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Coping strategies employed by women with endometriosis in a public health-care setting

Rizwana Roomaney¹ and Ashraf Kagee¹

¹Department of Psychology, Stellenbosch University, Private Bag X1 Matieland, 7602 South Africa

Abstract

This study explored how South African patients attending public health facilities reported coping with endometriosis. A total of 16 women with endometriosis were interviewed, and we explored how participants coped with endometriosis. All interviews were audio-recorded and transcribed. Thematic analysis was used to identify themes. Participants reported employing both problem-focused and emotion-focused strategies to cope with endometriosis. Problem-focused strategies included limiting physical activities, increasing knowledge about endometriosis, scheduling social and work activities around menstrual cycle, engaging in self-management and relying on social support. Emotion-focused coping strategies included accepting the disease, adopting a positive attitude, engaging in self talk and evoking spirituality.

Keywords

Chronic illness; coping; endometriosis; reproductive health; self-management

Background

Endometriosis is a chronic gynaecological disorder that affects 10 per cent to 15 per cent of women of reproductive age (Denny and Mann, 2007). The primary symptom indicating endometriosis is chronic pelvic pain. Other symptoms include dysmenorrhoea, sub-fertility, ovarian cysts and dyspareunia (painful sexual intercourse) (Mao and Anastasi, 2010; Sinaii et al., 2008). Pain experienced by patients is cyclical with periods of pain and relief based on the patient's menstrual cycle (Denny, 2004). Endometriosis can result in severe and in some cases debilitating pain that can impact all spheres of a woman's life and lead to social dysfunction (Peveler et al., 1996). There is currently no cure for endometriosis, and the emphasis is on managing the disease by reducing symptoms (Culley et al., 2013; Johnson et al., 2013).

Patients diagnosed with a chronic illness often experience their illness as a stressor and develop mechanisms of coping with their illness. Coping is an important concept in the field of chronic illness as it allows health-care practitioners to gauge the impact of a disease on patients. For this reason, coping has been investigated in relation to a number of chronic

illnesses such as HIV (Stowers Johansen and Kohli, 2012), diabetes (Collins et al., 2009), coeliac disease (Jacobsson et al., 2012) and rheumatoid arthritis (Ramjeet et al., 2008). Among women, coping research has extended to areas such as coping with infertility (Lee et al., 2010), ovarian cancer (Price et al., 2013) and polycystic ovary syndrome (PCOS) (Benson et al., 2010).

Most research relating to the social and psychological impact of endometriosis on women's lives found that the majority of research was conducted in high-income countries with well-developed health-care systems (Culley et al., 2013). To our knowledge, no research has been specifically focused on coping among women with endometriosis.

The focus of the article was on coping strategies employed by women diagnosed with endometriosis. While many women with this condition experience fear related to possible infertility, this was not the focus of our article.

Coping

Coping is defined as a person's ability to deal with a stressor and the management of emotions in relation to the stressor (Lazarus and Folkman, 1987). Two types of coping are most commonly referred to in the literature, namely problem-focused coping and emotion-focused coping. Problem-focused coping refers to attempts to change the environment in order to alleviate stress, whereas emotion-focused coping refers to changing the meaning of the stressful experience (Carver et al., 1989; Lazarus and Folkman, 1987). Problem-focused strategies tend to be used when people feel that something constructive can be done about the stressor, whereas emotion-focused coping is used when people feel that the stressor must be endured (Lazarus and Folkman, 1987). While this manner of describing coping has been critiqued for its lack of usefulness (Coyne and Racioppo, 2000), we nonetheless decided to use these categories to frame our research because it was well-suited for the purpose of the study which was to describe the coping strategies of our sample. Thus, the framework provided by Lazarus and Folkman provided a way of organising our qualitative data and was thus deemed an appropriate approach. Researchers have described how patients with a chronic illness experience a series of stages in the management of their illness. In a study of 21 chronically ill patients, Audulv et al. (2012) identified four phases of self-management, namely (1) eliciting information from friends, health-care providers and the Internet, (2) weighing up the benefits and costs associated with self-management techniques and discontinuing techniques that were not effective, (3) creating routines and plans, and (4) negotiating self-management techniques that fitted into patients' lives.

Collins et al. (2009) identified three types of self-care among patients with diabetes. These authors categorised their respondents as 'proactive managers', that is, those who attempted to adopt a healthy lifestyle in order to cope with their chronic illness; 'passive followers', that is, those who took control of some aspects of self-care but relied on others for other aspects of self-care; and 'non-conformists', that is, those who did not adopt a healthy lifestyle when faced with diabetes.

Women with chronic illnesses have reported using a number of coping strategies. Coping strategies used by women with fibromyalgia include a combination of problem-focused and

emotion-focused strategies such as planning, distraction techniques, coping with touch sensitivity, hiding the pain from others, medication and social support (Kengen-Traska et al., 2012). Researchers have found that women with coeliac disease also employed planning as a coping strategy (Jacobsson et al., 2012). Awasthi and Mishra (2011) found that diabetic women who believed strongly that the cause of their illness emanated from environmental, supernatural and psychosocial sources utilised emotion-focused coping strategies, whereas those who believed less strongly in these sources were more likely to use problem-focused coping strategies.

Various studies have shown that women with breast cancer rely largely upon emotion-focused strategies. In one study, the most common coping strategy used by breast cancer patients undergoing chemotherapy was self-statements, prayer and positive behaviour activity (Gaston-Johansson et al., 2013). Henderson et al. (2003b) found that patients used prayer, avoided negative people and maintained a strong will to live as coping strategies. Other researchers found that spirituality, family support, support groups and a positive attitude were utilised as coping strategies (Henderson et al., 2003a).

Walsh et al. (2003) examined how women coped with menstrual pain and found that women identified as high pain catastrophisers (i.e. those who are likely to amplify and focus on pain) utilised active coping strategies such as heat, massage and rest more than women who were identified as low pain catastrophisers. In the study, high pain catastrophisers scored significantly higher on the Pain Catastrophising Scale than low pain catastrophisers.

Endometriosis research reveals that patients implemented changes in their diet, exercise and health-seeking practices to manage the disease (Cox et al., 2003; Gilmour et al., 2008; Huntington and Gilmour, 2005). For example, Gilmour et al. (2008) explored patients' perceptions of living with endometriosis, the impact of endometriosis on their lives, and the strategies that patients used to manage their endometriosis. Their sample reported making dietary changes, increasing exercise, massage, meditation, acupuncture and Chinese Herbal Medicine (CHM) in order to cope with their endometriosis. A key element for participants was a need to become knowledgeable regarding the disease in order to enhance their ability to cope. Sources of knowledge included books, the Internet, endometriosis support groups, online chat rooms and information from other women diagnosed with endometriosis.

All of the research to date on coping with endometriosis has been conducted in regions of the world that are well-resourced. The aim of the current research was to explore how patients in a resource-constrained setting coped with living with endometriosis.

Method

Participants

The sample consisted of 16 women who were diagnosed with endometriosis. Their ages ranged between 23 and 42 years (average age 33 years). All participants spoke either English or Afrikaans as their first language. Eight were married, 3 were divorced and 5 listed their relationship status as single. Four participants were diagnosed 6 months prior to the interviews, 4 were diagnosed 1 year prior to the interview, 3 were diagnosed 3 years prior to

the interview and 5 were diagnosed more than 3 years prior to the interview. In terms of employment, 9 were employed full-time, 3 were employed part-time, 3 were unemployed and 1 was a student. Eight women had biological children and 8 were yet to have children. Of these women, 2 were embarking on fertility treatment at the time of this study. Eight participants were not receiving any treatment for their endometriosis, 4 were using contraceptive injections, 1 had undergone recent surgery, 1 had an intrauterine device inserted, 1 had the intrauterine device in combination with contraceptive injections, and only 1 was taking dienogest (a progestin, i.e. hormone).

Setting

Participants were recruited from the obstetrics and gynaecology department at a tertiary academic hospital in Cape Town, South Africa. A total of 15 cases of severe endometriosis were reported at this hospital in 2012 (Western Cape Government, 2013). This state-run facility offers health care to all, and is usually accessed by those who cannot afford private medical care.

Procedures

Participants were recruited using flyers at the hospital. Nurses identified patients with endometriosis and handed them the flyer. Those interested in learning more about the study completed a form granting permission to the researcher to make contact and explain the study to them. The researcher then telephoned potential participants and explained the study to them as well as their rights and responsibilities if they agreed to participate. Interviews were arranged for those willing to be interviewed and recorded.

Data collection

The 16 interviews were semi-structured and took place either at the researcher's office, the participants' homes or a location selected by the participants, such as coffee shops. An interview schedule was used to guide the interview. The interview commenced with the researcher asking participants, 'can you tell me about your experience with endometriosis?' A further 13 questions on the interview schedule served as a guide that explored participants' experiences with endometriosis. During the course of the interviews, participants spoke about how they were coping with the disease. The interviews were conducted by the researcher in either English or Afrikaans, depending on the preference of the participant. Interviews ranged between 31 and 84 minutes. All interviews were audio-recorded, with the permission of the participant, and transcribed. Participants received a token of appreciation for being part of the study.

Data analysis

The transcribed interviews were checked for correctness and entered into the qualitative data management programme, Atlas Ti version 7.1.3. Listening to the recordings and checking the interviews allowed the researcher to be immersed in the data. We used open coding for the first five interviews and then refined and organised the codes. An independent qualitative researcher coded the same five interviews and also refined and organised the codes. The codes from both the researcher (R.R.) and the independent coder were discussed until codes

were agreed on. The agreed on codes from the first five interviews then formed the basis of the code book. We then continued coding the interviews using the code book as a basis for codes but added new codes as the need arose. Data collection and coding occurred concurrently so that the researchers could identify emerging themes and determine the saturation point. The codes related to coping were then analysed by assessing the frequency of the coping strategies used by participants. Coping strategies reported by three participants or less were excluded from the analysis. Therefore, of the 11 initial codes, 2 codes (namely venting and humour) were excluded from further analysis, resulting in nine themes. The framework provided by Lazarus and Folkman (1987) and Carver et al. (1989) was used as a guide for organising the codes that were already identified. In keeping with this framework, coping strategies were therefore either identified as problem-focused or emotion-focused. Data analysis was conducted on the original English and Afrikaans transcriptions, and quotations selected for this article were translated into English after the final analysis was conducted.

Ethical considerations

Ethical clearance for the study was granted by the Health Research Ethics Committee of Stellenbosch University, and permission to conduct the study was granted by the Western Cape Department of Health. The nursing and reception staff handling the contact permission forms as well as the individuals responsible for transcription signed confidentiality agreements. When initiating contact with potential participants, the researcher informed each person that they had a right to decline participation, that the study was independent of the hospital and would not affect their ongoing treatment. They were also assured that their confidentiality would be maintained. Prior to the commencement of the interview, participants were again reminded of their rights with regard to the research and told that they could terminate the interview at any time or refuse to answer a question they found uncomfortable. All information containing participants' particulars was stored by the researcher, and pseudonyms were used to ensure their anonymity.

Trustworthiness

The interviewer (R.R.) received extensive training in conducting interviews. A research psychologist was recruited to code the data independently so that some verification of the results could be achieved. One of the authors (A.K.) reviewed samples of the data to check the coding as a way to enhance the trustworthiness of the analysis.

Results

The primary stressor that participants reported was pain related to their endometriosis. Nine themes emerged from the analysis of the interviews, namely accepting the disease, limiting physical activity, adopting a positive attitude, increasing knowledge about endometriosis, scheduling social and work activities around menstrual cycle, engaging in self-management, engaging in self talk, evoking spirituality and relying on social support. The themes were then categorised as either problem-focused strategies or emotion-focused strategies.

Problem-focused strategies

Participants commonly used a combination of the following problem-focused strategies to assist them in managing their endometriosis. These strategies included limiting physical activity, increasing knowledge about endometriosis, scheduling social and work activities around menstrual cycle, engaging in self-management and relying on social support.

Limiting physical activity—Participants stated that in order to cope with the pain and heavy bleeding associated with endometriosis, they limited their physical activity. The women reported that they would often resort to bed rest and not leave their homes when in pain, which was usually the case during menstruation. Staying at home meant that they were often isolated as they were less likely to engage with others socially. Some participants stated that they engaged in complete bed rest, while others opted to limit specific activities such as sport and social activity. Madeline, a 31-year-old woman, stated the following:

I was actually literally just going to work and at home. I was actually putting myself under house arrest.

Increasing knowledge about endometriosis—Most participants stated they had never heard the word ‘endometriosis’ prior to their diagnosis. While some reported that doctors explained the disease to them and that they were satisfied with the information they received, the vast majority of the sample stated that they did not think the disease was adequately explained to them. Some patients reported conducting their own research, mostly using the Internet, in order to help them cope with endometriosis. By researching endometriosis, they were able to gain clarity regarding medical aspects of endometriosis and find ways of managing the disease. For example, some women reported finding diets or exercise programmes that would help them manage pain. Other information regarding treatment options or information on surgery was also regarded as helpful to patients as they provided information that could help patients understand the treatment options available and prepare them for treatment and surgery. Finally, research allowed the women in our sample to feel less isolated as they would read about the experiences of other women with endometriosis. Access to other women’s experiences was important as no one in the sample knew anyone else with the disease with whom they were able to converse. Leona, a 25-year-old woman diagnosed with endometriosis 10 years prior to being interviewed, stated:

It does [research helps] in the way that I don’t feel that I’m the only one that is struggling with it, the things that I feel and the things that I’m going through, is the things that endometriosis is related to. It does relate to endometriosis. I’m not the only one who’s got this funny pain. I’m not the only one who’s feeling this bloatedness. I’m not the only one who is struggling with pimples in my mid twenties. It’s [symptoms] related to endometriosis, and not only endometriosis, it’s related to the, to the, the pills and all the things that I’m on to keep this intact. So ja, it does help me.

Scheduling social and work activities around menstrual cycle—Endometriosis often results in debilitating period pain. In order to cope with this pain, participants stated that they scheduled their social and work activities around their menstrual cycle. Thus they

engaged in considerable planning in order to be certain that they would not have to engage in these activities during their menstrual cycles. This scheduling of activities occurred in many areas of the patient's life such as activities relating to work, social interaction or household. Women reported that they would not plan social activities if they knew they would be menstruating, and some reported that they would complete their work before their period arrived so that during their period they would be able to rest. For example, one participant worked in a retail environment and would plan her monthly shifts with her manager in order to be on leave during the days she expected to menstruate. Gina, a 31-year-old patient with endometriosis, explained how she scheduled her work around her menstrual cycle:

The assistant manager told me if I know it's my time to get sick (menstruation) then I just tell them they can (plan) for me those two days (i.e. schedule work shift according to menstrual cycle)

Engaging in self-management—Self-management was the most commonly used coping strategy reported by participants. Self-management is similar to active coping as it represents steps taken by the participants to alleviate the symptoms of endometriosis. A number of self-management strategies were reportedly used by participants to cope with endometriosis. These included strategies aimed at alleviating pain and discomfort, such as taking analgesics or other home remedies. Self-management techniques included certain types of relaxation or stretching activities and changing their diets. Most participants stated that they used heat in order to manage their pain. For these women, cold was associated with pain, and during menstruation they would keep warm using layers of clothing and hot water bottles. Jeanette, a 42-year-old woman diagnosed with endometriosis 4 years prior to the interview, stated:

And what I do when the pain comes, then I heat washcloths in hot water, boiling water, to make them warm... and then I put it on my uterus and then it subsides. The warmth of the thing (washcloth) makes the pain calm down a little. (translated)

Relying on social support—Participants stated that they relied on social support from family members and partners. Mothers were a particularly useful source of support as they would take care of their daughters while they were in pain, care for their grandchildren when their daughters were unable to do so, and cook and clean for their daughters when they were in pain. This type of support was useful as it allowed the participants to rest and care for themselves and thus reduced the pressure of having to care for others. The participants reported that family members and partners would often rally around them when they were in pain and assist them by taking on some of their responsibilities or by providing them with analgesics or home remedies to alleviate pain. Family members also showed concern and would encourage patients to seek help from doctors. Madeline, a 31-year-old mother of two, stated:

So she [mother] was very supportive... she'll pick up first when something is not right when I've got pain stuff like that...She's very supportive because she knows what I've been through and basically when I've got pain you can see it in my face...she'll do whatever I have to do, she'll make sure that the kids are bathed...or

she'll help me put the water in the bath and get the child in the bath and stuff like that.

Emotion-focused strategies

In our study, the participants reported using four emotion-focused coping strategies to mediate their experience with endometriosis. These strategies included accepting the disease, adopting a positive attitude, engaging in self talk and evoking spirituality. All these strategies reflect methods of coping that involved reframing the way participants thought about their illness.

Accepting the disease—Some women reported feeling that accepting that they had the disease helped them cope with it. Accepting the disease meant that they focused on learning to live with endometriosis. Participants stated that as there was no cure for endometriosis, there was very little that they could do about the disease itself, and thus they were forced to live with it.

Adopting a positive attitude—Adopting a positive attitude towards their experience with endometriosis was another emotion-focused strategy used by some participants. Some who reported accepting the disease as a coping strategy also adopted a positive attitude. Again, the absence of a cure for endometriosis facilitated this shift towards a positive attitude. Leona (25 years old) also stated,

Because doctors have told me that there's not cure for it, so, in that way, it doesn't affect me, because I'm not going to sit in a corner and, ooh I've got endometriosis, I keep on living, I keep on going on. I'm a very, I must admit, I'm a very negative person, but in the endometriosis area in my life, I'm positive.

Engaging in self talk—In order to cope, some women in the study stated that they engaged in self talk. The self talk was used to assure themselves that they would overcome the pain that they were experiencing or to encourage themselves to relax in order to alleviate pain. An underlying belief was that their emotional responses could play a role in mediating pain, that is, if they were calm or less stressed they would experience less pain. Leona, a 25-year-old woman, stated,

I just sat down with myself and just told myself, okay, now you must try to, just relax and just live a little less stressful,[and] it's been going better.

Evoking spirituality—Participants stated that their spirituality was an important coping resource for them and was employed in various ways. Prayer was one strategy used and was demonstrated by reports of participants praying for themselves or appreciating others praying for their health. Participants reported that during times of pain they questioned God, spoke to God or read from the bible for relief. One participant sought counsel from a deacon at her church. Lauren, a 34-year-old single mother, stated,

That moment when you're alone, you have to talk to God and then I do that and then I read verses from the Bible and I pray and ask the Lord to just relieve pain.
(translated)

Participants referred to an existential reason behind their illness and adoption of a fatalistic attitude. The fatalism related to some participants feeling that they were predestined to experience endometriosis and therefore powerless against it. Again, the absence of a cure coupled with a lack of knowledge regarding endometriosis may be related to these attitudes. Janine, a 41-year-old patient diagnosed in 2007, stated,

But I think working on it to say that it's not that -- it's a bit hard. Proving to myself that it's fine people go through these things. But why do *I* go through it?

Discussion and Conclusion

We found that women with endometriosis in a public health-care setting drew on both problem-focused and emotion-focused coping strategies. This finding is similar to those on patients with fibromyalgia, even though the types of strategies differed (Kengen-Traska et al., 2012). While the patients with fibromyalgia and endometriosis relied on planning and social support, the patients with fibromyalgia also utilised distraction techniques, learned to cope with touch sensitivity, hid the pain from others and relied on medication in order to manage their fibromyalgia, which patients in our study did not. On the other hand, the patients with endometriosis in our study limited their physical activity, accepted the disease, increased their knowledge about endometriosis, adopted a positive attitude, engaged in self talk and self-management, and evoked spirituality, which the patients with fibromyalgia did not. The participants were diagnosed at least 6 months prior to the interviews and had experienced symptoms for some time before being diagnosed. As a result of living with the disease for this amount of time, the participants had developed practical ways of managing their symptoms. Participants reported that the pain they experienced was so severe that in order to cope, they often limited their physical activity and resorted to bed rest. Since the pain associated with endometriosis is cyclical in nature, that is, the intensity of the pain can be anticipated based on their menstrual cycle, patients could schedule activities and plan in order to cope. Planning has also been used as a coping strategy in patients with coeliac disease (Jacobsson et al., 2012).

Patients in our sample relied on analgesics for symptom relief, but in addition developed other practical strategies for coping. For many, pain was associated with cold, and the women interviewed tried to keep warm in order to avert pain by using aids such as hot water bottles. Other strategies included changes in diet and increased exercise. Most of these strategies were not recommended by doctors but learned by participants either through research or experimentation. Participants appeared to fit into Audulv et al.'s (2012) final stage of coping with their chronic illness as they had elicited information, weighed up the costs and benefits of coping strategies, created routines and reported being able to fit self-management into their daily lives. The patients in the study can also be characterised as proactive managers as they reported attempting to adopt healthy lifestyles in order to cope (Collins et al., 2009).

The emotion-focused strategies used by patients included accepting the disease, adopting a positive attitude, engaging in self talk and evoking spirituality. Emotion-focused strategies were also commonly used by patients with breast cancer (Gaston-Johansson et al., 2013;

Henderson et al., 2003a, 2003b). As participants reported that they knew very little about endometriosis but understood that there was no cure for it, they were forced to accept the disease and adopt a positive attitude. The women interviewed also reported that they would talk themselves through periods of pain. Self-statements have reportedly been used by women with breast cancer who underwent chemotherapy (Gaston-Johansson et al., 2013). Some women expressed their reliance on spirituality by praying for pain relief from a higher power. This coping strategy is similar to cancer patients who also reported relying on prayer (Gaston-Johansson et al., 2013; Henderson et al., 2003b). Few women reported feeling that there was an existential reason for their illness. Awasthi and Mishra (2011) found that patients who believed that their disease emanated from supernatural sources were inclined to use emotion-focused coping strategies. In our sample, even though some women alluded to an existential reason behind their illness, they still utilised a combination of problem- and emotion-focused coping. Similarities exist between some coping strategies in patients with endometriosis in this study and in previous research conducted in Australia (Cox et al., 2003; Gilmour et al., 2008; Huntington and Gilmour, 2005). Participants in these samples relied on self-management coping strategies such as dietary changes and increased exercise to manage their disease. Another similarity is that participants researched the disease in order to enhance their coping. However, participants in our study did not make use of alternative therapies as did those in the Australian samples who relied on these therapies to manage their pain and felt empowered doing so (Cox et al., 2003; Gilmour et al., 2008; Huntington and Gilmour, 2005). We hypothesise that this may be either due to a lack of resources or a lack of knowledge regarding alternative treatments. While we make no claims as to the effectiveness of alternative treatments, the fact that it was not considered in our sample may indicate that those with few financial resources have had limited options in managing the impact of the disease. In summary, the patients in our study relied on both problem- and emotion-focused coping strategies to manage the impact of the disease on their lives.

Recommendations

Given the qualitative nature of the study and the small sample size, it is not possible to make general statements about South African patients living with endometriosis. Thus, a large-scale quantitative study examining coping strategies in relation to other factors such as access to resources may provide some useful information. There was a large amount of uncertainty regarding the disease. The fact that participants wished for more information indicates the need for psycho-educational interventions to be offered to help participants with endometriosis to cope. Following recommendations by Jacobsson et al. (2012) regarding interventions to assist patients with coeliac disease in choosing more adaptive coping strategies, it is possible that patients with endometriosis may benefit from more information and support to enhance their coping. We suggest that, time permitting, doctors inquire about the ways in which their patients manage and cope with endometriosis and refer them to appropriate resources, including mental health professionals and support groups where available.

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