Self-Organization in Chronic Pain: A Concept Analysis

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The purpose of this article is to examine the concept of self-organization in chronic pain using Rodgers’ (2000) evolutionary approach. This article describes the antecedents, attributes, and consequences of self-organization in chronic pain. Self-organization in chronic pain may be achieved through the attributes of being believed, accessing credible resources, and taking action and responsibility. Self-organization occurs when the patient with pain develops a transformed identity, new insights, and is an active, in-control participant in care. Chronic pain is a common and costly problem, and recognizing the key attributes of self-organization in this condition is an important step in promoting positive health outcomes. Rehabilitation nurses play a key role in providing credible resources and working with the patient to take action and responsibility.

Chronic pain may affect 50 million people and costs more than $70 billion annually (Robbins et al., 2003). Unfortunately, healthcare professionals frequently undertreat pain (Jeffrey & Lubkin, 2002). Bedard (2003) states that there is discrimination against chronic pain patients in the healthcare system, and that women, racial and ethnic minorities, and the elderly are among those at greatest risk for undertreatment. Providers may perceive the pain to be simply a cry for attention. However, unrelieved pain may have negative health consequences, such as increased stress and pulse rate, delayed healing, impaired immune system functioning, decreased mobility, appetite and sleep disturbances, and suffering. It also may be linked to low self-esteem and depression (Bedard, 2003). There is a clear need to identify the factors that lead to a positive outcome for patients with this very difficult, and often ignored, condition.

Although chronic pain traditionally is not considered a “disease,” it is a chronic condition that must be managed well if a client is to function well. This article provides a concept analysis of self-organization within the experience of living with chronic pain in order to identify antecedents (things which occur prior to the process), attributes (certain characteristics or qualities of the process), and consequences (outcomes of the process) of this condition.

Review of Self-Organization in Chronic Illness

At the beginning of a chronic illness experience, uncertainty can cause disorder and chaos in the living system. This idea is derived from chaos theory and the concept of dissipative structures (Prigogine & Stengers, 1984). During this type of experience, fluctuations may lead to increased sensitivity to further fluctuations, so that disequilibrium seems chaotic. If the disequilibrium increases beyond a certain critical value, the system organizes itself into a wholly new pattern (Dombeck, 1996). This phenomenon is called self-organization, and can lead to new solutions (Dombeck).

Mishel (1990) defines self-organization as integrating continuous uncertainty into one’s being so that it is accepted as the norm, with the result that the individual has a “new sense of order.” The Reconceptualization of Uncertainty in Illness Theory (Mishel, 1990) added the concept of self-organization to the original Uncertainty in Illness Theory (Mishel, 1988) in an attempt to capture the process of living with a chronic, rather than acute, illness.

Uncertainty in chronic illness may create fluctuations in the personal system, and if the fluctuations go beyond what the person is able to tolerate, the system may become unstable. There are often complex and lengthy periods of adjustment to living with a chronic illness, and the adjustment period may involve reevaluating what is important in life, deciding where to spend one’s energies, and gaining an appreciation for what one has, considering how fragile life is (Mishel & Clayton, 2003). During the process of learning to live with, and adjusting to, a chronic illness, the system can then reorganize itself in multiple ways, until a new sense of order is formed (Mishel, 1990). This shift in thinking to a new sense of order is influenced by prior life experience, physiological status, social resources, and healthcare providers (Mishel & Clayton, 2003). Time for self-reflection is a critical component if this shift in thinking is to occur (Mishel, 1990).

Several studies have examined the process of living with uncertainty and have found the shift to a new perspective on life (Charmaz, 1994; Cohen, 1993; Fleury, Kimbrell, & Kruszewski, 1995; Mishel & Murdaugh, 1987; Nelson, 1996; and Nyhlin, 1990). Although these studies included patients with different disease processes (e.g., diabetes, breast cancer, and cardiac problems) and included both caregivers and patients, the one constant demonstrated across all studies was the outcome of a revised world view and a changed value system.

Because the literature is so diverse, the actual process of self-organization remains unclear. Identification of the process of self-organization within
specific categories of patients and diseases may allow specificities to emerge that will be helpful for anticipatory planning and guidance.

**Concept Analysis Method**

Rodgers’ (2000) evolutionary method was used to explore the concept of self-organization in chronic pain. Rodgers’ approach emphasizes that concepts are dynamic and evolving and not meant to be static. The activities for the evolutionary method consist of the following: (a) identify the concept of interest and associated expressions; (b) identify and select a setting and sample for data collection; (c) collect data to identify antecedents, attributes, and consequences; (d) analyze data; (e) identify an exemplar, if appropriate; and (f) identify implications, hypotheses, and implications for further development of the concept. The current exploration is meant to form the basis for further inquiry and development of self-organization in chronic pain.

**Identification of the Concept of Interest**

The concept of interest, self-organization in chronic pain, has been associated with the terms coping, adjustment, and adaptation. The terms transformation and expanding consciousness also were found to be associated with this concept.

**Sample Selection**

The target sample for the current concept analysis comprised qualitative and quantitative studies from nursing, psychology, and sociology that examined chronic pain. MEDLINE, CINAHL, PsychINFO, and Sociology Abstracts databases were searched. Terms entered were chronic pain research, living with chronic pain, chronic pain coping, chronic pain adjustment, and chronic illness.

**Data Collection and Analysis**

Each study was read initially to provide an overview of the paper. During a second reading, data were organized by clustering terms and phrases into groups that reflected antecedents, attributes, and consequences. These terms and phrases were extracted by asking key questions, including: “What happened before the patient received a diagnosis?” “What happened when the patient received the diagnosis?” “What facilitated movement toward a positive outcome?” “What hindered movement to a positive outcome?” and “What were the behaviors that patients exhibited when the outcome was positive?”

**Findings**

**Antecedents**

Antecedents of self-organization in chronic pain were categorized as (a) a time of chaos and confusion (see aforementioned discussion), (b) difficulty finding someone to believe the pain was real, and (c) feelings of loss of one’s prior identity. Initial diagnosis brought a time of chaos and confusion, with the patient desperately searching for a way to explain the experience (Asbring, 2001; Bullington, Nord, & Sjostrom-Flanagan, 2003; Groopman, 2004; Hellstrom, 2001; Kralick, 2002). Depression, anger, anxiety, and grief also often were present (Breen, 2002).

Chronic pain shows no apparent outward manifestations. Patients often suffer the disbelief of others regarding the reality their pain (Carson & Mitchell, 1998; Hellstrom, 2001; Lillrank, 2003; Seers & Friedli, 1996; Werner, Steihaug, & Malterud, 2003). Statements by patients with pain reflect this problem: “They didn’t answer when I said ‘Why have I got pain?’ “They were not concerned with how it affected me. Just shrugged when asked what can be done” (Seers & Friedli, 1996).

For the patients, these responses led to frustration and anger, which often intensified the pain.

Sensations of chaos also involve loss of identity, including what one used to be and what one used to do (Asbring, 2001; Bullington et al., 2003; Carson & Mitchell, 1998; Hellstrom, 2001; Morse & Carter, 1996). According to one individual, “As time passes I find certain things that I recognize from before, but the rest is actually new and it’s not me and I don’t recognize myself” (Asbring, 2001).

**Attributes**

Attributes of self-organization in chronic pain comprised three categories: (a) being believed by healthcare providers as well as family and friends, (b) accessing credible resources, and (c) taking action and responsibility. Finding a healthcare provider who believes the pain is real was an essential first step in moving forward (Carson & Mitchell, 1998; Hellstrom, 2001; Lillrank, 2003; Seers & Friedli, 1996; Werner et al., 2003). Having the problem identified gave patients a sense of control so they could begin to structure and reorganize the experience (Bullington et al., 2003). The diagnosis also helped family members to understand that the patient’s problem was real. If healthcare providers conveyed doubt about the legitimacy of the diagnosis, then support at home may have been lessened (Seers & Friedli, 1996). In addition, the patient’s perceived lack of credibility also undermined the patient’s self-esteem and dignity (Werner & Malterud, 2003).

Accessing credible resources was the second attribute, and these credible resources included professionals and other sources of support. Healthcare providers who have specialty training in working with chronic pain patients are able to listen and help the patient reflect on the situation in a way that allows the patient to move toward a positive outcome (Bates, Rankin-Hill, & Sanchez-Ayendez, 1997; Bullington et al., 2003; Davis & Magilvy, 2000; Neill, 2002; Paterson, 2001; Roberto & Reynolds, 2002; Roberts, Kent, Pryg, & Lewis, 2003). “If the patient’s voice were central,
the issues to be considered would not consist only, or even primarily, of medical options and prognostications. The issues would include the philosophic and ethical perspectives of the person, the person’s story or narrative, what the person hopes for, who else figures most prominently in what the person is facing, and how all these people together see the situation” (Chinn, 1996, p. vi). Kralik (2002) found that transition though chronic illness was facilitated by reflective processes. This reflection was enhanced by nurses who gained an understanding of the patient’s values and expectations. During the transition, it also was important that the patient received appropriate recognition and encouragement for progress through the transition.

Because of the complex nature of pain experiences, difficulties abounded when provider and patient did not share a common language (Roberts et al., 2003). But even when both spoke the same language, communication difficulties often occurred because healthcare providers might not have been well educated in chronic pain, and therefore treated it using an acute pain model (Seers & Freidli, 1996). Chronic pain is a multidimensional, biopsychosocial syndrome for which there may be no specific explanation that manifests with physical, psychosocial, and behavioral patterns (Breen, 2002) and calls for a very different treatment model than acute pain does.

Family, friends, and coworkers also were a part of the credible resources network. Supportive networks of people who are willing to work with the patient in the lengthy process of rehabilitation from pain are very important. Those patients who had social support reported stronger self-efficacy and saw everything more positively (Arnstine, 2003; Asbring, 2001; Davis & Maglivy, 2000; Dingley & Roux, 2003; Hellstrom, 2001; Seers & Friedli, 1996). An important part of what the credible resources provided was helping the patient perceive a better future through goal setting. Goal setting often was a motivating force that opened up the possibility of success (Bullington et al., 2001; Carson & Mitchell, 1998; Hellstrom, 2001; Kralik, 2002; McCracken, Vowles, & Eccleston, 2004).

Because perception of an illness and what it means influences patient reaction to the illness more than the actual severity of the illness (Paterson, 2001), perception of a positive future was encouraging in helping perform therapies and everyday routines when circumstances were difficult. Groopman (2004) states, “I pictured resuming activities so long gone. I imagined myself stronger, able to walk comfortably, to lift, to travel, to play sports. The power of possibility became too much to resist” (p. 157). Reaching into the future shows the patient is challenging the idea of being a person with an illness (Kralik, 2002).

Taking action and responsibility for one’s own health care, which is a part of self-management, is the third attribute. This attribute included learning when to withdraw from normal routines, when to ask for help, and consciously using comforting activities to make oneself feel better (Carson & Mitchell, 1998; Forbes, 1999; Neill, 2002; Paterson, 2001). Risdon, Eccleston, Crombez, and McCracken (2003) showed that taking control and focusing away from pain activities toward nonpain aspects of life moved the patient toward adjustment. Kralik (2002) showed that taking calculated risks, such as being assertive with healthcare providers when certain medical procedures were unacceptable, often were a part of the process. This attitude sometimes led to being labeled noncompliant by healthcare providers. However, management becomes more successful over time as patients learn a wider range of options to manage their illness and gain greater confidence the more they use them (Davis, 1992).

Consequences

Consequences of self-organization in chronic pain include: (a) transformed identity, (b) new insights, and (c) active, in-control participation in health care. The transformed identity includes an increased self-awareness about the interaction of body and mind (Asbring, 2001; Bullington et al., 2003; Davis & Maglivy, 2000; Groopman, 2004; McCracken et al., 2004; McWilliam, Stewart, Brown, Desai, & Codere, 1996; Werner et al., 2003). Bullington et al. (2003) described the healing process as achieving a sense of meaning and coherence on many levels, not simply the bodily level. Because chronic pain patients often rigidly compartmentalize different parts of their life and do not acknowledge how work, home, and other relationships can affect the mind/body relationship, much of the therapeutic work must emphasize the need for the patient to acknowledge that all aspects of life must not be denied but rather dealt with honestly, even if they bring about uncomfortable feelings. The end result is that the body is not a “thing apart” but once again owned by patient, emotions are experienced and accepted, memories are incorporated, feelings and sensations are felt rather than suppressed, and the self is connected to the past, present, and future.

New insights include formulating ideas about what is important in life and gaining the ability to let go of unimportant things, both of which reflect increased flexibility about the way one views the world (Bullington et al., 2003; Carson & Mitchell, 1998; Davis & Maglivy, 2000; Forbes, 1999; Morse & Carter, 1996; Neill, 2002; Seers & Friedli, 1996). Said one individual, “Everyone talks about the trifling things in the world, to enjoy them, but I have seen them as big things. Things like candlelight and the ticking of the clock. I sit at my kitchen table and just enjoy...these things in everyday life which one has never really thought about because they’ve just been so natural” (Asbring, 2001, p. 317).

A third consequence of self-organization is that the client becomes an active participant in making things happen and develops increased feelings of control for his or her health care (Davis & Maglivy,
Supportive networks of people who are willing to work with the patient in the lengthy process of rehabilitation from pain are very important.

Implications for Practice

Rehabilitation nurses often have the opportunity to have more frequent contact with patients and their families than other healthcare providers do (Miller, 2004) and therefore are well-positioned to facilitate the process of self-organization in chronic pain. Specific ways of facilitating this process are active listening and pattern recognition, which allow the healthcare provider to discern the patient’s goals and strengths, as well as the strategies patients use to manage their illness. This facilitation necessitates recognizing that the patient is an expert on his or her own life (Cowling, 2000). It also requires the healthcare provider to recognize the wholeness of the person instead of labeling the person as a chronically ill individual living with limitations (McWilliam et al., 1996). It is also important to evaluate how the patient is measuring success by understanding what is important to the patient. Active listening and pattern recognition necessitate a tolerance for situations that cannot be “fixed.”

Healthcare providers must move away from models of care that emphasize control and power and toward those that create a partnership with the patient (Newman, 1997). Uncertainty and ambiguity are frequently a part of this type of partnership and may create discomfort for healthcare providers. Rehabilitation nurses work in partnership with patients on a routine basis, emphasizing patient strengths and assisting the patient to live to the best of his or her ability with situations that may not be “fixable.” Therefore, many rehabilitation nurses may be not made as uncomfortable by ambiguity and uncertainty as nurses in other nursing specialties.

There are times when the patient’s needs may conflict with the provider’s wishes and directions. The patient’s perspective and actions often relate to what creates the greatest sense of well-being, and sometimes that necessitates placing the illness in the background (Paterson, 2001). Healthcare providers need to understand that taking time to get to know the patient by listening to their unfolding health story over time and making connections regarding patterns and meanings is a health-promoting and healing process (Smith & Liehr, 2003). Pattern recognition allows a shift to a level of wholeness that reflects the complex, continuing change through which people live (Newman, 2002). Active listening and pattern recognition must be accompanied by understanding illness transitions within the chronic pain experience (Kralik, 2002). Providers who have content knowledge and experience in the specialty are able to guide patients to self-organization through education, promotion of self-reflection, and assistance in recognizing possibilities for action.

Future research will demand a neomodernist approach, with scientists from different backgrounds approaching the same problem from different perspectives (Whall & Hicks, 2002). For example, genetics nurses may determine genetic markers for predisposition to chronic pain syndromes and work with patients on preventive strategies. Targeted drug therapy based on the genetic markers may allow more effective and focused pain control. With regard to the research mandate from the National Institutes of Health (n.d.) that calls for a reduction in health disparities, research is very much needed on the impact of culture, age, and gender on the attributes of self-organization in chronic pain.

Rehabilitation nurses are in an excellent position to take advantage of the exciting practice and research opportunities available to improve outcomes for patients with chronic pain.

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References


