

Key Points

1. Social researchers often use qualitative techniques to study and describe human behavior
2. Chronic pain researchers have identified a process termed self-organization, where some pain patients develop a new world view and changed value system
3. This study reviewed research literature to identify specific characteristics of this process
4. Found that self-organization occurs when patients are believed, have access to real resources, and take action and responsibility
5. The results are that such patients develop new identities, gain new insights, and become active participants in their care
6. Also found that time for self-reflection is important to achieving self-organization
7. Rehab nurses are well suited to help patients achieve self-organization

Definitions

antecedents - things which occur prior to an event or process, in this case, self-organization

attributes - specific characteristics of something, in this case self-organization

chaos theory - an area of systems research which examines how small changes can produce large, unexpected outcomes

consequences - results or outcomes of an event or process, in this case self-organization

qualitative research - a type of research which does not use numbers for data; usually involves in-depth interviews and observations

quantitative research - type of research which collects data in the numerical form which can be

How Some People Move Past Chronic Pain

March 20, 2006 -- A chronic illness like Chiari/syringomyelia, or more specifically, the chronic pain and loss of abilities associated with it, can have a deep and profound effect on a person's life. This publication has documented numerous physical, mental, economic, and even spiritual consequences of living with chronic pain. From high blood pressure, to destroyed brain cells, to bankruptcy, to divorce and depression, for many the pain and disability become all consuming.

However, this is not always the case. Some people are able to accept, adapt, and move on, no matter what their condition. How are they able to do this? What makes one person sink into depression and social isolation while another finds new purpose and a sense of spiritual awakening? Is one person's pain and suffering more severe than another's? Do some people have better support structures and access to more resources? While this is undoubtedly the case, it is also probably not the complete answer.

Diane Monsivais, a doctoral nursing student at the University of Texas, decided to look at the process of how some people are able to move past living with chronic pain and disease. For those who have either gone through the process, or are currently going through it, her results - published in August, 2005 in the journal *Rehabilitation Nurse* - may resonate deeply with their own experiences.

Because of the complexities of human behavior, social and psychological researchers often use what is called qualitative research in their work. Qualitative research does not collect data in the form of numbers or use statistics for analysis. Rather, qualitative research tends to collect information from open-ended surveys, interviews, and observations. Researchers will look for themes, trends, and concepts in what people say or how they act. While some people might argue that qualitative research is less scientific than quantitative research, when done properly, it can reveal deep insights into human behavior and thought. Ms Monsivais chose to use such a qualitative approach, specifically a concept analysis technique devised by Rodgers, in her study of how some people are able to move past living with pain and refocus their lives.

Previous work in the area of how people cope and adapt to chronic pain has led to an idea called self-organization. This concept recognizes that chronic pain and illness lead to disruptions and disorder in a person's life. This disruption is not isolated and living with chronic pain often leads to a series of further disruptions (many of us have experienced this as we discover more and more things we can't do). In an idea borrowed from chaos theory, it is believed that when this happens, a person actually becomes more sensitive to any type of disruption to the way they live their life. As the disruptions build, a person's life can seem chaotic (thus the overwhelming feeling that is expressed by so many). However, after a time, some people are able to adapt to this new state and essentially reorganize themselves. This process is called self-organization.

Self-organization can be defined as integrating continuous uncertainty into one's being so that it is accepted as normal. The result is that an individual creates a new sense of order and what is considered normal. Essentially, a person accepts the limitations and uncertainties associated with a chronic disease, adapts to the reality of their situation, finds new purpose in life, and moves forward. Interestingly, several studies have looked at this effect and have clearly identified a shift in chronic illness patients - suffering from a variety of diseases such as breast cancer, heart disease, and diabetes - to a new perspective on life, a new world view, and a changed value system.

However, the actual process of self-organization, and how these patients were able to transform, is not well understood. In her work, Monsivais examined the actual process of self-organization in an attempt to identify antecedents (things present prior to self-organization), attributes (specific characteristics of the process), and consequences (the results of self-organization).

To accomplish this, she searched the research literature from nursing, psychology, and sociology for studies dealing with chronic pain. She used the search terms chronic pain research, living with chronic pain, chronic pain coping, chronic pain adjustment, and chronic illness to identify relevant studies. From these studies she then extracted terms and phrases which could be grouped into antecedents, attributes, and consequences.

In her analysis, the antecedents she found were all too familiar to Chiari patients (see Table 1). Specifically she found the following features were common before self-organization: a time of chaos and confusion; difficulty finding someone to believe the pain was real; and feelings of a loss of prior identity.

She found that diagnosis often leads to confusion as people search for answers, wonder what will happen, and look for explanations of why it is happening to them. For many, this is a time of anger, anxiety, depression, and grief. Another common experience with the early stages of chronic pain is that no one else believes the pain is real. Since pain is often hidden, it is difficult for other people to understand what someone is going through. This

statistically analyzed

self-organization - in chronic illness theory, defined as integrating continuous uncertainty so that it is accepted as normal and a new sense of order is developed

cerebellar tonsils - portion of the cerebellum located at the bottom, so named because of their shape

cerebellum - part of the brain located at the bottom of the skull, near the opening to the spinal area; important for muscle control, movement, and balance

Chiari malformation I - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow

syringomyelia (SM) - neurological condition where a fluid filled cyst forms in the spinal cord

syrinx - fluid filled cyst in the spinal cord

confusion, panic, and lack of validation can lead to a loss of identity. Activities that were taken for granted before are no longer possible.

Yes, many Chiari patients have experienced what Monsivais found to be the antecedents of self-organization, but what is really interesting are the attributes she identified as accompanying the actual self-organization process: being believed by health-care providers, family, and friends; accessing resources; and taking action and responsibility.

She found that finding a healthcare provider who believed in their pain and illness was a critical first step for many along the path of acceptance. Similarly, finding providers who are experienced in dealing with these issues helped move the process forward.

Internally, she found that many who were able to adjust went through extended periods of self-reflection and in the end were able to visualize a new future and begin to establish goals. This in turn led to a more active role in managing their lives. Patients learned when to do certain activities, what activities to give up, when to ask for help, when to take chances, and how to focus on less painful activities.

The results, or consequences, for people who were able to accomplish this transformation were a transformed identity, new insights, and a more active, in-control participation in their care. Some people described the process as achieving a sense of meaning and coherence on many levels. Insights gained included a realization about what is important in life and an ability to let go of unimportant things. Patients described taking great pleasure in the little things of life and learning to enjoy a more relaxed lifestyle. For many, a new sense of purpose led to reclaiming a sense of control, especially in dealing with their illness and the healthcare system.

It is important to point out that while people can reorganize themselves to accept chronic pain and illness, symptoms and pain can fluctuate and acceptance can fluctuate with them. One patient summed this up by saying, "I may have come to terms with my illness in that I know I am probably stuck with it for the rest of my life, but I don't think I could say that I accept all the details [of it] all the time."

Monsivais believes that rehab nurses can play a critical role in guiding people through the process of self-organization and help them transform into a new way of life. If further research validates the process of self-organization it would be extremely valuable to apply it to those in the Chiari community.

Source

Monsivais D. Self-organization in chronic pain: a concept analysis. Rehabil Nurs. 2005 Jul-Aug;30(4):147-51.

Table 1
Antecedents, Attributes & Consequences of Self-Organization In Chronic Pain

Antecedents	1) Time of confusion 2) Difficulty finding someone to believe pain is real 3) Loss of prior identity
Attributes	1) Being believed 2) Accessing resources 3) Taking action
Consequences	1) New identity 2) New insights 3) Actively take part in health care

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