularly the interrelationship between self and language (p.9). The experience of self takes on meaning through language. Using narrative approaches to understand identity emphasises the way people talk about their 'selves' and moves the focus from conceptualising the self as an entity, a concept which traditional psychological approaches have predicated their studies upon. They worked from the assumption that there is a real 'self'; a self which can be found and described as any concrete physical object. In contrast, within the social constructionist paradigm, identity is conceptualised as a fluid self, ever-changing and open to a range of possibilities (Gergen, 1991).

People experience events, both positive and adverse, which they emplot into some sort of personal coherence and integrate into their identity. For example, concordant events such as success and good friendships may strengthen self-esteem, while negative events such as failure and separation may diminish it. Illness, or in the case of the women with endometriosis, chronic illness, is a disruption to the physical body, posing a challenge to an individual's sense of identity and threatening self-worth (Bury, 1991; Charmaz, 1983), thus reconstructing one's life story is of fundamental importance.

When faced with illness, an individual may realise that the meanings upon which her life had once been based no longer apply, and this realisation can lead to a perceived threat to her identity. Charmaz (1983) speaks of a 'loss of self' (p.168) in chronically ill people who watch their former self-images falling

apart. I understand this to mean that say, for example, a man had a perception of his 'self' as being a competent and successful merchant banker. He is involved in a car accident and suffers head injuries, the result of which means he is unable to continue with his job. He feels irritable and experiences short-term memory difficulties. He knows he can longer be a merchant banker and no longer feels competent and successful. There is a sense, for him, of watching his former self-image falling away. However, if he is no longer feeling competent and successful, then surely he must be feeling incompetent and unsuccessful. So while one image slips away, another one is constructed. There can be a sense of people feeling discredited by themselves as well as by others as they no longer function in the same way, due to the limitations of their illness. Relationships can suffer, careers upset and a deep sense of loss and suffering experienced among those with some form of chronic illness.

People talking about their illness experiences have two perspectives from which to speak, their illness perspective and the healthy person voice and, as Radley (1994) observes 'it is one thing to talk about health when hale and hearty, another thing to give one's views when suffering a serious illness'. It is likely, therefore, that we might discern a different perspective of their self, depending on what voice they are speaking from. Thus, as people tell their stories, they can choose how they will present their 'selves'. Within the following analysis, I describe how the women have chosen to portray their selves. The way a person presents his or her self is a product of a social construction and what self they present is influenced by who they are telling their story to. I believe, as Gergen (1994) notes, it is part of our human reflexive ability to change the present in light of the past and the past in light of the present. It is quite conceivable, therefore, that a person could construct themselves as a 'victim' of their experiences on one telling of their story and, on another telling present as a 'controller'. In this analysis I use the term

'victim' when the woman expresses a sense of helplessness in her situation and, at that point of the story, felt unable to take control of the situation. For example, she may construct her experiences as being at the mercy of endometriosis, something that is causing her pain and suffering. This perception may be reinforced through related events, such as not receiving appropriate treatment and perceived support. And, for the purposes of this study, I define the role of 'controller' as someone who constructs their experiences as overcoming and taking control of their adversity. However, what was evident in some of the women's accounts, was the way the victim role seemed to change to that of a controlling role, specifically so from pre-diagnosis to post-diagnosis. Time is captured as an integral part of narrative as we hear how a woman's presentation of self shifts in the telling across her experiences. The future, of course, is an important part of the temporal picture also. When a person is faced with a chronic health problem, the vision they hold of their future may need revising and so their life stories may be progressing towards a different goal or denouement. Thus, the individual may need to reconstruct her role, thereby affecting her sense of self.

I am aware that identity work is not just about reconstruction but it is also about the continuing validation of who I am. My analysis examines both. I analyse the threat to identity in relation to the endometriosis experience and how a woman may choose to reconstruct her identity in response to this challenge. I also examine stories where the women attempt to maintain their 'sense' of identities in the face of a threat.

My interpretation of the way the women expressed their identities is presented in four themes - infertility, relationships, occupation and self-concept, physical and psychological. Within these narrative themes, I use the term 'self-concept' as relating to how we experience ourselves. For example, a person might be

experiencing themselves during a long period of illness as helpless, unattractive and having a low self-esteem.

These themes were the main areas in which the participants talked about their endometriosis experiences and seemed to portray how they felt about themselves and I derived them from the second level of meaning. For example, with respect to not being able to conceive, a woman may feel her potential and expected role of mother being threatened. Her life is not unfolding as she had wished for and her future may well be very different from what she had planned. Another woman may talk about how she had come to believe that her pain was psychological and significant others in her life have not taken her health concerns seriously. Her story describes how, over time, she has come to understand her symptoms and how she has come to feel negatively about herself. Her sense of self-esteem and confidence appear to have been undermined.

Infertility

The role of motherhood has long been considered fundamental to women's identities, (Gillespie, 2000). Until recent times, while males constructed their identities around their careers, females' identities were defined by their roles of wife and mother as well as their partners' identities. Women defined themselves in terms of their relationships to others. Nowadays, for many women, their identities are also defined in terms of their vocations. Motherhood still forms an integral part of most women's identities. While women now grow up believing that they at least have a choice between career, motherhood, or a combination of both, having their fertility compromised can pose a disruptive threat to their identity as a future mother. Endometriosis can pose a significant threat to a woman's fertility and, as shown in the following

examples, this perceived or real threat can also be felt as a challenge to her identity.

The relationship between endometriosis and fertility difficulties is not clear cut. There are those women who make a connection between having endometriosis and their present inability to conceive. They are actively trying to have a child, have been doing so for some time and appear very concerned and distressed about these difficulties. There are other women who, once they learn they have endometriosis and understand the implications of it, express concern in case they are unable to conceive at a later stage. Lastly, there are those women who have had a hysterectomy which has prevented them from ever conceiving, or conceiving again, and this is also expressed as a source of concern or distress. The infertility story is often told with the women portraying themselves as a victim of the disease.

The distress of trying to conceive and its relationship to endometriosis can be understood in the accounts of Jacky and Vicky. They recounted long and distressing stories. After I finished interviewing these women, I recall thinking 'their stories are all about infertility and little to do with endometriosis.' At a later stage I realised that they were very much tied up with endometriosis. Endometriosis, in a slightly removed way, had been constructed as a very potent source of stress in their lives. While they talked of managing the associated menstrual pain, they could not control their inability to conceive. There was a perceived loss of control in their lives. I draw strongly on Jacky's story to exemplify these issues.

Jacky and her husband tried to conceive for two to three years before a laparoscopic investigation revealed she had endometriosis. At that time, the diagnosis did not hold any meaning for her:

'So he said to me, then, you know, that I had endometriosis and it was no big deal. It was just sort of, yeah, you know, you've got it. It didn't really mean anything...it just wasn't an issue..it was more the fact that I didn't ovulate and the endometriosis was just sort of there...Life just carried on as normal, so they could have told me I had anything really and it, you know, didn't make any difference because life just carried on.'

Jacky eventually conceived but her pre-term baby was delivered stillborn. Her story was completely overshadowed by the devastation she obviously felt at the death of her daughter. Over time, Jacky made a connection between endometriosis and her fertility problem. From the minor, bit part it had played previously, endometriosis had assumed a leading role in the drama of Jacky's passionate yearning for a child. The following extracts show how Jacky connected the endometriosis with her fertility difficulties. These extracts are taken from different parts of the story Jacky related to me, also demonstrating how I have made connections and meanings within her account. This process also exemplifies how time is expressed through narrative. When Jacky tells her story, it is mostly in a chronological order yet, at times, she will change from talking about the past, to what is happening in her present situation, then makes sense of the past in light of what she now understands in the present.

It didn't really mean anything. (*Did he not tell you anything about it?*) Well, yes, I knew all about it; it just wasn't an issue as such. It's only, really, sort of now, that I'm..we had one child; we had a stillborn last year. So, it's sort of now that we're trying again and nothing's happening, it is starting to be an issue.

I wasn't blaming the endometriosis or anything like that. It was sort of, I don't know, I hadn't really connected with that. ...I didn't sort of think, well, I've got endometriosis and that's what's causing all this. It was just all part of it, still part of the fact that I couldn't conceive. I think that was my main focus, as opposed to the endometriosis, because I had a period, if I took a couple of Neurofen, you know, I didn't get any pain, so it wasn't any handicap in that way. So, it didn't really affect me, and the only way it has affected

me, I suppose, is in the infertility and because I don't ovulate and my tube was stuck down, that was more of an issue than the endometriosis. (*Yeah, I see what you mean*)

...but we haven't conceived and then, going back to the doctor, and he's, he keeps saying, well, we don't know what the endometriosis does. So it's just now that it's starting to have an impact on me.

...we don't know what the endometriosis is doing, so that's where we now are starting to become an issue. ...I think the connection is the fact that it's now starting to become real. I mean, before, life just carried on as normal, so they could have told me I had anything really and it, you know, didn't make any difference, because life just carried on.

In this respect, we can see how she constructed new meanings or understandings of the endometriosis in light of her attempts to make sense of her inability to conceive. Endometriosis had become 'infertility', characterising the associated grief, envy, despair, anger and bewilderment so familiar with those people desperately trying to conceive. Jacky talked in the role of a victim at this point in the story as she expresses her negative feelings and reactions, which suggest a sense of helplessness about her situation.

'...I was, probably great mood swings, get really hyped up over things and get really depressed over things...'

With respect to trying to conceive, she speaks like she is tied to a regime she dislikes, but has to do if she is to fulfil her desire to become a mother. In this sense, she appears to construct herself into a victim role as she attributes the reason for her infertility to endometriosis. At this stage of talking, she expresses as feeling helpless in the situation. Despite her best efforts, she does not seem to be able to conceive again.

'I'm constantly thinking about it and ... I just sort of want a break ... It just takes over and you just, oh, I don't know, you get sick of it and

you just want to stop thinking about it and, like I said, if you stop thinking about it, you're basically saying no to, you're not going to have children'.

When she states 'it just takes over' it is as though she perceives herself as being controlled by the endometriosis/infertility issues. She wants to get pregnant, so she has to think about it yet, she is tired of thinking about it. She appears caught between a rock and a hard place. 'If you stop thinking about it, you're basically saying no to, you're not going to have children'. In this sense, I see her constructing herself as a victim of the infertility which she relates to the endometriosis.

However, once Jacky understood the possible role of endometriosis in her fertility difficulties, she talked in terms of being in control of her life once more. So, although the above extract portrays Jacky in a victim role, as her story progressed, she spoke less in terms of being a victim. The times she felt most low was when she was menstruating. However, for the rest of the month, she was able to get on with her life.

But, most of the time I'm OK about it. It's just like in the middle of the month when you're trying, so you're concentrating on it, then at the end of the month when you get your period, then you get all depressed about it. But, you know, the times in between, I can sort of get on with it and you have to look at life and think, well it could be worse.

She said she adopted a healthier lifestyle in order to bring herself 'in balance'. Meditating, improved diet and going for long walks with her dog, all reflected a strong resolve to improve her well-being.

X and I both meditate, so we do TM (*transcendental meditation*) and, with that, there's a healthy sort of lifestyle designed to bring yourself in balance, so I think I've sort of been concentrating on that more. Lifestyle changes and eating organic food and drinking pure water

and getting up early and going to bed early, and all that sort of carry on. ... Since I've lost A (*her baby*) I've gone vegetarian...and probably more conscious of what I eat because I feel that has a bigger effect on the body than what we really believe, so I think instead of concentrating on just endometriosis, I'm concentrating on the whole body and trying to keep my blood pressure down.. If my whole body's right then that will come too (*the endometriosis*).

She felt that her choice of a holistic path to regain control over her physical, emotional and spiritual health had started to deliver positive changes in her health. So, although she had constructed endometriosis as an overwhelming barrier to her fertility, Jacky had chosen to take control of her body, making great efforts to manage the condition, rather than let it manage her.

I certainly feel better now. ... I think now I do feel better for the changes that I've made. ... I don't know whether it's psychological, you think, because you're doing that, you feel better.

Jacky attributes her improved health initially to her healthier lifestyle, yet acknowledges the possibility of it being 'psychological'. I understand this statement as an example of how she has taken control of her body and, with this perceived sense of control, comes a feeling of empowerment and improved psychological well-being. It is in this sense, of taking control of her body, that I interpret she is constructing herself as a controller. Arguably, the improved life-style has also brought improved physical and associated psychological sense of well-being. The following example shows how Jacky associated one such life-style change, meditation, with feeling better. 'I ... started to get my period and meditated and the pain went away.' Jacky constructed this experience as a moment of success. Her efforts to take control were paying off and, accordingly, the regaining of a sense of control suggests a shift from the victim role. The sense of helplessness appears to have reduced and a sense of empowerment increased. The movement away from being a victim to one of a controller becomes more evident in such statements. She is showing that she

is diminishing the hold that endometriosis has upon her and turning it around. While she is still unable to conceive, she is not allowing endometriosis to now totally control her life.

Jacky's story illustrates how the retrospective view of her endometriosis experience had reshaped her ideas about why she had been experiencing fertility difficulties. Now she was able to make connections between events, emplot them into the story of her infertility, and adopt a set of ideas which made sense of her fertility problems. After the loss of her baby, there was a period, from when she started trying to conceive again until she started making these links, that exemplified a time of uncertainty. She could not understand why she was having fertility difficulties. In her search to understand her situation, she gathered up the threads of events which enabled her to revise the plot of her story. She had configured a coherent account of her infertility, moving from a time of uncertainty to a time of coherence and understanding. Now that she had accepted the strong possibility of endometriosis affecting her fertility, she mobilised her resources to minimise its effects. When Jacky told me this story, it was not a chronicle of events. It was expressed as a series of events which Jacky configured to understand her fertility difficulties. However, it was not something she had narrated for the first time. She had already been through this narrative task and was 're-presenting' her story to me.

Jacky's story exemplifies how various events, beliefs and attitudes in an individual's life can be woven as threads into a coherent narrative which makes sense of the present. In her story, Jacky speaks of how she came to accept and normalise painful menstruation as she spoke about the wider social and cultural context of her adolescence. Losing her baby was a defining moment in her life which she made sense of by accepting responsibility and blaming

herself. Gradually she emplotted the endometriosis condition into her infertility story and we learn how she has changed roles from victim to a controller.

Although infertility features as one of the effects of endometriosis, there are still many women who do conceive. It is easy for a woman to 'blame' endometriosis for fertility difficulties when they may be due to another issue. Vicky, for example, chose to attribute cause to her endometriosis for her infertility, even though she had been told it was probably not affecting it at all. She had a condition she described as an 'early menopausal thing' related to her ovaries, but she did not like to discuss it with other people and preferred to let others believe that the endometriosis was the cause.

'I do try and explain what's happening with us, but you just get bored of it. ... I know, it's cruel, but you let people think what you want to think (laughs) because it's easier. You know, apart from the immediate family ... they know there's something wrong with me; they know we're infertile and it doesn't really matter that they don't know that my ovaries are a little bit ... I don't like using the word 'premenopausal' or anything, because the minute you say that, people think of old women and, you know. I just don't like using that word with, so I prefer they just carry on thinking it's the endo.'

In this story, Vicky wants to distance herself from the connotations related to menopause. She has a strong desire to be a mother, yet she has a pre-menopausal condition which is associated with older women. Her identity is not defined in terms of being middle-aged and is incongruent with a young woman yearning to be in the role of mother. Endometriosis is then emplotted into her infertility story and is attributed as the cause when discussing her fertility difficulties with other people.

I analysed Vicky's story as meaning that she tacitly reinforced the idea of attributing her infertility to the endometriosis and, as such, led to her

construction of a belief in it. I began making this interpretation at the time of her telling me this story. However, as a researcher, while I considered it necessary to clarify issues, I did not believe it ethical to challenge her ideas. I was not about to say, well, on the one hand you say endometriosis has caused your infertility, now you say it might not, but you let everyone else think it has, and now you seem to believe in the idea yourself. I knew it was a better option to go away and analyse her story. As I look back on the interview and the process of my interpretation, I now consider that Vicky's construction serves her well and is thus another reason, ethically, not to challenge. The story, while originally constructed as way of an easy explanation for other people, has also served as a way to help Vicky maintain the 'young woman, waiting to become a mother' identity. In this case, Vicky's identity has been threatened and, instead of constructing a different identity, she attempts to maintain her 'sense' of identity. My analysis of Vicky's endometriosis/infertility story illustrates the configuration or emplotment process, showing how I was able to bring order and meaning to her story.

Not being able to conceive can threaten a woman's identity in various ways. Some women may feel less of a woman if they have not been able to procreate.

I used to think that I was, um, a lesser woman because I couldn't have children and I used to feel very, very inferior to other women. I don't so much now, coming out the other side, I've, I realise now it's just one of those things and um, it's unfortunate, but we all have, we all have problems in our lives and this is something I have to put up with, you know. But I did, a few years ago, I definitely felt inferior to women who could have children. I went through a really low time then; I didn't even want to talk to women with children. You know, young women with young children, because I wasn't in their 'club'. (Vicky)

Vicky constructs herself, using terms such as a 'lesser woman', 'very, very inferior' not being 'in their club' which exemplify her diminished sense of

womanhood. These terms are also illustrative of how we define ourselves in relationship to other people. If Vicky did not know other mothers, or about other mothers, she would not be able to construct herself as an inferior woman in this respect. However, there can come a shift in perception and, ultimately, construction of self, if one comes to understand and know other women who are not mothers and not perceive them as inferior to women who are mothers. That is, the defining of one's identity need not be limited to one particular role.

For some women, it is not only the lack of children which is a threat to their identities, but also not actually conceiving. One woman said she experienced two miscarriages before she went on to adopt a child, then give birth to another a year later. She observed:

I had a couple of miscarriages ... It was encouraging that I got pregnant ... I did feel a lot more like, "well, I am still basically a real woman, that something does work" yeah. (Amelia)

In Amelia's case, it was important to her that if she could conceive twice, even though she miscarried, she may go on to have a live birth. However, when she said "I am still basically a real woman" she is identifying the ability to conceive with what a 'real' woman means to her. This is part of Amelia's personal narrative which informs the way she identifies herself. For Amelia and, for many other women, part of their identity is connected to their fertility, and not just being a mother. While fertility has arguably been celebrated as the essence of womanhood, we must consider the binary implications of this sentiment. In order for fertility to be acclaimed, then is not infertility to be deemed as failure, even feared? A strong statement perhaps.. However, if this is the cultural story we are imbued with since young children about what it is to be a 'real woman', we can therefore understand that to be infertile is a perceived failure to reach this lofty pinnacle. In this way, women who are unable to conceive, can construct themselves as less of a woman. Their thinking is informed by the

cultural stories surrounding 'being a woman' and their meanings are constructed in relationship to other, fertile 'real' women. Thus, their identity is challenged.

The assumption of the prospective role of mother is very often taken for granted in a young woman. If that prospect is threatened, then that realisation can come as a blow. To me, this situation suggests the distinct possibility of a time of grief as the woman comes to terms with the loss of her expected, future self.

...maybe I'll never have children...just a bit of a depressing (Joy)

While the above statement relates to the threat to the expected future role of mother, the following example relates to the threatened prospective role of partner.

...if I can't have children, who's going to be interested in me? (Zoe)

For many women, being diagnosed with endometriosis constitutes the condition as something to be struggled with as they connect it to present, or possible future, fertility difficulties. One woman was told by the first specialist that she consulted that she would not be able to have any more children.

'That was probably the hardest thing being told that no, you can't have any more children. It's OK to say that maybe you don't want any more, but to be told that you can't is like taking something away from you'. (Diana)

Diana consulted a second specialist and as she tells her story, she makes connections to earlier events saying she had not given 'sufficient information or support by the first specialist' and wondered whether in fact she had been misinformed about her fertility. Although she had two children, she would

have liked the option of having a third. It is difficult to say whether her identity had been challenged in this regard, as she was already a mother. However, the option had been taken away from her by what she considered might be a misinformed specialist and, in this sense, there was a sense of disempowerment related to her fertility.

Subjunctivising elements are contained in those stories about possible future infertility contained in thoughts such as 'I may not have children. I may never be a mother', as exemplified in the following extracts (now expanded) that I drew upon earlier.

I'm single, I live at home, no boyfriend and suddenly, there's this sort of fact that my fertility was probably not that good to start with and suddenly there's that thought that maybe it's even worse now and I'm getting older and that though that maybe I'll never have children that, yeah, it was just a bit of a depressing... (Joy)

And that sort of not knowing has been kind of hard to deal with, because the sort of, well, you know, if I can't have children, who's going to be interested in me, I used to feel that way. But I know now there's a lot of other options too, I don't think it's wise to put all your eggs in one basket so to speak and say this is the way it has to be.
(Zoe)

The role of mother is questioned in these extracts. Are these women going to be childless and never assume the mother role? In Zoe's case, she is also questioning the possibility of being single 'who's going to be interested in me?' she asks, if she is not able to be a mother. This perception is part of Zoe's personal narrative: a prospective partner will not consider her as a long-term partner if she is infertile. Even though she had conceived in her last relationship, but then miscarried, she is fearful that endometriosis may prevent her from conceiving again, or carrying a child to full-term. However, she goes on to say 'I used to feel that way. But I know now there's a lot of other options

too...'. Such reflections suggest she is thinking of an alternative future; the options are there.

In their struggle to come to terms with this concern, some women talk of making concerted efforts to take control of their general well-being with measures such as improved diet, more exercise, meditation, keeping up with leisure activities and so forth. The earlier extracts relating to Jacky exemplify these efforts. Vicky talked of taking an improved holistic approach to her health and consulted an alternative health professional for advice in this area.

I don't drink much milk now. I have soya milk instead. I drink a lot of water. I don't use the microwave any more. (*Why is that?*) Because it's bad for you.

(*Is the not having milk, is that dairy products in general, or just milk?*) Dairy products in general is, um, dairy products are dead food, are dead products ... No-one should eat dairy products.

I go for sort of ½ to 3/4 hour walk every day. ... I don't drink alcohol much now.

... And I don't get ill any more, since I've been seeing this guy. I just don't get ill, the worst I have is I sometimes start a sore throat.. And I believe this is all because of the holistic approach I've been taking and seeing this guy.

Plus, we keep ourselves busy. ... and when I'm not working, I've got heaps of outside interests. (Vicky)

And Diana said:

I take multivitamins and antioxidants, and you know, I feel better taking them.

By their reports, such measures have resulted in improved health, both physical and psychological. In this way, the women overcome the earlier roles they portrayed as victims to this disease and shaped the way to becoming controllers. I would note here that being a 'controller' does not mean that the

woman, through her efforts, becomes fertile, conceives and lives happily ever after. I mean that she has made concerted efforts to take control of her endometriosis and, in a psychological way, has constructed her situation as something she no longer lets control her life completely. In this sense, it is more of a psychological 'controlling'.

With respect to fertility issues, women with endometriosis may choose to emplot their condition into their story of trying to conceive, whether in fact the endometriosis is playing a significant role in their infertility, or not. The role of mother is challenged as a woman struggles to come to terms with the possibility of not having a child, sometimes characterised by the expression of a victim role in the telling of their story of trying to have a child. Not being able to conceive can also jeopardise a woman's sense of being a woman, or a 'real' woman. As the story's events are tracked over time, a woman may communicate a reconstruction of her identity. This may be expressed as adopting a conqueror role as she no longer allows her body to be controlled by the endometriosis by taking action to take control of the condition herself. Identity reconstruction may also be expressed as women speak about the possibility of not becoming a mother and begin the process of constructing an alternative role.

Relationships

It has been claimed that women's identities are connected to others (Josselson, 1996), that is, the roles which women play, such as mother, partner and so forth are in close connection to other people. Traditionally, men have strongly defined themselves in connection to their occupations rather than their role of father, for example. Josselson's standpoint does not suggest that occupational commitment is not meaningful to women, rather its importance lies partly in

its connection to others. For example, a woman's job as an administrator, doctor, or teacher, may have strong connections for her in the role's relationship to the people she works with and for. I suggest that this viewpoint is holding less valid as more and more women are anchoring their identities to their occupations, regardless of the relationship aspects in that role. Broadly speaking, however, I think that women do value the relationships in their day to day lives. Thus, when these relationships are strained, for whatever reason, then the role the women play in those particularly relationships may also be stressed.

As discussed earlier, the role of mother is significant in the defining of many women's identities and is thus one of the many relationships that women have in connection with others. Further significant roles that women are either born into, or assume, include daughter, sister, friend, colleague and partner and, a significant role played by the women in these stories was that of patient. Many of the women spoke of experiencing strained relationships in various areas of their lives due to endometriosis.

Dismissive and unsupportive interactions with other people can strain relationships. For example, at school, Hannah said she did not receive any support or understanding about her 'excruciating' menstrual pain. Instead she 'got a good blast from the headmistress' who told her she was just seeking attention. Neither did she recall receiving any sympathy from her mother or sisters who 'sailed through their periods'. She said she ended up feeling like a 'hypochondriac'. Her life, which revolved around her periods; the pain, the flooding and chronic tiredness, set her apart from her family and peers. She spoke of becoming an unhappy and depressed woman. She came to believe that if her symptoms were normal, then it must be she who was abnormal. 'I just thought I couldn't accept pain and that I was weak'. She had come to

define herself as different from other young women; she believed she was weak, abnormal, having psychological problems which manifested themselves as debilitating pain and heavy menstrual flow. Hannah drew together various threads of her experiences and redefined herself in response to the cultural narrative of the menstruating woman. We can see how she has defined herself in connection to other people. If other people have similar menstrual experiences and can cope, and she cannot cope and finds the symptoms distressing, then she constructs herself as different from other women. This example illustrates the defining of oneself in relationship to other people and making sense of one's experiences through narrating them. In this case, Hannah chose, or created the meaning of her experiences.

For teenage girls, to start their young adult years with difficult menstrual symptoms may be hard to bear. Perhaps such disruptive symptoms have helped shape their identities in those critical early years of identity formation. Once again, I reiterate the point that such identity work, or formation, is carried out in relationship to others. It is not the experiencing of difficult bodily symptoms, *per se*, rather, it is the response to those symptoms in a psychosocial sense which, I interpret as being the issue. For example, one woman, who experienced severe symptoms from her early teens, felt her younger years were particularly marred by endometriosis. She was keen to go to dances, stay overnight at friends' places, go out with boys and have the option of a sexual relationship. These were not always options available to her as she had to always consider the intrusive effects of her menstrual symptoms. I quote below some of the comments Tess made:

It had an effect on my self esteem.

You could never in those days ... you didn't say to a guy, hey, I'm, I've got to be near a loo because I flood everywhere.

It was a great contraceptive - no chance of hopping into bed in those early days.

It was a real burden to carry, I mean there are a lot of worse things, but, no, I hated myself.

In this respect, she constructed herself as a victim of her menstrual difficulties, which were later diagnosed as endometriosis. Menstruation was conceptualised as something which was limiting and interfering with her social activities. She wanted to be the same as her peers, going out, having a great time and experiencing relationships with young men. I interpreted her expression of these experiences as her freedom and choices had been restricted and, in this respect, she was feeling disempowered. At a significant time of her psychosocial development, she was experiencing a limitation to her social activities and associated issues such as developing intimacy. Tess comments her difficult menstrual experiences had an effect upon her self-esteem and also says she hated herself. In this respect she is narratively constructing her identity at that time as being threatened. She no longer likes herself and does not feel good about herself. I thus interpret such comments as someone who is constructing themselves as a victim.

While Tess is only one individual who spoke with concern about her restricted activities as a young woman, her story reflects the accounts I have read and heard before with other young women. I consider, therefore, that this is an area which raises issues of concern, such as fear of intimacy through pain, embarrassment and physical limitations, together with restricted social activities and thus reduced social contact and reduced opportunity to develop close relationships. The severity of pain, menstrual flow, and so forth, is highly variable among women with endometriosis and so one would expect there to be a range of responses. Therefore, a woman experiencing severe pain and

severe 'flooding', is very likely to have restricted activities at the time of menstruation.

Some women refuse to allow their lives to be interfered with by the condition. Joy, for example, often used the term 'plodding on' with her life, despite pain and 'flooding' which necessitated frequent sick leave. On the other hand, despite other health problems, she continued to play sport, have overseas holidays, study and work full-time.

While listening to Joy's story, I wondered whether having endometriosis had anything to do with her, in her mid-thirties, being single and living with her parents. She said:

... I don't put it down to the fact that having endometriosis has caused the way life is. I'd still love to get married and have children, but you know...

For this woman, she talked of doing her best to lead as full a life as possible, yet also acknowledging there were times when physically it was very difficult.

... going right back to when I first got my period, I was determined that I wanted to carry on swimming and things like that, so that's where tampons came in at the age of 10 and that was it. So, I still did a lot of things that I wanted to do. Maybe later on there were times when I couldn't do the things, the sport and bits and pieces and a lot of it to do with the weight. Getting bigger and bigger (through medication for endometriosis) I perhaps didn't do things quite so much that I wanted to do. I played badminton and tennis and things like that, but you never wore the short skirts or the bits and pieces, just basically because I was so big.

I interpreted Joy's expression of determination to 'plod on' and 'carry on' with her sporting activities, as well as developing her career, as an example of locating her 'self-concept' in time, as discussed in Chapter Three. As her menstrual difficulties commenced at a young age, there was not a long period

of time leading up to that stage, yet, as a child she may have been energetic and outgoing and this is the self she has chosen to maintain. On the other hand, she may be linking her self with the way she has envisaged her future - continuing to play a lot of sport, developing her professional career through long hours and part-time study and overseas travel. I interpret her story as to mean that she is combining a past self with her present and projected self in ways which enable her to maintain her identity. In storying her experiences to me, Joy did not construct herself as a victim. She spoke as someone who got on with her life as well as she could while coping with difficult menstruation. Joy chose to construct herself as someone in control of her life. However, she also talked of 'harrowing' and 'embarrassing' situations when she 'flooded' and spoke of feeling great physical discomfort at times which related to menstrual pain, headaches and vomiting. While she told a story of physical and sometimes psychological discomfort, she also maintained a strong sense of her own identity in the way she constructed her experiences to me.

While difficult menstrual symptoms may characterise endometriosis, for some women, there are other symptoms which they find difficult and speak of as interfering with their lives. One woman, for example, spoke about her chronic fatigue, backache, leg pains and bleeding during and after intercourse. She felt that her sexual relationship with her partner suffered and her ability to join in pleasurable physical activities was greatly diminished. Her family did not understand what was wrong with her and she received little support or sympathy during some very difficult times. Her following comments relate to her difficulties with the sexual relationship with her husband.

I was left feeling uncomfortable ... you know after sex ... yeah, uncomfortable and not enjoyable. ... We continued having sex anyway and I suppose X (husband) has always been sort of keen and I would never have even thought, like in the position I took to say, "look, I don't want sex you know. It isn't pleasant anymore". I

would have just gone on having it anyway. ... I would have reduced the amount of sex we were having quite a bit if I'd been truthful, you know, if I'd been truthful to myself. ... And because he felt it was his right too, I think..and he would feel quite indignant and pissed off if he, you know, if he wasn't. I wasn't enjoying it at that stage, um, yeah, resentment probably crept in, you know resentment into our relationship. (Ann)

Comments and perceptions such as these led me to wonder about younger, single women. If they found sex uncomfortable, unpleasant or painful due to bleeding or pain, would they feel fearful of entering into further intimate relationships? Would they feel concerned about having a long-term relationship with someone? Perhaps some women may choose not to have further sexual relationships and forego marriage and children. I wonder also how that would affect a woman's identity through this reduced connection to other people. Perhaps these women would define their identities more strongly through their occupations and other societal commitments. And, to return to the issues of identity formation, if these young women are in adolescence, then the process of identity formation may constitute a struggle as they question their possible taken-for-granted aspirations of being partners and mothers. On the other hand, if they defined themselves as single, professional women, for example, then they would not necessarily experience a threat to their identity later when they found that their earlier identity choices needed re-evaluation.

The following extract is concerned with how one woman felt her relationships with friends were affected and lost owing to the problems she had experienced, directly related to her endometriosis condition.

So obviously when I came out of that surgery, I was devastated. I mean, I'd lost my, I was 28, and I'd lost my uterus, both ovaries, both fallopian tubes and had two major bowel resections...the pelvis had been completely obliterated by endometriosis. ... Looking back, I think I nearly had a breakdown, maybe I did have one and it wasn't recognised.

... I lost a lot of friends in that time because some of the feedback I got from a very close friend ... was, "oh, for goodness sake, hundreds of women have hysterectomies, why is she any different? Why is she not coping?" To this day, we are still not, we are acquaintances, but we're still not friends and I feel disappointed because we did have some great times together.

... I withdrew from everybody really, you know. "We're having a dinner party Saturday night, how would you like to come?" Oh no, wouldn't want to go. (Jay)

Another woman, Hannah, echoed similar sentiments about relationships with others being affected. When Hannah talked to a former acquaintance some time after she had been formally diagnosed with endometriosis, the acquaintance told her she had withdrawn from their friendship as "I just got sick of you" and Hannah attributed this comment as resulting from her mood swings and other perceived endometriosis-related difficulties.

I would argue that these examples exemplify many people's experiences with a chronic illness. They are not always understood by others, believe they are not understood by others, start losing friends and then withdrawing from people in order to avoid having to talk about their problems and be away from the critical gaze of those who do not understand. I conclude, therefore, that strained relationships and losing friends can have implications for a woman's sense of identity.

A woman's expression of her identity is strongly founded in her relationship to other people. When the threads of these connections start to unravel or, in fact, never weave together in the first place, then her identity will need to be re-evaluated and reconstructed. Endometriosis, in various ways, has been constructed as a condition which can threaten and diminish a woman's relationship with significant others in her life. Other people may not understand and dismiss the woman's symptoms, particularly when

undiagnosed. Difficulties with the symptoms themselves can impinge upon relationships when a woman is not able to participate freely in social activities. It can present problems for some women with their sexual relationships. Endometriosis, like many chronic conditions, can pose a barrier between people in that it is always there, it is not about to go away and people can tire hearing about it and the limitations it imposes on the sufferer.

Doctor-Patient Interaction

The women spoke of their encounters with the medical profession and I consider that these stories are important to examine with respect to identity. While the connection may not initially appear evident, I would argue that the way the women constructed their experiences, showed they made links between their medical consultations and the way they felt about themselves.

Shelley Taylor (1995) prefacing her chapter on patient-practitioner interaction by saying:

Good health is a prerequisite to nearly every other activity, and poor health can block nearly all one's goals. Moreover, illness is usually uncomfortable, so people want to be treated quickly and successfully. Perhaps, then, it is no wonder that physicians and other health care professionals are alternately praised and vilified: Their craft is fundamental to the enjoyment of life (p.341).

Taylor's observations certainly resonate with the comments given by the women in this study. The point here is that women may choose to portray the doctor in a particular way, for example, as someone who is empathic, or someone who is dismissive and, depending on the events being narrated, the doctor can be constructed as both. There were numerous examples of unfortunate encounters the women spoke about having with their general practitioners and gynaecologists, which were sometimes balanced by stories of concerned, supportive and caring doctors by other women, or encounters with

subsequent practitioners. However, upon analysis of these accounts, the main themes the women spoke about, focussed upon not being believed and experiencing dismissive treatment upon consultation with their doctors. The following exemplify the issues of the women's perceptions of not being taken seriously and being treated in a dismissive, patronising and, sometimes, judgmental manner.

... and it was a sort of middle-aged lady doctor, and I thought, this was good, she'll ... and um, I had a cold as well, that was one of the reasons I went and I sort of sorted that out. And I said "Oh, I have this, this, this and this, and I've read about endometriosis. Is it possible that I could have endometriosis. And she put her head back and laughed and said "what makes you think you're so important that you could have that?" And I promptly burst into tears because I was absolutely sure by this stage that it was going to be an answer to what I had been suffering.. (Vicky)

On being told by a gynaecologist that the best thing she could do for her severe cramps and very heavy bleeding was to have a baby, one woman reflected:

I was stunned.. at 16, have a baby. I don't quite think so. It just made me determined that I wasn't going to go back to him. Because I thought, well he hadn't really answered any questions for me and to say to have a baby at 16 was just ridiculous as far as I was concerned, and it didn't answer for me what was wrong, what wasn't wrong, what was going on. So, I basically just carried on.'

(Joy)

However, once Joy received a diagnosis, many years later, she had this to say of her current gynaecologist:

... but now this person who really annoyed me to start off with is a bit of a saviour. He's named it for me; he's sort of given.. And then I suddenly thought, well why did it take so long to actually get round to naming it?

Joy's comments certainly reinforce Taylor's (1995) observations that physicians can be both praised and vilified. I thus consider Joy's remarks significant. It is easy to sit back and criticise one's doctor when he or she cannot diagnose

what is wrong, when one is not able to conceive, when one has undergone a difficult operation, or whatever. For example, in one woman's view:

I'm not having surgery again. I just hated the whole hospital experience. I hated dealing with the medicos and even the nurses. Just the attitudes; I didn't like that.

(Can you tell me a bit about that - attitudes?)

Um, well it was an everyday occurrence to them and it wasn't to me. And there was the, the, actually any specialist I've met, or any doctor that I have talked to..but my actual GP's, they are all bloody men for a start, but, um, they just can't let you talk about it, yeah. So they are always solution focussed, rather than, I don't know. I expect more of them but, I don't like being asked questions and then not getting any feed back on what my answers are. (Amelia)

However, when one's health improves, or one conceives, or an appropriate diagnosis is finally made, then the doctor is often viewed in a different light. This issue reflects the temporality of the story; the doctor can be a 'villain' in one part and a 'saint' in another.

It is the meaning that the women construct from what the doctors say, and how they actually say it, which reflects this dissatisfaction with doctors not being able to diagnose as something actually being wrong.

...and he just sort of said, "tell me what I can do?". Well, he wasn't very good actually. ... I sort of felt he was saying "what are you whingeing about" or sort of he was saying "well, there's nothing I can do" and he looked at me like I was some sort of neurotic woman. I got the impression that he thought it was in my head. I said "look, I went out last night and I was lying down in the street. Is there anything that could be causing this sort of pain?" and he just, sort of, like "well, it's your problem". (Zoe)

It is the women's *experience* of these events which are being narrated. Zoe says "I sort of *felt* he was saying...". Arguably, some doctors do not take women's gynaecological problems seriously and can be dismissive. According to Radley (1994), gynaecological issues have been a cause of 'ambiguity and conflict' in

the doctor-patient relationship (p.110). Earlier research has found that there are appreciable differences between the way women and men patients are treated by medical practitioners. Armitage, Schneiderman and Bass (1979), for example, found that doctors gave men more wide-ranging diagnostic work-ups than they did for women, while Verbrugge (1980; cited in Radley, 1994) discovered that doctors are more likely to be unclear in their diagnoses of women's complaints, or to diagnose them with a mental disorder. In his discussion of illness and gender, Radley (1994) asserts that women and men do have different relationships to medicine on account of their reproductive differences and the fact that men's health is used as the standard reference point. Women's health issues are more susceptible to being perceived as being 'psychological' and so we can appreciate how women presenting with symptoms of endometriosis may not always be taken seriously. Pelvic pain, heavy periods, fatigue and so forth, can be explained away and not given the extensive work-up which is required to yield the diagnosis of endometriosis (if that is what they are symptomatic of). I conclude that when women narrated negative constructions of their experiences with medical professionals, they also constructed their sense of self as being threatened or challenged.

Issues surrounding diagnosis crop up frequently when women talk about their endometriosis experiences. Not being believed, being given insufficient and, sometimes, inaccurate information and being treated in a dismissive way, can understandably be problematic for individuals. One woman commented about her gynaecologist:

Although 'Z' is a nice man, he doesn't tell you much. It's a one way process and I really wanted to talk about the emotional side of it and, at one point, I had forced him to make a referral to ... a specialist fertility person in the hospital to talk about the counselling, the issues to do with it. (Amelia)

Two of the women were misdiagnosed with pelvic inflammatory disease (PID). The following extract is from a woman, diagnosed with PID, when in fact she had severe and widespread endometriosis, and expresses how she felt about herself when given this diagnosis.

... and said I was in an absolutely appalling state inside; I had severe pelvic inflammatory disease. I must look at my future and my activities and all they had done was open me up, saw the, the absolute shame inside..

... when I went back to the gynaecologist for the check up, he said, reiterated again, that virtually I had been a very dirty person, which I thought I must have been. I really didn't question him. That's what makes me angry, at the time, I didn't actually, I just felt so revolting about myself. I'd always been in control, had an outgoing personality, um, loved life, um, you know. I mean, I was family orientated, I loved dancing. ... I wasn't a pessimist about things, but when he told me that I was unclean and yucky, I felt it, I felt that I had had really, um, I had to look at my sexual habits and, yes, I had had more than one sexual partner, but I certainly hadn't had multiple partners, or anything like that. I felt so unclean and so filthy. ... I felt like I had a low self esteem; my confidence was just shattered. (Jay)

This extract comes from a woman who expressed herself articulately, a woman who presented as a confident and vibrant person. When she was diagnosed with PID, she was aware of the PID narrative; the disease being associated with an individual having multiple sexual partners, and thus related unpleasant connotations. It seems apparent that the gynaecologist viewed Jay as being unclean and promiscuous. He brought his values and moral stance to the diagnosis, making assumptions and judgements about his patient. In turn, Jay tried to make sense of this diagnosis and, while she had not had 'multiple' partners, searched through her past for events which may have accounted for this disease. This represented a time of incoherence as she tried to understand what was happening to her. Jay reconstructed her identity as a woman with a

questionable past, an unclean person and these perceptions left her feeling very low about herself and losing her previously high self-esteem.

While much has been written about the adverse doctor-patient interactions generally, it is easy to overlook the positive comments people make about their experiences with their medical practitioners. Some of the women in the study spoke about difficult experiences with their doctors, going back some years, yet were pleased with their current practitioner. Others were quick to acknowledge the supportive doctors from the past that stood out amongst the negative encounters they had experienced with others.

...and I had a really supportive GP who said that he didn't think at any stage it was, that I was going mad, but to really start, really seriously, monitoring my periods. (Hannah).

...and I went and sat down with the gynae, who was really good ... he is only a young fellow ... but I would certainly recommend him. He didn't treat me, he treated me exactly like I wanted to be treated. ... He's quite happy to look at natural remedies, natural therapies. He does a little bit of acupuncture himself. He's very good, he's wonderful. (Val)

(And you're quite happy with your present specialist?)

Yeah, he's really good. And the GP I go to now, he's a lot more up with it; he's really good. He explained a lot more to me. (Diana)

I conclude that difficulties surrounding diagnosis, in particular, and doctor-patient encounters, in general, have links to the way the women feel about themselves and can be perceived as a threat to their identities.

Occupation

The area of occupation was not discussed at much length in the women's stories. However, I consider it important to include the occupational realm as

for many people, their identities are strongly tied to their occupation. For others, occupational choice or commitment may not assume the central role in a woman's sense of identity, but as noted earlier, Josselson (1996) argues that it is in women's sense of connection to others that occupation is important in the defining of identity. I believe that identity is more strongly tied to both occupation *and* relationships since the advent of the women's movement, rather than just relationships as it once was for the majority of women. Societal expectations and, therefore women's own expectations, have undergone a shift with respect to their vocational lives. However, the concerns of the women in this study did not necessarily relate to defining themselves in a particular, occupational field, it was more whether they could physically do the work and put in the hours required. At menstruation time, many women with endometriosis feel unwell, often through pain as well as experiencing the discomfort of heavy periods. Fatigue is another debilitating symptom typically associated with this condition and, like pain, can be felt outside the menstrual period as well.

Some women can work around their symptoms so that their work life is not too affected.

... if I know when I'm going to get my period and they want me to work extra duties, I won't, because I find doing night duties when I've got my period is, it really makes it worse for some reason.
(Diana)

I started to have severe pain virtually every month. And, um, I, often at that stage, we had a business in town and, um, I was fortunate in the way that I could go, come home if I did not feel well and leave the girls in charge of the shop. But it was very hard because I had a young family and I worked full time and had a large garden to keep up and, um, you just sort of have to push yourself and keep going. (Judith)

Other women try to carry on with their work and try not to take sick leave. The following comments from one woman, who experienced severe menstrual pain and flooding, illustrate how some people struggle on regardless.

... so I had no sick leave for a year after I'd finished training when I first started nursing. Because I'd used so much up during my training time, they took a lump off my main sick leave so it left me with no sick leave for over a year, which was difficult because being sick and thinking, well, I can't afford to be sick. I just didn't have the time to stay at home because I didn't have the sick leave.

... I just tend to work through it because work's so busy, you have to try and forget about it and shove an extra pad in and carry on, or fill myself up until I rattle with anti-inflammatories and what have you. (Joy)

Not all women were able to work around their symptoms. The following excerpt is a 49 year old woman's reflections on employment.

... if I was younger, I mean, I find it difficult anyway, because I really didn't, never learnt a lot of skills when I was younger, to get back into the workforce and like I feel now that I'm this age, it's going to be extremely difficult, it's extremely difficult for anybody really to find work. But then, and when I think about looking for a job, I still think, oh hell, I've got that many days when I just wouldn't feel like going to work. And one of the things that I've always been grateful for, you know, having our income through other ways without me having to go into a job as such every day, is that I've always been thankful that I could flop on the bed if I need to, or just put my bloody feet up for a day, which I'll do now, you know. I've been really grateful for that because I know women that are swallowing tablets and having to struggle through their day at work. (Ann)

One woman experienced difficult mood swings which she associated with menstruation. In this respect, she talked about her job being affected. She said her boss 'didn't understand'; he told her she had to do something about her moods. She was finding the work particularly stressful and consequently left this position. This presented as a difficult time for her as it was a job she

particularly liked, yet she understood her mood swings hindered her work and her relationship with her employer.

The symptoms associated with endometriosis are constructed as difficult to live with. Pain, heavy periods, fatigue and related mood swings seem to impinge upon some women's ability to function well at their jobs. While the women in this study did not specifically talk about how not doing a particular job, or having a job, affected the way they felt about themselves, it might well be a real issue for women experiencing difficult symptoms. While this section is mostly descriptive, I defend its inclusion under 'Identity'. I concluded from the women's talk that there was the potential for a woman to experience a challenge to her identity if, due to difficult 'symptoms', she was unable to work, or work full-time, or be able to work in the sort of job she desired. I believe it is an area I have not covered well and needs further research.

Self-Concept

I conceptualise 'self-concept' as to how an individual experiences herself, including her physical appearance and the way she perceives herself psychologically. Related to self-concept, is self-esteem which refers to one's evaluation of self-concept, that is, whether one feels good or bad about one's qualities and attributes (Taylor, 1995). I only briefly address body image issues as, while women discussed their symptoms of bodily disturbance, only one talked about how she actually felt about her body. While only one individual talked about this area, it does not mean her story should not be included in the study. Other women with endometriosis may construct their experiences in a similar way. Thus, it is important to be aware of any way a woman's sense of identity may feel threatened if we are to gain a good understanding of endometriosis and related identity issues. I then move on to discuss

psychological perceptions. However, I would note that the latter perceptions are also discussed, to some degree, in the other sections relating to identity.

The time of adolescence is an important period in the formation of an individual's identity. According to Erikson's theory of psychosocial development, developing a sense of identity is the principal task of adolescence (Erikson, 1980). At this age, identifying with one's peers develops. I believe, that for women, menarche, or the onset of menstruation, can play a significant role in this area. For example, the attitudes towards menstruation, situated within the cultural narrative of menstruation and which girls receive from their families, friends and society in general can be a major influence (Dye & Richardson, 2000). Gergen and Gergen (1993) go further to claim that bodily changes at puberty can pose a huge issue for establishment of identity, suggesting that it can make one repulsive or desirable. I contend that the endometriosis condition, owing to its close links with menstruation, can also be talked about in these terms. However, it is not just the onset of menstruation and difficult symptoms which can be problematic, it is the ongoing implications for these women who have endometriosis that are also of great concern.

Body Image

Even as small children, most of us are conscious of the significance of our appearance and, by adolescence, young women have absorbed the cultural message, embedded in a cultural narrative, that beauty equates with desirability and acceptability. The media portray sparkling clean, attractive and sexually appealing women in their endeavours to sell products from fly spray to four wheel drives, while the film industry, particularly in the United States, leans heavily on the employment of beautiful actors and actresses. Successful career women are beautiful; kind, loving mothers are always

attractive and, of course, young women are stunning. Or, so such media and film portrayals would have us believe.

I did not raise the subject of body image in the interviews with the women and Tess was the only woman in the study who specifically spoke about the issue. Tess talked about how her extremely heavy periods, commonly known as 'flooding' made her feel undesirable as a young woman. Her menstrual problems seemed to control her life as they affected her daily activities. 'It used to scream at me from the calendar' and she would have to plan her life around her period and only go away for weekends, for example, when she was not menstruating. Although she was able to keep the pain bearable, she was not able to control the flooding. She was not able to be spontaneous, or impulsive.

I hated myself when I was a teenager ... it was a real burden to carry ... I always felt unclean and so bloated, I mean, really bloated before I got it. You know, a dress that would fit a week before, wouldn't fit me, and it was always seemed to be when some nice guy had asked me out'.

When she was feeling this way, she felt her image as a sensual and attractive woman was marred - 'it probably affected my general feeling of feeling beautiful'. When she was at school, Tess said her mother made her wear plastic pants when she was menstruating after she 'flooded' at school on a couple of occasions. 'And they used to crackle every time I sat down and they'd sweat and I felt really smelly and dirty and oh, dreadful time, dreadful, dreadful'. Tess's concerns, illustrate how her endometriosis symptoms posed a threat to her perception of her image. However, at the time of talking to Tess, she was going through menopause, she had undergone a hysterectomy and although still suffering to a much lesser degree with some symptoms, she spoke of feeling much better. 'Life's just beginning really ... No, I feel really good, yeah,

and I've certainly, I've certainly got my sex drive back again'. From these latter comments, it seemed that the emotional and physical experiences of very heavy bleeding had affected the way she felt about herself and her body and, now that she no longer menstruated, despite other discomfort, she was feeling good about herself and her life.

When talking about having a hysterectomy, two women commented that the procedure did not leave them feeling less feminine. I conclude from such comments that they believe other women do feel less 'feminine' when they lose their reproductive organs and thus their ability to procreate.

One of the things that has happened in all of this is that through having my organs removed, I have never ever felt less of a woman, or less feminine, which is really good. I think, I don't know whether that's, I know that I have heard some women feel that way, they don't feel a woman anymore. I have never felt less feminine or that I'm not a woman anymore. I have never had those feelings. (Jay)

I don't feel any sense of losing my femininity about having a hysterectomy. (Val)

It is worth noting that in the case of these particular women, Jay had already borne a child, which is symbolic of being a 'woman' or 'proof of womanhood', while Val did not want to have children. I consider it important to be aware of the possibility that women who have not conceived a child, and who want to, may construct their experience of being a woman as being challenged.

While only one woman in the study spoke about the relationship between having endometriosis and her sense of a negative body image, it is an issue which could well be explored further in future studies. Arguably, a woman experiencing such a diminished perception of the way she views and feels about her body, could also experience further difficulties as a result of this construction.

Psychological Aspects of Self-Concept

The following addresses the psychological aspects associated with having endometriosis, as expressed by the women and interpreted by me. These aspects are often portrayed in the victim and conqueror roles and these roles are woven into their endometriosis stories. Endometriosis can be experienced as a disruption and, therefore a challenge at some level, to a woman's self-concept.

The victimic identity, according to Polkinghorne (Polkinghorne, 1996), is a 'self-story' in which the individual has lost power to effect change in his or her life. All the women in the study talked of suffering in some way with respect to endometriosis and, in this sense, were victims. However, by conceptualising the victim role as part of a 'self-story', we can see there is a distinct difference between believing a woman may be a victim because of her experiences and her storytelling her experiences as a victim. That is, upon listening to an individual's story of physical suffering, for example, a person may conceptualise that individual as a victim. However, what we are concerned with here is whether the woman narrates her story in a victim role. In the endometriosis narrative, a woman may portray herself as a victim in a physical and/or psychological sense. Suffering in either of these ways can result in a woman being unable, or unwilling, to participate in activities such as sport, while her ability to work may be compromised. For some women, this may occur on a regular basis, one to two days each month while, for others, chronic fatigue, ovulation pain, backache, painful intercourse, to name a few, are experienced as problems which affect them on and off all month. The pain associated with endometriosis can be severe and, particularly when the cause is not known, that is, prior to diagnosis of the condition, can lead to psychological distress. Through her suffering, a woman may feel different about herself and

experience a challenge to her identity. Brown and Gilligan (1992) point out that a sense of connection with others is central to women's development and, when there is disconnection, psychological crises can arise. I would argue that when women with undiagnosed endometriosis symptoms experience a lack of connection with other women, that is, a sense of feeling different and not knowing why, then they are also at risk of psychological distress and may experience a threat to their identity.

Recognising that physical and psychological pain and adverse effects of medical procedures can lead to suffering for the chronically ill, Charmaz (1983) argues that the nature of such suffering is the 'loss of self' (p.168) experienced by many chronically ill people. She notes that the meanings and experiences upon which these people had formerly founded their positive self-images, were no longer available and that, over time, the 'accumulated loss of formerly sustaining self-images, without new ones, results in a diminished self-concept' (p.168). In narrative terms, I understand these 'self-images' as part of the personal story a person constructs about themselves. While a woman can feel she is a victim of debilitating symptoms, the perception of her symptoms not being validated by others, such as the medical profession or family, can lead to the experiencing of a diminished self-concept. The dilemma of feeling ill, but not having the support and understanding of family, or the sanction of the general practitioner, paves the way for self-doubt and, according to Charmaz (1991) can shatter people's trust in themselves. I see this diminished 'trust in themselves' as a challenge to the individual's, personal story. Such lack of support and understanding, Radley (1994) says, can lead to feelings of isolation and consequent lowered self-esteem and confidence. Charmaz (1991) also notes that some people prefer to receive a devastating diagnosis rather than believe themselves to be neurotic, or malingerers. The pre-diagnosis part of the endometriosis story is a time of making sense of what Radley (1994) terms

'bodily disturbances' and try to either accept them as normal, or continue seeking medical validation. The following extracts are examples of two women's reports of how they felt after consulting a medical professional.

Using simple, but powerful imagery, 'like a hunk of dirt', Hannah managed to convey to me a sense of being belittled, dismissed and a lowered sense of self-esteem.

I felt like I wasn't believed. ... I felt I was a hypochondriac. ... I had troubles with depression. (*And, after another medical consultation for her undiagnosed symptoms*) ... well, I walked out of there feeling like a hunk of dirt ... I was really angry; I didn't feel listened to.
(Hannah)

And, to draw once again upon Jay's experience with a gynaecologist:

I felt like I had a low self-esteem; my confidence was just shattered. I just didn't feel good about myself at all. ... and for the first time in my life, I knew what it felt like to have little or no confidence. I felt pretty devastated with myself.

At this point, I turn to a story related to me by Tess. I have termed this account a 'defining moment' as Tess had chosen this story to illustrate to me how she had suffered from endometriosis. She talked of her frequent flooding experiences and how she felt embarrassed and humiliated. Just before she started the story, she commented "terrible, it made life really miserable". She continued:

I remember going to Pak 'N Save once and standing in the queue and starting to leak everywhere and asking the girl behind the counter if I could use the loo and she said "no, union rules". You remember, those days where you weren't allowed to use the loo? And I said, "well, I have to go" and there were people all round me, and she said "well, um, if you leave your groceries here and go home". I said, "I have to go now". And, in the meantime, I had blood, literally

running down my leg. I was just.. (*oh, how awful*) Yes, and crying. She just she got the manager out, and he said the same thing. So, I walked out to the car park just the same, with it still streaming down my leg. Left my groceries and um, I wrote them a letter, and I said, you know, I have heavy periods and, you know, I found the whole thing humiliating. Didn't reply, didn't reply. I hoped he felt embarrassed about it. But those situations happened often.

If those situations occurred often, I wondered how being frequently 'humiliated' and 'embarrassed' affected the way she felt about herself from day to day. However, we do know from her first comment that having endometriosis was terrible, making her life 'really miserable' and I can only interpret this to mean that if her life was really miserable, *she* felt really miserable and did not feel good about herself. She had a physical condition, over which she had no control. She often felt embarrassed in public and, from her account, did not receive understanding or support. I maintain that if one is supported through difficult situations such as Tess had been experiencing, then one is more likely to retain a sense of dignity and self-esteem. Thus, one's image of one's self is not threatened and one's wider personal narrative within which one's sense of self is contained, is left coherent and unified.

From the women's stories, I have concluded that the time of diagnosis can be a defining moment. To have one's symptoms recognised as belonging to a recognised condition, that they are not just 'psychosomatic' can be a great sense of relief and be a time of liberation. Differing responses to the diagnosis are often tied up with how a woman had perceived her symptoms previously, the severity of her symptoms and the implications of having the diagnosed condition. The following extracts exemplify the sense of relief and validation that was experienced by these particular women. These excerpts are also good illustrations of 'defining moments' in the stories these women related to me:

... and I went in to have a laparoscopy ... and when he came and saw me next day and told me I had endometriosis, I just went 'YES!!!' (*Great emphasis, hands up in the air*) I was so excited. Because it was just so neat to have a name for something which all these years had been causing me so much pain, and it wasn't up here (*points to her head*) and I wasn't going loopy, you know. I was over the moon. I was so excited to have a name. I hadn't realised how much, um, how much stress I'd put myself under by not knowing and there was going to be nothing wrong with me and it was all in my mind. I was really scared that at the end of this, the gynaecologist would say "there's nothing wrong with you Hannah". I was really scared it was going to happen. (Hannah)

And when I had the diagnosis of endometriosis, it was like there was a weight lifted off my shoulder, because finally, OK, there's a diagnosis. (Val)

... when I had the laparoscopy, I was pleased that I did have endometriosis because I really wanted to have a name to my condition. (Vicky)

It was such a relief when it was, because of, because you're seen a bit as neurotical complaining and that bothered me too. ... the relief was that it wasn't the terminal thing. (Ann)

The foregoing illustrates clearly the sense of relief associated with being able to put a label upon one's symptoms. Such medical validation bestows a sense of normality with respect to an individual's psychological state; they are not 'neurotic' or experiencing 'psychosomatic symptoms' and, further, they are not malingering or exaggerating these symptoms. Importantly, having a diagnosis also enables the woman to learn about how to relieve and accommodate the symptoms, learn what exacerbates and what improves the condition, as well as avail herself of the various endometriosis treatments. Such knowledge is empowering and enables an individual to take control of her illness, rather than the condition controlling the individual. Knowing oneself and understanding the implications of having endometriosis contrasts with the pre-diagnostic

stage of confusion and ambiguity. Physically, the symptoms may be the same, but psychologically, the woman has changed. There is the assumption of control over her body and renewed confidence in herself in relation to her self-concept.

While the time of diagnosis was constructed as a turning point in several of the women's stories, I have constructed and analysed it as a 'defining moment'. It was from that point in the narrative that women spoke of change, feeling differently about themselves, becoming enabled to take control of their condition and their lives.

One woman spoke of knowing what was wrong with her as 'a huge powerful tool' which enabled her to cope with her symptoms. She had assumed greater control of her life and was making an effort 'to do something for myself'. For another woman, recognising that she had been treated in a dismissive, and sometimes patronising manner by her doctors and gynaecologist, was a source of anger and provided a stimulus for her to become more assertive. The validation of symptoms were empowering. She decided that in future she would consult a woman gynaecologist, in the belief a woman would be more understanding and less dismissive. Even since her diagnosis, she had felt that her gynaecologist underrated the effect of the endometriosis upon her life and that she would come right once she had passed through menopause. She commented:

I'm grateful, you know, I haven't had such terrible problems as some women, but I felt like saying, "well, even if it's four years, even if it's three years, it's still a bloody long time to be having constant problems" (well, it is) you feel like shaking, I felt like shaking him and saying, "well, you bloody well see how you'd like to put up with that, even if it's bloody two years or three years, it's still a long time".
(Ann)

I continue to draw upon Ann's story to illustrate how a sense of empowerment, control of one's body and subsequent assertiveness can be constructed after diagnosis. While Ann's comments illustrate her anger, I believe they also portray a woman who is no longer prepared to put up with dismissive attitudes. In her endometriosis story, we can understand how the cultural story of surrounding the godliness of doctors informed the way she had behaved when consulting her GP.

I was brought up, sort of, in that generation where the doctor was God, you know, and parents treated them with such, sort of, absolute courtesy, and they would never have questioned anything that the doctor had said and I grew up like that.

I analysed Ann's sense of growing assertiveness and empowerment as stemming from her diagnosis, becoming informed about the way she could manage her condition as well as an evolvement of her maturity. Listening to her story, one could feel the sense of control gradually coming back into her life, and the assertiveness appearing in the story, after Ann learned about and understood her condition. The assertiveness starts appearing in her story, tentatively, at times, and more strongly at others.

...you know I'm changing a bit that way with, you know, with my feelings for sex you know. Or, whether I've just become assertive enough 29 years of being married to say, "look, just, I bloody don't feel like it". ... sometimes with sex now, there's quite a lot of blood when we're having sex, you know, there's quite a lot of blood. And..... well, I'm just not prepared to do, now, like digging and things. I'm just not prepared to do the things that I used to do. ... And I used to be prepared to do things and then suffer and then feel pissed off with, you know.. I forget, I still hike over fences and chase animals and end up bleeding and things but, because I enjoy it, I'm prepared to do...

Ann has challenged her own personal narrative here. Where her personal narrative contained ways of behaving, such as having sexual intercourse with

her husband when he wanted it and she did not, she is now changing that part of her narrative. With respect to endometriosis and its associated discomfort, she is deciding when and when not to have sex, dig the garden, climb fences, or whatever. This extract illustrates how Ann has learned what exacerbates her endometriosis symptoms and has decided what she is and what she is not prepared to do. She will sometimes do things which precipitates the bleeding, but is prepared to put up with it at times if she is enjoying the activity. On the other hand, Ann talks about her annoyance with herself when she has not been assertive and this story relates to her consultation with her GP.

... I read somewhere that you mark it on a calendar (*the days when she bled*) and show it to him. ... so I took this, I took my calendar in, and it was just full, the months were just full of the days of bleeding really, and showed him, but he, I just slid it, instead of saying "this is, and I bloody don't think this is right" sort of just winkled it out of my bag and sort of put it on his desk and it wasn't really taken any notice of, really. When I think that it was bloody well just dismissed. And the gynaecologist too, because you know, I was still going in between, ... and he just didn't even want to even look at it either ... and annoyed with myself for not being more assertive.

Ann's disenchantment with the attitudes of the medical professionals she had consulted resonated with the opinions expressed by other women in the study. I interpret this disenchantment as the stage in their stories where they no longer live by the cultural narrative regarding doctors and, in its place, a new one was emerging. Doctors do not know everything, their word is not gospel, they make mistakes and it is important to question them. It may be necessary to seek another opinion, and/or change one's doctor. I interpreted these sentiments from the women's stories which seemed to employ the alternative cultural story surrounding doctors.

On the other hand, the process of diagnosis can be a mixed blessing. It has provided a name to those worrying symptoms, but it also spells out the

implications of this diagnosis - possible fertility difficulties, no cure, the likelihood of ongoing symptoms until at least menopause and so forth. How do people react to such concerns? One woman was diagnosed with endometriosis around the time she experienced a miscarriage and said:

I had quite a severe depressive episode ... from the miscarriage and my diagnosis. I found it (the diagnosis) really difficult. ..There's this fear that endometriosis is going to see me have one or two more as well, I don't know, in terms of miscarriages.

For some women, there is clearly a shift from the role of victim as characterised by lowered self-esteem, depression and so forth, to the role of controller, a person who is confident at taking control of their body and perhaps their life once more. For others, there may be a sense of moving into the role of victim as the implications of having endometriosis are assessed and understood in terms of their life plans, particularly with respect to having children. I have discussed the infertility issue in an earlier section. However, it is not just the concern of not being able to have children, it may be the thought of possibly having to endure many more years of distressing symptoms. This is particularly so, historically, where treatment has tended to only bring temporary relief of symptoms.

I turn now to Judith's story as an example of someone who did not portray herself as a victim yet, one could easily perceive her as one as she went through years of pain and illness, culminating in the development of a malignant endometrioma. A couple of months after our interview Judith died. Judith described the severe menstrual pain she often experienced and, at the time of our interview, the abdominal pain she was experiencing. The extract shows how she had learned to manage the pain to some extent and not become a victim of it. She maintained a strong sense of her identity.

And I have had abdominal pain for so many years that I go to bed with the pain and I know exactly how to get to sleep with it. I know I have to read until I get really, really tired, until my eyes virtually shut and then I put the book down and I just go out like that.. Ever since I had endo I suppose, it's just one of those coping strategies that you somehow learn yourself to do, because you need, I need my sleep ... over the years I have learnt to fade the pain back into the background by reading and keeping busy.

While Judith had endured many years of pain, severe illness at one stage and, now cancer, she still spoke positively and quite matter-of-factly about her life. For example, she made a point of talking about what she could do and what she did not suffer.

I've never had PMT, I've never had mood swings or anything like that ... in that way I feel I've been lucky because some women do put up with such a lot. ... and I have been very lucky in that way too, it's never affected our relationship. ... I can still work a whole day and I don't get tired other than the physical tiredness that you would get through, you know, digging in the garden, or whatever. Yeah, so no, it hasn't affected me like that.

I'm just thankful that I've lived as long as I've lived and if ... two or three years down the track I succumb, well OK, that's just the way that life is going to be for me and I just try not to get depressed or think about it too much. I feel sorry more for my children, much more than I do for myself actually, but then I think I suppose mothers are like that aren't they? ... I'm just determined that I'm gonna live the life as best I can and I was always like that with endo; I never wanted it to stop me doing what I wanted to do. It never stopped me doing my garden; it never stopped me going to work, um, I just managed my life around it, yes, I have.

Judith's poignant story is somehow, sadly ironic. She did not express as a victim, yet ultimately she died of the endometriosis-related cancer. Judith's story illustrated how an individual can be a physical victim, yet not a psychological victim of their condition. While the physical illness can be a barrier to activities an individual wishes to be involved in, it is not always a

source of psychological distress. For some women in the study, it certainly was not the case. Joy also spoke of how endometriosis had never stopped her doing the things she wanted to do in her life apart from the possible threat to her fertility. Along with severe pain and flooding with each period, Joy also developed two other chronic illnesses, yet still spoke of 'plodding on'. As mentioned earlier, she also gained three stone in weight after being on certain medication for the endometriosis. Despite all this, she expressed as a survivor and was adamant that her conditions were not going to interfere with her life.

Judith and Joy are two examples of how, despite difficult physical symptoms, and illness related to endometriosis, can pose physical barriers to a woman's life, she may not construct her experiences as a victim. In these stories, the women have maintained their identities and they have retained a sense of unity in their personal narratives in the face of challenges.

Summary

The women talked about their endometriosis experiences in ways which expressed their sense of identity namely, fertility, relationships, occupation and self-concept, both physical and psychological. Their stories relate a variety of experiences of their endometriosis and a variety of ways they have responded to such experiences. Some talked as victims of their undiagnosed symptoms, or victims of having endometriosis, while others denied that endometriosis had interfered with their lives. They spoke to me about having children, relationships, their work and the way they felt about themselves, areas which expressed their sense of identity and portrayed the way it could be challenged and reconstructed over time. I did come to understand, however, that having undiagnosed symptoms can diminish the way a woman feels about herself. After diagnosis, I also learned from the way they talked, that their identities

could be reconstructed, for example, through feeling empowered, confident and feeling good about themselves. Other women maintained their sense of identity in the face of challenges and were able to cohere with their personal narratives. Fertility was one area where diagnosis could lead to feelings of worry, or concern as some of the women wondered whether they would be able to have children. In this respect, one can understand how their perhaps, taken for granted, prospective role of mother was threatened and the personal narrative was strongly challenged.

The women talked about their experiences within the roles they held, or expected to hold in their lives, expressing themselves as victims and controllers. Like chronic illness in general, there are various realms in an individual's life where the condition is perceived as a barrier and, subsequently, the person's identity can be challenged and reconstructed. The analysis has shown how a woman can emplot various events into a coherent story which, in turn, expresses their sense of identity and which can be reconstructed over time.

Chapter Seven

Making Sense of Events

*We live immersed in narrative, recounting and reassessing the meanings of our past actions, anticipating the outcomes of our future projects...
(Polkinghorne, 1988)*

In the social sciences, one of our endeavours is to understand human experience. To achieve this end, we can listen to, read, analyse and draw meaning from people's stories. Individuals can make meaning of their lives through the activity of emplotment in the storying of their experiences. We continually tell ourselves stories, emplotting events from the past, and what we wish for in the future, into our daily lives. Through our story-telling, we are able to make sense of our world and, according to Murray (1997), attain psychological cohesion. When we are unable to make sense of our world, the experiences of our daily lives are chaotic, confused and without meaning. As Polkinghorne (1988) explains, narrative meaning does not just comprise the events, but also the significance the events have for the narrator with respect to a certain theme. Further, an individual's life events are open to different kinds of emplotment, thus, as we examine our research participants' stories, we are aware of the various ways and perspectives, through which they understand their lives. Certain events are woven into their stories while others may not be included.

Using linguistic or narrative techniques to understand and interpret human experience, obviously does not bestow the researcher with the ability to make predictions or wide generalisations about human behaviour. However, this type of research does display connections between events by highlighting their significance. While the researcher can use a ‘what-if’ strategy, imagining what may or may not have happened if a particular action had not been taken (Polkinghorne, 1988), the main objective of narrative explanation is to provide insight into people’s behaviour. In chronic illness narrative research, among other issues, we are concerned with how people understand their illness, how they have made sense of their condition and how they have emplotted related events into their stories. For example, how do they make sense of ‘symptoms’? How do they understand they have come to have this particular condition? And, as discussed in the last section, we can start to understand how the way people make sense of events, can lead to a changed sense of identity.

Emplotting one’s illness into one’s life story does not suggest that one has come to terms with such illness. What it does indicate is that the person has somehow integrated the condition into their lives. They have integrated it into their personal narratives whether they have perceived it as an invader, something to be struggled with and battled against, or whether they have accepted it as part of one’s body and something to be understood and managed. Chronic illness can be conceptualised as a disruption to one’s life story. The events surrounding it need to be accorded a certain significance and a particular place and, therefore, a sense of understanding. This chapter examines how the women in this study made sense of the events surrounding endometriosis in their lives. I give particular emphasis to the way women made sense of ‘symptoms’, prior to being diagnosed with endometriosis. In this way, we can expect that the story will change from telling to telling. My objective is to show how I have interpreted the way the women have made

sense of their experiences and exemplify these interpretations by extracts from the transcripts.

With respect to endometriosis, expressions of meaning relate to how the women understood the condition, that is, what did having endometriosis mean to them. For example, some people might perceive their condition as a burden that has stripped them of their independence and changed their lives in a negative way, or, for others, it could mean that the experience has strengthened them and has brought more 'meaning' to their lives.

The previous chapter relating to identity also refers to making sense of events and of course this is part of any narrative analysis. However, this chapter is devoted to this aspect of narrative, as I wanted to analyse the process of making sense, particularly of 'symptoms'.

The first section of this chapter examines how the women made sense of symptoms such as severe pain and heavy menstrual flow prior to a diagnosis of endometriosis. I have conceptualised this by describing them as normalising narratives and resisting narratives.

Making Sense of Symptoms

In the initial stages of analysis, I became quickly aware that the women spoke a lot about having 'symptoms' and how they tried to make sense of them. Much of this talk was characterised by their stories of visits to general practitioners and gynaecologists and issues of diagnosis. While I wanted to know about their experiences of the diagnostic process, I did not always have to raise the question myself. The women tended to talk about how they wanted help to deal with difficult symptoms and subsequently the events surrounding

diagnosis were emplotted into their stories. Drawing upon the cultural narratives of illness, the women consulted medical practitioners in order to receive a diagnosis, so they could make sense of their symptoms. However, until they received the 'diagnosis' they wanted to understand why they were experiencing their symptoms. As I worked through the process of analysing how the women made sense of symptoms, I understood that there were two narratives, or stories, which had been constructed. One, I have termed the 'normalising narrative' where the women construct the symptoms as being normal, that is, part of the normal process of menstruation. The other story, I have called the 'resisting narrative' and this is where the women construct their symptoms as not normal and resist efforts by doctors, family and friends to convince them otherwise.

Before moving into discussion of the normalising narrative, I present some of the talk that has surrounded menstruation, showing how social constructions have emerged in a predominantly negative way. Although endometriosis has symptoms which may not be directly connected to menstruation, as constructed by the biomedical account, many women's first experiences of this condition are tied up with their periods. The following uses extracts of people's talk, often drawing upon very early references. It will help orient the reader by putting the normalising narrative into some sort of cultural and historical context.

Firstly, a glance at some past pronouncements on menstruating women.

When a woman has her regular flow of blood, the impurity of her monthly period will last seven days, and anyone who touches her will be unclean till evening. Anything she lies on during her period will be unclean, and anything she sits on will be unclean... (Leviticus).

It is an undoubted fact that meat spoils when touched by menstruating women (British Medical Journal, 1878; cited in De Beauvoir, 1952).

Many a young life is battered and forever crippled on the breakers of puberty; if it crosses these unharmed and is not dashed to pieces on the rock of childbirth, it may still ground on the ever-recurring shallows of menstruation, and lastly upon the final bar of the menopause ere protection is found in the unruffled waters of the harbor beyond reach of sexual storms. (Address from Dr Engelmann, President of the American Gynecology Society in 1900; cited in Ehrenreich, 1979).

The above extracts attest to the fact that since recorded times, menstruation has been surrounded by various stories, superstitions and taboos. Accordingly, young women have often begun their experiences of menstruation with misinformation, in what Culpepper (1992) describes as a social context which is mostly negative. Looking back historically, we can read about the negative views held and, often perpetuated by men, about menstruation. For example, one strongly held opinion, actively expressed in the late nineteenth century, was that menstruation was not compatible with education. Cayleff (1992) cites from Cook, 1895, p.571, Dr A.F.A. King, speaking before the Washington, DC Obstetrical and Gynecological Association in 1895:

Any drain upon the nervous powers of whatever character, was liable to unfairly influence menstruation in girls. And the method of education in the schools was a large factor in producing menstrual disorders.

No doubt, people such as Dr King, were against women pursuing intellectual endeavours and, by asserting menstruation was an ailment, used it as a way of exerting influence against their seeking further education. However, certainly around the time of the late 19th century and early 20th century in America, menstruation was constructed as a period of illness and a state which affected women emotionally and physically.

Although these early ideas may seem laughable to us now, looking back from the enlightenment of the early 21st century, differing stories still exist and the messages young women absorb at menarche may be still mixed and negative. The secrecy and taboos connected to menstruation seem to ensure that at least some of the earlier views still survive. Ussher (1989) points out the importance of the relationship between menstruation and reproduction and sexuality, also areas of taboo. Talking about menstruation has never been an acceptable topic of conversation and, even today, many women and men feel uncomfortable talking about it in mixed company.

It seems a fairly acceptable premise that menstruation can be heavy, can be accompanied by pain and, for some women, is a time of discomfort or dis-ease. In 1952, Simone de Beauvoir wrote that ‘Menstruation is painful: headaches, overfatigue, abdominal pains, make normal activities distressing or impossible.’ (De Beauvoir, 1952, p.329). However, in more recent times, there is also another message that young women have received. While menstruation may bring pain, this is normal and that possible emotional problems may amplify any discomfort. For example, Goudsmit (1994) states that women have traditionally been viewed as weak and emotionally unbalanced and menstrual pain in such ‘highly strung’ women can be exaggerated (p.8). As Goudsmit rightly argues, some of the literature does not recognize that perhaps emotional distress may result from the physical distress rather than being the cause.

Menarche, or the beginning of menstruation, is a significant developmental stage for young women, marking the point of physical transition from being a girl to being a woman. For many women, it is a time of jubilation, a time to celebrate and a time of welcome by other women to womanhood. For others, it is a time of resignation, confusion and even fear. As a biological event, according to Llewelyn & Osborne (1990), its meaning derives from the social,

political and economic aspects of a woman's life. However, leaving aside any political and economic considerations, we can see how the social construction of menstruation is a major influence on the way a young woman will perceive this normal event. Ussher (1989) notes that each woman spends the equivalent of six years continuously menstruating and that negative social constructions of menstruation can have a detrimental effect on a woman's self-image and identity, resulting in six years of life being viewed as useless if these constructions go unchallenged.

From a narrative outlook, it is the stories surrounding menstruation which women draw upon to understand this process. They are culturally situated and the messages are mixed. Menstruation is normal, it is a time of celebration, it means being a woman. It is unpleasant and unclean. It is painful and awful, it is a time for sorrow and resignation. It can be secret and taboo, so you don't talk about it. You accept it and get on with it. If you can't cope with the pain, then it is probably psychological and you are responsible for the discomfort. It is all in your head. Many of these stories have roots in the distant past, while new stories are vying to be heard. The messages that women internalise from these stories can affect the way they perceive menstruation and how they might deal and cope with pain. For women who have the symptoms of endometriosis, it is understandable, therefore, that many have normalised their distress and, subsequently, have not always been able to find ways of easing such distress.

The Normalising Narrative

The normalising narrative is characterised by the women's attempts to perceive their 'symptoms' as normal. Where symptoms, such as heavy bleeding and pelvic pain, are connected to menstruation, the women may believe that their symptoms are normal as they draw on the cultural menstruation narrative. It

talks of periods being sometimes painful and heavy, that it is normal and just part of being a woman. Its message is imparted by doctors, mothers, sisters, teachers and, no doubt, a message which is understood by a greater part of our society.

Yeah, I think so, they sort of just, yeah, my doctor really didn't, he just sort of said, oh, you know, periods, it happens, type thing, yeah. So, sort of, just each time I'd go to see him, I'd say, it's still sore and I'm still having these problems, but he really didn't sort of know what it was and just said some women get more pain with periods than others. (Diana)

... and, you know, when you're at high school and they give you class lessons for P.E. (physical education) and whatever, and they tell you that you get your cramps and all the rest of it, so you assume you're going to get pain with your period anyway and some get it more than others. So it was never any big deal and from then on, it was basically the minute I knew I was getting my period, I'd just pop a couple of painkillers and that would kill it and I'd be right. (Jacky)

And his (GP) reaction was ... you've just got normal periods and it's a woman's lot, and accept it. (Hannah)

The next extract illustrates the initial stages of a woman going through the process of trying to make sense of what was happening to her. She is talking through the issue and attempting to make some sense of it.

I'd think, crikey, why does it keep on happening? (*Severe symptoms*) Why is it? Why me? Why do I have to keep on going through this? Nobody seemed to be able to answer why it kept happening and people just sort of say it's normal. (Joy)

Normalising of symptoms by significant other people in the women's lives helped shape their ideas that pain and heavy periods were normal. Even when the woman was debilitated by pain and burdened with flooding, in the

normalising narrative, she would talk of her accepting that this was her lot and just part of being a woman.

It was par for the course really for us to have pain, a lot of pains, and you know, that was, that was their view of it, is that that was part of their period (you mean women in general?) Yes, yeah, to have a lot of pain, so you just sort of got on with ... I thought that was what most girls had. ... I was just on the floor pulling up my knees in agony, but even at that, I, I really didn't really tell anyone, and I don't think, because it seemed to be an accepted part of it all. (Ann)

... I had quite severe pain and just put it down to, well, that's your period and that's what you get. That's your lot. (Jacky)

To ascertain whether one is normal requires a comparison of oneself to other people. A woman is more likely to accept her symptoms are normal if other women she knows say they have similar symptoms. Even when the symptoms are severe, having a mother and/or sisters, for example, who have also experienced painful, heavy periods, can have a normalising effect.

I think it was devastating enough getting a period at ten without having everything else that went on (severe cramps, very heavy bleeding), but it was classed as being normal. My mother had had long sort of heavy periods right from, probably not as early as that, but it was just, sort of, oh well, it's something that ran in the family. (Joy)

Mum said, well, she had the same problem, so, you know, I just thought I'd inherited it from her. And that was my lot. (Tess)

To normalise severe, debilitating symptoms is difficult, particularly where there is no family history of it. It can create an incongruence which constitutes a psychological struggle. This incongruence typifies what White and Epston (1990) state is a lack of fit between the cultural narrative and the actual lived experience of people. For women with severe symptoms associated with

menstruation, their lived experience of menstruation is different from the prevailing cultural narrative construction about menstruation. Although this narrative portrays pain and heavy periods as normal, severe pain and flooding are extremes which do not fit in with this narrative and what other 'normal' women are experiencing. Their lived experience is different from the norm and, accordingly, does not cohere with the cultural narrative. A woman experiencing such dissonance needs to construct a meaningful story to make sense of what is happening to her. So, in order for her to normalise what is happening, she needs to find some reason to account for why she actually finds her experience abnormal. One way of doing this is to blame the perception of the severity of her symptoms on to herself.

I just thought I couldn't accept pain and that I was weak. Everybody has it, that's what the doctors said. That all women have the same type of period ... And these things aren't happening to me, so it must be in my head ... (Hannah)

The following is a further example of a woman who questioned her psychological state. Initially reluctant to have a laparoscopy, she was trying to convince herself that there was nothing physically wrong despite having periods she described as 'nightmares'.

I was fairly stubborn and I think I accepted what he (gynaecologist) said. I thought, how could I have possibly got myself in this position where I had become psychosomatic, which is the word he used. How could I have ever got myself like this; I must be failing. ... I did go back to work, however, I didn't cope.. (Jay)

Trying to accept that what is happening to their bodies as just part of a normal process of being a woman is a difficult thing to do. It would seem that severe symptom experiences limit the power of normalising. Even when the woman has normalised the symptoms, where the symptoms are quite severe, she will still question why she is experiencing such troublesome periods. Women with

severe pain, extreme fatigue, possible migraines and heavy bleeding cannot normalise these symptoms to the extent that they can just ignore them all the time. Frequent absenteeism from school or work may be necessary and this was not always understood or acceptable to others. There is still a sense of dissonance between what they are experiencing, what other people say about their symptoms and how they are trying to perceive them.

I was always at least one or two days a month having to come home from school and then when I started nursing at 17, I lost a lot of sick leave with being off. ... Why me, why do I have to keep on going through this? Nobody seemed to be able to answer why it kept happening (flooding) and people just sort of say it's normal. (Joy)

I did get really angry with my mum and my sisters ... there's Hannah again! Because I just felt that when I was at home, I'd just go to bed and read and so they saw that as me coping out of doing things. And so it's misunderstanding... (Hannah)

One can appreciate the situation where a woman may vacillate between thinking something is wrong with her body and normalising her symptoms. Perhaps this is due to the frequency and/or intensity of the symptoms and whether they can be alleviated. The onset of symptoms outside the menstrual phase can also signal to a woman that all is not right. If one is told that all is well and there is nothing to be concerned about, there is the chance that one may accept this counsel and normalise symptoms. How a person deals with illness, Radley (1994) points out, depends on others' attitudes. Although Radley is referring to a diagnosed condition, his point is also relevant to how people perceive the signs of bodily disruption - are they normal, or not? Such perceptions or beliefs are shaped by the social context in which the symptoms are set, or in other words, what do other people, such as one's GP, have to say about them? What does the prevailing cultural narrative have to say about them? In other words, people construct a coherent narrative which make sense

of such symptoms as menstrual pain and heavy bleeding. The following extracts illustrates the way a woman can waver between normalising signs of bodily disruption and between thinking they were not normal. It illustrates the process from thinking symptoms are normal, wavering and then finally rejecting the normalisation perception and resisting it.

I thought it was just heavy periods. I thought that was normal. No, I didn't think that was normal. Well, yes I did, I sort of accepted it...

Well, I didn't think it was abnormal, it was just, it was heavy and I was bleeding, but I suppose...

Initially, I thought they were normal and perhaps on the more high end of the period symptom continuum; just worse than other women, but normal ... I coped with it because, when I was young, I thought, well, that's normal. And, it was until over the years, having, I suppose a little bit more knowledge, being medical, but getting to the stage where this is just ridiculous, I can't, I need to be controlled by a medication to live my life, and then finally thinking, well, this is ridiculous! ... No, no, this is stupid. That was probably an evolvement of my maturity, as well as a person, and as a woman, I suppose. (Val)

In the normalising narrative, we see links to a biomedical cultural narrative (for illness) in which the doctors are perceived as experts. The doctor is consulted, a doctor diagnoses, dispenses advice and perhaps medication, advises on any further treatment, the patient accepts the doctor's advice as he/she is the expert, the gatekeeper to the knowledge of things medical. One does not question the doctor; one believes and accepts. While this narrative does not hold so true for today, for the women who drew upon it, they spoke of it as being valid to them, at that time in their stories.

I was brought up, sort of, in that generation where the doctor was God, you know. And parents treated them with such sort of,

absolute courtesy and, and they would never have questioned anything that the doctor had said. And I grew up like that. (Ann)

If this is a “specialist” in inverted commas, and he knows, well it’s his job, and he knows about these things, and he has much more knowledge than I do. (Hannah).

Well, I said to the doctor about that, because I’ve always felt ... So, well, you know, they must know. (Jacky)

The women’s perception of their symptoms as normal are shaped by what significant others say about menstruation, particularly where the significant others, such as doctors, are believed to be experts. The cultural menstruation narrative which normalises pain and heavy bleeding, and the biomedical narrative in which the doctors are experts, are thus shown as links in the way women talk about and perceive their symptoms as normal. Living this narrative, a woman may remain undiagnosed. As discussed, this normalisation is usually connected to what their doctor has told them about their symptoms. However, some women who talk about doctors being dismissive or belittling them, also talk in terms of being disempowered and unable to seek further medical help for some time. For example:

And I said, oh, I have this, this this and this, and I’ve read about endometriosis. Is it possible that I could have endometriosis? And she put her head back and laughed and said “what makes you think you’re so important that you could have that?” And I promptly burst into tears. ... She belittled me; she embarrassed me. (how long ..until you approached your GP again? (not the former GP)). Oh, it must have been 2 ½ years later. (Vicky)

Some women who initially normalised their symptoms, later came to resist this idea, either due to symptoms worsening, no longer being prepared to put up with them, additional symptoms, or a combination of these reasons. Other women resisted the normalising story, right from the outset.

The Resisting Narrative

The resisting narrative is the story of how women do not accept their symptoms as normal and will continue to seek help until an acceptable diagnosis, which explains their symptoms, is received. Women who once normalised their symptoms, may come to resist this idea over time for reasons such as worsening of symptoms. These are perceived as not normal, that there is something causing them and a diagnosis is sought. The women in the resisting narrative do not always accept what significant other people say about their symptoms and they do not necessarily subscribe to the doctors are experts story.

I was aware that my aunt had endometriosis, so I knew what it was and I just thought I might possibly have that too. And his (the gynaecologist) suggestion was like, go for a d & c and have my womb tipped back, or something, and I thought that was a load of gobble de gook. (Zoe)

Some of my smears were irregular, you see. I thought that was the problem, or, you know, that was causing it or.. (So, what made you go finally to get help again?) Um, because I thought there had to be more to it than just, you know, abnormal smears. A lot of people have abnormal smears and don't have pain and a lot of other problems, so yeah. (Diana)

Some symptoms of endometriosis do not occur at the time of menstruation. Pain associated with ovulation, bowel movements, physical activity and with intercourse are commonly experienced, while some women bleed at times outside menstruation. When such symptoms occur, a woman is likely to seek help. She cannot normalise this type of pain and bleeding, as there is no cultural narrative available to make sense of these symptoms. However, even so, she may experience her doctor as minimising her symptoms or even be misdiagnosed.

After intercourse I was bleeding and having a lot of backache and things. So that was about 20 years ago, and I went to a gynaecologist, or I was referred to one about the bleeding and so, I, but I mean, I wasn't diagnosed then, because he, he, he gave me an internal examination ... he said he couldn't find anything that would be causing it and I looked like a fairly normal healthy girl and I got a pat on the shoulder and he said I should do back exercises for my back. (Ann)

"Ho, ho. You've got a grumbling appendix here". (Then later..) He couldn't find anything wrong on pelvic exam, except that I had a low pain tolerance and he wondered whether I should in fact stop thinking about myself ... and consider returning to work or something of that nature. (And later..) I had had a laparotomy, the appendix had been removed... and he said I was in an absolutely appalling state inside. I had severe pelvic inflammatory disease. I must look at my future and my activities and all they had done was open me up saw the, the absolute shame inside, removed the appendix, aspirated one ovary and closed me up again ... he couldn't actually see at laparoscopy for scar tissue and adhesions ... he misdiagnosed ... (Jay)

In the face of symptoms being dismissed, minimised and, sometimes, misdiagnosed, the women in the resisting narrative resist what has been told to them by the medical professional as it does not make sense. For example, Jay certainly considered the PID diagnosis, trying to make sense of it by searching back into her past for anything she may have done to initiate the disease.

I felt that I had had, really, um, I had to look at my sexual habits. And, yes, I had had more than one sexual partner, but I certainly hadn't had multiple partners or anything like that. Yes, certainly, I felt so unclean and so filthy. I'd always, you know, I was a normal teenager and, um, and that sort of thing, I would imagine normal sexual experiences and a normal marriage in terms of our, um, being, having one partner, you know, I wasn't like that. But I look back and thought that I must have been, it must have been something I'd done, maybe that I didn't even know about..

Making Sense of Events

Nothing turned up in her search for a reason, so she could not make sense of this diagnosis. She even wondered whether it was something she had done that she didn't know about. This example shows how a person strives to seek connections between events and find coherence. In the case of women with debilitating and undiagnosed symptoms, it is a time of incoherence and chaos until they are able to make some sense of them. In Charmaz's (1991) discussion relating to undiagnosed chronic illness, she points out how the lack of a medical validation of illness can leave people believing their doctors are thinking their symptoms are psychologically induced, that they are feigning or magnifying symptoms. These beliefs, in turn, lead to the individual feeling discounted, destroying their trust in themselves and their perceptions.

The resisting narrative is about women who continue to seek an acceptable explanation and treatment for their symptoms. The time of chaos, or incoherence, is difficult to live through, so further attempts are made to be listened to and correctly diagnosed.

I was just in dire straits, real dire straits, and I said to my husband, look we are going to have to go to hospital ... I was really, was in agony and I was getting very blown up in my abdomen. ... I was in hospital, I think for about 10 days on an intravenous antibiotics all that time and I was absolutely in agony. I've never had pain like it. ... and they said, oh no, it's just a PID (pelvic inflammatory disease). And so when I was discharged I went to Dr X...who, at that time wasn't long in town as a new gynaecologist, and I had heard he was very good, so I went to see him. ... I said I don't want this any more. And previous to that I had tried to find out what was wrong with myself, because being a nurse, you're inclined to self-diagnose and the doctors really couldn't give me any answers, so I looked up medical books and had decided that because of the symptoms that I had, it was endometriosis. ... I remember him coming back from theatre and saying to me, "you've got endometriosis ... it is absolutely everywhere ... you were just like concrete inside. It has taken me five hours to get your uterus out".
(Judith)

Another woman, also a nurse, made links between her symptoms and the possibility of having endometriosis. This is evidenced by her conclusion to her story when she says 'things suddenly pieced together'.

... and then suddenly I'd have a four month gap without anything at all and then, all hell would break loose again, when it did arrive back again. I'd gone back to him and by that stage, I'd started to think, well, maybe it's something more and I think even then, I'd started to feel that I wonder whether it could be endometriosis. ... Things suddenly pieced together. (Joy)

Both the normalising and the resisting narratives tell the stories of women struggling to come to grips with undiagnosed symptoms. Each, in their own way, needed to make sense of bodily disturbances which may be painful and distressing. In the normalising narrative, the women have accepted the message of the prevailing cultural narratives which relate to menstruation and the medical profession. The message of normality enables them to normalise their symptoms. However, even where the symptoms appear far from normal, some women will take responsibility for them on a psychological level. It's all in her mind. In this way, she can construct a coherent story about the symptoms and accept that there is nothing physically wrong. On the other hand, the women in the resisting narrative resist the discourse surrounding menstrual symptoms and do not see them as normal. This particular narrative is also about women who experience symptoms outside the time of menstruation and those particular symptoms enable a woman to keep seeking answers for her discomfort.

Until a woman has made sense of her symptoms, in these stories through being diagnosed, there can be a time of chaos as she is caught up in the struggle of trying to make sense of what is going on in her body. This time is evidenced

in both narratives. It is as though one cannot live for long in a state of chaos. The experience of such incoherence is a strong motivator to push us on to, somehow, construct a story which brings coherence back into our lives.

After Making Sense of Symptoms

The diagnostic experience and, importantly, understanding the implications of having endometriosis, features as a reference point in the stories. 'Crossing the diagnostic divide', a term I have adapted from Albert Borgmann (1992; cited in Frank, 1995) is appropriate to describe this reference point.

Journeys cross divides. Once on the other side, the traveller remains the same person, carrying the same baggage. But on the other side of certain divides, the traveller sense a new identity; that same baggage now seems useful for new purposes. Fundamental assumptions that give life its particular meaning have changed. (Frank, 1995, p.4)

Once a woman has received a diagnosis, she is then able to start making sense of her previously undiagnosed symptoms and allot them a place, that is, within the diagnosed condition. At the point of diagnosis the narrative shifts for the women who have previously normalised their symptoms. As they learn and understand that their symptoms were not normal, they revise their conceptualisation of them and emplot them into the endometriosis narrative. For some women, the period of time between the onset of concern over symptoms and eventual diagnosis can represent a time of confusion as they struggle to make sense of their bodily disturbances. This time of chaos can be likened to losing the plot. What is going on in the present does not make sense and, what has gone on in the past, suddenly, does not make sense in light of the present and the individual is unable to story a coherent account of herself. The eventual diagnosis brings coherence back to their narrative as the present now makes sense in light of the past.

In illustration, I refer back to Jay's story, as she talked about how her sexual habits were brought into question in light of her (mis)diagnosis of pelvic inflammatory disease. She searched back into her past for events which could clarify what was happening to her in the present. She had not had multiple partners, had not been sexually promiscuous and had never identified herself as a woman with a questionable, 'unclean', sexual history. Her past was not making sense in light of what she was being told in the present. It was not until she received the diagnosis of endometriosis that the past events could take their proper place in her personal narrative and she could form a coherent story of what she was presently experiencing.

While receiving a diagnosis can bring great relief to women who have struggled to make sense of difficult symptoms over a long period of time, it can also be a time of dismay for others, particularly those women who wish to conceive and/or are having difficulty conceiving. I draw upon Amelia's story to illustrate this point:

(What do you feel, about being 33 and getting all these symptoms...)

Yeah, but mild, manageable, but starting to make sense that maybe there was more so that, had the laparoscopy and um, he did five of them, or something, that afternoon and we were all in a bit dozy, and woke up, and you can hear him go into the first cubicle and you can hear exactly what he is saying to the person. There is absolutely no privacy at all. It was really horrible. And he said to her that she had a slight case, no, mild case, 'cos, mild, moderate, severe. Mild case, but that we would do this, that and the other thing and um ... So, I'm sitting there, think, oh yeah, he's going to say the same to me, so I was quite shocked when he came in and said you've got a moderate case (laughter). I thought, oh well, it's better than a severe case, but it was a death knell to me, because I was thinking they are not going to be able to fix this, you know. ... Why does she get mild and I get moderate, you know, you go through that in your head. Um, because, he sort of said, you know, you've only got a 50/50 chance

and I tended to think on the black, you should think on the positive side of that, but I didn't. I mean, that was just grieving.

In Amelia's story of her diagnosis, we can see how she has compared herself to another woman; the woman with the 'mild' case. She questions the fairness of it "why does she get mild and I get moderate". Amelia is constructing her response to the diagnosis as 'unfair' within a social context. If the other women had received a diagnosis of a 'severe' case of endometriosis, perhaps Amelia might have constructed feelings of relief at only being 'moderate'. She then goes on to add "that was just grieving". Her concerns with endometriosis are strongly connected to her fertility difficulties and she constructed the diagnosis, at the time, as "a death knell".

The next examples show how a person makes sense of a past event, in light of new information. The following women talk of their present understanding of certain pain they had once experienced, in light of the endometriosis diagnosis.

It was sort of like PID (pelvic inflammatory disease); that sort of intensive pain, but now, looking back, it was just obviously, was just endo. (Judith).

I used to get a lot of lower back pain and I thought I had a bad back for years. Now that was well into my 20's, and, very bad back pain, and that was obviously related. (*To endometriosis*) (Amelia)

Similarly, another woman, experiencing fertility difficulties, gradually made sense of them by relating them back to her diagnosis of endometriosis which she had received a couple of years earlier. After trying to conceive for two to three years, a laparoscopic investigation determined that she had endometriosis.

It didn't really mean anything ... it just wasn't an issue ... it was more the fact that I didn't ovulate and the endometriosis was just sort of there ... Life just carried on as normal, so they could have told me I

had anything really and it, you know, didn't make any difference because life just carried on. (Jacky)

Her main focus was on trying to conceive and not find out why she had endured severe menstrual pain at times. She had adhesions, and one of her fallopian tubes was adhered to her bowel yet, at this stage, she did not connect this to having endometriosis. Eventually Jacky conceived, developed toxæmia and her pre-term baby was delivered still-born. During her grief, she said she blamed her obstetrician, herself, God and everybody else. Over time, it dawned upon her that perhaps the endometriosis was causing or contributing to her fertility difficulties. She had started to make a connection between a seemingly, harmless condition and her sometimes, overwhelming problem of not being able to conceive. From the minor bit part it had previously played, endometriosis had assumed a centre stage role in the drama of her passion yearning for a child. Endometriosis had become 'infertility' and had characterised the associated grief, envy, despair, anger and bewilderment that is so familiar with those people desperately trying to conceive a child. Jacky's story illustrates how the retrospective view of her endometriosis experience had reshaped her ideas about why she had been having trouble conceiving again and how she made sense of her current experience of infertility. Now she could make connections between events and adopt a set of ideas which made sense of her fertility problems. After the death of her baby, there was a period of time, from when she started trying to conceive again, until she started making these connections. This period exemplified a time of incoherence. She knew she could not ovulate without the aid of a fertility drug and she knew she was able to conceive. She did not know why the conception had taken so long and why she had been having difficulty conceiving again. If it was not due entirely to the ovulation factor, then what was the reason? This phase of living in uncertainty and confusion seemed to push Jacky into facing her

endometriosis condition. It was as though, hitherto, she had denied its potency and, perhaps existence.

As discussed earlier, by picking up the endometriosis thread, Jacky was able to make sense of painful menstruation and her fertility difficulties, while enabling her to tell a new story in light of its influence.

When we are trying to understand a situation, it often requires a testing out of theories and ideas to see if they can form a coherent account of events. The following extract is a good illustration of the testing of ideas, to make sense of something (unusual bleeding) and provide a (narrative) explanation:

... because I had an extremely regular period around the time I was having all this post and pre-bleeding and um, yeah, no, I don't know. Maybe the fact that I was on the Pill then and it was doing things to my hormones ... Yeah, maybe, possibly it was the Pill. Perhaps just lifestyle. I was travelling for years and years. And perhaps a more sedentary lifestyle now. (Vicky)

Coping with the symptoms of endometriosis often necessitates a woman to be able to make connections between those things which exacerbate and those which relieve the symptoms. In other words, certain events are emplotted into her endometriosis story. She is then bringing a greater coherence to the story as she begins to make sense of the whole experience. For example:

Yeah, it is fairly manageable some months. I find some months if I've had night duty and under a bit of stress, it is worse, but if things are going smoothly, then it is manageable, yeah. ... I find doing night duties when I've got my period is, it really makes it worse for some reason. I don't know whether it's because I'm mucking all my clock up by not sleeping at the right times, or what it is. Yeah, and I've found if I've got a weekend off and my period's due, it's totally different, but if I'm doing night duty, it's like I muck my whole cycle up and it puts me out of kilter. (Diana)

... and I get not just discomfort, but bloating pain and so I kind of live with that in the back of my mind that maybe this bowel is actually not going to last the distance. Maybe it will be a colostomy, um, it doesn't, I don't always, I can't always, I can't drink wine for instance. Alcohol really. I just get the most dreadful cramping pain with any alcohol, so occasionally I do, but I usually suffer afterwards. (Jay)

... when I very first had that very first really bad pain, I had been drinking. It was Friday night, we'd been out to the pub and we'd come home relatively early and that was when I was sitting and the pain just ... I think alcohol does make it ... aggravate it. But I don't drink alcohol much now. I have to have a special occasion to drink it now. ... around the time that the endometriosis really started showing, when I did drink alcohol, I got a terrible hangover. ... all of a sudden, I just became incapacitated with hangovers, which helped me give up the alcohol too (laughter). So I hadn't sort of put them together, but it is possible, because that happened around the time that the endometriosis started to really feature in my life. So.. (Vicky)

In the above extract, Vicky connects the pain with drinking alcohol, going on to say that she also started experiencing awful hangovers. As she relates these experiences, she is making connections, saying "I hadn't sort of put them together, but it is possible, because that happened around the time that the endometriosis started to really feature in my life".

The following extract is from Hannah, talking about how the outcome of the diagnostic process had been empowering for her:

... it (*the endometriosis symptoms*) had been steadily been getting worse but I could cope with it because I knew what was wrong and that was really important to me. It (the diagnosis) was just such a huge powerful tool, to know, so I kept building on it..

When it was found that Hannah had a cyst (endometrioma) and it was decided that she would have surgery, she also felt empowered by this knowledge and was better able to cope.

... I would come home at 3 o'clock and have a rest and the weekends I would spend most of it in bed or just lying on the couch because I was too tired and I certainly couldn't do very much at all and, um, so I was quite ready to have the operation. I was ready to try anything. And knowing I was going to have the operation was really helpful; I think that gave me some encouragement, you know. I feel better because I knew that something was going to be done and yeah.

Some women spoke of 'symptoms' which they made sense of by emplotting them into the endometriosis story:

... the cold, the fact that I feel the cold. I'm quite sure that's to do with it (*endometriosis*) because nobody feels the cold, well, nobody. I haven't asked any other endometriosis sufferers if they feel the cold, but I've definitely seen that put down in quite a few places. ... Oh, I'm so chronic. (Vicky)

With respect to fatigue being constructed as an endometriosis symptom, the following woman understood this connection through monitoring her periods:

I've always got really tired and I never knew why. (*And after the endometriosis diagnosis*) Now I know and as, um, you know, and I was told perhaps there was something wrong, to monitor my periods. And I've noticed that most of the time I'm tired, but particularly when I've ovulating and when I've got my period. (Hannah)

The next example illustrates how the connection is made by perceiving a difference in types of fatigue.

I had fatigue too. That was another symptom that I have had over the years and, um, that's really hard to judge what the cause of the fatigue is, because I was a pretty hard worker anyway but, it does seem to me a different quality of from having worked hard in a garden to being, waking up like that, and waking up like a dead log is what I felt like. It was like dragging a log around behind you sort of thing, and a very, I used to be often quite light-headed, um, fuzzy from the tiredness. (Amelia)

The last extract shows how the fatigue is connected to endometriosis in the absence of any other logical explanation:

I think fatigue and things I must have mentioned to my doctor, which I gave up going to, but it wasn't, I suppose, there was nothing they could pin on ... And I used to say, "look, I'm fairly fit. I feel that I should be a fit lady, you know. I do a few things and" ... if I'm maintaining a certain level of fitness that I shouldn't be fatigued as I was. ... I was mentioning the fatigue and, you know, the whole worn out bit, so I felt a bit pissed off because I feel he wasn't really addressing.. (Ann)

Although this extract does not suggest Ann is definitely 'blaming' the endometriosis for her tiredness, one can appreciate how she is trying to make sense of it. However, later in our discussion she talks of her fatigue and having endometriosis in the same breath:

I mean, I don't go round say, "oh, you know, I'm stuffed, I've got endo".

These extracts show how the women had symptoms which did not necessarily fit the privileged (by doctors and many women) biomedical account of endometriosis, yet to make sense of them, they emplotted them into the endometriosis story. These women are making a shift from privileging the biomedical account by constructing a story surrounding endometriosis which makes sense of *their* experiences.

As a woman makes sense of her pain, she is empowered to learn ways of coping with it. Judith talked of discerning different types of pain and I interpreted this to mean she could attribute them to the endometriosis, the cancer, or whatever:

And I've had pain for so long that every niggle, you feel it, and you think oh, that's that pain again, or that pain's different from that

pain, you know, and I know exactly the different pains that I get.
(Judith)

The following woman talks of connecting her fitness with dealing with the pain.

But the pain was something I was able to control. I was very, very fit, so that possibly helped a little bit as well.

(In managing the pain, or in the intensity of the pain?) (Me)

Probably in the intensity of the pain. (Val)

It is not just the physical side of endometriosis that women make sense of in retrospect, but also the psychological, or emotional aspects of the condition:

... it was a period, and it hurt. I wasn't aware of the emotional side of it back then; that's probably just come in the last few years when I've been more aware of how I've been. I tend to become a bit of a cow; I get really bitchy. But I wasn't aware of it back then, I don't think. (Joy)

Another woman expressed interest in a possible psychological aspect to her periods as she tried to make sense of them.

... I'll have a really short sharp one (*period*) and the next one will be a really long drawn out one, you know, short sharp could be like four days and it's completely and utterly over with, and it's like, major heavy stuff for two days. And the other one could be eight days, but, you know, fairly light, you know, so it is irritating ... that's how I view it you see, it is a bit of an irritation in my life, even the whole aspect of it. I would be interested in the cognitive belief systems and how they affected whether I psyched myself into some of this stuff to a certain extent. (Amelia)

When an individual is feeling depressed, she may seek reasons for this feeling and, in the case of women with endometriosis, it is perhaps understandable that they may make sense of it by emplotting it into their endometriosis story. However, the reasons for depression are not always clear cut and, in the

following extract, we can see how one woman made sense of it and partly linked it to her endometriosis problems.

Depression's played a big part of my life. It's also, um, related to other things.. So, some of my depression is clinical, so to speak, using that term. But, you know, a lot of is just like, you know, straight out PMT (pre-menstrual tension). And once again, when I charted it, after I'd finish a period, I have three good days and I'm just wonderful, and life's a breeze and I can cope and, after that, I start getting ... I think a lot of it now is to do with my cycle. I think now that my depression is related in part, to my, um, to endo and to my period. (Hannah)

The women also spoke of making sense of other issues, once they had made sense of their symptoms. Hannah talked about why she felt she was single:

It's not my choice, but I do think I've set myself up to be alone because of my depression. ... and I know that in some relationships they haven't understood and that's been really clear. And really hurtful because they haven't understood me and I haven't known why I've been like that. ... Because I didn't understand myself. Now, in hindsight, now, I can see more clearly.

She went on to talk about how she understood herself better, now that she knew she had endometriosis.

And so I think, for me, it is more to get healthier and if I lost weight too. ... to get fitter would play a big part for me. ... I understand myself more and, so therefore, I feel more confident to go and do more things ... to join the tramping club, for example. I'd really like to work in an area where I can encourage women, or whatever, and I have.

The foregoing has examined the different ways the women made sense of their symptoms and other issues related to their condition. They started with either a normalising or resisting narrative, or vacillating between the two. They made sense of the symptoms by emplotting them into the biomedical endometriosis

narrative. However, some women also emplotted other 'symptoms' which may not be included in the biomedical account, into their endometriosis story. I conclude that some women go on to construct their own stories about endometriosis and do not always privilege the biomedical account. This conclusion not only is drawn from the emplotting of other 'symptoms' within the narrative, but also the way some women adopted alternative therapies to the biomedical treatments. If they constructed these therapies as being helpful in alleviating their symptoms, then they were not necessarily accepting the biomedical endometriosis story which contained specific medical treatment regimes. They were adding to the endometriosis story which is now larger than the biomedical account. This is what I call the collective endometriosis story.

The following section examines what meanings the whole experience of endometriosis have held for the participants.

Meanings

The meanings people derive from chronic illness emerge, (Bury, 1988) and can change, over time (Charmaz, 1991). As we gain more and more new experiences, we are able to reconstruct the past, or reinterpret the past, so that it has meaning for the present and, according to Good and Good (1994), new possibilities for the future. We might expect, therefore, that endometriosis may hold different meanings for different women in different ways over a period of time. In this section, I examine meaning with respect to constructions of endometriosis as well as the concept of going through an experience which has 'brought meaning' to someone's life.

As the foregoing extracts have demonstrated, the women have talked about past events according them significance as they connect them to their endometriosis experiences. Charmaz (1999) considers that someone who, for whatever reason, did not acknowledge earlier suffering, may later celebrate it in stories as she or he was now able to position it in the past. However, how the women talk about endometriosis from the present perspective, portrays the meaning they have attached to the experience and, in turn, the present meaning informs their future intentions. I would note too that the present perspective is also coloured by whether the individual is talking in an illness voice or a healthy voice. Hyden (1997) suggests that to speak in the illness voice is to identify with the illness and attendant suffering while, to speak in the healthy voice, is to identify the illness as external to the person. Of course, the person can shift between voices and perspectives during the same narrative about their illness.

I turn now to one woman's portrayal of endometriosis. Tess spoke in a very expressive way about endometriosis and her experiences and her vivid use of imagery certainly conveyed her perception of the condition.

(Endometriosis) was embedded in the pelvic floor, but it was wrapped around a whole lot of nerve endings ... it had burrowed its way right in ... Like an alien creature.

It's (endometriosis) absolutely disgusting. Such a long, horrible, you know, almost like a swear word.

From this short extract, one can understand how this particular woman perceived and objectified endometriosis. Endometriosis was an invader 'like an alien creature' 'burrowed its way right in'. As it was causing her such severe and debilitating pain, she spoke in terms of not being able to live with it 'I really thought I was for the high jump. I just wanted to die actually...I just said to him, I can't live with this. ... It was a bit like a death sentence really.' In this

regard, to Tess, endometriosis was not an invader with benign intentions; it was an attacker, threatening her very existence. She said it made her life 'really miserable', she had 'humiliating' experiences with endometriosis and that it was 'a real burden to carry'. For women like Tess, the condition is perceived as an enemy which has caused suffering, both physical and psychological.

Other women spoke of endometriosis as something to be controlled, struggled against, a nuisance, interfering with their day to day lives. Words such as 'annoyance' 'embarrassment' and 'inconvenience' often cropped up in discussing their perception of endometriosis. Joy, for example, not only found the condition a nuisance, but often commented throughout her interview with me how expensive she found it.

... and the expense, and everything that went with it every month, started to mount up because by the time you'd used a box of 30 odd tampons a month, plus a box of pads, it got very expensive.

Joy also related a story, or defining moment, to me, to illustrate the embarrassment as well as the expense she experienced through having endometriosis. While this is a long quote, I believe it exemplifies well her sense of embarrassment, the sense of inconvenience and the extra expense of having to buy some clothes to change into.

The thing that got me, it was the flooding, but doing it in places where it would be embarrassing. You'd be standing in the middle of a supermarket and suddenly, whoosh, and on a bus, or whatever. I did it once on a bus in Auckland. I was going into town and I was just lucky that I had dark trousers on, because it suddenly appeared in the bus and I got out at the other end and it was, I sort of, kind of wrapped my coat around me and went to try and find the nearest toilet that I could, to sort of suss out the situation, and then went back downstairs and went and bought, I had to go and buy some new knickers and some new trousers. So, that was just suddenly I had this \$40 or \$50 dollar expense of buying some clothes. And then had to go back up to the toilet and get changed as best as I could, and

clean up and then walk around down with this bag of soiled trousers and underpants for while, which was a bit, sort of, harrowing. But I was more conscious of the fact that I was hoping that nobody would see me than anything else, or people wondering what on earth I was doing flipping in and out of the toilets, which is a bit embarrassing, but...

Endometriosis is understood within a social context when Joy constructs her feelings of embarrassment. She is on a bus, then she goes to the toilet, she goes to a shop, goes back to the toilet and then walks around town. During this time, she is highly conscious of having soiled clothes, as well as the perception that others may be watching her actions. She does not want to be perceived as odd, or different because of her behaviour, and is thus embarrassed. In this respect, we can see how the experience of endometriosis has been socially constructed as embarrassing and harrowing. Joy's story of 'flooding' is somewhat similar to that of Tess's account of her flooding at Pak'n Save. The meanings each woman drew from the social context of the situation related to embarrassment and, for Tess, humiliation.

As shown from previous extracts, some women talked about taking control of the endometriosis by learning about ways to manage it, for example, improved nutrition, rest, exercise and other lifestyle changes. Perhaps having a name to attach to difficult symptoms enabled women to reconstruct their attitudes towards them. One woman talked at length about her negative perceptions of the condition but, as her story progressed, she started to speak in almost, positive ways about living with endometriosis:

I was quite pleased not to take anything (medication). ... I was quite happy to carry on as I was with my endo ... I've been lucky ... end up being at home when I got the pain. (Vicky)

This example reinforces the point Charmaz (1991) makes when she notes that meanings of illness can shift and alter as the illness progresses or recedes into the past. While endometriosis may not necessarily be constructed as an illness, *per se*, for each woman, this chronic condition can be perceived as an intrusion into daily life. Accordingly, the meanings women construct from endometriosis help determine how they deal with it. If it is identified as being intrusive, then they can learn to accommodate it in their daily lives. Joy, for example, frequently used the expression 'plodded on' throughout our interview. From this term, I interpreted that, despite her sometimes severe pain, flooding and migraines, she accommodated the condition and just got on with her life.

Once the symptoms are under control, women are able to construct a future which is more positive than the life they had been experiencing before. For example, Tess commented 'It's just good to be pain free. ... life's just beginning really. ... I feel really good. ... and I've certainly got my sex drive back again'.

The existential idea of finding meaning in suffering is not always forthcoming during an interview. Firstly, not all people 'find meaning' in their suffering in this respect. Others may do, but do not necessarily talk about it, unless specifically asked. Others may do, but first need to come to an understanding of this, over time. While I did not address meaning, in particular, with each woman, I was still able to interpret it.

Taylor (1983) proposed that part of the adjustment process to a chronic illness, in part, involves the search for meaning in the experience. Bury (1991) expresses a similar idea when, in his discussion on coping with chronic illness, he says 'coping involves understanding a sense of value and meaning in life,

in spite of symptoms and their effects' (p.461). In this study, sentiments were expressed which suggested that the meanings that some women derived from their endometriosis experiences were related to their self-concept, such as 'I have become a stronger person'. One woman spoke of becoming a 'much better person' for the experience and had become dedicated to helping other women with endometriosis. This had become a 'passion' in her life. Another talked of being more empathic with other people and how she had learned to 'count her blessings' in life. Another woman said she had been able to learn from her experiences, in particular, she talked about becoming more aware of her body and the importance of nurturing it in all ways 'physically, mentally, emotionally and spiritually'. She expressed her belief that any experience can be turned into a positive one and felt that her experiences had enabled her to empathise with, get alongside and help people; a view, certainly reinforced by my knowledge of her work with other women with endometriosis. These few examples reinforce Taylor's (1995) belief that chronic illness may lead people to re-evaluate their lives and prioritising those activities which are most meaningful to them.

How did the women feel about themselves since time had lapsed, at least two years, from being diagnosed? To finish this section, and to expand on my above comments, I quote various extracts from the women which seem to conclude their stories and, for some, express how they then felt about themselves.

... that's what I so objected to (taking away your confidence and self-esteem?) Yeah, yeah, that's what I so objected to. And rightly so, I had every right to feel that way, so now I think I'm actually really good. I think that I've, um, I've learnt a lot and come through a much better person and a better woman than I was. (Jay)

I asked Tess if anything positive had come out of her endometriosis experiences:

No, quite the reverse. I seemed to have such a succession of things go wrong that was just, no, nothing positive out of it at all.

However, she did comment:

... so life's just beginning really. Apart from the fact that being menopausal means that you're getting old and things, but, no I feel really good, yeah, and I've certainly, I've certainly my sex drive back again. (Tess)

I don't think it's really stopped my doing a lot of things, which is good. ... I just see myself plodding on ... I just seem to find myself just carrying on.. (Joy)

It took a long time to come to terms with it and when you did come to terms with it, you think, oh well, let's get on with life. It's not a healthy way to deal with it. I could be doing more in terms of my health and my exercise and my spiritual well-being and being kind to myself, and that sort of thing, if I was more conscious of my endometriosis. But I tend to only address it when I need to.. I would hate to have to, you know, focus on it for two weeks at a time. Two weeks of my month - aghhh! That would be horrendous. There's not enough time in the day as it is now (laughs). I can't imagine how people can do that. So, I don't know whether that's significant. (Amelia)

You sort of just get on with things, and have a pretty positive attitude toward it. I don't, sort of, let it hold me back and, yeah. (Diana)

I try and take things as they're coming. I mean, at the moment, I'm not troubled by symptoms or anything, so when they crop up, then I'll see what I can do. You know, I don't think it pays too much to worry about the future 'cos there's plenty of now to be enjoyed, yeah. (Zoe)

I coped with it because when I was young, I thought, well that's normal. ... As far as the gynae was concerned, you know, he was happy to do a hysterectomy there and then. You know, he said, do you want a family? I said, I don't ... but you know, if I'd had it done years before, or fifteen years before, it would have made a big difference to my life I think. (Val)

I also spoke to Val on the phone in early 2000 when she said that she had now 'gained control' of her body.

I think we are starting to think more of living for now and probably not thinking, you know, putting things off and thinking so much of what will happen. So, yeah, I think, you're probably more aware of people's suffering ... of what people must be going through, because you've been through such an upheaval yourself, so I suppose, whether that makes you more empathetic with people, probably. I think that's one thing, and I think one thing I do more now, ... I count blessings all the time. You know, I count my husband as a blessing ... I have a good life, I had a good education, and things like that. And I have a good family, good friends so.. probably, yeah, those are the main things. (Jacky)

I think anything that happens to you, whether it's good or bad, can be turned into a positive one. So that my depression and all that - I've been able to turn that into something positive and I can now empathise with people in that area, and I have done, especially my last job. To get alongside people and help them. And, so I believe that I can change what's been a negative experience, I can change that into something positive. (Hannah)

(1 year later after 2nd interview) ... I've got to look after myself and do something, and that's changing my attitude, like that knowing it, and making myself look for things and doing either, go out visiting, or whatever. (Hannah)

Probably, I'm a bit stronger than some people who haven't had to go through these sort of things ... I just think it's one of those things I've mounted and gotten across and now I'm just like any other woman. It certainly hasn't wrecked my life, but it hasn't made it any easier either. No, I always try and think there's people worse off than me. There's other people with way bigger problems than I've got. ... I do try and look on the bright side of life (laughs). It just doesn't work all the time. (Vicky)

I'm just not prepared to do the things that I used to do. ... I've come to the conclusion that there's only one person really, that, you know, suffers physically, and it's going to be me. (Ann).

To finish this section on the women's commentaries, I would like to write briefly, but specifically about Judith. This thesis is dedicated to her memory and the excellent work she did in being a founding member of the NZ Endometriosis Foundation. Judith spoke of enduring many years of pain and discomfort, yet managed to cope with the pain and finding ways to minimise the effects of endometriosis where possible. This enabled her to get on with her life. At times, she spoke quite angrily about ending up with cancer. Judith was diagnosed with a malignant ovarian cyst which she believed was directly related to the endometriosis. At the time of interviewing Judith, she knew she was dying. To her, endometriosis, through the connection to the malignant cyst, was taking her life. However, her concern was more of the effect that her death would have upon her family, rather than for herself. I will finish this section with two extracts from Judith's interview.

Well, I'm a bit of a fatalist Ruth and I just think, if that's my lot, that's my lot. I suppose in a way it's the same with cancer. I'm just thankful that I've lived as long as I've lived and, if in the end, two or three years down the track I succumb, well, OK, that's just the way that life is going to be for me. And I just try not to get depressed, or think about it too much. I feel sorry more for my children, much more than I do for myself actually, but then I think I suppose mothers are like that aren't they?

The last extract relates to Judith's discussion on the work of the Endometriosis Foundation.

... and I have insisted right from the first time we met that we were not going to be a doctor bashing organisation, because if you do, you don't get anywhere. You don't get anywhere being negative. You have to work with gynaecologists and they, I think, they felt

threatened actually by the work, the work that we have done. ... But if they are more caring and take the time to try and understand, then it's not so bad, but then they have their off days as well. You know, they probably get sick of hearing about women's problems that they know they can't really do a lot to fix and they really can't do a lot about endometriosis. The main thing is to try and empower the women to change the way they do things or to accept the fact that they have got something and to get on with life and do the best they can with what they have got and not necessarily look to doctors for a cure, because there isn't a cure.

Summary

The women's stories about their endometriosis reflect the ways they have made sense of their experiences. Specifically, they have expressed how they made sense out of bodily disturbances such as severe pain, very heavy menstrual flow, fatigue and fertility difficulties. The ways they have understood these symptoms I have termed 'normalising' and 'resisting'. The normalising narrative is informed by the cultural menstruation narrative as well as the narrative that relates to doctors being the experts. The endometriosis diagnosis has enabled women to reconstruct their previous understandings of their symptoms and make connections between events, such as infertility and endometriosis. Such connections are also known as narrative explanation.

The meanings that have been drawn from the endometriosis experience were explored variably. Firstly, what having endometriosis has meant to the women was addressed. Such meanings were related to the condition being constructed as an intrusion, an annoyance and, for some, an enemy. Secondly, the concept that some meaning and thus benefit has been derived from the experience was discussed. For example some women constructed themselves as a better or more empathic person because of the experience.

Making Sense of Events

I presented an extract from each woman which, I consider, expresses what they have felt at the time of the interview, that is, at the end of narrating their stories to me. The final words on endometriosis was given to Judith, a founding member of the New Zealand Endometriosis Foundation and who sadly died of endometriosis-related ovarian cancer in 1998.

Chapter Eight

Summary and General Discussion

This chapter gives a general overview and discussion of findings. The findings are discussed in relation to earlier studies as well as stating the contribution I believe my study has made to the knowledge of endometriosis in particular, as well as chronic illness in general. Limitations to the study are also discussed.

Stories were constructed as a time of struggle as the women tried to make sense of and cope with unexplained symptoms. Stories were told which illustrated the ways in which their sense of identity had been challenged. These were examined and discussed in the narrative themes of infertility, relationships, occupation and self-concept, physical and psychological.

Identity

Women expressed themselves in certain ways, either in the role of 'victim' or in the role of 'controller'. The victim role was characterised by the individual expressing a sense of helplessness and lack of control in her situation. In this respect, the endometriosis was constructed as controlling the woman. The controller role, on the other hand, was expressed as a woman taking control of and managing the condition. My analysis showed that many of the women experienced a challenge to their identities. In response, some women reconstructed their identities while others were able to maintain a sense of their identities.

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Infertility emerged strongly as an area where women expressed a sense of threat to their identities. The role of mother is still constructed as fundamental to many women's sense of self and plays a central role in the cultural narrative about what it is to be a woman. The victim role was evident in these stories, particularly where the woman experienced a sense of helplessness and lack of control over her fertility. Reconstructions of identity were exemplified in statements such as feeling a 'lesser woman', 'very, very inferior' when not able to conceive. One single woman expressed concern for her ability to have a long-term partner if she could not conceive. Throughout the study, there were occasionally specific instances such as this which only one woman expressed. However, I believe that the particular is as important as the general in these studies and can provide valuable insights into the women's experiences.

Relationships, whether they be with partners, friends, employers or peers, can be strained with respect to an individual experiencing endometriosis. While experiencing severe, unexplained symptoms, some of the women came to define themselves as different from other women using terms such as 'weak', 'abnormal' and so forth. I analysed these feelings of difference as a sense of disconnection with others. These women talked of feeling unsupported and sometimes not believed by others. Some women talked about symptoms such as pain and bleeding as interfering with their sexual relationships with their partners and in some cases were affecting their relationships. These stories reinforce Weinstein's (1987) writings with respect to painful intercourse and erosion of intimacy and romance.

I believe that there are wider, social implications associated with experiencing endometriosis with respect to relationships. For example, what is it like to live with a woman who has severe and distressing symptoms? What is it like to work with her? We have heard how the women expressed their perceptions of

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relationships being affected, but what about their partners, friends, family and colleagues? This area would be worth addressing in future qualitative research.

The area of occupations was not strongly addressed in this study and, in retrospect, I consider I could have questioned each woman about her experiences of employment and so forth, in connection to endometriosis. What did emerge from the women's stories was that difficult symptoms, such as severe pain, fatigue and very heavy periods can lead to absenteeism, inability to work long hours and, in one case, difficulty with the woman's employer. Ballweg (1995) also noted this in her discussion on women's experiences of endometriosis.

Body image, under the heading of 'self concept' was only talked about by one woman. Tess spoke of how her symptoms of severe pain and frequent experiences of 'flooding' affected the way she felt about her body as well as severely limiting her leisure activities as a teenager. This story makes a valuable contribution to the growing understanding of how endometriosis can be constructed as challenging a woman's identity. However, a large focus of this study was on the women's sense of identity and how it was reconstructed over the course of their endometriosis experiences. Learning about how they constructed the way they felt about their bodies would have certainly added to what we learned about their 'self-concept'. In retrospect, I can see it would have been a fruitful area to have explored with other women.

While only one woman spoke of feeling depressed, I conclude that the way some women constructed their stories with respect to helplessness and expressions of being a victim suggested that they may have experienced times of feeling depressed as well, for I believe these feelings are often linked to a sense of depression. The studies discussed in Chapter One which relate to

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endometriosis and to groups of women with pelvic pain in general, for example, Lewis et al, 1987; Low, Edelmann and Sutton, 1993 and Waller and Shaw, 1995, found mild levels of depression and anxiety in these groups. One reason given was that the experience of chronic pain may be the pathway to disturbances such as depression and anxiety (Waller & Shaw, 1995). Redman's (2002) study has also established a relationship between women with endometriosis and depression. From my research, I conclude that a woman may construct these feelings when she does not understand why she is experiencing severe symptoms, if her fertility is threatened, and can also reflect the individual ways women can construct the experience of having endometriosis. I interpreted from the women's stories which expressed the distress of severe pain, that beyond that physical suffering, was the psychological suffering linked to not being able to explain why they were experiencing such pain. Thus, these women did not feel good about themselves; they were experiencing physical and emotional distress.

My study has demonstrated that some women experienced a real threat to their identities for various reasons associated with the condition. On the other hand, in the face of such challenges, others maintained a strong sense of their identities. I was able to show how the women constructed these 'challenges' and how they came to make sense of the events surrounding the endometriosis experience.

The Process of Diagnosis

The experience of unexplained symptoms and waiting a long period of time prior to diagnosis was constructed as a significant issue. Women related stories of difficulties surrounding the diagnostic process, problematic interactions with medical practitioners, such as not being believed and being treated in a

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dismissive manner, as well as experiences of mis-diagnosis. Some expressed sentiments such as losing confidence and not feeling good about themselves after difficult encounters with doctors. These stories reinforce some of the findings in Grace's (1995) study of women with pelvic pain, many of whom had also been diagnosed with endometriosis. Unlike my study, Grace took into account the women's socioeconomic context of her participants' lives. Her findings have certainly fostered a greater understanding of that particular context of the women's experiences. On the other hand, my findings exemplify the way women can radically reconstruct their identities in response to not being believed, not being understood or being mis-diagnosed. The way the women constructed their experiences with respect to their interactions with medical professionals and their experiences of long delays before they understood their symptoms, were similar to the way many of the women expressed their experiences across the Internet and in endometriosis support group newsletters. Redman (2002) found in her study that delays in diagnosis largely resulted from the women not consulting a doctor at an early stage. That led her to note that increased education for women about endometriosis would help improve the situation. I also believe that many women have experienced very lengthy delays owing to not receiving appropriate attention at their first visit to a medical practitioner. When a teenage girl is told to get pregnant and that would alleviate her symptoms, it is understandable she may put off seeking further help. To be told that one's symptoms are just part of a woman's lot and to put up with it, or when some women are led, either explicitly or implicitly, to construct their symptoms as being neurotic or psychosomatic is, I would argue, disempowering. Hence, we can understand how some women experience a strong challenge to their identities.

Overall, the experiences which the women expressed in their stories, largely reinforced other reports, case studies and comments on and by women with

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endometriosis. While Weinstein's (1987) findings constructed the treatment phase as being very stressful and marked by disruption and confusion, this finding did not come through the stories in my study. This is not to say the women in my study did not find this a difficult phase in any way. I interpret that there were other issues which they constructed as holding greater significance that they wished to express in their stories at the time of interviewing them. I acknowledge that I helped create the diagnostic process as a reference point in the stories which may be viewed as me framing the study towards this area. However, the women certainly did speak of treatment, side effects of medication and surgical procedures, yet these experiences were not constructed as a problematic part of having endometriosis.

Making Sense of Events - Normalising and Resisting Narratives

One way of making sense of unexplained symptoms was to normalise them and this story I called the normalising narrative. In this narrative, women constructed a coherent narrative in connection to others, drawing upon their personal narratives and upon the cultural narratives available to them. The study exemplified the ways they came to make sense of their symptoms and by emplotting them into the biomedical endometriosis narrative. It also showed how, living by the normalising narrative, the women told their stories of putting off seeking help, or further help, for long periods of time. In this way, they were in a situation where they lacked support and possible access to therapy for relief of symptoms. However, where the symptoms were severe, there was a lack of fit between the cultural narrative of menstruation and the lived experience of these women. Some women experienced a sense of dissonance in their narrative and went on to reconstruct their story. I conclude that the severity of symptoms can limit the degree of normalising.

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The second narrative, I termed the resisting narrative. The women who expressed this sort of story did not accept their symptoms were normal, often despite being told they were by doctors and other individuals. They spoke of continuing to seek help, changing doctors or gynaecologists and struggling on until they were able to make sense of what they were experiencing.

I concluded that not all of the women privileged the biomedical account of endometriosis and were prepared to attribute 'other' symptoms, and adopt alternative therapies, thus constructing their own stories about the condition. Accordingly, all of the women's stories, together with my interpretation of their accounts, add to an endometriosis narrative which is larger than the biomedical story. I see this as a collective endometriosis narrative which is contributed to by biomedical people, social science researchers and, of course, the women who have endometriosis.

Meanings

I examined briefly what meanings the women derived from their experiences of endometriosis. 'Meanings' in this sense related to how they constructed endometriosis as well as the idea of going through an experience which 'brings meaning' to a person's life. Using imagery and metaphor, some of the women constructed endometriosis as something alien, an invader and being external to themselves. This construction is similar to some of the depictions of endometriosis in the drawings of the women in the focus groups as reported by Ballweg (1992). For others, it was an annoying, inconvenient and sometimes embarrassing condition they had to put up with. For some women, endometriosis was constructed as something that was part of their bodies, something that needed understanding, knowledge and management. They talked about taking charge of their bodies and just getting on with their lives.

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With respect to what meanings the women constructed from going through the endometriosis experience, women talked in various ways such as having become a stronger person, a better person, being more empathic, wanting to help others, counting the blessings they had, and that the experience could be turned into something positive, and so forth.

As women with endometriosis cross the diagnostic divide, they carry the same symptoms and, while there may be no actual change in their condition for some time, the signs of bodily disturbance are overlaid with different meanings. As they start to make sense of symptoms, stories of their suffering and endometriosis experiences are revised. The meanings of their symptoms shift and change as they cross this divide. No longer do these symptoms have to be linked to being just part of a 'woman's lot' with respect to menstruation, or to being weak, or psychosomatic. They assume a new role and are emplotted within the endometriosis narrative. Meanings are changed as they are made sense of in the new light of diagnosis. Just as the past is revised, so can the woman's future be revised with this new found knowledge. A sense of a new identity may emerge for the endometriosis traveller as she crosses the 'divide'. The time prior to her making sense of symptoms, through the process of diagnosis, is often narrated as a time of confusion and incoherence. Once the diagnostic divide has been negotiated, there is a shift of meanings and constructions of self.

The Collective Narrative

The idea of the collective narrative was introduced in Chapter Three where I wrote about illness narratives being transformed into a collective experience. I conceptualise the collective endometriosis narrative as a cultural narrative, belonging to the illness narratives within our culture. It is a growing store of

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knowledge about the condition, contributed to by a variety of sources and perspectives, hence the use of the word 'collective'. Accordingly, it is more than a traditional biomedical account of symptoms, etiology, treatments and prognosis. Endometriosis research can be conducted by several disciplines, for example, sociology, nursing studies and psychology, and each can be informed by different theoretical and methodological perspectives. The present study, for example, places a strong focus on giving the participants the opportunity to tell their stories and thus bringing a more personal contribution to the collective narrative. Women who share their experiences across the Internet, women's magazines and in support group meetings and newsletters are also participating in the building up of this store of knowledge. While the latter may not be deemed to constitute a formal, or academic source, the telling of stories, in whatever form, is a relevant contribution.

The collective narrative encompasses a range of issues, attitudes and beliefs about the condition and is open to new information and ideas. Different ideas may be added as new research challenges older beliefs, yet the latter remain as they shape the earlier part of the narrative. For example, endometriosis was once associated with women in their thirties who have delayed childbearing. Endometriosis is now related to women from menarche to menopause, and sometimes older women, yet the earlier part of the story is still told as part of the historical background to the knowledge we have today.

My research has certainly added to the collective illness narrative about endometriosis by privileging the women's individual stories. Endometriosis, being a 'woman's complaint', has been marginalised and it would seem that, until the past decade, many general practitioners were less than knowledgeable about endometriosis. Such ignorance has resulted in these doctors being dismissive of women's concerns with distressing menstrual symptoms. They

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were constructed as women's problems, part of being a woman and just a normal part of menstruation. Further, as a chronic condition, one would expect there to be associated psychosocial concerns yet, endometriosis has received little attention from researchers. Therefore, the narrative that we did have about endometriosis was mostly a biomedical account. That is not to say that women with endometriosis and people supportive in some way of these women did not also voice their experiences and views. What I do believe is that their voices were not always heard. The biomedical story was privileged and the condition was reduced to prevalence, uncertain theories of etiology, laparoscopies, endometrial tissue, adhesions, pelvic pain, heavy menstrual flow, synthetic male hormones (eg Danazol) and laser surgery! With a recent increase in research into the endometriosis experience, we should see a greatly enriched collective narrative. Thus, medical practitioners will have access to the experiences of women constructed in psychosocial terms, while individual women with endometriosis will have access to the biomedical knowledge as well as the knowledge gained from other women and their experiences.

Hopefully, future endometriosis studies will fill in the gaps in knowledge we presently have about the psychosocial aspects of the condition. This study has already identified the possibility of a closer examination of occupational issues, as well as the area of bodily self-concept.

The Illness Experience

I now refer to Chapter Three, where I discussed the functions of the illness narrative. I noted the four main functions being: a means of expressing the illness experience; making sense of symptoms; reconstruction of identity and revision of personal life; and adding to a growing collective illness narrative. My analysis has shown that these four functions were carried out by the

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women's stories or, perhaps I should say, the women carried out these functions in the process of constructing their stories.

Firstly, they expressed their experiences of having endometriosis, imparting a sense of the suffering, frustration and confusion they may have felt. In the co-construction of their stories, we were able to move from the disease model, as discussed by Morse and Johnson (1991b). Instead of the physiology of the disease playing the leading role, the woman telling her story was the main player. What significance she gave to certain events and how she chose to emplot them was entirely her construction. As Williams (1984) notes, the individual can reconstruct her past, so that it has purpose or meaning for the present and this idea was evidenced in some of the women's stories. Some used subjunctivising elements which illustrated Good & Good's (1994) point that each story told can offer a possible different outlook for the future.

Secondly, as shown in the analysis, the women made sense of their symptoms. I learned that this could be a long and confusing process for some women. I also learned some of the process of how they made sense of their symptoms and other events. In the narrative, they can make retrospective sense of the past, for example, lower back pain while menstruating, in light of the present knowledge of learning about the various symptoms associated with endometriosis. Some women will associate symptoms with the condition on their own accord. In other words, they create their own stories about endometriosis. Making sense of their symptoms also involved drawing upon personal and cultural stories. I refer back to Hyden's (1997) argument that the illness narrative can be conceptualised as a testing of our basic moral premises as people seek to find reasons for their illness. Jacky's story of her stillborn daughter perhaps illustrates this point when she talks of how she thinks she was not eating properly and she had not paid enough attention to her health

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and had not lived in a balanced, holistic way. She seemed to construct herself, for that period of time, that is the pregnancy, as not being a worthy, healthy person to give birth. In this way, the story seemed to say she may have felt responsible for getting endometriosis.

With respect to reconstruction of identity, my analysis has shown that several of the women experienced endometriosis as a 'critical moment' (Radley, 1994) and a 'biological disruption' (Bury, 1982). The course of their lives had been disrupted and they experienced a challenge to their identities. I showed how they experienced these challenges and how they reconstructed and, in some cases, maintained their sense of identity.

As already discussed, the knowledge that has been gained from this study will add to a growing collective narrative.

Finally, I would like to relate my findings to Morse & Johnson's (1991) Illness-Constellation Model. Stage I of this model, they have termed the Stage of Uncertainty, when the individual becomes aware of signs of illness and tries to make sense of these symptoms. The second stage, the Stage of Disruption, is when the person decides that the illness is serious and they seek help. If very ill, the person may become totally dependent upon health care professionals and family members at this stage. The family members and others involved may experience a stage of disruption to their lives, as well as the ill person. Stage II, the Stage of Striving to Regain Self is when the person tries to make sense of the illness, looking back to the past for reasons why they may be sick and looking to the future as they imagine possible scenarios. 'Preserving self' Morse & Johnson (p.318) notes, involves conserving and focussing energy. "He or she must constantly negotiate and renegotiate with others in order to preserve his or her self-identity, control and roles" (p.318). The last stage, Stage

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IV, the Stage of Regaining Wellness, is the stage when the individual “attains mastery” (p.318) by regaining former relationships and the control of self. The individual decides when he or she is better or adjusts to an altered level of functioning. The stories told by the women with endometriosis were similarly constructed. They went through the initial stages of detecting something was wrong, trying to make sense of their symptoms, seeking help and, sometimes, still trying to make sense of the signs of not feeling right. Some of the women spoke of examining their past in order to make sense of the present, as well as predicting possible future outcomes. Some stories were told of the women’s efforts to preserve their identity and roles, while others reconstructed their identities. While Stage IV of Morse & Johnson’s model relates better to illness that is not chronic, the women in my study did express the ways they made attempts to accept and adapt to a changed level of functioning and thus regaining control of their lives. I think this is an important point to consider. While the women with endometriosis are experiencing a chronic condition, at least until menopause, there was that sense of making adjustment, acceptance and taking control again of their lives, even though the symptoms may still have been causing them distress. Thus, this psychological adjustment to chronic illness appears to be an important step forward in regaining a sense of control of one’s life, and the positive implications associated with that control, despite the prospect of any cure of physical distress being very remote.

Methodology

When I selected participants for the study, I had a criterion of no less than two years since diagnosis of endometriosis. In this respect, I had privileged the biomedical endometriosis narrative. However, apart from needing some standard which provided access to women with endometriosis, I wanted to understand what it was like for women before they were diagnosed, that is, had

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unexplained symptoms and, gain some sense of how they experienced the time after the symptoms had been explained. I had already constructed the time of diagnosis as a reference point in the study. Nonetheless, I did not launch into questions such as 'what was it like before you were diagnosed?' and 'what was it like after you were diagnosed?'. Rather, I initiated each interview by saying something like 'tell me about your first symptoms of endometriosis, even if you did not know what they were'. From there, the women started their stories and, in several cases, they went on to construct the diagnostic experience as an important event in their narratives.

Owing to personal constraints, I restricted the participants to the Manawatu area. If I had been able to widen the area, I believe I may have yielded a larger and richer source of information. For example, I did not have any very young women in the study. Hearing the stories from a younger perspective may have helped me learn more about experiencing endometriosis as a teenager. Much older women could also have added a different perspective. Future research could include different ethnic groups as these women would be drawing upon different cultural narratives to construct their stories. Once more, this would do much to broaden our understandings of the condition.

I found it a difficult issue to decide whether to let a woman just tell her story and preserve a relaxed conversational style to the interview or, whether I should have had a more formal, but brief list of questions to ask each women. I am still uncertain on this point. However, at the outset of the study, I had considered it important to just let the women tell their stories. Through giving them a sense of freedom of what they spoke about, I was hoping to hear what was important to them. I wanted *their* stories; what they wanted to tell me. I can see now that I could have addressed areas such as occupation and body image, towards the end of the interview, once they had expressed what the

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experience of endometriosis had meant to them. In retrospect, I believe I could have given the issue of identity more consideration before the interviews and perhaps I would have realised that the area of occupation and body image needed addressing. However, at the time, I believed I was taking the appropriate approach by giving the women full rein to tell their stories in the way they wanted to tell them.

The process of trying to find an appropriate way of using narrative analysis for my study was long and difficult. I struggled to find the 'right' way. The analysis which finally evolved does demonstrate how, as Polkinghorne (1988) states, narrative is a form of 'meaning making' (p.36) where events are configured into a meaningful whole. While the narrative analytic process was explained in Chapter Five, under 'The Process of Analysis', in the analysis contained in Chapters Six and Seven, the process was not described explicitly. While part of the process is apparent, it was not possible to present the analysis in three clear-cut levels of explanation. The following sets out the rationale for this apparent lack of reference to the analytic process.

The first level of the analysis involved writing the individual stories which gave a clear idea of what each woman was trying to express at that time. It served to initiate the analysis, providing an orientation towards a basic understanding of each woman's story. This first level of meaning lead through to the identification of narrative themes as explained in the second level of meaning and these themes were discussed with respect to the identity analysis.

However, the third level of meaning is more implicit within the analysis as both the content and the process is examined. It is also implicit in the way individuals make sense of experiences, emplot or configure events (Polkinghorne, 1995), subjunctivise (Bruner, 1986) and so forth in their day to

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day lives. For example, if a woman has menstrual pain and a heavy menstrual flow, and it seems unusual to her, she will look for an appropriate explanation. She may talk to her mother who informs her that both she and her grandmother experienced similar periods. Her doctor may say that it is a normal experience of menstruation. The woman may then make sense of her 'symptoms' by saying they are normal by connecting her mother's comments and saying that it 'runs in the family' and connecting the doctor's comments by believing other women can have similar experiences. Later on, it may transpire that she is diagnosed with endometriosis, and she may learn that infertility, feeling the cold and being fatigued are also associated with this condition. If she is having difficulty conceiving, feels the cold and tires easily, she may make sense of these events by emplotting them into her own personal endometriosis story. The individual events are thus given meaning within a whole (Polkinghorne, 1988).

The emplotment process is carried out by individuals, often without conscious thought. As noted on page 72, we engage in the linguistic process of emplotment daily when we tell stories, read stories and listen to stories. One does not usually think in terms of 'can I find other events in my life which support this idea?'. However, as the researcher, I *was* aware of the emplotment process and tested out my ideas by moving back and forth between the reading of the transcripts, listening to the tapes, re-reading my notes and jotting down further ideas. As Polkinghorne (1988; p.19) notes "An appropriate configuration emerges only after a moving back and forth or tacking procedure.." While I was aware of this process, it was also something that was going on throughout the whole study. I did not just carry out the first level, then the second level and then start on the third. The emplotment process, the notes of imagery and subjunctivising elements, and so forth, were not done as separate tasks. Much of this work flowed in and out of the differing levels of

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analysis. In order to explain the process of what I had done, it made sense to describe a three-part level of description, meaning, interpretation and explanation.

Through the third level of analysis, I was able to analyse how the women constructed their experiences, how they drew upon personal and cultural narratives to inform their constructions and how they made sense of their experiences. For example, how some individuals adhere to a cultural story surrounding the expertise and the 'word' of doctors, was demonstrated. The cultural story of growing up to become a mother, or the story about what menstruation is like were also used several times. These stories could be seen to inform the woman's own personal story and how this personal story could be challenged. The reconstruction of the personal story enables the individual to make sense of her life as she continues to experience a chronic condition (Radley, 1993). Polkinghorne (1991) expresses this idea as an 'operating plot' breaking down, the person's identity beginning to disintegrate and the need to revise the plot. Hannah's story of how she came to view herself as weak, her problems being psychosomatic and a sense of being different from other women, demonstrates the above. Jay's story exemplified an identity challenge where she operated for some time in a state of chaos. In both women's stories, the endometriosis diagnosis enabled them to configure and bring meaning to distressing symptoms.

Thus, by listening to and examining the women's stories. I was able to understand how the women came to reconstruct their sense of identity across time and how they came to make sense of events across time. Making sense of events in the past in light of their present understanding was often illustrated throughout the study. I learned how the women subjunctivised their realities (Bruner, 1986), by testing out alternative, future outcomes and what these

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meant to them. I discussed and illustrated the ways they emplotted their stories and how, in some cases, imagery and metaphor were used.

In this analysis, therefore, the focus was not solely upon themes or roles or types of narratives. Focus was also upon analysing the ways the women constructed their stories, made meaning from events, made connections between events and so forth. That is, the process was attended to, along with the content. Further, the general as well as the specific was examined. For example, in Tess's story where she spoke of body image, the story was specific and could not be discussed in relation to the other women's stories.

A limitation of narrative analysis relates to the researcher's construction or interpretation of the women's stories. The researcher decides what is included in the analysis, what is not included and what meanings to draw from the accounts. In other words, the researcher decides what holds narrative significance. There is always a possibility, as with any form of qualitative analysis, that an important issue is overlooked or not accorded the importance it is given by the narrator. As a committed and ethical researcher, however, I have endeavoured to construct my interpretations in a context of integrity and represent and interpret the women's stories to the best of my ability. This was achieved by being reflexive, by going back to the transcripts, listening to the tapes again and, even ringing up a couple of the women, to clear up any uncertainties. As noted earlier, it was difficult to settle on a way to analyse the transcripts in a way which I personally found acceptable. I was not prepared to seize some form of narrative analysis and make my narrative data fit into it. I believe this approach is entirely unacceptable and unethical.

In conclusion, my research has added to a store of knowledge about endometriosis. While I have termed this a 'collective narrative', it can also be

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conceptualised as a cultural narrative. In other words, initially it begins as a collective narrative, contributed to by medical researchers, other cultural stories, women's talk of their personal endometriosis experiences, along with researchers such as psychologists, sociologists and nurses from the results of their research involving talking to women with endometriosis. Now that women's talk has become privileged, we have a collective store of knowledge which includes their stories. My own personal endometriosis story, particularly with the way I connected it to my earlier, long period of infertility, has given me a depth of understanding and empathy towards the women in the study. I do not consider my story has blinkered my thinking, rather, I would argue that it has added positively to my constructions of the women's stories. I construct this study as adding richly to a slowly growing collective narrative which gives voice to the marginalised group of chronic illness sufferers, in this case, women with endometriosis. In time, it will become a cultural narrative and will be a rich source of knowledge from which to draw.

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The Experience of Endometriosis

Information Sheet

My name is Ruth Mortimer and I am a doctoral student in health psychology, working under the supervision of Mr Kerry Chamberlain and Dr John Spicer, Senior Lecturers in the Psychology Department at Massey University. I would like to let you know about the research project I am doing on endometriosis and find out whether you are interested in taking part. I was diagnosed as having endometriosis 15 years ago and so I have a personal understanding of the condition.

What is the study about?

The aim of this study is to gain understanding of the experience of endometriosis by listening to and analysing the first-hand accounts of women who have experienced endometriosis. The information will be of potential use to counsellors and other health professionals who work in the area of endometriosis. Additionally, participants may also benefit from talking about their experiences. *I am interested in interviewing women who have received a diagnosis of endometriosis no less than two years ago.* Participants are being invited to take part in this study from the Endometriosis Support Group for the Manawatu region.

What would I have to do?

If you think you might be interested in taking part, please fill in the enclosed Consent to be Contacted Form and return in the stamped addressed envelope. I will then telephone you and discuss any queries you may have. Participation is purely voluntary and you have the right to decline to take part. If you would like to participate in this study, we will arrange an interview at a time and place convenient to you.

At the interview I will ask you to sign a consent form which gives consent to:

- being interviewed which will be recorded on audio tape
- being quoted in reports in such a way that protects your identification

The interview, which I expect will take 1-2 hours, will take the form of an informal talk. I am particularly interested to hear about your experiences in your own words. I would like to know how you discovered you had endometriosis, why you think you have it, how you deal with it and what effects you think it may have had upon you.



What are my rights?

You have the right to:

- decline to participate in the study
- refuse to answer any particular question & ask for the tape recorder to be turned off at any time
- withdraw from the study at any time
- ask any further questions about the study that occur to you during the interview
- provide information on the understanding that it is completely confidential to the researchers and that you will not be identified in any reports of the research
- be given a copy of your transcript so that you can make any additions, deletions or alterations
- be given a summary of the findings from the study when it is concluded.

It is important to emphasise that I will not be offering any medical advice or counselling support. If you have any concerns arising from the study, I will be happy to refer you to an appropriate medical or counselling agency. If you would like more information, please ring me on 350-4117/4118 or John Spicer 350-4137 at Massey.

Ruth Mortimer

The Experience of Endometriosis

Consent to be Contacted Form

I have read the Information Sheet and now consent to be contacted by the researcher.

I understand this is not a consent to participate, but purely consent to be contacted to discuss any queries. If I decide to participate, an interview time will then be made.

Signed: _____

Name: _____

Phone: _____
(private/work)

Time convenient to ring: _____

Date: _____



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27 August 1997

Dear Jackie

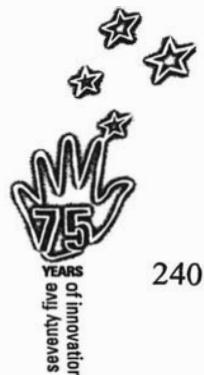
Re: Endometriosis Study

Further to my phone call, I just wanted to let you know it may be a couple of weeks before I can interview you.

I look forward to meeting you and will be back in touch as soon as I can. Thank you again for agreeing to participate in my study.

Yours sincerely

Ruth Mortimer



The Experience of Endometriosis

Consent Form

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate and I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researchers on the understanding that my name will not be used and the information will be kept confidential. The information will be used only for this research and publications arising from this research project.

I agree/disagree to the interview being audiotaped.

I also understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:



COLLEGE OF HUMANITIES & SOCIAL SCIENCES



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26 April 1998

Dear Ann

Re: Endometriosis Study

Thank you again for participating in my endometriosis study. I know you are a very busy person and really appreciate the time you gave up for the interview. Each woman's story of her experiences is a very valuable contribution to the research.

Enclosed is a copy of the transcript, which I would like you to read over and make any necessary amendments, additions or deletions. If you do not wish to make any changes, you are free to either keep or destroy the document. If I do not hear back from you within three weeks, I will know it is alright to proceed with the analysis.

Thanks again Ann and all the very best for the coming year.

Kind regards

Ruth Mortimer



Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey

Appendix 6 Sample Story - Hannah

Hannah - Interview 1

It was one evening shortly before Christmas of 1996 that I first met Hannah. I went to her home to interview her; she was the first woman I interviewed for my study and our time together remains in my mind as a rather special time. This was to be the first of two interviews along with several phone conversations we had over the next 3-4 years. Hannah was working part-time for the Endometriosis Foundation in an administrative and supportive role for its many members. She was the first port of call for often desperate women ringing in to talk about their endometriosis symptoms or women concerned about their teenage daughters with endometriosis. Throughout my research, I would ring the Foundation from time to time for information and end up having long chats to Hannah. I subsequently got to know her much better than I did the other participants in the study and felt quite close to her at times.

I was 5 months pregnant with my second son at the time of our meeting. I had checked out with Hannah beforehand to see if she was comfortable with me interviewing her while I was pregnant. Knowing that women with endometriosis can experience fertility difficulties and also knowing beforehand that she had no children, I did not want to distress her unduly by my pregnancy.

Hannah was 38 when I first met her - single, childless, unhappy and unwell. However, she impressed as a woman who took pride in her appearance and was always smartly dressed. Her beautiful eyes would sometimes light up and twinkle with amusement and then brim with glistening tears as she re-lived and reflected upon some of her life experiences. She lived in a small and pleasantly furnished home unit. A couple of pieces of finely crafted furniture were the legacy of a job she once had where her employers were unable to pay her a wage. I was soon to learn that Hannah's employment of recent years had become fraught with stress and disappointment.

I started the interview, as I did with the ensuing interviews, by asking when she first experienced symptoms of endometriosis, even if she didn't know what they were. And, Hannah's long story of suffering, distress, depression and grief began. She started menstruating when she was 13, immediately experiencing heavy and painful periods. Being the only girl in the class at a small country school, she felt it was very 'obvious' when she took days off each month due to

her menstrual difficulties. She consulted her GP who advised her that her periods would come right if she had a baby. Hannah felt 'disgusted' by this remark, but did take the contraceptive pill prescribed by the doctor to ease her symptoms and remained on it for 5 years. Hannah's school days were marred by her menstrual problems. Despite being on the Pill, she still had heavy, painful periods which she managed, rather inadequately, with hot water bottles and mild painkillers. Her symptoms prevented her from being able to participate properly in school sports and, consequently, Hannah came to dread sport. At her boarding school, she recalls 'we had to play sport all the time, you know, and I couldn't play. And you know, playing hockey and netball and I used to just feel like Niagara Falls...I certainly couldn't do running, like athletics time, I just couldn't do it'. Hannah would have been surprised to know that years later, after being diagnosed, she would express a desire to play tennis again and consider taking up tramping.

After 5 years on the Pill, Hannah took a break from it and didn't take it again for another two years. During that time she suffered 'excruciating' pain and recalls sitting in class, immobilised. Instead of receiving support and even some sympathy normally afforded a person suffering such pain, she 'got a good blast from the Headmistress' who told her she was just seeking attention. Hannah recalls receiving no sympathy from her mother or sisters who 'sailed through their periods'. She was often advised to get out of bed while being told 'it's all in the mind...periods aren't painful...every woman has them...it's not a big deal'. Hannah ended up feeling like a 'hypochondriac'. Her teenage years were a misery. From the age of 13, her life revolved around her periods, the debilitating pain, 'flooding' and chronic tiredness setting Hannah apart from her family and peers. Her subsequent frequent time off school and inability to play sport highlighted to Hannah that she was different from other young women. She was not believed; her symptoms were dismissed and, accordingly, she received little sympathy or support.

Overlaying the physical distress of her symptoms, Hannah also experienced chronic, long-term depression. She attributed her depression to premenstrual tension, endometriosis, to issues from her past which she chose not to elaborate upon to me. The Pill had resulted in a significant weight gain which also made her feel depressed. However, since she received a diagnosis of endometriosis, she had been able to monitor her symptoms and discern a pattern in much of her depressed feelings, noting their relationship with her menstrual cycle. In her short, three week menstrual cycle, she could only identify three days within that time where she felt good 'I have 3 good days and I'm just wonderful, and life's a breeze and I can cope'. This brief period of time was set in sharp relief against the misery and despair she felt during the rest of her cycle.

Hannah believed her symptoms were normal and, over time, came to believe that it was she who was abnormal. 'I just thought I couldn't accept pain and that I was weak. Everybody has it, that's what the doctors said'. When she was around 24 or 25, on her return from a few years overseas, Hannah 'plucked up courage' to consult a gynaecologist. She was not coping with her periods, her mood swings made life difficult for her and she needed help. The following extract relates to Hannah's encounter with the gynaecologist:

'I explained how my periods were really bad: they were erratic, painful, flooded and I didn't relate then, about depression, because I didn't think about it. I knew that I had moods...I told him I had mood swings...and his reaction was.. "Well Hannah, you've just got normal periods and it's a woman's lot, and accept it". Well I walked out of there feeling like a hunk of dirt. So I thought, well, it's me. I was really angry; I didn't feel listened to. And he'd backed up, you know, what my mother had said, like just get on with life.'

I asked Hannah what she meant by her remark 'well, it's me'. She replied:

'That all women have the same type of period and if this is a "specialist" in inverted commas, and he knows, well it's his job, and he know about these things and he has much more knowledge than I do, so I am wrong. And these things aren't happening to me, so it must be in my head...'

Not long after that encounter, Hannah started having 'intense counselling' in order to help her understand and cope with her depression. She had found a job which she really enjoyed but she was having difficulty coping with her mood swings and her menstrual problems. 'I'd really struggled with my depression, struggled with my periods...and I just thought life was the pits really...and, I got this really good job....the best job I've had...ever. And I got told (by her employer)...I had to do something about my emotional instability'. She was reluctant to consult another gynaecologist for fear of having a similar experience to the one she had earlier. Fortunately, her GP was supportive and who 'didn't think at any stage...I was going mad'. He helped her to monitor her periods, gave her appropriate medication to stop the excessive bloating she had been experiencing. '... I can't wear my normal skirts when I ovulate, or when I get my period'. Hannah's erratic menstrual cycle made it difficult to take her medication at the appropriate time; sometimes too early and sometimes too late. However, she still needed help with her mood swings, which she had come to realise were often hormonally related. Through her counselling, she had learned to recognise and discern the differences in her depressions; sometimes it was a depression related to her past experiences and sometimes it was obviously tied up with her premenstrual phase. Her GP referred her to another gynaecologist, reassuring

her that this man was very good and would listen to her. Hannah recalls how fortunate she was to have medical insurance as she was able to consult the specialist privately and immediately. He recognised her symptoms as relating either to fibroids or endometriosis, organised a laparoscopy and definitively diagnosed endometriosis. 'I just went 'YES!!!' (Great emphasis, Hannah's hands up in the air, eyes lighting up) I was so excited!' And, Hannah looked excited.

'...it was just so neat to have a name for something which all these years had been causing me so much pain, and it wasn't up here (points to head) and I wasn't going loopy, you know.'

(It sounds like it was a tremendous relief for you.) (Me)

'Oh it was, I was over the moon. I was so excited to have a name. I hadn't realised how much, um, how much stress I'd put myself under by not knowing and that really... and there was going to be nothing wrong with me and it was all in my mind. I was really scared that at the end of this the gynaecologist would say, there's nothing wrong with you Hannah. I was really scared it was going to happen'.

It had taken Hannah 24 years before she was diagnosed with endometriosis. Diagnosis, for Hannah, brought positive and negative feelings and experiences.

Hannah talked about feeling more in control of her life since being diagnosed. She could understand her symptoms in relation to her menstrual cycle and anticipate when she was going to feel low. Whereas, prior to diagnosis, she talked of 'always battling depression', post-diagnosis she felt a sense of control which enabled her to take steps to improve her life-style, understand her depression and feel a greater optimism about her life. Consequently, she noted she did not cry as much as she used to. By understanding what factors contributed to her depression, Hannah was able to make choices which minimised it. For example, when the gynaecologist suggested she go on Danazol (synthetic male hormone), she declined as she knew that weight gain and depression were common side effects. Instead, she sought further information about endometriosis and talked to the Endometriosis Foundation. She learned measures which would help her manage her symptoms. She took more natural remedies for pain relief, improved her diet and took greater care of her body.

'...because I couldn't handle being more depressed, or putting on more weight, because it makes me more depressed anyway; so for me.. to do it as naturally as possible...and by trying to get my lifestyle into gear. And being really sensible, like when I know that I am ovulating, now, I won't go and like, lift bricks, or garden, do heavy gardening. I'll take care of my body.. I'll give it a rest. Whereas before, I didn't know...I'd just think, well, I've just got

to keep going. Like it's just not as bad if I look after myself. Like I don't go to bed all the time'.

Hannah's new found sense of control and, perhaps assertiveness, enabled her to make choices which reflected her resolve to take care better care of herself and her body. If she was asked to do something one weekend and she knew it was not a good time of her cycle, she felt 'OK' with herself to say that she wasn't able to. She felt that a greater acceptance of her symptoms, as opposed to her earlier resistance, has enabled her to take a better control of her life 'and that it's not also going to stop me from having a life'. Her sense of control appears to stem from several issues. Firstly, she understood that her symptoms were real, thus removing all doubts about her sanity and ability to cope with pain. She became informed about endometriosis which empowered her to make plans about treatment and management of the condition. She was no longer isolated and different from all the other women. In some respects, her discovery of having symptoms which were not normal, but in fact common to many other women, actually normalised the way she felt about herself. Thinking about symptoms as being abnormal and caused by a disease, enabled her to see herself as normal once again. To think of symptoms as normal and oneself as abnormal must have some psychological implications. Her discovery of finding that she was normal seemed to set her free to take up the reins and leave the shackles of hopelessness and helplessness behind her.

For Hannah, having a name to put to her symptoms and learning that there are many other women with endometriosis, reduced the sense of isolation she had long felt. 'I wasn't the only person in the world who had this. And so, therefore, then I felt really good about it'. She was now able to talk to other people who knew what she had been through: 'it's really important that you have support and from people who understand'. Hannah found that the women at the Endometriosis Foundation were able to give her information, encouragement and support.

Support and understanding also came from unexpected sources. A male colleague from her work rang Hannah while she was in hospital to see how she was. She told him she had endometriosis. They also talked about premenstrual tension and, because his wife experienced it, he could understand how it had affected Hannah. '...he was really understanding. He was excellent. For a male, I was really (laughs) amazed. That's just because of my experience with males. I was really astounded.' Unfortunately for Hannah, her mood swings were affecting her work, her boss 'didn't understand' and she was finding the work particularly stressful. Consequently, Hannah chose to leave this position. She had enjoyed her job and felt very sad. Although many women with endometriosis talk about PMS (premenstrual syndrome) there are arguably many women who experience PMS

and do not have endometriosis. Whether the condition just co-exists with endometriosis or is affected by the condition is difficult to judge.

Hannah talked to her family about endometriosis and explained its effects. Consequently, they became more understanding of her symptoms and, in particular, her mood swings. This contrasted sharply with their lack of understanding, patience and support prior to her diagnosis. 'They can accept it far easier than not knowing what's wrong with me...I felt relieved at giving it a name. It's easier to say to people "I have endometriosis and these are the effects on my life".

Hannah felt that the diagnosis was a 'huge relief to know that I had something and that I could do something about it'. She was given a few options about treatment by her gynaecologist, one of which was a hysterectomy.

Hannah felt she understood herself better and believed this understanding promoted a feeling of confidence to 'go and do more things'. She talked of joining a tramping club the following year, she talked of her dreams of walking the Milford Track and she planned to 'get healthier' and also lose some weight. Now that she understood her condition, she felt it was easier to plan her life around her menstrual cycle.

The elation, which she experienced post-diagnosis, was tempered by the sadness and resentment she felt at having gone all those years without being diagnosed. 'If I had known all these years ago that I had endo, I reckon it would have saved me just so much heartache'. Hannah was grieving and expressed this grief in terms of a 'lost life'. While she talked to me about her loss, she cried. She cried for all that might have been and what she had missed. She was sad about having to leave the job she had so loved 'and I felt sad because if I had this knowledge before...if I had known all these years ago that I had endo, I reckon it would have saved me just so much heartache'.

Hannah joined the Endometriosis Foundation as a part-time field worker and administrator. Through her personal experience of endometriosis and the misery it has brought to her life, she has been able to empathise with other women, reaching out and supporting them in a way only someone who has been through it can.