

GOOD RELATIONSHIPS ARE NO FAIRY TALE

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Introduction

If Snow White had fibromyalgia, how would that change the story? Would her stepmother still be consumed with jealousy? Would the seven dwarfs let her stay? Would she have the energy to cook and clean for them? Would the prince want to marry her, despite the grimace of pain on her face and the bags under her eyes? Would the prince want her ability to predict the weather? Clearly, fairy tales do not give us a realistic base from which to view our relationships.

How does fibromyalgia syndrome (FMS) affect your relationships? Does it upset you because your mother worries about you? Is your sister tired of your fatigue? Does she just want you to move on? Is there strain because your partner wants to walk up that mountain and you just aren't up to it? Does your friend want you to go to the late movie and you know there's a price to pay if you're not in bed by 10:00? And are you brought closer to yet others because of FMS? Fibromyalgia may not be who you are, but it will likely influence your life and your relationships.

As someone with fibromyalgia and a psychotherapist, I have become very interested in how people cope with the chronic stress. Having fibromyalgia is an ongoing process which is stressful on our minds and bodies. FMS-related stress, added to the other stresses in our life, may put a strain on our relationships. Like other human beings, we need those relationships and can contribute our part. If the stress of fibromyalgia is getting in the way of your life or relationships, consider consulting a health care professional.

Emotions and Symptoms, Day to Day to Day...

The ongoing struggle of FMS may trigger inner emotions, especially depression, anger, and anxiety, that may strain our support network. Depression is common in chronic illness. Illness is a loss of our health, our former way of life and, potentially, the future plans that formerly seemed so sure. Anger is also common. Anger may understandably surface because of the losses (i.e., I can't do what I once found so easy; I don't have the health that others take for granted, and after all, why did this happen to me?). Anxiety may grow out of uncertainty. Will the symptoms progress? Is there something out there that will help? Will tomorrow be a good-symptom day or a bad-symptom day?

We all have to learn how to take care of ourselves when these emotions take control and we lose our equilibrium. How do you take care of yourself? Plan for self-care, such as stretching, walking, meditating, bird-watching, drinking hot tea, taking a hot bath, or getting a massage. Know several strategies that help you. By taking care of yourself, there is more likely to be something left to give to a relationship.

The symptoms of FMS may also stress our relationships. Fibromyalgia is invisible, so others may believe that we look fine and, therefore, feel fine. This may mean that outside expectations of us are unrealistic. We may need to spend time educating the important people in our lives. In fact, we may first need to learn what is realistic ourselves and communicate our findings to those around us.

The complexity and severity of symptoms that each individual experiences with fibromyalgia vary widely. Common symptoms include fatigue and pain, and these may hinder the cultivation of relationships. It may be hard to be outgoing when you just do not feel well. You have something special to contribute even though you may be limited in how you contribute it. Negotiate with the other person for mutual benefit. Giving and receiving support from others is vital to us as humans.

Supporters may face a dilemma as well. Because they know someone they care about does not feel well, they may find it harder to ask for their own support. This could lead to feelings of resentment because the relationship may start to seem one-sided. In addition the person with FMS may develop thoughts and feelings that (s)he is no longer needed or important. This could cycle out of control and cause problems rather quickly. Let each other know what is going on.

What Do Others Find Supportive?

I would like to relate a partial overview of the results of a study I did with women with endometriosis because I think endometriosis and FMS have some similar coping aspects, and because I hope it will help you in articulating your support wants to others in your life. My research examined 46 women's experiences with social support.

Endometriosis is a gynecologic illness where the cells that normally line the uterus, the endometrial cells, grow outside the uterus, typically in the pelvis. Presumably these misplaced cells go through similar cyclic changes as those in the uterus, causing cyclic bleeding. This typically results in inflammation and scar tissue formation. Symptoms of the disease include pain and/or infertility. Like fibromyalgia, there is no definitive cure, no known cause, and the condition is chronic and invisible.

A questionnaire was developed to study the social support experiences of women coping with endometriosis. I then asked for volunteers from WITSEND0, an Internet Listserv that serves as a support network for coping with endometriosis. Fifty-nine women with endometriosis volunteered and were sent a questionnaire. Forty-six women or 81% completed and returned the survey. The majority of research participants were from the United States and were white, in their thirties, well educated and affluent (Whitney, 1995).

Within the context of endometriosis, women stated what they found supportive and did not find supportive. The survey divided social support into four categories: spouse or partner, friends and family, others with endometriosis, and health care providers. (I will consider each of these specific categories shortly.) Rated as most supportive were other women with endometriosis,

next was spouse or partner, then came friends or extended family. Rated as the least supportive were health care providers. Some of the themes which respondents identified were limited to one category, but some very strong overarching themes were present in all four categories. For example, the participants, in general, wanted their social support network to really listen to them and believe that their symptoms are real, be knowledgeable about the disease, understand the context of the disease, and share information about the disease.

How does this compare with what you want from your support network? Determine your hopes and needs and discuss them with important others. Communication is vital. Just because someone is close to you does not mean they are mind readers. Asking for help may not be easy, but at least others will know what you really want. And supporters, do not hesitate to ask what is most wanted or needed at a given moment. Talk about giving and receiving support.

Spouse/partner

Having a chronic medical condition like FMS is likely to put a strain on your relationship with a spouse or partner. FMS can affect joint life-planning decisions such as child bearing or rearing. It can mean re-thinking which activities are done together. It may mean re-negotiating who does which chores. It could lead to an alteration in the sexual relationship.

My research participants with endometriosis indicated in their questionnaires that to be supportive, their spouse/partner should: listen to them, believe them, understand them, and be knowledgeable about their disease. In addition, the participants liked to be asked what they needed and to be comforted and helped. They also wanted the partner to be committed, patient, caring, and to express feelings. Respondents preferred that partners not try to fix the problem, nor judge nor blame. They also wanted them to recognize the impact of endometriosis on the sexual relationship. Selected comments from participants follow:

The best thing to do is listen and then ask what you can do to make life easier or more comfortable.

My spouse helps me by reminding me that he married 'a packaged deal.' Problems and all, and that 'in sickness and in health' is just as real to him now as it was ... when we married.

It's OK not to fix things! Men (in my experience and in what I've read) love to fix things and sometimes get frustrated when they can't be Mr. Fix-It. Even though they can't fix it, don't give up - just being there, listening and being supportive is a big help.

What is your spouse or partner already doing that is supportive? How would you describe the support you want from your spouse or partner? How can you go about telling him/her?

Friends and other family

This category is quite broad and could include varying levels of closeness that will likely affect the impact of FMS. How our fibromyalgia affects our children will be quite different from how it affects a third cousin we rarely see. You may choose to educate about FMS and provide

reciprocal support to those you are closest to. This may be where energy levels have a high impact. Choose which relationships are deserving of your energy.

The research participants with endometriosis also reported wanting their friends and extended family to listen to them, believe them, and be knowledgeable about endometriosis. In addition, they also hoped for sympathy and/or empathy as well as support with their disease struggles. They did not wish to be blamed or have their experiences minimized and they did not want to be worried over. A couple of comments from participants follow:

Being more informed about the disease helps to be more understanding towards the people suffering from the pain (physical and/or emotional) of endometriosis.

Understand that each woman's experience is real and valid, that you need to be careful to listen without being judgmental.

How would you describe the support you want from your friends and family? How are they supportive now? What is the best way to open a discussion?

Others with Similar Condition

Others with fibromyalgia can provide important support. Even though people are different and symptoms vary, those with FMS can share information, trade coping tips, and network with each other. The Fibromyalgia Association of Greater Washington (FMAGW) publishes a directory of support groups available in the U.S. and Canada. Also, there are Internet support groups, chat rooms and Listservs where you can connect with others with FMS.

My endometriosis study participants shared what they wanted from other women with endometriosis: to network, commiserate (but not focus on misery), be informed, and be recognized as an individual. I illustrate some of these themes with the participants' own words, as follows:

The fact knowing that there are other people with the same problems as you is really one of the best supports available because you don't feel alone.

The help from being able to compare notes with others in the same medical boat has been invaluable.

It MUST be remembered that the disease produces erratic symptoms.

What support are you currently receiving from others with FMS? How would you describe the support you want from them? How can you improve your communication with these similar others?

Health care providers

With a chronic condition like FMS, the physician-patient relationship is particularly important. Because there is no definitive cure, the relationship may have additional strain. There are

helpful treatments, however. The journey of finding what is helpful for you may tax relationships with health care providers.

The study participants with endometriosis wanted health care providers to listen to them, believe them, be knowledgeable about endometriosis, provide information, not have a condescending attitude, and to recognize that each woman is an individual. Representative comments from participants about health care providers follow:

Take their symptoms seriously. This is not a disease that is in their heads.

Don't minimize their problem and/or feelings.

I want them to do their reading, keep up with journals, go to conferences, and stop blaming patients for diseases which as yet are idiopathic.

I think it is crucial that physicians let women have a say in the care they are given. Give them the options, tell them the pros and cons (and for crying out loud be HONEST about it!) and let them decide which option is best for them.

How would you describe the support you want from your health care provider? If you are not getting that, try talking to your provider or switch providers. Contact your local FMS support group for the names of practitioners in your area who are familiar with fibromyalgia syndrome.

Related Research

In general, research has found that social support is an important factor in coping with other chronic medical conditions. While identifying an association between variables, it does not necessarily indicate cause and effect. The following are overviews from several studies.

A study examining the coping resources of 54 women with premenstrual syndrome (PMS) found that the more one has access to and uses a network of caring others, the less the severity of PMS (Warren & Baker, 1992). Another study of 125 women with chronic illness--either breast cancer, fibrocystic breast disease or diabetes--reported that the higher the women's perception of affect and affirmation from her partner and family members, the better her self-reported marital quality and family functioning and the lower her illness demand and depression (Primono, Yates, & Woods, 1990).

A study of 158 women with diabetes mellitus indicated that the higher the perceived levels of social support, the better the psychosocial adjustment to illness (White, Richter & Fry, 1992). Social support in that study was defined as including areas of intimacy, social integration, nurturing, worth and assistance. In addition, the study demonstrated that with lower levels of perceived social support, health was poorer.

Another study examined 521 chronic pain patients and found that patients who described their families as supportive reported having less pain intensity, less interference from pain, less reliance on medication and greater activity levels than patients who described their families as

non-supportive (Jamison & Virts, 1990). Overall, this research on social support indicates an inverse relationship between social support and illness factors, with increased support associated with decreased problems from illness.

House, Landis and Umberson (1988) reviewed other studies that looked at social support and mortality. They noted that mortality for both men and women can be predicted based on their social relationships and that lower mortality rates are associated with a higher level of social integration. These authors go on to state that the level of social integration appears to be a stronger predictor of mortality than cigarette smoking. (House, Landis & Umberson, 1988). In general, the cited research results indicate some health advantages to having a supportive social network.

How can this research be helpful to you? It may inspire you to seek more supportive relationships. I have included it with that hope. I think there is a certain dilemma with mind-body research that may lead to an over-psychologizing of illness. There is a potential blame trap. Thinking that, "If I had only done something sooner or had done something better, I would not be sick", is self-blaming and not helpful. Doing all you can to survive and feel better is quite different. I hope that I have inspired, as was my intent.

Summary

Fibromyalgia Syndrome is a chronic stressor in our lives and is likely to affect our relationships. Like other human beings, we need those relationships and can contribute our part. Consider discussing mutual needs and wants with people in your support network. It is no surprise, that research suggests that social support is an important factor in health. Snow White might not have had fibromyalgia, but you can realistically have good, supportive relationships outside of fairy tales.

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