WHOLISTIC HEALING PUBLICATIONS

THE INTERNATIONAL JOURNAL OF HEALING AND CARING

WHOLISTIC HEALING PUBLICATIONS

WHOLISTIC HEALING RESEARCH

September 2002 **Volume 2, No. 3**

Illness as Tranformative Gift in People with Fibromyalgia

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ABSTRACT

This qualitative study focused on chronic illness as a transformative mechanism to a more authentic self. Through grounded theory analysis, taped interviews with 8 subjects were coded for process, and 10 components were found to be associated with the central category, "transformation to a more authentic self."

Eight subjects volunteered to be interviewed for this study through snowball sampling and had answered affirmatively to the concept of illness as transformative gift. All had been officially diagnosed with fibromyalgia syndrome (abbreviated as FM or FS) and had had FM for at least 3 years. FM, a rheumatologic disorder associated with widespread musculoskeletal pain, is diagnosed by assessing tenderness upon palpation of at least 11 of 18 tender points. Also present may be chronic fatigue, sleep disturbances, irritable bowel syndrome, cognitive impairment and other symptoms.

Through grounded theory analysis, ten components of their process to transformation were delineated in association with the central category, "Transformation to a more authentic self." The components emerged under five general areas: Somatic changes, Emotional changes, Mental changes, Spiritual/religious changes, and Social changes. They include: 1) Develops somatic awareness; 2) Makes healthier life choices, 3) Maintains positive stance, 4) Reviews past and present psychological life, 5) Becomes self-authority, 6) Develops ability to gain broader perspective on healing process, 7) Supports psyche-soma connection, 8) Develops spiritual or religious life, 9) Expresses gratitude, and 10) Becomes teacher/mentor for others. One additional finding was that the onset for the majority of cases was preceded by an identifiable trauma.

Although not the original intent of the study, the majority of subjects (7 out of 8 within a year of the completed study) considered themselves no longer suffering from FM, despite an average of 5 years of pain. Each one of these subjects was able to get out of unremitting pain and fatigue, through various methods. Given the fact that this syndrome has no known cure, this is distinctly noteworthy. Five of the eight subjects are now living fully functioning lives, having resumed full life activity free of pain. Two others have almost no symptoms. All are committed, in any case, to continuing their journey to wholeness, having changed their lives considerably.

Introduction

This study focused on how some persons with fibromyalgia syndrome (fm), a chronic, disabling illness, have come to see their illness as a positive mechanism for transforming their lives. The hypothesis was that there are some individuals who have found meaning through working with their illness, and have made changes which ultimately have enriched their lives, despite ongoing symptoms. How they arrive at this attitude, that there is some meaning above and beyond the sickness itself, was the focus of this qualitative study.

"FM is a common rheumatologic condition characterized by widespread musculoskeletal pain, stiffness and tenderness at specific anatomic sites, known as tender points. The pain in fibromyaglia is experienced primarily in muscles, although other areas are also affected, including in and around the joints, ligaments, tendon insertions, subcutaneous tissues and bony prominences. Fatigue and disturbed sleep are commonly present. There is no known etiology, nor are objective pathophysiological abnormalities associated with FS. FS patients generally experience a greater degree of psychopathology and medically unexplained somatic symptoms than do patients with other chronic pain conditions. However, it has not been established whether psychological factors are causes, concomitants, or consequences of FS" (Eisenstat, 1997).

Research Question

How do people with fibromyalgia use this chronic syndrome as a mechanism for transformation in their personal life? The study demonstrates part of the process by which some people with fibromyalgia have been transformed through their struggle with this chronic illness.

Importance of the Study

"In 1990, the term 'fibromyalgia' formally entered the medical lexicon. Now, ten years later, nearly six million Americans are said to be suffering from fibromyalgia – more than four times as many as will develop cancer this year, and six times as many as are living with HIV. Ninety percent of the afflicted are women, and the majority are Caucasian. Many cases follow a traumatic event, such as surgery, but others have no apparent cause" (Groopman, 2000). In total, 9% of Americans suffer from chronic pain, and experts say four out of every ten with moderate to severe pain do not get adequate relief (Neergaard, 2000). Clearly, fibromyalgia and other chronic pain syndromes are costly - to the medical community, to our society as a whole, and most of all to the individuals with FM and their families. It is costly not only financially, but also emotionally, socially and mentally. Chronic pain puts people in a challenging position. They can no longer fully function in society, and yet the world goes on moving while they are immobilized. Understandably, they can feel overwhelmingly helpless and frustrated.

Unfortunately, the medical community is at a loss about what to do. "During the late 80's and 90's, a group of researchers… monitored more than 500 patients who were receiving care at some of the top fibromyalgia centers in America. After seven to ten years, there was no significant diminution in pain, psychological distress, or degree of disability" (Groopman, 2000). "One doctor referred to these patients as 'the bane of the medical profession'" (Groopman, 2000). Many sufferers seek help in the maze of alternative medicine, with varying degrees of success. This syndrome is a mystery. And yet some have overcome FM, and now live pain-free, energy-filled lives. How did these unique individuals do it? What can we learn about healing through their example?

METHODS

Research Design

This study is a qualitative study, using grounded theory (Glaser and Strauss, 1967: Strauss and Corbin, 1998). Grounded theory enables the researcher to work with suppositions, which change and evolve as the study progresses. The dynamic nature of doing qualitative research was most valuable to exploring this question.

Participants

Participants were seven Caucasian women and one Caucasian man between the ages of 32 and 60 (mean 47). Subjects were included in the study with the following criteria: having had FM for at least 3 years, and answering affirmatively to the question, indirectly asked (so as not to bias or shape their responses about this factor), whether she had experienced a positive transformation through the experience of dealing with this chronic syndrome. All had been officially diagnosed with the chronic rheumatologic condition fibromyalgia. Three of the subjects (37%) had experienced symptoms of FM for over 20 years, two (25%) for 18 years, one (12%) for 9 years, and two (25%) under five years. At the time of this study, three subjects were married, three divorced, and two single. One had four children, three subjects had two children each and four subjects had never had children. Previous to their problems with FM, seven of the eight subjects had been working full-time. Currently, only two were working full-time, with three holding part-time jobs, two being full-time students, and three being part-time students. (One person is a full-time student and also works part-time.) Two of the subjects were unable to work at all at the time of the interview; one year later both are functioning again, both going to school part-time.

Results of the current study were obtained by analyzing interview transcripts with grounded theory methodology, as outlined by Strauss and Corbin (1998). Interview sessions took place at a private location set by the participant. Sessions lasted from one to three hours, most taking about two hours.

Sampling Procedure

Snowball sampling is “the method (that) yields a study sample through referrals made among people who share or know of others who possess some characteristics that are of research interest” (Biernacki, 1981). In this case, my first subject, a fellow graduate student, had been involved with the fibromyalgia network in the mid-West for many years, and thus is connected with others who are of like mind. The first subject had been a CEO of a hospital in the mid-West prior to developing FM. Her FM started after a bout of mycoplasma pneumonia. After struggling to continue her job for two years, she eventually quit, as her ability to work effectively had decreased significantly due to cognitive and energy deficits. In her journey toward recovery, she tried various standard medications, such as Klonopin (for anxiety), until she finally achieved a full remission from FM working with psychological kinesiology (using muscle testing to validate therapeutic inverventions) three years later.

She had networked extensively with other FM sufferers in the mid-West while searching for approaches for dealing with her FM, and it was through the few people she felt would fit the criteria of this study that the snowball sampling started. From the first two names, others who had transformed were recommended and contacted for interviewing. In the end, five people connected with this first subject were used for this study.

While this approach provides a focused method for sampling, its drawback is that this is not a representative sampling of all adults in the population.

Data Collection Procedure

Initially, each subject found through the snowball method was given an introductory letter.

Once the subject had qualified for the study, an interview was scheduled and the researcher obtained an Informed Consent form from each subject, and gave the subject a Confidentiality Statement. The interviews lasted from one to three hours and were tape-recorded. Notes were also taken during the interview. The questions asked were followed by discussion in an open-ended manner, and the participant was allowed to deviate from answering the questions concisely. This study had been approved by the Human Subjects Review Board at the California Institute of Integral Studies prior to the onset of interviewing.

DATA ANALYSIS

Methods

Grounded theory includes many steps. According to Strauss and Corbin, "In open coding, the analyst is concerned with generating categories and their properties and then seeks to determine how categories vary dimensionally. In axial coding, categories are systematically developed and linked with subcategories. However, it is not until the major categories are finally integrated to form a larger theoretical scheme that the research findings take the form to theory. Selective coding is the process of integrating and refining categories"(Strauss and Corbin, 1998). It is important to note that this research focused on process rather than on a single phenomenon. Thus, a slightly different methodology was used, eliminating the development of properties and dimensions. However, all three steps were followed as prescribed by Strauss and Corbin.

Analysis

Open coding techniques were used to generate initial categories. In all, there were 151 codes developed under open coding for this study. Then, these categories were clustered through axial coding into the following three groups: *Conditions*, including causal, intervening, and contextual, *Action/Interactions*, including routine and strategic, and *Consequences*. There were 79 codes used for axial coding. Then, in the final step, selective coding, 10 associated components were found around the central category. These steps follow those outlined by Strauss and Corbin (1998) in order to unfold a process. (A more detailed analysis of the process is available upon request.)

RESULTS

In "transformation to a more authentic self," ten components of change emerged as central to the process. There were five overall areas of change: somatic, emotional, mental, spiritual/religious, and social. Under these arose the following: 1) develops somatic awareness; 2) makes healthier life choices; 3) maintains positive stance; 4) reviews past and present psychological life; 5) becomes self-authority; 6) develops ability to gain broader perspective on the healing process; 7) supports psyche/soma connection; 8) develops spiritual or religious life; 9) expresses gratitude and 10) becomes teacher/mentor for others. These will be discussed in detail shortly.

FROM AXIAL TO SELECTIVE CODING

Central Category - "Transformation to a More Authentic Self"

Subject learns who she really is, as opposed to what societal or familial expectations had led her to be, and lives her life from that place.

> *Example:* "I've just really had time to discover who I really am and what I want, as opposed to what I guess I thought everybody thought I should be my whole life. So, I was very good at big business, and what I really wanted to do was work with teenagers. I was really good

> at big business, and I moved out here and it became something I had to do to stay alive, and I was good at it, and I just kept growing and after twenty years, it took its toll and I needed the time to figure out that that was not where I was going to be at all. So that's been heavenly for me, and just in this past weekend I had a huge opening about what my life is, what I'm here to do, and it's a really full circle kind of thing. And now I'm just figuring out how to do it, and take care of myself at the same time and continue to receive what I needed to get well, as well as create my vision…that's a balance." (Subject #2)

> "I started to get to know me through FM, and it has brought me to a new place. The person who I was when I was in pain, the person I was even two years ago, I'm not that same person anymore. I've been changing all along, and I'm still changing." (Subject #8)

Discussion: This central category, "transformation to a more authentic self", contrasts with what might have been expected, for example, perhaps 'transformation to a pain-free life'. This is a significant finding. All the subjects were not focused on the chronic illness per se at this point, but rather on developing themselves as individuals on their unique paths. If they still were in pain, then they felt this was a signal that there was more work to do. And, even still, they were working on themselves in a continuing manner to express themselves fully in the world, with or without pain.

Somatic changes

Develops somatic awareness

Subject becomes more in touch with what her body is trying to say through ongoing attention. Now responds to somatic pain by looking at psychological elements of her life which may be interfering with her continued well-being.

> *Example:* "I do think that the path of healing is to get more and more connected to yourself, and that a lot of disease comes from being disconnected. So it's first connected, and then creating a life out of that, and these diseases force you to get real, force you to get cured, to get to know who you are. I think there are certain ones of us that get pushed more than usual. To do that, I know that many things I never would have done but the pain just put it to me to get to my center. I guess that's the positive." (Subject #7)

Discussion: Many elements have been studied over the years in relation to FM, such as sense of coherence, locus of control, and optimism, among others (Astin, 1999, Herman, 1992, Peterson, 2000). What has not been studied in health psychology, however, is a person's relationship to her awareness of her own body. Here, the subject listens to what her body is trying to tell her. It is more than simply adjusting to her new limitations, it is a step beyond. It means responding to her somatic pains by looking at psychological elements of her life which may be interfering with her continued well-being. This can range from simply expressing herself more directly to her loved ones to changing careers or even to getting a divorce. The most important aspect of this category is looking inside at what the somatic clues are indicating.Makes healthier life choices

Subject changes elements of his everyday routine, including developing consciousness of his diet, awareness of an exercise regimen, commitment to stress reduction practices, and often reprioritizing where to spend his energy, at work, home, etc.

> *Example:* " I just couldn't think of a way to spend my limited energy than trying to do more of that crap. (CEO of hospital) So, I ended up cutting a deal with them, and in 199-, I quit and took a package which gave me a year and a half of severance." (Subject #1)

Discussion: This is the area most examined by allopathic medicine (Buckelew, 1998, Turk, et al 1998, Keel, et al 1998, Bennet, et al 1996). Needless to say, exercising as possible, eating well, sleeping well, and working on stress reduction are all components of good health. It is

useful to note that the subjects all made some positive changes in this area; however, it seems this alone was insufficient for a shift into full remission as evidenced by those (500 patients) who went through standard FM protocols and yet did not get better (Groopman, 2000) .

Emotional changes

Maintains positive stance

In an ongoing manner, subject has held hope for a positive, pain free future despite considerable setbacks.

> *Example:* "I think that having a positive outlook is important. I don't believe in being sick. I don't believe in taking medications, those are huge. I believe your attitude dictates. It's kind of like, you are what you think, thing. You know? It's a bit simplistic, but I think that the attitude determines so much in your life, about who you are, and I think that I was given and born with a very positive attitude, and that's huge to me." (Subject #6)

Discussion: "Maintains Positive Stance" is akin to the concept of 'hope' or 'positive expectations,' used in various studies (Cousins, 1981, Hafer, 1996, Forbes, 1998). "Researchers know that across a wide range of illnesses, patients who think they will feel better are more likely to do so. Expectation operates more specifically as well (Brown, 1998). It seems that maintaining the belief that one can get well is an essential component of recovery, as depression and hopelessness are associated with a negative prognosis (Alfici, et al, 1989, Birnie, et al, 1991).

"Dossey documents many cases in which the way a patient frames or imbues meaning about disease, hospital experiences or patient-physician interactions leads to apparently immediate or complete changes in disease status, for better or worse, and regardless of the 'real' facts of the situation as defined by allopathic medicine. Perhaps through psychoneuroimmunology or psychophysical pathways, operating under a set of optimistic or health-influencing beliefs, or simply expecting a healing or miracle or response to prayer may be enough to heal" (Levin, 1996).

Reviews past and present psychological life

Subject has undergone extensive psychotherapy, looking at the roots of her emotional issues and reconfiguring her life accordingly.

> *Example:* "It meant getting constricted work out; it meant getting constricted relationships out. It meant working a lot with my own psychology; I do a lot of EMDR. It meant diffusing a lot of old stuff that was in me. Switched work, switched location, switched my inner life." (Subject #7)

Discussion: "Reviews past and present psychological life" is akin to psychotherapy. Two studies (Keel, et al, 1998, Bennett, et al, 1996) also found psychotherapy to be useful to patients with FM. Indeed, as high frequencies of traumatic history have been found in those with FM (Amir, et al, 1997, Boisset, et al, 1995), it is not surprising that addressing some of these issues might be useful. In fact, six of the eight subjects had identifiable trauma preceding their onset of symptoms. It remains to be clarified whether trauma contributes to the development of FM or is a chance finding in this population sample. In fact, trauma literature reveals a possible correlation between trauma and chronic pain syndromes (Levine, 1997, Bernhardt, 1992, Butler, 1996).

Mental changes

Becomes self authority

Subject now references her life choices from within herself instead of giving her authority to others. However, this does not preclude working with knowledgeable professionals that she chooses.

> *Examples:* "Empowering yourself, getting out of dis-empowering things no matter what they are, whether it be work, whether it be a relationship, a problem with the medical system. Or a component of doing both, but emotionally, I'm quite a rebel, even though I work with it a lot, in terms of prognosis, I never, ever bought the prognosis." (Subject #7)
>
> "So I'm convinced that the question is whether we've been so snookered by this society that you don't have to take responsibility. You just find a therapy, a pill, something that you don't really have to own up to, that it's not me, it's them, and that's just not going to fly, and if there is a way that I could help convince people that they didn't have to change that way, life could change, and they could be better." (Subject #1)

Discussion: In becoming self-authority, the subject now references her life choices from within herself rather than from an outside authority, such as a medical professional, husband/partner, conventional role or societal expectation. This is a key component to transformation, as it relates to taking full responsibility for one's condition, rather than holding to the belief that it has to be this way because of an external locus of control (Buckwald, Garrity, 1994), or – more accurately - to an internalized perception of an external locus of control. After many frustrating experiences with conventional medical interventions, and being told there was no cure, these transformers said, "I don't believe that" and proceeded to find their own ways back to health. They made good use of outside experts in their search for wholeness. They knew they didn't have all the answers, and searched until they found people who could help them find the answers for their situation.

It is important to note that each of the five subjects who transformed the most found her own, unique path to healing. Subject 1 worked with a healer who used many methods, including psychological kinesiology. Subject 2 used extensive psychotherapy and energy healing. Subject 3 used psychological kinesiology. (Subject 4 did not transform, and was an outlier in this study.) Subject 5 used theophostic ministry work, (a reflective process similar to psychotherapy, combined with a spiritual component), together with Monroe tapes to help her shift her sleep cycle (delta sleep tapes). Subject 6 used psychotherapy, shamanic work, and regulated work-outs with a trainer to regain her muscular strength. Subject 7 used EMDR, as well as shamanic healing. Subject 8 felt that Jesus had healed her, through her hands-on healing work and theophostic ministry work. Each found the unique solution to regaining her sense of health. Most importantly, each employed a more proactive stance, receiving guidance as well as working with the issues at hand.

Develops ability to gain broader perspective on the healing process

Subject is able to step back from her personal situation to theorize how her healing, others' healing and community healing may occur. Able to see complex interactions and allow for inconsistencies.

> *Examples:* "I've talked to so many people with FM, so many, and usually when you get to talking with them, and really get honest, there's something in their lives, and most of the time they're aware, that they know is putting pressure on them, and that they don't think that they can or want to deal with." (Subject #1)
>
> "I think I'd like to let people know that if they're not ready to be well, they're not ready. And let their life happen, and they'll be ready eventually. You only want to take so much pain in

your life. Because it's basically some kind of emotional pain, that's why it's happening in the first place. I believe that is true. And that once they determine they're ready to be well, they'll find whatever it is, whether it be Monroe tapes or some other kind of way for them. But there is a way to heal and be well." (Subject #5)

"Actually this is a process, and if you can keep that in mind that there's something bigger at work here, then maybe you can go into it open to learning what that something bigger has to teach you." (Subject #2)

Discussion: "Develops ability to gain broader perspective on the healing process" means that each was able to step back from her personal situation to theorize how her healing, others' healing, and community healing may occur. This included being able to see complex interactions and to allow for inconsistencies. This may be considered akin to developing an overriding framework for their life stories, creating new meanings in and for their lives. This development of meaning in their lives through the illness itself has also been explored by Jankey (1998).

Supports psyche/soma connection

Subject develops an ability to interface with her mind, body, emotions and spiritual life to make ongoing life choices which reflect her whole being.

Example: "So now I will rest more; I do not work as hard in my home on the details. I still try to maintain, but I just do as needs to be done. And what needs to be done has greatly changed; my perception has changed. Things do not need to be in perfect order all the time. I try to do more for myself than I did before. I tend to exercise more, as far as, if I want to go for a walk, go jogging, I'll do it. If something else could be done, well, the walk precedes it. Things do not disturb me to the level they did before, I think that I have more patience." (Subject #8)

Discussion: The subjects were no longer in pain yet still listened carefully to what their bodies and emotions were saying, even years after they had become pain/fatigue free. They felt that they were on a life path to discovering themselves, and thus it became an ongoing process. All still went to psychotherapy on a regular or as-needed basis. All continued their spiritual practices, and worked on living daily from their new-found world view. This was not simply a case of getting better and returning to their former life. This was a deeper transformation. They were changed for life.

Spiritual/religious changes

Develops spiritual or religious life

Enters spiritual life in a new way, whether by having a faith, belief or awareness reconfirmed, redirected or entered into for the first time in an ongoing way.

Examples: "And I truly believe, and you can use the term God, which I'm going to use, because that's my belief system, for somebody else it might not be that. I do not believe you're on the path you're supposed to be when you have a chronic condition, a chronic illness, I mean. I've got to think that there are some things that happen out there just because they do, and they've been exposed to a chemical, there are things, you know, there are things that happen, so I'm not trying to say it's across the board. But we're not listening, and we're not in the path we're supposed to be, and we're not listening. And God will find a way to wake us up and have us listen." (Subject #5)

> "I guess it's my personal evaluation that it was the power of Jesus Christ that brought healing to me. I feel like there were stages that I went through in the healing process, and I think for my own self, God wanted me to get more in touch with myself, before there was no more pain. I needed to understand how to be responsible about resting properly, and not doing too much, and taking better care of myself. And then I needed to go through a place of forgiving myself. I don't remember the exact time, it just seemed like an evolutionary process. And as far as laying on of hands, you know, I would do laying on of hand sessions here and there with people, myself. And I suppose it's my understanding that when I would do laying on of hands for another person who might need it, that maybe God was also blessing me by giving me additional healing as well. How He did that, I have no idea. It seemed like a process of me,just, I guess, starting to get to know me, as crazy as that may sound." (Subject #8)

Discussion: "Develops spiritual or religious life" is also not a new concept, and has been studied extensively in relation to health (Hafen, et al, 1996). Although the researcher was surprised at this finding, religiosity and spirituality have consistently been found to be positively correlated with well-being (Levin 1999; Koenig 2001; Mellors, 1999). "Of all aspects of the person, the spiritual dimension has received the least attention in contemporary western medical thinking. This omission is ironic, since western medicine, like other healing traditions, originated within spiritual institutions and continues to have much in common with them" (Hiatt, 1986).

<u>Expresses gratitude</u>

Feels and expresses gratitude for the process through which he has learned so much

> Examples: " I can't believe I'm going to cry about this, but I'm really grateful I've had this condition. I'm so grateful because it has changed my life. I am so grateful for it And I'll always be grateful for it." (Subject #8)

> "I have a whole different appreciation for being alive. And I weigh things differently. However, there's part of me that's almost lost. I mean, you are losing part of yourself, I mean, that was who you thought you were, that's who you were for a long time. So there is that loss. But mostly it's good loss." (Subject #6)

Discussion: "Expresses gratitude," may be considered as part of religiosity, making meaning, or holding hope. However, it seemed important enough to have in its own category, as this particular concept is one not found in health psychology studies on FM. Finding gratitude for having an illness from which they suffered an average of 9 years may be difficult to understand, and may even seem shocking at first glance. This is not an entirely new concept, and seems more associated with other, shorter illnesses, from which people recover with a new world view. It was particularly poignant, given the lack of support they found from most of the medical community and from the community at large, in their extensive searches for help for their long-term suffering - . The forgiveness and letting go implicit in their gratitude is distinctly noteworthy.

Social Changes

<u>Becomes teacher/mentor for others</u>

Takes lessons learned from experiences with FM and directly or indirectly uses wisdom gained to help others; gives back to the larger community what she has learned personally.

> *Example:* “Because it’s almost like, those of us who have been given this FM, who have transformed, I look at us as being the teachers. Because if we’re here we need to teach what we’ve learned, because guess what, there are a lot of people in line for this.” (Subject #6)

Discussion: Finally, under Social Changes, the subjects became official or usually unofficial “teachers/mentors for others.” Again, this is a concept not addressed in the FM literature at all, nor generally in health psychology studies. The concept is not a new one, however, and is evident in the structure of Alcoholics Anonymous, for example, where there are guidelines for sobriety, and peers rather than leaders to help in their healing process. Wanting to give back to the world what one has received and learned is human nature. Perhaps it reinforces what one has learned, as well as a way of repaying your debt of having received help by helping others who are going through what you yourself have suffered and struggled with.

> *“My belief is in the blood and flesh as being wiser than the intellect. The body-unconscious is where life bubbles up in us. It is how we know that we are alive, alive to the depths of our souls and in touch somewhere with the vivid reaches of the universe” (D.H. Lawrence as in Levine, 1997).*

SUBJECT COMPOSITE

A composite of a subject who transformed might be look like this:

“Georgia” experienced the trauma of a car accident and initially felt the recovery was slow. However, after a period of time, the symptoms continued and worsened. She had trouble sleeping, had inexplicable aches and pains, was fatigued and had irritable bowel syndrome, and cognitive problems. She ignored this for awhile, but then sought out conventional medical help.

The doctor told her it was all in her head, or perhaps, if she was lucky, she was diagnosed with fibromyalgia within a few years of suffering symptoms. The doctor told her there were some medical treatments to help alleviate the pain, but no cure has been found.

She tried some medications, and after a while felt the side effects were worse than the help they gave, if any. She had cut down her job responsibilities, and then quit work altogether due to the constant pain and fatigue. She began to wonder if she was crazy. She started seeking further options, and went to alternative practitioners for help. She tried acupuncture, chiropractic, vitamins, energy healing, and other forms of healing. Despite some relief, the effects did not last, and she realized these were only temporary cures.

She had to search further, and decided to explore psychotherapy. Through developing a greater degree of awareness and understanding about the emotional aspects of her FM, she realized she was resentful about certain aspects of her life, and changed her agreements with her spouse, family, coworkers, and boss. She learned to speak up for her real needs, and began to see the outside world’s requirements for “being good enough” as irrelevant to her new sense of self. Only what she wanted started to matter, not her roles in the world. She had been trying to exercise, but it often made her worse, and then she had flare-ups from which it could take weeks to recover . Psychotherapy helped somewhat, but she needed something more.

So she went to an alternative practitioner who combined talk therapy with cathartic release (such as psychological kinesiology or theophostic ministry). This helped her release old, pent-up emotions and also taught her HOW to listen MORE EFFECTIVELY to what her body was telling her. She began to realize there may have been a purpose to all this; that this may have been part of a larger picture - and reaffirmed her faith and developed a spiritual connection with something larger than herself.

Through these various methods, she learned to trust herself more than any outside authority, and developed a theory as to why shehad gotten sick and how to get better by herself.

She started to get better, slowly, and continued to work on her life, continuously checking in with her body and psyche about every decision. She grew ever stronger in her realization that she could no longer afford to do things solely because shewassupposed to, and finally felt that she was on a path to being her true self.

She worked with her spiritual side as well, in order to gain the support and confidence she needed to do her real work in the outer world from a place of spiritual centeredness inside herself.

As a result of the wisdom gained through this process, she became a teacher for other FM sufferers, in both informal and formal settings. Through this or a similar process, she developed ways of repaying the world for the gifts she had received. . A

Finally, she came to a most unanticipated place - expressing gratitude for this illness which had given her so much, in so many ways, on so many levels.

DISCUSSION OF FINAL RESULTS

Could it have simply been a placebo effect? “Success of religious healing is greatest where there is a great psychological involvement in the illness, where the disorder is primarily of a psychosomatic or hysterical nature” (Mc Clenon, 1997). Certainly, many studies on FM have suggested that FM is psychosomatic in nature (Wolfe, et al, 1984, Celiker, et al, 1997). Then again, maybe it was their stubborn hold onto hope for their eventual recovery. Is that all this process is, simply a variation on the placebo effect?

There is absolutely no way of knowing the answer to this question, but if it is relevant, it took up to nine years, in one case, for the placebo to take effect. Pain and fatigue had been well established at that point. In one study, people suffering from short-term depression lasting less than three months were more likely to benefit from a placebo. But longer-term depression, lasting more than a year or so, often did not improve after placebo treatment (Brown, 1998). The least amount of time a subject in this study suffered the FM syndrome was three years. Thus, the patterns should have been well-established in the system and a placebo effect is a less likely explanation.

In case of placebo effect, having a sense that a condition is known and controllable is often key. In one study in England, only half as many subjects (39% vs. 64%) receiving a placebo recuperated when they were told that the cause of their ailment was unclear, compared to others who received a clear diagnosis and reassurance from their doctors (Brown, 1998). How might this apply to people with a diagnosis which is unclear, and in many cases even doubted? Fibromyalgia is an unclear diagnosis. There are many symptoms, and even the verified ones, such as tender points and fatigue, are still debated. Sufferers can take years to even find someone who can diagnose it, and then when they are diagnosed, there is no known conventional cure or remedy. This, in and of itself, may exacerbate the condition.

Another possibility is that these subjects may be merely in temporary remission. It is true that they went through psychological work, and transformed within themselves, but still, it is possible that at a certain point, something changed and some variation on the theme of a placebo, or self-healing effect occurred. If so, the findings of this study lead us to ask, “Why not try to help as many as possible with this effect?” As Brown (1998) observes, “If physicians can see placebos – like many conventional drugs – as broadly effective therapies, whose mechanisms of action are not completely understood and which tend to be more effective for some conditions than others, they can then offer placebos both honestly and as plausible treatment.”

The snowball sampling, as mentioned above, could have biased the results to indicate a stronger effect of spirituality as a causal factor in recovery from FM than may be the actual case in the general population.

Yet, in the end, do these questions matter? Empirically, the factors identified in this study combined to bring about significant changes in people with chronic illness, whose prognoses were not favorable for the dramatic improvements they achieved.* By changing their somatic awareness, by doing their psychological work and taking as good care of their bodies as possible, by standing up for their authentic truths, seven out of these eight people transformed themselves - from having a chronic, severely debilitating syndrome which has only rare success stories to being much more functional and in some cases even returning to being normal. This is remarkable, in view of the general natural history of FM.

It may be time to listen to the successes, rather than focus on the shortcomings of those suffering in chronic pain. In over 70 studies on FM, the common factors identified are overwhelmingly negative: trait anxiety (Celiker, et al, 1997); depression and loneliness (Bolwijn, et al, 1996); early life stress, negative paternal relationships and chemical intolerance (Bell, 1998); self esteem (Johnson, 1997); PTSD (Amir, et al, 1997); traumatic history (Boisset, et al, 1995); pain mechanisms (Nicassio, et al, 1995); pain threshholds (Lautenbacher, 1994); stress (Soderberg, et al, 1997; Krall, 1995); and the list goes on. Some of the studies have

been extremely useful in showing that FM does have neurological reality (Lautenbacher, 1994, 1997), and that certain treatment modalities are helpful (Holroyd, 1996, Budelew, 1998). Yet not one study asked the patients what worked for them, what their solution was, what meaning this had for them in their lives.

> ***In sports, one studies the successes and learns from them. Why not in health? What do we need to learn from the winners, those who see transformation in the midst of pain, and even without it?***

Each subject in this study learned new things through dealing with the pain of FM, and took the challenging path towards a greater authenticity, even when this required hard work and involved considerable suffering. Perhaps in this process the unimportant was weeded out, and their existentialist search for themselves began.

An essential final element for all of the subjects who transformed, a new and/or stronger connection to a religious or spiritual belief, was seen as a central outcome of their experience with FM.

Similar observations have been made about people challenged with cancer. “Various experiences of relationship with God (e.g. Presence) were related to more positive appraisals of the current cancer situation as well as to the greater use of the non-religious coping behavior of focusing on the positive… In fact, religious resources may be particularly relevant in dealing with situations of severe stress which involve an element of personal threat or loss such as in the case of illness” (Gall, 2000).

What does religion or spirituality do? The mechanism is uncertain, but it is clearly correlated with physical well-being and ability to deal with stressors in many studies (Koenig 2001; Levin, 1999; Mellors, 1999). “Prior research has found that absorption and hypnotizability have psychophysiological correlates, and that religiousness shows protective effects against morbidity and mortality. In light of this work, the present findings suggest that certain religious cognitions, emotions, or experiences may generate an internally focused state that enhances health and attenuates disease through self-soothing psychophysiological mechanisms” (Levin, 1998).

Whatever the psychophysiological realities, we need to work with people in chronic pain as individuals, not as statistics. In the course of working through their pain and fatigue, it seems they learn what their body and mind wants, and we as helpers can facilitate this process. As they journey into those dark places of emotional transformation, we can cry with them, applaud their courage, and support their new discoveries. As they speak their truths, and step out of their conventional life roles, we must respect and encourage their new life choices. The path to authenticity is not easy, but it may be required for regaining one’s full health - in body, mind and spirit.

Limitations

The sample size of eight subjects in this study (as in all qualitative studies) is small, but this is a limitation nonetheless. It might have been interesting to have interviewed only those completely out of pain, in order to make this study more uniform. However, the focus here was on transformation rather than on complete alleviation of symptoms.

The sampling method was snowball, which meant four of the subjects were introduced to the researcher by the first. Thus, five of the participants were loosely related to each other. Some of their beliefs and opinions could have been acquired through shared learning.

One subject (the outlier) did not fit the transformative criteria, despite a positive initial interview on the phone. While this at first seemed an issue, in hindsight it raised more interesting points than not, and upon reevaluation, it would have been useful to have had more subjects like her to compare and contrast. If this study were to be replicated, it might be useful to interview two groups, those transformed and those who were unchanged.

In addition, it seems that most of these subjects were more open to alternative medicine than may be the norm, although they may have come into that as a result of the chronic pain process itself. Thus, they may not be reflective of the average FM population.

The majority of subjects were female, with only one male subject. However, as 90% of FM sufferers are female, this seems reflective of the population.

Finally, participants may have answered the interview questions differently had they been interviewed by someone other than the researcher. Each person brings herself into a room with her, and so the subjects' sense of how to answer may have been somewhat influenced by the researcher's presence, holding her own particular point of view. Although the researcher has dealt with a chronic pain condition, she has not dealt personally with FM. Her first-hand knowledge, therefore, is missing, and her original second-hand knowledge was limited to her sister's experience. This could be seen as positive, as the researcher was more objective and removed from the FM phenomena in her stance. However, it also may have affected her view of the subjects as "othersince she herself had not experienced the syndrome. [This was taken into consideration. HOW?]*

Implications for Future Research

Studies in health psychology are frequently quantitative, and only one qualitative research project was found on the subject of fibromyalgia. Thus, doing a study using grounded theory was a clear contribution, and allowed the researcher to delve into the details of each subject's voice and story.

This qualitative research project uncovered interesting data that warrants further quantitative and qualitative study. The results found in this study differ from previous studies and may be considered provocative. Although specific factors of disease and well-being have been touched upon in studies, no-one has considered the process of transformation to health and authenticity which takes place in facing the illness of chronic fatigue syndrome. Studies have focused on factors associated with getting well, as sense of coherence, hope, expectations, locus of control, faith, etc. rather than on what the FM disease process is telling the person. In studying the experiences and views of those who transformed to a more authentic self, new information came forward which had not been identified previously.

Replications, particularly with larger numbers, are needed to verify the results. With more substantial numbers of subjects who had transformed out of this syndrome, one might be able to verify some of the components that worked for all. As in this study, however, we could anticipate that no one method of transformation or single answer to questions about the transformation process would probably arise.

Transformation is not an easy process, and is unique to each person. Clearly, having possible pathways delineated for those in chronic pain is helpful. Furthermore, in viewing the process differently, there may be less blame put upon the person herself as well as on the medical profession. FM, which until now has been perceived by patients and therapists as frustrating and daunting, may now be viewed with new attitudes. We can expand our ways of thinking in order to encompass the possibility of gaining authentic well-being through the process of working with a chronic illness.

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