

Pain and palliative medicine

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Abstract—Severe pain is highly prevalent, with rates of 40% to 70% in patients with advanced cancer, liver disease, heart failure, human immunodeficiency virus, and renal failure. Wide variations in pain assessment and reporting methods and the measurement of multiple symptoms should be addressed in future studies. Regarding psychological approaches, determining whether hypnotherapy or other individual psychotherapeutic interventions reduce pain and/or psychological distress in a palliative care population is difficult. Interest is increasing in the concept of demoralization syndromes and the role of post-traumatic stress disorder in modulating responses to pain at the end of life. We review evidence from multiple studies that the use of rehabilitative therapy improves functional status and pain control among patients with advanced cancer, and we raise the possibility that rehabilitation therapy will be helpful in patients with other advanced diseases. We summarize ongoing clinical trials of electronic order sets, clinical care pathways, and care management pathways to improve pain management in palliative care. Wagner’s Chronic Illness Model provides a way of analyzing how healthcare systems can be changed to provide adequate and continuing pain management in palliative care. Much work remains to ensure that pain is recognized, treated, and monitored effectively.

Key words: cancer, health services, heart failure, HIV, information technology, pain, palliative, PTSD, quality care, rehabilitation, veterans.

INTRODUCTION

Pain is highly prevalent in palliative care populations and pain management is one of the hallmarks of good palliative medicine. This article summarizes and discusses new concepts in a number of areas important to both clinicians and researchers.

Abbreviations: AIDS = acquired immunodeficiency syndrome, CBT = cognitive-behavioral therapy, CI = confidence interval, COPD = chronic obstructive pulmonary disease, DNR = do not resuscitate, ESAS = Edmonton Symptom Assessment Scale, HIV = human immunodeficiency virus, NQF = National Quality Forum, PTSD = posttraumatic stress disorder, SUPPORT = Study to Understand Patient Prognoses and Preferences for Outcomes and Risks of Treatment, TENS = transcutaneous electric nerve stimulation, VA = Department of Veterans Affairs.

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EPIDEMIOLOGY

Population

The fact that patients with advanced cancer often experience pain is well known. The Study to Understand Patient Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) study found that in 316 patients with metastatic colon cancer, the prevalence of pain increased from 30 percent at 6 months prior to death to 45 percent in the last 3 days; the prevalence of confusion was 20 percent starting 1 month prior to death. Similar findings were obtained for 747 patients with advanced non-small-cell lung cancer [1]. In a survey of 240 medical hematology oncology patients, 94 (67%) of 140 inpatients had pain, and 47 (47%) of 100 outpatients had pain. Non-malignant pain accounted for 34 percent of inpatient pain diagnoses and 74 percent of outpatient pain diagnoses ($p < 0.001$). Arthritis was the major nonmalignant cause of pain for the outpatients [2]. This finding highlights that patients with advanced cancer can experience pain from other chronic medical conditions (e.g., arthritis, low-back pain), complications of pain medications (e.g., constipation), and painful side effects of cancer treatments.

What surprised the SUPPORT investigators was the prevalence of pain in other terminal conditions. Of 539 patients with congestive heart failure who died within 1 year of hospitalization, the prevalence of pain and dyspnea increased over time, with pain increasing from 20 to 40 percent of patients, and dyspnea from 30 to 60 percent of patients [3]. In 416 patients with advanced chronic obstructive pulmonary disease (COPD), during the last 6 months of life, moderate to severe pain was reported by 20 to 30 percent of patients and dyspnea by 70 to 80 percent of patients [4]. A higher prevalence of pain was reported by Elkington et al., who performed a retrospective study of companions of 399 patients who died from COPD. The 209 respondents' answers regarding symptoms yielded figures of 98 percent breathlessness, 96 percent weakness, 77 percent low mood, and 70 percent pain [5].

Of 166 SUPPORT study patients with end-stage liver disease who died during the study, 30 to 40 percent experienced moderate to severe pain in the 6 months before death. Other symptoms included confusion and dyspnea, with a similar prevalence in the 1 month before death. The median age was 52 years [6].

Of 417 patients greater than 80 years old who died during the Hospitalized Elderly Longitudinal Project study, moderate to severe pain was reported by 25 to 30 percent of inpatients in the last 6 months of life and increased from

18 to 35 percent in outpatients. Pain was associated with orthopedic and infectious conditions, falls, cardiac and gastrointestinal disease, depressed mood, level of activity, and site of hospitalization [7].

Pain is also highly prevalent in two other disease categories associated with palliative care: chronic renal failure and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). In a survey of a cohort of 205 Canadian hemodialysis patients, Davison found that 103 patients (50%) had pain. They described their worst pain as severe, and causes included musculoskeletal disease (63%), dialysis procedures (13.6%), neuropathic pain (12.6%), and peripheral vascular disease (9.7%). Worst pain was greater than 7 out of 10 for half the patients with pain, and strong opioids were used in 10 percent of all pain patients [8]. In a multicenter study of deaths of 131 dialysis patients, Cohen et al. found that 42 percent of 79 patients available for follow-up were in pain in the last 24 hours of life and 5 percent were in severe pain. Other symptoms included agitation (30%), dyspnea and myoclonus (28%), and dyspnea (25%) [9]. In a recent survey of AIDS patients receiving palliative care in a 14-county rural area in Alabama and in Baltimore and New York City, pain was reported by 64, 74, and 69 percent of the patients, respectively. The mean number of symptoms ranged from 10.9 to 12.7 [10].

In other broader surveys, Tramner et al. compared symptom prevalence in very ill hospitalized patients with cancer or noncancer diagnoses. They found that symptom distress scores were similar for both groups of patients, although cancer patients were more likely to report pain and nausea, while noncancer patients reported dyspnea and cough [11]. Solano and colleagues performed a systematic search for reports of symptom prevalence in five different disease states: cancer, HIV, heart failure, COPD, and renal disease. They found that pain and fatigue had a high prevalence in all five conditions and that many other symptoms such as breathlessness, depression, and nausea were present in all five conditions as well. Solano et al. postulated that this commonality of symptoms supported the presence of a common terminal pathway [12].

Setting

Recent reviews of hospice patients suggest pain remains highly prevalent. Walsh et al. reviewed symptoms in 1,000 consecutive patients referred to a palliative care service from 1990 to 1992. The most common symptoms were pain (84%), fatigue (69%), weakness (66%), and

anorexia (66%) [13]. In a survey of 178 hospice patients admitted with cancer, McMillan and Small found the most prevalent symptoms were lack of energy (89%), pain (83%), dry mouth (78%), and shortness of breath (70%) [14]. In another survey of 400 patients referred for palliative care, the most prevalent symptom was pain in 64 percent of all patients, and the highest prevalence (75%) was seen in patients referred to outpatient care [15].

Another increasingly important site for palliative care is nursing homes. Buchanan et al. analyzed the Minimum Data Set, a comprehensive assessment, for 40,622 nursing home residents who were receiving hospice care at the time of admission to a nursing home from June 1998 to September 2000. More than 70 percent experienced pain and 50 percent reported daily pain. Pain intensity was rated as "mild" for 13 percent, "moderate" for 57 percent, and "horrible" for 30 percent. Half the patients had cancer as an underlying diagnosis [16].

Another Minimum Data Set study of 6,042 patients stratified by living area (urban, large town, small town, and rural/isolated) found a similar prevalence of pain across sites but that rural/isolated patients received less intravenous medications and wound care [17]. For home hospice patients, one survey of hospice providers of 348 patients noted pain in 76 percent of the patients, lack of energy in 83 percent, and lack of appetite in 63 percent [18].

Weiss et al. interviewed 988 terminally ill patients from 6 cities selected by their physicians from March 1996 to 1997. Moderate to severe pain was reported by 52 percent of patients with a diagnosis of cancer, 47 percent of patients with heart disease, 45 percent of patients with COPD, and 51 percent of patients with other diagnoses. Poor physical functioning, depressive symptoms, and low income were independently associated with pain. Interestingly, half the patients with moderate to severe pain wanted to stay on their current medications; fear of side effects and addiction were frequently cited as reasons for not wanting more or different medications [19].

Pain is highly prevalent in different palliative care settings and is associated with other symptoms. One of the major limitations of most of the studies addressing the frequency of the symptoms has been the wide variation in assessment tools and the wide variation in inception cohorts. Even within the term "palliative care unit," some centers admit almost exclusively acutely distressed cancer patients, while others admit a majority of chronic noncancer patients. Better definition of the different

patient populations in addition to increased uniformity and reporting will allow for more definitive conclusions.

The data clearly demonstrate that multiple physical symptoms occur in patients with a variety of painful diseases. Therefore, a focus on the regular monitoring of pain alone is limited. Future improvements in clinical care should address the measurement of multiple symptoms using very simple tools [20], an understanding of which dimensions of pain are most important in palliative care, pain assessment in the cognitively impaired patient [21], and a delineation of the sources of pain in noncancer palliative care patients.

PSYCHOLOGICAL ASPECTS OF PAIN MANAGEMENT

Psychological symptoms (e.g., depression, anxiety, posttraumatic stress disorder [PTSD]) and ways of being (decreased functional ability, perceived locus of control, self-efficacy) affect the perception and experience of pain. Psychological factors related to pain in palliative care remain highly relevant to both clinical and academic palliative medicine.

Research on psychological interventions for pain has focused primarily on patients who experience chronic pain or have newly diagnosed illnesses and not on palliative care populations. The most widely used form of psychological intervention for chronic pain has been cognitive-behavioral therapy (CBT) [22]. This therapy is based on the theoretical assumption that dysfunctional thoughts influence emotions and behavior [23]. Specific skills training within this CBT framework often incorporate relaxation training, with techniques such as controlled breathing, biofeedback, and progressive muscle relaxation [24], as well as attentional training techniques including cognitive distraction techniques, imagery, and hypnosis [25]. Cognitive strategies entail restructuring of usual thoughts and attitudes (symptom reappraisal), coping self-statements (belief in personal mastery), and problem solving activities (identifying difficulties, as well as generating and evaluating options for behavioral change). Overall, CBT has produced significant changes in experience of pain, mood, cognitive appraisal, coping styles, pain behavior, activity level, and social functioning [26]. Similar benefits have been reported for CBT interventions in specific symptoms associated with cancer treatment, such as chemotherapy-induced nausea and vomiting [27]. The

impact of such interventions are exerted through the impact on psychological style (e.g., self-efficacy, locus of control), which in turn changes individuals' perception of their pain and improvement in the broad constellation of affective distress and functional activity. Given the complexity of the causal links between pain and functional capacity, drawing firm conclusions regarding the relationship between CBT interventions and chronic pain is difficult.

Aspects of CBT (such as use of hypnosis) have been studied in patients with advanced cancer. In a review of the use of hypnosis to treat symptoms in patients with advanced cancer, Rajasekeran et al. noted that although many studies reported improvements in physical and psychological symptoms, including pain, these results must be interpreted with caution. They found that most of the studies they reviewed reported small sample sizes, variability in techniques, and weak articulation of outcome measures. They expressed further concern regarding efforts at controlling for confounding variables and use of validated measures. Therefore, at present, determining whether hypnotherapy actually serves to reduce pain and other symptoms in a palliative care population is difficult [28].

Psychotherapeutic literature has been emerging with the premise of incorporating existential conceptualizations and techniques into psychological treatment at the end of life. Such work was spearheaded by the group work of Spiegel, Classen, and colleagues, who have developed supportive expressive group psychotherapy for patients with advanced illness [29–30]. Success of this group intervention has been measured in improvements in psychological well-being (reduced anxiety and depression) and improved coping and control of physical symptoms, including pain [27,31–33]. Similar therapies, including meaning-centered group psychotherapy [34] and therapies targeted at demoralization [35], are currently in clinical trials with advanced cancer patients. To date, no research has been conducted on the effect of individual psychotherapeutic interventions on pain and/or psychological distress in a palliative care population. Individual psychotherapies that incorporate existential aspects should also be developed and tested given the practical issues that may interfere with the group work. Quantification of brief and informal contacts by professionals such as consultation-liaison psychologists and psychiatrists that incorporate the above interventions may also be relevant.

Currently, efforts exist to establish screening tools for anxiety and depression tailored specifically to palliative care patients, including measures to distinguish depression

from preparatory grief (Terminally Ill Grief or Depression Scale) [36] as well as measure demoralization (the Demoralization Scale) [37]. Use of these tools may prevent mischaracterizing as pathological the “normal” emotional distress from the complications of severe physical illness. Such mischaracterization likely stems from the use of screening measures designed to pick up depression in an otherwise healthy individual. Measuring vegetative symptoms such as lack of appetite, sleep and sexual disturbances, and fatigue may create false positives. It is important that palliative care specialists, especially mental health professionals, distinguish between the despair indicative of an affective disorder associated with a pain magnitude that is disproportionate with disease state (e.g., symptom magnification) and the dysphoria that stems from diminished functional activity inherent in the disease process. Recent investigations into the etiological pathways of depression and determinants of quality of life in chronic illness are illuminating the interactions between physical and psychological conditions and offer the prospect of more effective pain management [2,38–42].

Depression, decreased functional ability, perceived locus of control, self-efficacy, and personal trauma histories have an inextricably woven relationship with perception of pain. Evidence is growing that these constructs are an inherent part of a demoralization syndrome. Kissane et al. have emphasized the importance of developing a taxonomy that differentiates common distress syndromes in the medically ill as they hypothesize that depression and demoralization are overlapping but differing constructs [43–45]. The degree of existential suffering/demoralization experienced by patients likely affects perception of, and coping with, physical pain. Identifying which individuals experience a sense of bleakness about their disease process and helping them identify achievable goals within the confines of their physical limitations may ameliorate their demoralization. This, in turn, may yield improvements in depressive symptoms and subjective reporting of pain. Interventional research using measures of despair, hopelessness, and demoralization while assessing levels of functional activity and magnitude of subjective pain will allow for a deeper and more nuanced understanding of suffering at the end of life.

Such future studies are particularly relevant to veteran populations, given their exposure to devastating injuries, suffering, and death, during which psychological ramifications beyond those experienced by the civilian population are likely. In a recent article addressing the potential effects

of combat PTSD in a palliative care population, Feldman and Periyakoil suggest that trauma may have a complex influence on dealing with terminal illness and the dying process [46]. The threat to life inherent in terminal illness may mimic an original trauma experienced on the battlefield, exacerbating previous symptoms that may have been controlled. Although this is a clinically acknowledged phenomena, at this point no empirical studies exist regarding pain management in veterans exposed to combat trauma. Also of interest is how this phenomena is expressed at the end of life. How do associated reactions such as anger, shame, or survivor guilt influence the perception of pain and interpersonal relations during the course of advanced disease or dying? Observing the differences among patients who have experienced different combat experiences, different trauma experiences (e.g., prisoners of war, World War II vs Vietnam veterans), and different levels of PTSD treatment both in their conscious and unconscious states is fascinating. The way patients cope with their disease symptoms and decline (e.g., denial, avoidance) may mirror the way they have coped with their trauma and resulting PTSD symptoms (especially if untreated). In our experience, patients with combat experiences often present as anxious and hypervigilant; they feel trapped by their deteriorating bodies and want to “escape.” During the last days of life, these patients may be more agitated and restless and may experience a longer, more stressful dying process (e.g., have difficulty letting go). Incorporation of measures, such as the Terminally Ill Grief or Depression Scale, to differentiate levels of sadness due to helplessness or guilt associated with combat experiences might help delineate pathways of interventions.

A dearth of efficacy research exists in the area of individual therapy and pain. Given the vulnerability of the palliative care population, research must begin to better inform clinicians how and when to appropriately intervene. Such research needs to be conducted along two fronts. First is the further development of appropriate screening tools for psychological distress in terminally ill patients. Second is the conduct of randomized trials of psychotherapeutic interventions for patients at the end of life. These steps will lead to better understanding of the sources of the patient’s physical pain (e.g., nociception versus existential suffering versus clinical depression) and how best to intervene.

PHYSICAL MEDICINE AND REHABILITATION APPROACHES

The concept of physical rehabilitation is gaining increasing attention in palliative care patients. The goal of rehabilitation in the palliative care patient is to eliminate or reduce disability by optimizing functional status, physical independence, and quality of life through appropriate treatment [47]. The use of rehabilitation in palliative care should be individualized and account for the overall life expectancy and the patient’s desire to actively participate in therapy.

Palliative care patients with cancer experience high levels of physical disability and pain, which are in turn related to disease progression, direct tumor effect, paraneoplastic syndromes, or local or systemic effects of cancer treatment and its complications [48–52]. Progressive functional decline and pain characterizes the last months of life of cancer patients [1,53]. The impairments of physical function and chronic pain are significant contributing factors to decreased quality of life of these patients [54]. In a large randomized national survey of 340 seriously ill patients, 89 percent stated that they did not wish to be a burden to their family [55]. Dependency is regularly cited as a reason by patients who request euthanasia [56]. The goals of rehabilitation are correspondingly very attractive to patients and their families. Axelsson and Sjoden documented that physical strength, hours spent in bed, and the ability to do what one wants are ranked highly by cancer patients and their spouses with respect to overall quality of life [57]. Yoshioka found that 88 percent of his hospice patients who received rehabilitation expressed a strong desire for ambulation or wheelchair mobility [58].

Evidence is increasing that rehabilitative therapy improves functional status and pain control among patients with advanced and end-stage diseases. In a study of the use of rehabilitation in 239 hospice patients, Yoshioka demonstrated a 27 percent improvement rate (defined as the percentage of potential improvement that is actually achieved) in mobility scores using the Barthel Mobility Index. Responses obtained from 169 families of deceased patients indicated that 88 percent of patients had previously indicated a desire for ambulation and wheelchair mobility, 78 percent were satisfied with rehabilitation in the terminal stage, and 63 percent considered the terminal rehabilitation to be effective. Yoshioka also found that almost all patients who underwent rehabilitation experienced some degree of pain relief [58]. Similarly, Sabers et

al. demonstrated significant functional gains in 189 cancer patients who received rehabilitation services on a consultation basis. Quality of life questionnaires, while limited by completion rate, showed significant improvement on multiple parameters such as pain, mood, quality of life, mobility, and comfort with going home after rehabilitation interventions. In this study, 18 percent of patients were thought to have a terminal disease with a life expectancy of less than 6 months, 46 percent were being treated with palliative rather than curative intent, and 60 percent had metastatic disease [59]. Marciniak et al. showed significant functional gains in cancer patients in a comprehensive inpatient rehabilitation unit. The presence of metastatic disease did not influence the functional outcome, and functional improvement was greater in patients receiving radiation therapy [60]. Scialla et al. showed that elderly patients with cancer-related asthenia improved in both physical and mental function from inpatient rehabilitation [61]. Laakso et al. investigated the impact of physiotherapy on the quality of life and functional status of 40 palliative care patients treated in an oncology ward. They found that patients who received a structured physiotherapy intervention experienced statistically significant decreases in pain, fatigue, and appetite disturbance. They concluded that the provision of an adequately resourced physiotherapy service incorporating early intervention and community follow-up can contribute significantly to the maintenance of functional independence and quality of life among patients receiving palliative care [62]. Movsas et al. found that 87 percent of patients admitted to a medical oncology ward had remediable rehabilitation needs on admission [63]. More recently, Montagnini et al. described the use of physical therapy in patients treated in a Department of Veterans Affairs (VA) inpatient palliative care unit. They found that deconditioning and pain accounted for 90 percent of the functional disabilities in patients who received physical therapy. When used, 56 percent of patients benefited from physical therapy. A higher serum albumin level was a predictor of functional improvement [64].

While rehabilitation is widely clinically accepted as an adjuvant therapy in cancer pain management, research in this area is limited. Physical therapists use thermal therapy (heat, cold, ultrasound), massage, transcutaneous electrical nerve stimulation (TENS) to manage musculoskeletal pain [65]. These modalities of treatment can be considered adjuncts to pharmacological therapy in cancer pain when musculoskeletal or soft tissue pain is present. Caution must be taken in the application of heat for

patients with sensory loss, arterial insufficiency, metastatic tumors, bleeding diathesis, or cognitive deficits [66]. Research on TENS in chronic nonmalignant pain shows positive results after 1 to 3 months, with approximately 25 percent reporting relief and continued use after 4 years [67]. Few studies, however, have focused on the efficacy of TENS for cancer pain management [68]. Massage and therapeutic exercise can be used to treat muscle spasm and improve function. Weinrich and Weinrich showed that massage therapy was effective in improving short-term pain control in a small group of cancer patients treated at an oncology ward [69]. Wilkie et al. documented that a massage intervention improved relaxation and pain control among patients receiving hospice care [70].

The use of rehabilitation techniques in palliative care requires further study. While much of the rehabilitation work cited has been on patients with cancer, application of these interventions to patients with other painful care diseases may confer similar benefits in pain control and functional well-being. Emphasis should be given to the development of larger, prospective randomized controlled trials to better define appropriateness and response to these types of therapies for pain control, symptom management, and function of patients with life-threatening and advanced diseases. Interest is increasing in the application of alternative nonpharmacological approaches to pain, such as acupuncture and acupressure [71–72]. Proper pain control and symptom management as well as physical independence are essential to the quality of life of these patients.

CLINICAL TRIALS

Clinical trials of pain medications face great hurdles in palliative care. These include the clinically unstable nature of the patients, the frequent presence of multiple pain syndromes, difficulties in recruitment and symptom assessment [73], and resistance to the clinical trials in this population. Requirements for 3-month follow-up by regulatory authorities make it very difficult for a company to get a labeling indication for a product for symptom management in palliative care. On the other hand, impetus for clinical trials comes from the weak evidence base for this group of patients, the enormity of the clinical problem, an evolving consensus in assessment of pain severity [74–75], pain instruments [76–77], determination of clinically significant differences in pain [78], and in outcomes of

pain trials [79]. Further impetus comes from the burgeoning array of drugs to be tested as our understanding of pain mechanisms increases [80–81]; drugs that may help target intractable problems such as bone pain and neuropathic pain [82–83]. The development of oral transmucosal fentanyl citrate for breakthrough pain proceeded through randomized trials [84] and open trials [85]. Recently, Bruera et al. reported a randomized multicenter comparison of morphine to methadone in hospice patients [86]. This experience suggests that randomized multicenter trials of pain medications in palliative care settings, while challenging, can be done successfully.

Although improvements have occurred, such as the development and widespread use of new sustained-released medications in oral and topical form, and structural mandated changes, such as the adoption of routine assessment of pain on a 1 to 10 scale as the “fifth vital sign,” it is not always clear that pain control is significantly better.

On a broader level, the disconnect between the intent to treat pain and the actual treatment of pain has been suggested by a number of studies. Kravitz performed a small randomized clinical trial in which two groups of inpatients were assessed regularly for pain, and one group had pain-intensity levels displayed at the bedside. No difference was found in pain control between the groups [87]. SUPPORT study investigators recorded the preferences of patients regarding pain control early in their disease course, as expressed by willingness to be dead rather than be in pain or willingness to have a treatment with shorter survival rather than be in pain, and found that these preferences had no bearing on whether that patient experienced severe pain a few days later in the hospitalization.

One major reason was that only one-fourth of patients communicated their preferences to their doctors. In a patient-centered system, one would have expected if attention was paid to these preferences, results would have shown a difference [88]. In a chart review of 205 consecutive patients who died at a major medical center, 72 percent were recognized as dying, 77 percent had “do not resuscitate” (DNR) orders but only 46 percent had “comfort care” plans. The median length of time from patients being made DNR to death was 5 days and the median time from comfort care to death was 2 days, approximately after two-thirds of the hospitalization had elapsed and 3 days after the DNR order was written [89].

These findings contrast with reports from palliative care units where a more hopeful picture is emerging. For 314 patients admitted to a palliative care ward in Italy over 1 week, pain decreased from an average of 7 to 4 ($p < 0.001$), as did many other symptoms measured by the Edmonton Symptom Assessment Scale (ESAS) [90]. In another study of 267 cancer patients admitted with pain to a palliative care ward in Denmark and assessed with the ESAS and the European Organization for Research Treatment Cancer Quality of Life Questionnaire, significant decreases were found in pain measures and for other symptoms after 1 week [91]. Pain improvement has also been reported in other settings. In a study of 76 cancer patients with severe pain treated in a hematology oncology service, mean pain severity decreased from 8.3 to 6.0, and average pain relief increased from 40 to 80 percent after 1 week [92]. In a retrospective study, patients seen at a multidisciplinary symptom-control outpatient clinic reported significant improvement in pain and other symptoms [93].

One simple variable that could explain these findings is the willingness and ability to write orders. If orders are easily available and training is present, care will be delivered. One area is the art of opioid titration for cancer pain, where the evidence base is weak [94]. A protocol that can be carried out by nurses with physician supervision has been developed and tested in 27 patients and is now undergoing further clinical trials [95]. A larger concept is to bring the hospice approach into an acute-care hospital. Currently ongoing within the VA system is an evaluation of a “comfort care” intervention that targets physician, nursing, and ancillary staff, training them to identify veterans who are dying and to implement care plans appropriate for the last days or hours of life. Preliminary results show that for a patient actively dying in a VA hospital, this set of interventions increased the rate of having an active opioid order at time of death from 57.1 percent to 83.2 percent and the rate of pain assessment in the daily notes during the last 7 days from 29.0 to 57.9 percent of all patients after the intervention. The chances of receiving any opioid medication at all in the last 72 hours of life increased from 13.9 to 71.3 percent of all actively dying patients [96]. However, linking improvement in patient outcome as measured by a self-assessed pain score is not possible because so many patients cannot provide assessments when they are this ill. This intervention is now being tested at other facilities as part of a multicenter trial funded by the VA Health Services Research and Development Service. An electronic

comfort care order set will be integrated into the VA Computerized Patient Record System to facilitate the use of these interventions.*

Another system intervention is a clinical care pathway, which is composed of an interdisciplinary care path, a daily documentation flow sheet, and a physician order sheet [97]. A trial implementation of this system in a teaching hospital showed improvements in symptom assessment and management, higher likelihood of DNR orders, and decreased number of consultations [98]. This clinical pathway has been piloted on an oncology unit in a VA hospital with findings of more frequent care plans and symptom assessment and documentation [99].

An even more general model for interventions is quality of care. Wagner et al. has suggested that quality gaps are largely due to incomplete assessments and irregular follow-up, inadequate patient education and involvement in care, omission of effective interventions, and undetected or unmanaged psychosocial distress [100–101]. A 4-year randomized controlled trial of a system-of-care intervention to assess its impact on important end-of-life outcomes, including pain and nonpain symptoms, is currently under way at the VA Greater Los Angeles Healthcare System, based on promising pilot data [102]. Medical inpatients who have been identified by their admitting physician as having at least a 25 percent chance of dying in the following year and who consent to participate are randomized to either usual care or an intervention that employs palliative care assessment followed by longitudinal nurse-led care management. The care management intervention employs critical elements of Wagner's Chronic Illness Model, including interdisciplinary patient and family education about the condition and prognosis, as well as symptom-management strategies, protocols for telephone monitoring of symptoms and palliative care needs and for communicating those needs to providers, continuity and coordination of care across providers and care venues, and 24/7 availability of expert palliative care support to providers, patients, and families. The intervention's impact will be assessed through intergroup comparisons of processes and outcomes of care, including pain and symptom management, quality of life, satisfaction with care, family assessment of patients' dying experience, and medical resource use and costs.

*Bailey FA. Personal communication, May 16, 2006.

INFORMATION TECHNOLOGY AND PAIN

Interest in improving healthcare quality raises the issue of how to best leverage routinely collected information about pain that is available in some administrative and clinical databases. Databases can provide information about populations of patients and may provide important insights into the quality of pain assessment and management as well as pain outcomes. Some organizations such as the Veterans Healthcare Administration maintain relatively clinically rich data repositories, whereas these resources are often much less developed in other healthcare organizations. A review of administrative databases in Canada found that while the databases are large, they may not be comprehensive enough for clinical purposes and billing is not the same as treatment [103].

Much attention has been focused on pain as the fifth vital sign. This routinely collected numeric rating scale is well validated in research settings as a tool for assessing pain both cross-sectionally and longitudinally. The usefulness of screening for pain as a quality measure has become an area of considerable interest because of increasing evidence that this 0 to 10 scale, as implemented in American hospitals, has major limitations both as a screening and follow-up tool. These limitations include deficiencies in documentation and adherence to guidelines, as well as wide interobserver variability in pain ratings [104–107]. The Quality Oncology Practice Initiative of the American Society of Clinical Oncology evaluated answers in 15 practices to questions derived from previous surveys [108] such as whether pain was assessed in either of the last two visits (95% confidence interval [CI], 81%–88%) prior to death, and whether pain was rated numerically (95% CI, 37%–46%) [109]. Variation was found in these parameters suggesting room for improvement. Further studies are needed to evaluate the usefulness of the fifth vital sign approach as a component of quality pain assessment and management and to show how routine pain screening can better influence clinical care.

Palliative care was one of the three areas addressed by the National Quality Forum (NQF) effort to identify quality measures for cancer care [110]. To inform these efforts, NQF completed a systematic review that described the state of measurement with respect to palliative cancer care. Literature and web searches retrieved 5,182 documents, from which a total of 17 potential quality measures for pain, 5 for depression, 5 for dyspnea, and 26 for advance care planning were identified. However,

most of these measures address relatively rudimentary aspects of pain and palliative care delivery and few have been adopted routinely in healthcare systems to actually measure or improve quality [111–112].

The quality measures identified by the NQF review that were related to pain and palliative care require data points such as the timing of pain assessment, severity of pain, and documentation and timing of interventions including medications, as well as subsequent pain levels. The availability of pain data in some data repositories fits well with the emerging interest in quality measurement. Many of these metrics are either within the capacity of current VA information systems or, we hope, will be shortly. For a comparison of facility-level performance that would provide responsive information to guide real time system performance, one would prefer that measures be available as administratively derived tools. Certainly, all of them are readily accessible through chart reviews, a common source of quality information at the VA nationally. Newer generations of VA data repositories are expected to provide increased flexibility (e.g., evaluating the timing of medications). The ability to collect and analyze quality measures will drive system performance and, ultimately, patient management.

SYSTEMS ISSUES FOR PAIN IN PALLIATIVE CARE—HOW TO GET IT RIGHT

The SUPPORT study highlighted the importance of the system of care in effective pain and symptom management [113]. The primary problem with pain management lies less in technical ability to manage treatments and more in failures to effectively translate treatment strategies into patient care, over time and across care settings. Optimal pain management requires systems of care that can (1) identify pain when and where it occurs, (2) initiate appropriate treatment, and (3) follow-up to determine that treatment is effective. In practice, these seemingly simple three steps require a complex set of processes involving multiple providers and care settings working longitudinally over time and calling for active participation on the part of patients and caregivers. Unfortunately, little research has been conducted either to clarify how these processes determine a care system's overall success in managing pain or to identify which system interventions are most likely to improve overall pain management.

Effective pain management from a healthcare system perspective necessitates mechanisms for promptly identi-

fying pain. Because most patients spend relatively little time in the hospital or clinic, health organizations must develop methods for identifying patients' pain when they are at home or in other nonhospital settings. Patient education and empowerment are particularly important for patients who are outside the hospital, where routine monitoring by medical personnel does not occur. Innovative approaches to facilitate timely access to providers when patients experience pain, including telephonic and Web-based communication, are currently being instituted within the VA. Research assessing their acceptability to patients as well as their impact on organizations' success in identifying and managing pain is needed.

In addition to identifying pain, healthcare systems need to be able to initiate management of pain in a timely, technically competent way. Because pain is influenced both by disease physiology and by nonphysiological factors, including emotional, spiritual, and interpersonal distress, technical competence includes both pathophysiological and psychospiritual interventions.

First, systems need to ensure that providers are competent in physiological approaches to pain management. Approaches designed to improve pain management competence include provider-targeted interventions, such as standardized pain management guidelines [65], educational programs (e.g., physician continuing medical education in pain management is required by state law in California [114]), as well as more collaborative approaches in which providers are supported by pain-management specialists when difficult-to-manage pain arises [115]. Nursing-led interventions that combined educational and system approaches have led to improvements in pain management in hospice settings [116]. In addition, given the multifactorial contributors to pain, high-functioning systems employ an interdisciplinary approach to pain management. Within the VA system, relevant developments include the online clinical reference system available to all providers, the national VA programs for pain management and for palliative medicine, mandated palliative care consultation teams [117], the development of hospice veteran partnerships [118], and increasing use of telemedicine. Research examining the role of an interdisciplinary approach rather than a strict pharmacological approach to pain management is clearly needed.

Because pain is a dynamic symptom that changes over the course of a patient's illness, care systems must also ensure that pain is continuously well-managed. Longitudinal management of pain requires processes for reassessment after initiation of treatment and mechanisms to ensure

that patients and caregivers have the skills necessary for ongoing monitoring and treatment. Organizations can implement processes to ensure patient and caregiver education in managing breakthrough or accelerating pain, including administration of as-needed medications and timely contact with providers. Once again, little research currently exists to identify patient and caregiver preparedness in managing incident pain or the ability of educational approaches to enhance patient self-management skills.

The difficulty of achieving effective pain management has been borne out across a range of research studies. Studies have documented deficiencies in a range of areas, including inadequate assessments and poor follow-up of pain complaints [119], inadequate technical expertise in treating pain, insufficient education of patients and families in self-management strategies, unaddressed emotional and social factors contributing to pain [120], and poor coordination of pain management between inpatient and outpatient settings and across providers. Finally, regulatory barriers to effective pain management, such as restrictions on amount of medication dispensed and on refills, make it difficult to build effective systems for delivering opioid pain medication promptly to patients who need it, particularly in the outpatient setting.

Good pain management has been regarded by patients and caregivers as a hallmark of quality palliative care [121]. The quality deficiencies identified for pain management in advanced illness have important parallels with those documented in a wide range of chronic illnesses [122]. Wagner's Chronic Illness Model details a range of interventions by which quality may be improved, including the incorporation of explicit plans and protocols; reorganization of care for patients who need more time, closer follow-up, or broader resources; attention to patients' information and self-management needs; ready access to technical expertise; and information systems that support provider adherence to quality-of-care guidelines as well as interprovider communication. The categories of interventions that Wagner proposes, which have been shown to improve care in advanced congestive heart failure [123], diabetes [122], asthma [124], and depression [125], are readily applicable to pain, for which optimal management requires a similar systems-oriented approach.

The systems and processes of care outlined here, augmented by Wagner's Chronic Illness Model conceptual framework, lead to a range of unanswered questions for pain-management researchers. Which assessment strategies

are valid and reliable in identifying pain in patients with advanced illness when administered in real clinical settings as opposed to research laboratories? What system barriers impede the routine assessment of pain by providers in hospital and clinic settings? What are the barriers to patient self-reporting of uncontrollable pain, and which patient education and empowerment interventions are most effective at activating patients and caregivers to proactively report pain? What is the impact of provider education on knowledge, skill, and attitude in eliciting and managing pain, and which educational approaches are most effective at achieving these ends? Which is the best organizational approach to delivering evidence-based treatment of pain—provider education, collaborative care with specialist providers, or some combination of the two? After pain has been identified and treatment initiated, what are the system-of-care barriers to effective longitudinal pain management? What impacts, both in terms of benefits and harms, occur as the result of patient and caregiver pain-management strategies? What is the role of modern information technology, including telemedicine and Web-based approaches, in facilitating communication between patients with pain complaints and providers with pain management expertise? Answers to these important questions, and many others, will allow healthcare systems to translate what is achievable in highly controlled research studies into the care that is actually delivered to patients with advanced illness in need of pain management.

CONCLUSIONS

This article describes the scope of pain, and newer approaches to the management of pain, in palliative medicine. These approaches include understanding the effects of PTSD and demoralization on patients with advanced illnesses and their perception of pain, rehabilitation medicine, and exploration of how systems of care can influence the delivery of pain management. Some of these ideas are made possible by the new information technology that is becoming available to clinicians, and new ways of thinking about pain management from other disease models. These concepts complement the paradigm of biomedical science and pharmacological trials and may provide new answers to the question of why pain is often not adequately assessed and treated. Pain remains a highly prevalent and challenging problem in palliative medicine, with many advances to date, and much more work to be done.

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