An Exploratory Investigation of Women's Experiences in Treatment for Endometriosis: Implications for Treatment

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As more is known about mind-body connections in chronic pain, practitioners who work with women with pelvic pain have a unique opportunity to capitalize on this connection by providing comprehensive treatment. Research literature indicates that psychosocial factors play a role in endometriosis, although the specific relationship between psychological issues and endometriosis is not yet understood (Weller & Shaw, 1995). Overall, it appears that patients experiencing the chronic pelvic pain associated with endometriosis also experience higher levels of depression, anxiety, and psychological distress than women without chronic pain (Savidge & Slade, 1997; Richter, Holley, Chandraiaih, & Verner, 1998), which is likely due to the psychological stress of dealing with such an enigmatic, life-changing chronic pain condition and the psychosocial stressors that go along with it.

While data highlighting the correlation between psychological distress and chronic pelvic pain does not indicate causality, there are concerns that this symptom pattern may influence physicians to believe that chronic pelvic pain is psychogenic (Kennedy, 1991; Zadinsky & Boyle, 1996). Grace (1995) found that the majority of women with endometriosis who she surveyed believed that their reports of pain were dismissed and, that at some stage before diagnosis, many (43%) had been told that nothing was wrong with them. Further, women in Grace's study reported that their disease was only understood through technological examinations, rather than incorporating the women's experience of pain and other symptoms into the understanding of the disease.

Having one's pain minimized is an unfortunate experience for any chronic pain patient, but in the case of endometriosis, such an experience may lead to a delay in diagnosis. A study by Hadfield, Mardon, Barlow, and Kennedy (1996) found that the mean delay in diagnosis for endometriosis was 11.73 years for women in the United States and 7.96 years for women in the United Kingdom. The authors contended that "the delay in diagnosis for endometriosis is considerably longer than that for other chronic diseases like rheumatoid arthritis" (p. 880). Kennedy (1991) also reported that women with endometriosis "frequently complain that the diagnosis was made only after months and months of being ignored by doctors," that "doctors provide them with insufficient information about the nature of the disease and the implications of treatment," and that "they are adversely affected by a delay in making the diagnosis" (pp. 8-9). This delay is especially significant because women may not receive the medical treatment they need, and because endometriosis is generally characterized as a progressive disease that worsens over time (Wedell, Billings, & Fayez, 1985).

In addition to delaying appropriate medical treatment for endometriosis, a psychogenic explanation of pelvic pain may actually decrease the likelihood that patients seek appropriate psychosocial services. The potential benefits of psychological services such as group support and pain management techniques are well documented (Cipher, Fernandez, & Clifford, 2002), yet little literature exists on the application of such techniques with endometriosis patients (Metzger, 1997). Grace (1995) noted that even when women believed that their symptoms were seen as psychogenic, they were not

given a referral for mental health services. Selfe, Matthews, and Stones (1998) examined factors influencing pain reduction among patients with chronic pelvic pain and found that two factors associated with significant pain reduction over a one-year period were the patient's participation in exercise and the report of a positive experience with the physician upon initial consultation. Thus, in their sample, psychosocial factors (experience of understanding and support, physical exercise) were very important in decreasing pain. The study also points out the importance of integrating an awareness of psychosocial factors into the treatment of chronic pelvic pain

In essence, women with chronic pelvic pain are in danger of being told that their pain is psychogenic in nature, leading to inadequate medical treatment. At the same time, it seems likely that women who are receiving appropriate medical treatment for endometriosis could benefit from adjunct psychological services to address the psychosocial impact of the disease, as do other chronic pain patients.

Our study was designed to explore the experiences of women who have been diagnosed with endometriosis with medical professionals and mental health services (i.e., psychotherapy and psychotropic medication) and, in particular, to understand the factors that would maximize the likelihood of accepting and benefiting from psychological services. Data were collected to investigate the relationship between medical care received and diagnosis delay, as well as medical care received and referral for mental health services, follow through with referral for mental health services, and experience of mental health services. Participants were also asked to share their experiences with medical and mental health services in their own words, as well as provide information and coping strategies related to endometriosis.

Participants in the study included 63 women between the ages of 18 and 51 who had received a formal diagnosis of endometriosis. Participants were recruited through recruitment postings on five on-line endometriosis support resources (four Internet message boards and one Internet list serve). Participants completed a survey consisting of questions related to gathering demographic information, 15 dichotomous true/false questions related to participants' experiences in treatment for endometriosis, and seven open-ended short answer questions related to experiences in treatment for endometriosis and coping strategies.

While this study was exploratory in looking at patterns of women's described experiences, the results fit nicely with previous research that highlights potential problems that women diagnosed with endometriosis may experience with the health care system. As expected, when women believed their health care concerns were taken seriously, they were less likely to report that they had been told that their pain was psychologically based, and were less likely to report that their diagnosis had been delayed. Conversely, when women believed that their concerns were not taken seriously and told that their pain was psychological or stress related, they were more likely to report that diagnosis was delayed. In these cases, a picture emerges of women feeling that pain is minimized, problems are attributed to emotional difficulties, and medical problems are being missed. These findings echo concerns expressed by women seeking treatment for chronic pain who have reported "feeling rejected, ignored, and being belittled, blamed for their condition and assigned psychological explanation models" (Werner & Malterud, 2003). Interestingly, the weakest correlation occurred between believing health concerns were taken seriously and being told that pain was psychological

or stress related, indicating that some women may feel that there are psychosocial contributors to their pain. This finding points to the need to see psychological factors in more complex, relative terms. Certainly, in other areas of health psychology there is an emphasis on psychological factors that may influence an illness rather than attributing causality to psychological factors (McDaniel, Campbell, & Seaburn, 1995). The pattern of correlations in this study may imply the need for clinicians to be sensitive to psychological stressors while clearly taking the patient's symptoms seriously.

Women were also asked about their experiences of having physicians recommend psychotherapy and psychotropic medication. Participants indicated that they would be more likely to follow through with recommendations for psychotherapy and medication if the recommendations occurred in conjunction with, rather than in place of, medical treatment. Again, these results are intuitively consistent. Patients who are looking for help with chronic pain do not want to feel that they are being "passed off" to another professional (Campbell, 1996); consequently, they follow through with a referral reluctantly, if at all, if they perceive that their pain is being misunderstood as a mental health rather than a physical problem (Knight, Green, & Hinson, 1997). Optimally, however, the offer of psychotherapy or psychotropic medication could be perceived as helping the patient develop greater resources for dealing with a very difficult medical illness. The offer of additional resources may be especially welcome to the subset of women diagnosed with endometriosis who experience depression, anxiety, or social problems as a result of their illness. However, it is worth noting that when women were referred for psychotherapy in conjunction with medical treatment, they were not more likely to find psychotherapy helpful. Further, the correlation between receiving a psychotropic medication recommendation in conjunction with medical treatment and finding that medication helpful was one of the weakest in the study. These findings indicate that openness to psychotherapy or psychotropic medication will not necessarily make such treatment helpful. While one may speculate that mental health interventions are underutilized with this population, it is important to remember that such interventions are not likely to work for all patients. Additionally, when looking at why participants did not pursue psychotherapy as a resource, the majority reported that they did not believe that their pain was psychogenic. Again, one must wonder how the rationale for psychotherapy was presented in these cases.

One of the most fascinating results of the study came from the fact that 98% of participants chose to answer the final open-ended question related to effective coping strategies, and within this pool a large number of coping strategies emerged. Women clearly wanted to share their expertise in dealing with chronic pain. Practices such as research/education regarding the disease, on-line support groups, family support, prayer, pain management techniques, meditation, and exercise were endorsed in this survey, which is consistent with other chronic pain literature supporting strategies such as utilizing family support, prayer, pain management techniques, meditation, and exercise (Flor, Fydrich & Turk, 1992; Whitney, 1998). This finding is similar to research on coping with chronic pain, which supports the benefit of contextual cognitive-behavioral techniques such as acceptance and meditation (McCracken & Vowles, 2008; Vowles, McCracken, & Eccleston, 2008). Finally, it is interesting to note that the one of least endorsed strategies was surgery. Interpreting this finding hopefully, it points to

numerous options for women to receive help with chronic pain, even when surgery is not a viable option or is not desired.

In sum, multidimensional views of chronic pelvic pain are thought to be more helpful, as chronic pelvic pain is likely to be affected by a combination of physical, social, and psychological factors (Grace, 1995; Fry, Crisp, & Beard, 1997). Moreover, the issues involved in chronic pelvic pain call for multidimensional treatment that addresses both physical and psychological factors (Knight, Green, & Hinson, 1997). This exploratory study is one step toward empirically validating anecdotal literature on the topic of women's experiences with treatment for endometriosis. The results suggest that current treatment continues to reinforce mind/body dualism rather than a holistic, integrated approach. It is important that medical and mental health professionals work collaboratively together; listen to, support, and validate women's described experiences of pain; acknowledge the real existence of physical pain, seek a physical pathology, and not rush to psychological explanations; assess the impact of this pain and its symptoms on women's lives; and treat the whole woman, rather than just the dualistic pieces.

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