Psychosocial Effects of Chronic Pain: The Six Stages

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1. Initial trauma

The onset of chronic pain can be caused in numerous ways: trauma, cancer, tumor, disease, accident, infection, and genetic or degenerative disorder. It is important to understand that the onset of chronic pain occurs at the time of the initial trauma.

This creates a crisis, which sends messages to other parts of the body and to the brain. The body perceives the trauma as an attack on the system and promptly goes into a defensive mode to protect itself. Messages are sent to every system of the body, not only to the trauma area.

The person seeks medical and/or alternative modes of treatment depending on his personal orientation to health. The search for a provider can precipitate a crisis state because of the person's vulnerability, limited medical insurance, transportation problems (arranging and getting to appointments), and trying to comprehend medical information. Many times decisions have to be made rather quickly, and this creates more stress. After medical appointments, there is often a great deal of stress related to obtaining more information and making preparations for treatment.

Family and friends usually rally around the person in this time of crisis, resulting in their own elevated stress levels. Witnessing a person's emotional and/or physical trauma can trigger increased awareness of personal vulnerability. This can create interpersonal conflict and disrupt relationships. Some family members or friends may distance themselves quickly from the person. If there are children, temporary arrangements are often made, and children are merely told that their parent will recover soon.

Responsibilities in work and/or as a family caregiver are greatly affected, depending on the severity of the trauma, medical procedures required, and changes in physical/mental capabilities of the worker and/or parent. In most cases, employers readily respond to the worker's needs, believing that this will be short term.

2. Recovery/normal healing from physical trauma

The person believes that after the appropriate recovery time from trauma, he will recuperate and return to normal. There is hope, and he anticipates an end to pain.

Treatment is seen as temporary, encouraging recovery, and includes rest, medications, physical therapy, occupational therapy, or alternative treatments

such as acupuncture, traction, massage, bio-energy and diet/nutrition, all depending on the type of injury or disease.

The person still has support from his family and community. Everyone still believes things will get back to normal before too long.

The recovery stage ends here for many. Life returns to normal. Those who do not recover enter stage three.

3. Time lapses into months: The sufferer is not recovering as predicted by medical providers

During this stage, the pain remains high. Due to the length of time the body has been dealing with pain, the entire physical system has been stressed. At this stage, it is recommended that the person should not go to a doctor alone. The person needs an advocate because he often has difficulty expressing himself when experiencing pain. Many times it is hard to hear what is being said by the doctor, and there may be misinterpretation of what is being said. The person can also be hurt by what the doctor may say, such as:

"You are a special case."
"Most of my patients usually recover by this time."
"You are too sensitive to pain."
"Could it be something else?" (Alluding to psychological problems)
"You just have to learn to live with it."

These comments tend to minimize and even discredit the person, blame the person for his problem, and play into the person's unconscious thoughts that perhaps the pain is not real. There are some patients seeking treatment whose primary issue is psychological in nature. However, in many cases these emotional stressors manifest into physical pain, and they must be taken seriously. Continual pain creates emotional stress. Support group members have said that they were labeled obsessive compulsive, psychosomatic, seeking attention, and that maybe they needed "to see a psychiatrist" when they were not responding to treatment or when the cause of pain could not be detected.

After the above comments have been made, usually the medical provider grudgingly adds, "But let us do more tests to see if I am missing something." At that point the patient begins to feel guilty, experiences self-doubt, and feels something is very wrong with him, because all the doctor's other patients heal on time. The doctor may order tests or refer the person to another specialist. The person may feel angry and violated at being "dumped" and passed along. This can turn into feelings of being extremely vulnerable. Often the person experiences a state of turmoil, thinking, "What am I going to do now?"

During this stage, the physician will probably try to prescribe different medications to see if the pain level changes. Frequently, patients are not informed of the possible side effects and how to respond should the medication make them sick. When there is an adverse reaction to the medication, the body can have extreme reactions due to the heightened sensitivity that the chronic pain has created in the body.

The patient's pain often becomes worse due to the side effects, and the emotional stress is pushed to the maximum. The patient tries to contact the doctor for help. The doctor may be busy and not return the call, or a different doctor with no knowledge of the patient's history may be on call. This is a very tedious stage for both the doctor and the patient. Case management and a special working relationship need to be developed if treatment is to succeed. Unfortunately, in the majority of cases, there is no case management, and the patient is left to fend for himself.

Referrals to other physicians often occur at this stage. The provider feels helpless and sometimes fed up with the patient's complaints after an unsuccessful medical intervention. The term "complaint" refers to specific medical symptoms, but it may also imply the patient is "complaining," which can minimize the patient's pain. The patient now becomes a "sufferer" rather than a patient—a new category to emphasize the chronicity of symptoms.

Each referral to a new provider is experienced with mixed emotions. The patient hopes that this new provider will be the one to understand and give appropriate treatment. However, there is also mistrust that this provider may not take the sufferer seriously because of previous experiences. Sufferers can become traumatized from experiences with medical providers. Most sufferers do not disclose all of their symptoms to their doctor for fear that the doctor will think they are whining, complaining, or hypochondriacs. Often patients become hostile when they feel dismissed and misunderstood.

The worst message that a chronic pain sufferer receives is, "You just have to live with it." This can contribute to the sufferer entering into a deeper state of depression, anger, despair, or hopelessness—without a treatment plan that includes healing.

New research in the field of pain has shown that after an initial trauma, secondary injury can occur in the nerves of the spinal cord, which creates new pain in another part of the body. Central sensitization develops in the dorsal horn of the brain, and the brain becomes "super sensitized" to feeling pain. This explains one of the reasons why doctors are hesitant to treat pain patients when they are told of pain unrelated to the original source of pain. The pain cannot be seen on an MRI, and patients are often told they are malingerers, dismissed, and sent to see psychiatrists. Only recently, the fMRI (functional Magnetic Resonance Imaging) has become available to show the parts of the brain that are activated by different types of physical sensations. It is now possible to see increased blood flow to the activated areas of the brain by the sensations of sound, touch, or sight. Pain can now be seen in the brain. Unfortunately, the fMRI scan is extremely expensive and mostly used in research.

In addition to the issues that arise with medical practitioners, by this time many friends and relatives are distancing themselves from the sufferer. Many feel the pain sufferer is malingering or say, "Just try and keep a stiff upper lip," "Why aren't you getting better?," "You're so young to have pain," and "All that from a small accident?" This can put the sufferer on the defensive for having pain. He feels angry that no one believes him, which can lead to withdrawal and further isolation.

The immediate family has become more isolated because of being unable to participate in activities. On an unconscious level, grieving often starts among family members for the person they knew, especially when they hear the message that their loved one will not get better. Sometimes they are also angry at the person for not being who he was and may feel guilty about these feelings. Since pain is invisible, children have a hard time understanding why their parent cannot engage in many activities.

For the single person there are additional stressors such as being alone and solely self-reliant. Seeing other people in relationships and feeling unable to have a partner can result in feeling insecure about the future. This can heighten fear and trigger questions such as, "Who will want me or take care of me?"

Since people cannot see the intensity of pain, they often make insensitive comments to sufferers, such as "You look so good," which implies that you are not in as much pain as you say. Friends/acquaintances also do not realize that there are days that the sufferer may leave the house for a single errand and then go home quickly before the pain level intensifies.

Psychologically, the sufferer may also feel guilty for still being in pain. He feels remorse and self-pity for not being able to do what he used to do. The majority of chronic pain sufferers were extremely functional and active before their trauma. Resentment can become a major issue because they may feel left out, and watching others go on with their normal lives makes their loss greater. This all leads to feeling very alone, lost, and misunderstood.

Depression can be a co-occurring condition with chronic pain. The depression is two-fold for many. For some it is a direct consequence of the chronic pain. The nervous system is affected by the pain, and the pain tends to deplete the body of many of its natural vitamins and minerals. The secondary depression develops from losses due to life changes. Every aspect of the sufferer's life has been affected—physical, psychological, intellectual, and spiritual.

These *forced* changes deeply affect the careers and work lives of sufferers. For many, career and self-esteem are directly linked. Depending on the level of pain, the work schedule may become limited. The sufferer can have difficulty concentrating, focusing for lengths of time, and keeping the same pace. He may be irritable and unpredictable, never knowing if he will be able to complete a project on time due to his pain level. This creates further tension. Co-workers, who initially were understanding, now become impatient and even angry at the person. They may feel the person is faking and getting special treatment. The sufferer feels humiliated that he even has to ask for changes. Sometimes he tries to deny the pain and attempts to work at his old pace, which can make him get even sicker and exacerbate the pain.

The sufferer may increase medication in order to maintain a work schedule, but the side effects of the medication may hinder the quality of work. Some medications have noticeable side effects, such as incoherence, sleepiness, irritability, and forgetfulness. He may be labeled as a drug addict and feel humiliated once again. This cycle could create a relapse and lengthen the recovery process.

Many sufferers become unable to work and lose their jobs. Depending on their work situation, they may have to apply for workers' compensation or disability. This involves lengthy litigation and a continual fight for insurance benefits. These procedures create enormous stress on the sufferer. They often feel blamed for their disabilities. They also do not want to see themselves as permanently disabled. The process is so grueling and time-consuming that many give up because they do not have the energy to fight. If they continue with the process, they are constantly asked to prove why they cannot work. The message is that they are "faking" their condition or malingering. For example, one female sufferer was able to attend her child's school play, and this was later held against her. She was filmed going to an IME (independent medical examination), and the film was shown in court to prove that she was okay. Thus the sufferer is victimized again, and it becomes a "catch-22" situation. Many feel the government system is deliberately trying to find a way to avoid giving them the benefits that they worked so hard to receive.

The loss of wages can also put a heavy financial burden on the sufferer and family, which creates another major crisis.

4. Chronic stage has been set in motion

The sufferer realizes by this stage that he needs to take more responsibility for his treatment by researching medical literature and by looking for answers, different treatments, clinical trials, and alternative modalities. There is a realization that the doctors do not have all the answers or the time to research individual cases. The sufferer must become an expert and begin advocating for himself. In the end, it is his body, and he must live with it.

Medically, the sufferer has probably undergone a variety of tests such as X-rays, MRIs, CT scans, and nerve tests. He has also been prescribed numerous medications. With some pain conditions, the original pain may spread, affecting the once healthy parts of the body.

Most patients are told to overlook or minimize these secondary side effects, but the new pain has become just as uncomfortable and painful. For example, gastrointestinal problems arise along with problems of weight gain or loss, which also affect the person's self-esteem. Not all medications prescribed can be taken at this point because of the effects on the secondary condition. This increases the complexity of medical management. The patient is often referred to another specialist to deal with the new problem.

Chronic pain and medications affect the sexual abilities of a person, which in turn can adversely affect the sexual relationships in his life. This creates a new life issue problem, which is often not directly addressed by professionals.

Although addiction to opioid medications is not common, it is important that clients be screened for any pre-existing addiction issues and monitored accordingly. Detoxing or weaning off of medication can be a painful process. Also, many times patients do not receive the opioid medication that they need and are under-treated due to a variety of reasons, primarily related to stigma and

misinformation regarding the rate of addiction. Studies have also shown that different racial and ethnic groups are not given needed medication as they are perceived as drug-seeking (Payne 2000).

Along the way, the sufferer has learned to pick up survival skills to get through a medical appointment. Many sufferers are seen by different specialists who are prescribing medications that may cause harmful drug interactions. There is a lack of case management between the different specialties. The sufferer is treated as separate body parts instead of as a whole person.

Psychologically, the sufferer may be going through a major identity crisis due to the life changes caused by the pain. He may have been referred to a psychiatrist, psychologist, social worker, or counselor to deal with the effects of pain. A major problem is that the mental health professionals usually define the emotional disorder as the primary diagnosis. While this may be true in a small percentage of cases, it is certainly not the case for the majority of sufferers. This implication creates more doubt, despair, and anger in the sufferer who once again feels misunderstood. The problem is compounded by the fact that the majority of these professionals have no knowledge or training of how chronic pain affects the individual and family or how to treat it. Frequently, mental health professionals are considered the dumping ground by "burnt-out physicians" who have not been able to cure the client and have given up on them. When a doctor gives up or "fires" a patient, this often creates another crisis.

Family members are deeply affected by the changes in the sufferer. The changes vary according to the level of pain and the ability of the sufferer to maintain life activities. Children can be traumatized by the personality changes and physical limitations of their parent. Their normal demands for care and attention are met with answers like "I can't," "I don't feel well," or "I am too sick." When the parent is in intense pain, he is so depleted that he has little to give. He may be feel impatient, sad, depressed, or guilty that he cannot spend much time with his child. The child feels insecure and may conclude that it is her fault that her parent is in pain. Separation anxiety occurs in the child, fearing something else may happen to that parent or to the healthy parent. Self-confidence can be affected because the parent may be unable to encourage the child by attending activities or unable to model activities. Children need to be told, as many times as needed, that it is not their fault, that it is the pain which has created this new situation. Children need to be encouraged to go on with their lives and told that they may enjoy themselves. They also need to be told that the family will find a way to deal with the problems.

A spouse may feel overwhelmed by the new demands of responsibilities previously taken care of by the sufferer. If there were marital problems before the trauma, this may be the breaking point for many marriages. Otherwise, the spouse may try to be very supportive but generally has no prior experience with or knowledge of dealing with the new circumstances. The spouse may feel guilty for doing fun things the sufferer is unable to do and resentful for the losses of a normal life. The spouse feels helpless watching the sufferer because she cannot stop the pain. During this stage, many families become more isolated and unable to participate in normal community activities. The family members may need counseling for their grief, a fact often overlooked by providers.

5. Coming to terms with how pain has changed the sufferer's life

The sufferer has come to realize that medications, operations, and procedures cannot cure all of his pain and changes need to be made in his daily life. The client is ambivalent—at times accepting and at other times angry and resisting. The initial shock of the trauma has faded, and reality gradually sets in.

The sufferer realizes the physical limitations that he must now live with. The sufferer is angry about these changes and wants his old life back. The pain forces the sufferer out of complacency. He is not who he was in a physical or emotional sense. He comes to realize that what he thought was "real" and of value in his life may no longer hold true. It may be hard to understand that the pain has changed his life and now given him an opportunity to change. With this new lifestyle, there is the need to re-prioritize daily activities in order not to exhaust himself or intensify the pain. If he does not change and chooses to live in the past, he will live in a constant struggle by overextending himself physically and mentally. This will only intensify the pain, which creates a need for more pain medication. The sufferer then feels worse because the pain is too intense for the medication to work. This cycle then creates a relapse with longer periods of recovery and remorse. The goal instead is to learn to normalize the pain experience by moving out of the crisis mode and into a new life pattern.

Learning to set reasonable goals is based on how the sufferer is in the present moment. If the person lives in the past, it only leads to despair and deeper depression. However, grieving for multiple losses in their life and their old self is expected. This also holds true for the sufferer's family and significant others. Working with clients to navigate the stages of grief is important for the healing process. After the grief process, there is the need to redefine the self by recreating a new self image. This is an extremely difficult process and needs to be undergone with a therapist who is knowledgeable about chronic pain.

Joining a support group can be very important in the healing process; it gives the sufferer the sense of being in a community that understands his experiences. It helps the person learn to cope by discussing the physical and emotional pain and the importance of the healing process. When seeking a support group, it is crucial to seek leadership that helps with coping skills instead of a group that mainly complains and wallows in negativity.

Many people also seek spiritual/religious counseling to help deal with pain and to receive support.

6. Healing: Learning to change the messages

There is usually a point when the sufferer feels that he has exhausted all the available resources. He has probably seen at least six to ten doctors, as well as numerous other medical and mental health professionals. He has tried all the latest pain medications, physical therapy, acupuncture, and much more. There is a sense that the pain has encompassed every aspect of life and there is no future. Some may want to commit suicide. In fact, most sufferers have thoughts of suicide, which is normal, but are afraid to tell anyone. Most want the pain to stop so they can be "normal" once again.

What contributes to hopelessness and suicidal thoughts are the "hopeless" messages people receive from themselves and others, such as the often repeated advice to "learn to live with it." There comes a time in the healing process when the person finally realizes he needs to take charge and use his inner strengths to assist in coping in a new way with the pain.

Pain can bring out a person's dark side. Pain can be extremely "ugly" and the sufferer may be forced to witness a side of himself that he sees as unacceptable. Dealing with this is the greatest challenge in healing: self-acceptance. The sufferer must choose whether to give into the darkness or to create light—a new life. If the person decides to let go of the past and accept healing, it is at this point that he starts transforming into a new being, a new identity, one with genuine self-acceptance and self-love.

The sufferer no longer sees himself as the pain, but sees the pain as only one part of his life. It is extremely important not to minimize the amount of pain the person lives with, but to stress that the person now knows how to cope with the pain and take care of himself. At this point the person is no longer a sufferer but a person living and coping with chronic pain.

We now have research that demonstrates how people can begin to cope with pain. Two separate studies were done, in Japan and the Netherlands, on patients with chronic fatigue syndrome (CFS) using high resolution magnetic resonance imaging (MRI). The studies revealed that CFS patients have less gray matter, which results in fatigue and difficulty thinking. Gray matter is made up of neurons and dendrites that are the computers of the brain. The researchers discovered that cell death had not occurred, but rather that the cells had become smaller in size. We now know that gray matter can increase by practicing meditation, learning new skills, or playing games such as Scrabble®.

Stress and holding onto negativity intensifies chronic pain and strains every part of the body. The daily use of meditation and guided imagery can be very helpful in lowering the pain level. Recent research studies by Yale, Harvard, Massachusetts General Hospital, and the Massachusetts Institute of Technology used MRI to show that 40 minutes of daily meditation can actually increase gray matter.

Researchers have also learned that the brain, to some extent, cannot distinguish between what is real and what is imaginary. Guided imagery activates the same area of the cerebral cortex (brain) as seeing a real image, thus tricking the brain into believing it sees a waterfall, smells the ocean, or feels soft material, for example. Guided imagery sends signals to the autonomic nervous system (which controls bodily functions), limbic system (the feeling center of our brain), and the endocrine system (the control center for hormones, such as cortisol, adrenaline, and norepinephrine). Thus the pain messages are disrupted, and the pain level is lowered and may disappear. This gives the person control over her pain and an alternative to taking more medication.

Gentle yoga that is modified for people with chronic pain can be helpful in dealing with stress by emphasizing deep breathing and by stretching the

body slowly and carefully. Yoga builds strength, releases muscle tension, and improves flexibility, which brings the body into balance.

A support group is extremely important when bonds develop among members, which assists them in their healing process. This gives the majority of people strength that they can now find in themselves. There is a sense that they are no longer alone; they feel understood, which in turn empowers them to be more assertive and helps them make needed changes. The group gives each participant permission to take care of himself without feeling guilty.

What is stressed in the healing process is that the body has changed and it must be listened to. It is important not to give up on the body. The body is trying to heal, and everything possible needs to be done to help it do so. Healing is a never-ending process when dealing with pain. A person must be creative and open to new ways when the usual ways of dealing with pain do not succeed.

References/Bibliography

de Lange, Floris, F.C. Donders Centre for Cognitive Neuroimaging, Netherlands, "Matters of the Brain," *The CFIDS Chronicle*, CFIDS Association of America, Summer 2006, www.cfids.org/sparkcfs/delange.pdf.

Devine, Elizabeth C., PhD, RN, FAAN, "Effects of psychoeducational care for adult surgical patients: A meta-analysis of 191 studies," *Patient Education and Counseling*, 19(2):129–142, 1992.

Dreher, Henry, "Mind-body interventions for surgery: evidence and exigency," *Advances in Mind-Body Medicine*, 14(3):207–222, 1998.

National Pain Foundation, *Using Guided Imagery to Help Relieve Chronic Pain – An Interview with Dr. Marty Rossman*, www.nationalpainfoundation.org/MyTreatment/MyTreatment_GuidedImagery_Rossman.asp.

Neimark, Neil F., MD, "Mind/Body Solutions for Surgery," *Mind & Body: The Newsletter for Health and Healing*, Special Edition Issue #7, Autumn 1998, www.mindbodymed.com/Newsletter/issue7.html.

Orme-Johnson, David W., Robert H. Schneider, Young D. Son, and Zang-hee Cho, "Neuroimaging of Meditation's Effect on Brain Reactivity to Pain", *NeuroReport*, 17(12):1359–1363, 2006, www.neuroreport.com/, www.eurekalert.org/pub_releases/2006-08/muom-tmr080706.php.

Payne, Richard, MD, "Hurting While Black: Racially Based Disparities in Pain Care," *The Pain Connection*, Fall 2000, www.painfoundation.org/Publications/PCN00fall.pdf.

Shealy, John Steven, PhD, "At Home in Our Bodies: An Interview with Jon Kabat-Zinn," *Tricycle Magazine*, 12(2), 2002, www.steveshealyphd.com/kabatzinnart.htm.

Sherman, Karen J., PhD, Daniel C. Cherkin, PhD, Janet Erro, RN, MN, PNP, Diana L. Miglioretti, PhD, and Richard A. Deyo, MD, MPH, "Comparing Yoga, Exercise, and a Self-Care Book for Chronic Low Back Pain—A Randomized, Controlled Trial," *Annals of Internal Medicine*, 143(12):849–856, 2005, www.annals.org/cgi/content/full/143/12/849.