Assessment of Quality of Life in Cancer Patients with Chronic Pain: An Analysis of Quality of Life Instruments for Clinical Practice

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Abstract

The desire of cancer patients to be pain free while maintaining or improving their overall quality of life is frequently reported in the literature. Nurse practitioners managing cancer patients with chronic pain need to routinely assess pain and quality of life in order to achieve a holistic perspective and treatment plan. Numerous quality of life scales have been developed for a variety of purposes, each with specific strengths and weaknesses. This article will provide an overview of the relationship between pain and quality of life, aspects of cancer-related pain and an evaluation of the quality of life instruments available to use. Upon review of the most current instruments, the Ferrans QOL scale appears to be most suitable for cancer patients with chronic pain. The Ferrans QOL tool has a statistical reliability of 0.93. Ultimately, the routine assessment of quality of life for cancer patients with pain is a reasonable goal for advanced nursing practice.
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Introduction

Nearly 50% of patients with cancer report having pain, while over 70% of cancer patients with pain feel that their pain is undermanaged (Okuyama et al., 2004). Although the current guidelines for treating chronic non-malignant pain recommend the use of quality of life (QOL) measures to guide pain management (Institute for Clinical Systems Improvement, 2005), these suggestions are notably absent in the document entitled, *Guideline for the management of cancer pain in adults and children* (Miaskowski et al., 2005). The assessment of QOL is extremely important for pain management because pain can directly affect functional status; a factor this is of high priority for oncology patients (Verhoef, Mulkins, & Boon, 2005). Thus, QOL assessment in cancer patients with chronic pain should be a standard of care for nursing practice.

Statement of the Purpose

Finding an appropriate QOL assessment tool to guide clinical practice can be a challenging task for practitioners. Although several tools currently exist, many do not adequately address all domains of QOL or are applicable to general patient groups. In order to address this gap in practice, this paper will provide an overview of cancer-related pain and quality of life, a discussion about the various aspects of cancer-related pain and an evaluation of the current quality of life instruments.

Cancer-Related Pain and Quality of Life

Pain has numerous physiologic, psychological, and personal implications for patients. The responsibility lies with the provider and nurse to address not only
pharmacologic management of pain, but also the implications it has on the patient’s QOL. Pain management is a major issue of concern when treating patients in a cancer care setting. Ultimately, nursing provides the closest look at patient care and outcomes because the administration of care begins with nursing practice. QOL assessment coincides with the holistic nursing approach to pain management that has been a mainstay of nursing practice.

Several QOL surveys have been formulated and utilized in the clinic setting. However, the utilization of QOL surveys is not consistently implemented by practitioners. The fast paced nature of medicine does not always allow enough time for providers to complete the assessments they would like. It is because of this limit on time that providers must prioritize assessments, which is why QOL should not be forgotten. Nursing practice and standards of care are driven by patient outcomes; QOL being one of the greatest factors. Pain has been documented as both a physiologic, psychologic, and multidimensional experience just as QOL. Therefore assessing QOL on all of these dimensions can help the practitioner to understand the patient’s pain within the context of their QOL and vice versa.

Verhoef et al. (2005) completed 42 personal interviews with cancer patients to better understand the desired outcomes. The common goals patients discussed were: “to improve state of being, to be cancer free, to have more energy, more effective pain management, and improved quality of life” (p. 5-61). This study demonstrated that pain and quality of life are both major concerns for cancer patients. Therefore, the provider must be sensitive to both concerns with regard to assessment and treatment.
Many nursing theories address patient outcomes and QOL. The Synergy Model describes the relationship between nursing practice/actions and perceived outcomes for the patient. It is the responsibility of the nurse to understand the pain process, adequate management of the disease process, and the use of QOL surveys to provide holistic care for the patient.

**Conceptual/Theoretical Framework**

The Synergy Model, initially begun by critical care nurses, can be used to describe the relationship between patient needs and nursing practice. The goal is for the needs of the client and the practice of the nurse to be in synergy, or to be working together. The Model of Synergy was first published in 1998 by Curley to help drive the practice of nursing to better suit client needs. Since then, the Model has been transformed and used in various care settings. The Model focuses upon three major premises: patients' characteristics of concern to nurses, nurses' competencies important to patients, and patients' outcomes that result when patients' characteristics and nurses' competencies are mutually enhancing (Curley, 1998). Within the context of cancer pain, the Synergy Model would encourage patients to express their pain and the impact on their quality of life. It also guides the essential need for nursing knowledge on how pain management can affect quality of life and effective pain management. Essentially, the model encourages the nurse and patient to become partner in working toward the goal of achieving optimal QOL. Nursing management of a cancer patient in pain should address quality of life as a standard of care when using the Synergy Model.

*Quality of Life Defined:*
Quality of life (QOL) is a concept composed of many different aspects of the individual’s life. An excerpt from Aaronson and Beckman (1987) series on cancer treatment and research uses the following three part definition of QOL:

[First] quality of life can be related only to individuals. The second is that the concept must be broad and cover all areas of life. The third is to suggest ways by which the quality of life might be improved and emphasizes the importance of personal growth and development (p.7).

_Cancer and Pain:_

Cancer is a term used to describe abnormal cells which grow at an excessive rate and can invade or destroy nearby tissues. Considerable research has been conducted into cancer genetics and precursors. Two major genes have been focused on the most in cancer research: proto-oncogenes and tumor suppressor genes. The proto-oncogene “codes for components of the cellular growth-activating pathways. Overactivity of proto-oncogenes enhances cell proliferation and predisposes to the development of cancer” (Copstead & Banasik, 2000 p.137). Physical, genetic, and environmental causes have all been found to cause cancer.

Cancer treatments involve a varying degree of severity from: pharmacologic (including chemotherapies), immunotherapy, stem cell transplantation, radiologic, surgical, and genetic therapy. Many side effects have been identified and managed for the cancer patient including: nausea, vomiting, anorexia, pain, and others. Pain experience in the cancer patient depends upon the cause of pain. Some cancer therapies are known to cause somatic pain, visceral pain, and neuropathic pain. Bony metastases are known to cause severe pain as well. Okuyama et al. (2004) states that up
to 70% of cancer patients feel that their pain is undermanaged. Nursing knowledge of
pain in the cancer patient has been found to be less than ideal (Sturgis-Wagnerowski,
2003). The Effect of Nurses’ Knowledge & Attitudes Regarding Pain Survey was the
result of Sturgis’ research and has been used in various settings to compare nursing
knowledge at various institutions.

Pain Defined:

Pain is defined as an “unpleasant sensory and emotional experience caused by real
or potential injury or damage to the body” (International Association for the Study of
Pain, 2007). Pain is a difficult phenomenon to define because it is experienced differently
by individuals. For example, a relatively minor injury may cause excruciating pain in one
individual; while a very serious injury may cause little to no pain in another. Culture and
social constructs have been known to influence the experience of pain. Stoicism is
commonly addressed in this context and has been implicated in many sub-cultures around
the world.

Pain is a common complaint of cancer patients. Pain has been documented as
having physiologic and psychological implications. Therefore, it would imply that a full
pain assessment should include several domains of quality of life, not just the physical
manifestations of pain.

Aspects of Cancer-Related Pain

Physiology of pain.

Pain physiology is complex and involves the nervous system for perception and
integration of information. A stimuli is typically present to alert the body that damage or
potential damage may be occurring. Nociceptors are the universal pain receptor in the
body and transmit pain signals from the periphery to the brain. There are two main types of nociceptors in the body, A-delta fibers and C fibers. The A-delta fibers are insulated, larger, and conduct signals quickly. The C-fibers are uninsulated, smaller, and conduct signals slower (Copstead & Banasik, 2000). Nociception is described by Copstead and Banasik as:

“The activation of nociceptors by potentially tissue-damaging stimuli, resulting in the perception of pain by the central nervous system. Nociception includes the processes of receptor transduction, signal transmission, perception, and signal modulation” (p.1081).

The chemical agents responsible for transmission of pain signals are neurotransmitters. These agents are transmitted along neuronal pathways from the site of injury to the brain for integration and interpretation. There are both positive and negative feedback loops that influence future pain transmission. Some chemical modulation occurs via inflammatory cytokines, which have become the focus of many recent research studies. Interleukin-6 (IL-6) specifically has been studied to look at residual neuropathic pain syndromes in patients with cancer, rheumatoid arthritis, and other inflammatory diseases (Rose-John, 2006). In addition, IL-6 has been linked to the transition from acute to chronic inflammatory states.

Psychology of pain.

Pain is integrated in the brain and helps the individual formulate perceptions, memories, expectations, and emotions within the context of pain. This greatly influences how the individual will respond to similar stimuli in the future. The psychologic domain is an important component because of the high degree of variability of pain reaction by
patients. One stimuli may cause little discomfort in one patient, while it causes excruciating pain in another. Post traumatic stress disorder has been documented as causing alterations in response to stimuli in which a small stimuli can elicit a dramatic response. The most notable being “shell shock” in which patients will react in excess to a loud noise. The brain has a complex organization of emotions, memories, and perceptions that can alter the memory and future reaction to a stimulus. That is why providers must not forget the role that the mind can play on a pain patient’s quality of life. QOL tools should also include a component to address psychologic responses.

*Culture of pain.*

Culture has been documented as an influence on pain perception and manifestation. Studies have focused on various groups and have studied how pain is expressed or repressed as an expectation of the group. Rituals and rites of passage are common in most cultures, but are often misunderstood by the outsider.

Masi, Mensah, and McLeod (1993) discusses the various cultural beliefs and expectations that specifically apply with a cancer diagnosis and treatment of pain. One group frequently discussed were Chinese patients who believe that a diagnosis like cancer is the result of a sin, that it is shameful to the person to be diagnosed. He described several clinical situations where patients refused to disclose their diagnosis to friends and co-workers because they were too ashamed. Masi also discussed that Chinese patients are often “stoical about pain” and that a study done comparing their cultural cohort to others found that Chinese patients were far less likely to make demands on staff, to cry, or to request medications. Chinese cultures have also been documented as having two reasons for resisting pain medication including: “a fear of being out of control; and a belief that
pain killers cause a person to sweat and that this loss of body fluids induces weakness” (Masi et al, 2003, p.28).

Intention, history, purpose, and implications can hold great meaning to people within a given culture. A provider must acknowledge these cultural beliefs as being within the context of their patient’s world, and their quality of life. Therefore, when assessing quality of life, culture is an essential component to address.

Management of cancer pain

The World Health Organization (WHO) provides an evidence based approach to pain management. The WHO recommendations for cancer pain management is a three-step analgesic ladder approach. The treatment for mild cancer pain “can begin with analgesics such as acetaminophen or NSAIDS” (p.17). For moderate pain, “weak or episodic short-acting opioids can be added” (p.19). For severe, intractable pain “more potent long acting opioids are recommended” (p.21). Adjuvant therapies can be added at any point according to the WHO recommendations.

Mercadante (2004) suggests a similar approach to cancer pain management in children involving a multidimensional approach. Mercadante discusses “appropriate analgesic administration at regular dosing intervals, adjunctive drug therapy for control of adverse effects and associated symptoms, and nonpharmacologic interventions are recommended”. The use of opioids both orally and intrathecally are techniques that have been found to be beneficial in pediatric populations.

Strasser, Walker, and Broera (2005) discusses the generalized view of pain management as “integrated analgesic treatments, psychological, rehabilitative, and existential interventions, in consideration of individual expectations and outcomes
"The holistic view of pain and importance of an individualized approach is looked at as an advantage over sticking with a specific lateral method of treating different degrees of pain.

Recent research which has looked at proinflammatory cytokines, specifically interleukin-6 (IL-6) show that new therapies may soon arise. These studies have shown an increase in IL-6 in patients with inflammatory diseases (including cancer) and pain issues. A recent study by Nowell and colleagues (2003) demonstrates that supplementation of glycoprotein 130 may inhibit some of the signaling caused by IL-6. Initial trials in patients with rheumatoid arthritis have shown inhibition of arthritis progression.

The current research shows that pharmacologic interventions are the mainstay of cancer pain management. However, most studies also say that adjuvant therapies (surgical, radiation, genetic, and behavioral) have benefit throughout the pain management process.

Evaluation of Quality of Life Instruments

In a comprehensive literature review utilizing ProQuest, CINAHL, and various printed texts, over 50 quality of life surveys were assessed. Of these, seven were found to be specifically addressing cancer patients with pain. Each of the surveys has different strengths and weaknesses. Many were originally written within the context of a clinical trial for a specific type of cancer and are, therefore, not generalizable to all cancer patients. However, all of the QOL surveys attempt to assess different domains of life in order to provide better understanding and outcomes for cancer patients.
Although many quality of life surveys are in print, many will attest to the difficulties in assessing all aspects of patients’ lives. Most surveys discuss major categories of quality of life with varying opinions of which categories to include. Few quality of life surveys have been specifically modified for addressing pain issues in cancer patient care. Disease burden on a physical, economical, social, and psychological level makes quality of life more difficult to assess.

The two most commonly cited cancer quality of life models are: Ferrel, Grant, Padilla, Vemuri, and Rhiner’s City of Hope Model (1991) and the Ferrans and Powers QOL model (1992). Both models describe quality of life as a multidimensional and subjective experience of the individual and helped to guide the creation of the presently available QOL instruments.

Rhiner developed an additional model which discusses the impact of fatigue and pain on the dimensions of quality of life uses the categories: physical well-being and associated symptoms, psychological well-being, social concerns, and spiritual well-being. The physical category includes: functional ability, strength/fatigue, sleep and rest, nausea, appetite, and constipation. The psychologic category includes: anxiety, depression, enjoyment/leisure, pain distress, happiness, fear, and cognition/attention. The social category includes: caregiver burden, roles and relationships, affection/sexual function, and appearance. The spiritual well-being category includes: suffering, meaning of pain, and religiosity (Ferrell et al., 1991).

Padilla and Grant (1985) formulated a model which addresses the nursing process and various dimensions of quality of life in a cancer context. The quality of life dimensions are: psychological well-being, social concerns, body image concerns,
physical well-being, and diagnosis/treatment response (Padilla & Grant, 1985). The nursing process variables that were correlated to quality of life outcomes were: promoting a caring attitude, implementing standard nursing process, and promoting self care and autonomy. The model places tremendous responsibility upon the nurse to assist with the mediation of the experience and the overall outcomes for quality of life.

Together, these models address the importance of measuring QOL throughout the trajectory of care provided for the patient with cancer. They also helped to formulate the important constructs of QOL for instrument development. The following paragraphs describe available QOL instruments that are readily accessible for clinical use.

Grant and colleagues (1992) formulated a quality of life survey that is specific to bone marrow transplant patients which has several categories of quality of life. The categories discussed include: Physical well-being, psychological well-being, social concerns, and spiritual well-being (Grant et al., 1992). Statistical reliability of the tool was broken down by each category with the overall rating alpha 0.98, physical well-being was 0.77, psychological was 0.89, social was 0.81, spiritual was 0.71. The questionnaire also provides areas for the patient to elaborate on specific situations, so that they are not just choosing the best of various answers. It is one of the few QOL measures that requests the patient to give written answers to questions.

Carol Ferrans was one of the first researchers to make a quality of life index that was specific to cancer patients. The questionnaire asks a variety of questions within the context of how satisfied the patient is with the subject, and also how important the subject is to the patient. The QOL model formulated in 1985 addresses various areas of QOL and asks the patient to select from a variety of answers on a scale. In 1992, Ferrans and
Powers performed a psychometric analysis of the original QOL tool and found a validity of 0.77 and an overall reliability as 0.93.

The Daily Diary Card-Quality of Life Scale has been used in cancer clinical trials when patients are on chemotherapy. It is a self administered card that demonstrated short-term changes in quality of life categories as a result of chemotherapy treatment (Gower et al., 1995). This quality of life card was used specifically on patients with small cell lung cancer. A similar scale used in clinical trials is the FACT-G scale developed by Cella et al. in 1993. The FACT-G scale looks at 33 quality of life indicators.

Finkelstein and colleagues (1988) formulated a quality of life assessment in patients with metastatic lung cancer to be used during clinical trials. The functional living index-cancer (FLIC) scale was the result of their research. This scale assessed the patient in the following domains: physical/occupational function, psychological state, sociability, and somatic discomfort. The scale was originally started in 1988, but has been modified for use in patients with other forms of cancer.

Implications for nursing/nurse practitioner practice

Assessment of the QOL surveys demonstrate that the tools needed to do an adequate assessment of cancer patients exist, and that the responsibility lies upon the provider or nurse to use them. Overall, the Ferrans QOL scale provides a different viewpoint than many of the models that may be helpful to address. This scale not only asks the patient about QOL domain adequacy currently, but the patient’s overall desires on the different topics. The Ferrans QOL instrument also had a high statistical reliability of 0.93, meaning that it consistently measures the constructs of pain implied in the instrument. This is an important approach for providers to understand that not every
person is going to have the same goals or needs, therefore a standard tool and strong communication skills are necessary. Ideally, a new tool should be written to encompass a generalized view of quality of life within the context of cancer pain with the inclusion of cultural components, a construct that is lacking in currently available instruments. QOL assessment should be done during the initial visit and on a quarterly basis. However, any major changes in the disease progression or QOL indices that the patient discloses to the provider should warrant an additional assessment. Adequate assessment of QOL in cancer patients with pain will assist the provider in making clinical decisions about treatment and referrals.

Summary

Cancer pain management standards should include a comprehensive quality of life assessment. Studies have shown that nursing actions and knowledge can improve patient outcomes. Utilizing the Synergy Model to implement nursing interventions and patient goals with respect to quality of life measures may dramatically improve overall outcomes. Knowledge of the current QOL surveys and the empiric use in clinical settings can help the provider and nurse to adequately assess their patient. Utilizing the Ferrans QOL scale can assist the provider to understand not only what the patient’s needs are, but if they are being met. The QOL scale has a high statistical reliability and an opportunity to assess additional data provided by the subject. Although complete pain control may not always be available, improvement of quality of life is always a possibility for the provider or nurse. Conversely, treating pain only and not addressing quality of life concepts can leave the patient with unresolved issues. Ultimately, assessment of quality of life of cancer patients with pain is a reasonable goal for nursing practice.
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