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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