

Revisiting Chronic Pain in the Life Care Plan

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Abstract

The practice of life care planning is now well into its fourth decade. At the time of life care planning's inception, the phrase "pain management" was barely in the lexicon. During the same time period, the way in which chronic pain is perceived and treated has changed greatly. Numerous new medical techniques and procedures for treatment of pain have been introduced which were unheard of 20 years ago. There are multiple pain management associations, and volumes have been written on this subject. In addition, the topic of pain has become much more central in American public consciousness than at any time in history, and a well-chronicled crisis of the abuse of pain medication has arisen. With this heightened awareness of chronic pain, new issues have begun confronting the life care planning community. How should the treatment of chronic pain be viewed by the life care planning discipline? Is it possible to recover from chronic pain? Should opioid pain medication be included in a life care plan for extended time periods? Are we witnessing the birth of a new breed of life care plan, focusing solely on prescription pain medications for the evaluatee's lifetime?

Though few life care planners can claim to be experts in the treatment of chronic pain, many are now called upon to address it in their practice. Here, we offer perspectives from life care planners, an occupational therapist, rehabilitation counselors, and a pain management specialist on this subject. This article does not purport to offer the answer to chronic pain treatment, nor does it give a road map for the manner in which a life care planner should address pain management when developing a life care plan. Instead, it is an effort to look carefully at this trend, to encourage life care planners to stay abreast of developments in the treatment of pain, and to serve as a reminder to make well-informed decisions in a life care plan where the treatment of chronic pain is central.

The Nature of Pain

Pain appears to be subjective and is measured by self-report. According to research, pain threshold is similar from person to person and culture to culture, but pain tolerance can vary greatly (Lester & Litwack, 2010). "Pain threshold is the lowest amount or intensity of a stimulus that will produce a sensation or elicit a response" (Thomas, 1993, p. 1944). "Pain tolerance is the degree of pain that a person can

withstand" (Thomas, 1993, p. 1963).

The definition of pain varies; however, according to the International Association for the Study of Pain, the definition of pain is "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Merskey, 2014, p. 13). Additionally, the definition of chronic pain ranges from a pain that persists for six months (Lester & Litwack, 2010) or continuous or intermittent pain that lasts longer than the normal expected time for healing (Merskey, 2014).

Chronic pain is well documented to be a biopsychosocial disorder, which include physical, mental/psychological, and cultural viewpoints to understand the effects of the pain. Thus, the etiology and diagnosis of chronic pain is oftentimes multidimensional and requires a multidisciplinary, multimodal, multidimensional or interdisciplinary approach (Caudill, 2009; Tauben & Theodore, 2014). Persons are recognized as assigning a meaning to their pain experience (Lelwica, 2016); the meaning a person assigns to their pain will likely aid or, unfortunately in some cases, may contribute to his or her ability to cope with it.

As rehabilitation professionals, we often encounter ongoing, chronic pain in the profile of a person who has experienced a traumatic injury. As we seek to assist an individual with a chronic pain experience, we find that our rehabilitation case planning includes not only services designed to ameliorate the objectively defined impairment but also the need to address the individual's subjective complaints of pain. In forensic practice, we attempt to factor the role of pain in our evaluatee's eventual ability to gain and retain employment and/or the regimen of ongoing pain management treatment in matters involving longitudinal planning. We periodically encounter an attorney questioning, "But the experience of pain is subjective, isn't it, Mr./Ms. Life Care Planner?" We are left to respond that, yes, it is subjectively reported. The implication here is that pain, being a subjective experience, is to be discounted or dismissed as a factor affecting an individual's life.

The World Health Organization's conceptualization of disability incorporates the idea that impairments become disabling in the absence of accommodation. The fundamental objective of all disciplines in the global field of rehabilitation is to enable optimal independence to an

individual experiencing impairments to function. It follows that if chronic pain is, in fact, a functional impairment, then the objective of holistic rehabilitation case planning (including life care planning) would be to minimize pain to optimize an individual's ability to function daily.

In 2001, The Joint Commission hospital accreditation body (JCAHO) first established standards for pain assessment and treatment in recognition that information about a patient's pain experience is a valuable and crucial piece of data that completes that patient's history and informs his/her treaters and noted that there was a widespread problem in the under treatment of pain. The Universal Pain Assessment Tool is a common part of history-taking in most healthcare settings. Relative changes in a patient's subjectively reported pain experience comprise a significant part of a healthcare professional's determination of the effectiveness of a treatment regimen.

Treatment Measures

One in four Americans or 116 million people has some form of chronic pain. According to the Institute of Medicine's report (National Academies Press, 2011), an estimated \$560 to \$625 billion dollars is spent annually to provide medical care and for lost productivity secondary to chronic pain. This is greater than the costs of heart disease, diabetes, and cancer combined.

The past 20 years have witnessed a proliferation of treatment modalities for the management of chronic pain. In addition to TENS units and spinal cord stimulators, we now are seeing the introduction of radiofrequency ablation of nerve centers, ketamine infusion therapy, and medical marijuana. In a recently published text (Benzon et al., 2014), there are eight chapters regarding nerve block techniques alone.

Currently, opium and its derivatives are the most commonly used medications for the treatment of chronic pain. Many side effects of opioid medications have been documented (Pasero, Quinn, Portenoy, McCaffery, & Rizos, 2011). Hanna, Ouanes, & Tomas (2014) provide a short list of some side effects including: cognitive impairment, sedation, respiratory suppression, constipation, and urinary retention. These side effects alone may give pause to any life care planner who is asked to give a simplistic projection for continuance of a patient's pain medication regimen over an indefinite period without diligent consultation with a treating physician.

Pain management specialists recommend carefully exploring alternative therapies to reduce pain before electing to take opioid medications (Webster, 2015).

Review of pain management literature indicates that multiple modalities are favored by many physicians in treatment of individuals with chronic pain. These have included water therapy, physical therapy, occupational therapy, cognitive behavioral therapy, electrical stimulation and meditation, along with prescription medications (Stanos

& Rader, 2008). This suggests the proclivity of many medical professionals for an interdisciplinary approach. Smith, Knight, Smith, and McCracken (2015) have reported encouraging progress through residential inpatient clinics for pain management; and outpatient interdisciplinary clinical treatment programs are preferred by others, such as Angst et al. (2009). The insurance industry, including workers' compensation, initially embraced comprehensive, multidisciplinary inpatient pain management programs in the 1980s; however, due to high costs and, to a lesser degree, without good scientific outcome data, most carriers refuse to authorize these treatment programs. As a consequence, the availability of multidisciplinary inpatient pain management programs has gradually waned.

Treatment efforts are customarily geared towards preserving ability, following a diagnostic methodology to find what physiological process is causing the pain, making changes in a technique such as transferring from a wheelchair, and initiating therapy targeted at helping the person respond better and, thus, being able to continue functioning (Thompson, 2004).

To be clear, the impetus for this article was "chronic pain in life care plans" which includes the usage of prescription medication only in treatment of persons with chronic, residual pain. But we are not differentiating between opioids and non-opioid medications. Stated in another way, our interest lies in exploring the pros and cons of prescription-medication-only life care plans.

Multidisciplinary teams involve multiple health care providers such as physicians, physical therapists, occupational therapists, recreational therapists, pain psychologists, biofeedback specialists, and vocational rehabilitation counselors. The team communicates with one another throughout the treatment program of the patient to meet the goal of restoring the patient's function. Treatment programs by the multidisciplinary team are guided by understanding what is the origin of the patient's pain, related musculoskeletal impairments, compensatory biomechanical patterns used by the patient due to pain, duration of the pain, patient's functional deficits, and related psychosocial factors (Stanos, 2011).

One component to the interdisciplinary team is occupational therapy. Occupational therapists receive their training from accredited university programs. "Occupation" in occupational therapy does not only refer to jobs but all the activities that occupy our everyday lives. Occupational therapists address the problems that interfere with people being able to perform self-care activities, taking care of their family, and all other activities which may be meaningful or pleasurable. Chronic pain is certainly a problem which interferes with people performing everyday tasks. Some activities may stimulate pain. Occupational therapists can teach ways to adapt the activity or the environment which can help decrease the pain and make the activity more doable. Occupational therapists are familiar with various types of

adaptive equipment which can help people perform tasks while minimizing pain. Occupational therapists can also help teach patients how to cope with the feelings of loss, anger and other emotional challenges commonly associated with chronic pain. Occupational therapists traditionally take on the role of being advocates, and in that capacity they have knowledge of community resources (Klinger & Klassen, 2011).

Occupational therapists involve the patient in identifying and setting goals for their therapy. Goal-setting is intended to increase the patient's motivation and participation which will help to improve therapy outcomes. The following are a few treatment approaches occupational therapists use to address treatment of chronic pain:

- **Proactive pain control:** Patients are taught to independently use pain control modalities such as heat/cold therapy.
- **Safe body mechanics and ergonomics:** Patients learn how to perform activities of daily living and community activities, using adaptive techniques or equipment that reduce or prevent strain on body structures. Also, ergonomics assessments will help to modify the environment to reduce pain to improve function.
- **Neuromuscular re-education:** With the use of neurodevelopmental techniques and/or modalities, occupational therapists teach patients to perform tasks with the appropriate muscle groups instead of abnormal movement patterns and postural deviations.
- **Muscle tension reduction training:** Teaches patients how to relax muscles and calm the mind to reduce pain.
- **Communication skills training:** Teaches patients assertive behaviors of expressing their needs and desires which will help them manage their disability with less conflict and frustration.
- **Pacing activities:** Teaches patients how to pace their activities to help avoid fatigue which leads to flare ups of pain.
- **Occupational therapists** can refer patients for additional services which will help get the best practice and achieve optimal therapy outcomes.

Dealing with chronic pain can be a barrier to progress in therapy if the person begins concentrating more on the pain than the task at hand. In those circumstances, cognitive-based therapy is often beneficial. Occupational therapists also educate about the relationships between pain, stress, tension, and one's thought processes. The cognitive-based therapy can aid in teaching the person to replace negative thoughts about events with positive thoughts (Burch, 2013; Darnall, 2014; Otis, 2007; Reed, 2001).

The foundation of multidisciplinary, multimodal, or interdisciplinary treatment will be a comprehensive evaluation. The evaluation will identify biomedical, psychosocial, and behavioral factors that influence an individual's pain. The comprehensive evaluation will

include a thorough physical assessment that includes detailed physical, neurological, and musculoskeletal exams. Also, a thorough psychological assessment will be performed to provide data about an individual's motivation and suitability for treatment methods such as invasive procedures, surgeries and/or medications. The comprehensive assessment should be followed up by subsequent evaluations to monitor the individual's progress (Seng, Kerns, & Heapy, 2014).

Difficulties Associated with Long-Term Use of Prescription Pain Medications

Long-term use of prescription pain medications can potentially lead to undesirable side effects. Some potential side effects are addiction, respiratory problems, cognitive impairments, digestive problems, drowsiness (most common right after beginning to take pain medications or after increasing the dose), pruritus (itching – this is not dangerous, just bothersome), nausea, overdose (besides side effects, overdosing can lead to death), and sexual side effects (Health, 2016). Gastric ulcers, renal function impairments, increased risk of bleeding, tinnitus (ringing in the ears), and peripheral edema (due to sodium retention and renal impairments) are also potential side effects (Zacharoff, 2015). Depression and vitamin D deficiencies also can occur from long-term pain medication use (Saint Louis University Medical Center, 2013). Additionally, long-term pain medication use can lead to osteoporosis, emotional imbalances, trouble sleeping, metabolic changes, and cardiovascular problems (Darnall, 2014; Lasich, 2011).

Extensive use of prescription pain medications can lead to developing a tolerance to the medication, thus causing the person to require more pain medication at higher doses to achieve the same degree of relief. These medications may affect the neurological system by causing the patient to become more sensitive to pain. Long-term use of pain medications can also cause the patient to begin losing physical function; this will require a multidisciplinary approach to help restore function and to learn how to manage chronic pain so that they can maintain an active lifestyle (Darnall, 2014; Parker-Pope, 2013).

Chronic Pain in Regard to Life Care Planning from the Perspective of a Pain Medicine Physician

The primary purpose of this article is to address the concern of the life care planner in determining the future needs of patients suffering with chronic pain. The previous sections written by life care planners, an occupational therapist, and rehabilitation counselors describe their perspectives and address their roles in treating and managing patients with chronic pain. From my perspective as a pain medicine physician, I am usually at the center of the patient's care and am asked to figure out why are they in pain and how can we help control their pain. What is really being asked most times is not how can we help control their pain but is how can we cure their pain.

This leads to a very difficult discussion for patients and clinicians in that the etiology of chronic pain is complex and not completely understood. Chronic pain is a term that has a definition as previously described above but is not the same syndrome throughout all parts of the body and, as such, is not one problem but is a complex interaction between body and mind. Our understanding of the mechanisms and processes underlying chronic pain is evolving, and our ability to treat is always improving; yet we still do not possess that elusive panacea that everyone is looking for. At one point, we thought we might have found the best alternative to a cure, a long-term treatment to ease suffering.

Opioids have been used for thousands of years, originally in the form of opium derived from the seedpod of the poppy. In 1806, the pharmacological production of opioid drugs began (Ballantyne & Mao, 2003). Over the years, opioids have been used to treat various conditions, including colic, diarrhea, and dysmenorrhea. In the early part of the 20th century, opioids became very tightly controlled and could be used by physicians only according to very strict regulations. More recently, toward the latter part of the 20th century, opioids were reserved for terminal and cancer-related pain (Ballantyne & Mao, 2003). At the same time, the medical community was faced with the challenge of treating patients with chronic non-cancer pain, with experts advocating expanding the role of opioids to treat all types of pain. National organizations including the American Academy of Pain Medicine and the American Pain Society published consensus statements to help guide physicians on how to prescribe opioids (American Academy of Pain Medicine and American Pain Society (1997). So, in the late 1990s, opioid pain medication moved from treatment reserved for acute and cancer-related pain to encompass treatment for all types of pain, in particular, chronic non-cancer-related pain. At that point, there were no high-quality studies looking at the efficacy of opioids for chronic pain; and, to this day, there is little evidence for its efficacy, with no long-term placebo-controlled trial (Centers for Disease Control and Prevention, 2016). Physicians and patients were told that using opioids were safe and efficacious, with little risk for addiction. This idea of a safe and efficacious means of treating all types of pain was propagated by individual clinicians, professional organizations, and pharmaceutical companies. Experts used one particular article as support, which noted a very low rate of addiction in patients, widely touted as less than 1% (Porter & Jick, 1980). Unfortunately, this data was misinterpreted, and new data shows that the rate of addiction amongst opioid users for chronic pain ranges from 2%-14% in pain clinics (Centers for Disease Control and Prevention, 2016a).

Over the past few years, the burden of chronic pain has moved to the forefront of our collective consciousness. This has primarily occurred due to the national epidemic of opioid use and abuse, leading to the highest rate of opioid-related

deaths ever seen. In fact, from 1999 to 2014, there were more than 165,000 opioid prescription-related deaths (Centers for Disease Control and Prevention, 2016b). This epidemic has spurred the medical community to rethink their stance on chronic opioids, particularly with published guidelines from the pain societies (American Society of Interventional Pain Physicians, 2012). Most recently, the Centers for Disease Control published guidelines for prescribing opioids for chronic pain (Centers for Disease Control and Prevention, 2016a). These initiatives are helping to pull the medical community together so that there is more uniformity in prescribing practices and awareness for abuse and diversion.

These guidelines can help the life care planner understand where their patient might fall in terms of severity of pain, risk of addiction, and need for further testing and treatment. These guidelines also emphasize that when chronic pain is treated it should be approached from a multimodal perspective. As a life care planner, one should expect care to revolve around addressing the root cause of the chronic pain and figuring out a specific, tailored plan to help that patient cope with the nature of the disease; namely, that it is chronic and complex. Input from the patient's primary care doctor is paramount as they see the whole picture, integrated from the various practitioners. Coordination with a pain physician for treatment options should also be at the forefront of the multidisciplinary team to help guide care not only from a medication standpoint but also in regard to advanced interventions. There are many different types of medication that can be used for treatment, including nonsteroidal anti-inflammatory drugs (NSAIDs), anticonvulsants, selective serotonin reuptake inhibitors (SSRIs), serotonin and norepinephrine reuptake inhibitors (SNRIs), tricyclic antidepressants (TCAs), and, of course, opioids in the proper setting. Interventional pain management can run the gamut from simple nerve blocks to nerve ablation, neuromodulation, and intrathecal therapy. Psychological counseling, using cognitive behavioral therapy, has also been shown to help with coping, as well as with treating the pain itself (Ehde, Dilworth, & Turner, 2014). And, of course, physical therapy and occupational therapy play an integral role in functional restoration as detailed above.

As a professional entrenched in the field of pain medicine, I see the value of having a truly multidisciplinary team addressing the needs of the chronic pain patient. When evaluating the success of any treatment, one needs to look at the subjective, as well as the objective, improvement from all perspectives. This very difficult endeavor needs to be addressed by a team of professionals who can effectively communicate in order to coordinate the patient's care and bring about meaningful change. The life care planner can certainly be at the center of this team model, realizing that no one treatment holds the answer, and all members of the team play an important role in improving the quality of life for

chronic pain patients.

Issues for Consideration by Life Care Planners

Early life care planning literature did a good job identifying the need for treatment of chronic pain, and it effectively delineated most, if not all, current pain treatment modalities. It is not clear, however, whether life care planning pioneers foresaw the advent of “chronic pain life care plans.”

Historically, life care plans have been recognized as collaborative and rehabilitative in nature. In other words, professionals from multiple disciplines are giving input which informs the final work product, with the goal of enabling the evaluatee to reach his or her optimum functioning potential. What, then, should be the attitude of the life care planner faced with a case in which treatment of chronic pain is a central issue? Is the life care planner to adopt a passive stance; i.e., only making projections for the pain medication regimen currently being administered to the evaluatee? Is he or she always safe in assuming there will be no improvement for the person who is the subject of this life care plan?

As in other types of cases, we believe a life care planner engaged in developing a life care plan for a case in which chronic pain is pivotal is well advised to review both the literature and the International Academy of Life Care Planners' *Standards of Practice* (2015). Has careful consideration been given about which members of the evaluatee's treatment team will be consulted? Is the life care planner knowledgeable about pain treatment alternatives beyond those presently being utilized which might benefit the evaluatee? What does the evaluatee desire; what are his or her personal goals? Has a comprehensive re-evaluation of an evaluatee's medication and treatment regimen been projected at a future date in the life care plan?

It is useful for those of us who are rehabilitation experts to embrace the best practices of chronic pain management and to define a methodology, melding those best practices into an informative long-term care plan with accompanying costs.

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