

Palliative Nursing Summit: Nurses Leading Change and Transforming Primary Palliative Care:

## Nursing's Role in Providing Pain and Symptom Management

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### Abstract and Introduction

#### Abstract

Effective pain and symptom management is a crucial part of the care of those with life-threatening illnesses and their family members. Nurses in all settings have a vital role in providing this essential care. A recent summit held on May 12, 2017, "Nurses Leading Change and Transforming Palliative Care," convened by the Hospice and Palliative Nurses Association and attended by leaders of 26 nursing organizations strongly endorsed the importance of nursing's role in pain and symptom management and developed an agenda to advance these efforts. The agreed-upon goals of pain and symptom treatment include care that is effective (as defined by the patient), efficient (delivered in a timely manner), and safe (reduced risk of respiratory depression, prevention and early management of adverse effects, as well as attention to methods to prevent diversion such as safe storage and disposal). Through an iterative process, desired patient outcomes and nursing actions were outlined to support effective pain and symptom management in primary palliative care. These recommendations were categorized as education, clinical care, research, and regulatory concerns. This article reports on the outcomes of this summit related to pain and symptom management.

#### Introduction

Effective pain and symptom management is a crucial part of the illness journey for those living with life-threatening illnesses and their loved ones. Pain relief and reduced symptom burden not only diminish the suffering encountered by those with advanced disease, but will also ease the grief experienced by loved ones after the person's death.<sup>[1,2]</sup> Nurses in all settings have a vital role in providing this essential care. A recent summit convened by the Hospice and Palliative Nurses Association and attended by leaders of 26 nursing organizations strongly endorsed the importance of nursing's role in pain and symptom management and developed an agenda to advance these efforts. The summit, held on May 12, 2017, in Washington, DC, under the theme, "Nurses Leading Change and Transforming Palliative Care," was designed to create a collaborative national agenda for primary palliative nursing. The work of the summit focused on 3 aspects of palliative nursing: communication and advance care planning, coordination/transitions of care, and pain and symptom management. This article reports on the outcomes of this summit related to pain and symptom management.

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### Pain and Symptom Management: Current State

Pain remains one of the most frequent and feared symptoms of advanced disease, interfering with physical function and quality of life.<sup>[3-9]</sup> Research reveals that as any life-threatening illness progresses, pain prevalence increases.<sup>[7]</sup> This pattern has been consistently demonstrated in cancer pain,<sup>[8,9]</sup> end-stage renal disease,<sup>[4]</sup> amyotrophic lateral sclerosis,<sup>[5]</sup> multiple sclerosis,<sup>[10]</sup> cystic fibrosis,<sup>[11]</sup> and other diagnoses frequently seen in palliative care settings.<sup>[7]</sup> Similar patterns exist for nonpain symptoms, such as dyspnea, fatigue, anxiety, delirium, and others.<sup>[12]</sup> Numerous barriers to adequate control of pain and symptoms persist, including those related to professionals, patients, and caregivers, as well as the health care system.<sup>[13]</sup> These barriers lead to undertreatment and unrelieved pain and symptom management. An updated systematic review found that while undertreatment of cancer pain decreased from 43.4% to 31.8% when comparing publications before and after 2007, approximately one-third of patients still did not receive pain medications appropriate to their level of pain intensity.<sup>[14]</sup> In pediatrics, pain is also reportedly undertreated.<sup>[15]</sup>

Nurses are key to reversing the undertreatment of pain and other symptoms for those with life-limiting illnesses. All nurses must possess basic competencies to provide primary palliative care. In addition, the health care institution must offer the tools that can support this provision, such as policies, formularies, staffing, education, and other

factors. The role of nursing was strongly endorsed during the summit along with steps to advance the agenda needed to improve pain and symptom management. Through an iterative process, desired patient outcomes and nursing actions were outlined to support effective pain and symptom management in primary palliative care. For clarity, these recommendations were categorized as education, clinical care, research, and regulatory concerns. The agenda was organized by the desired patient outcomes and the necessary nursing actions to effect this change.

## Patient Outcomes and Nursing Actions: Improved Pain and Symptom Management

The goals of pain and symptom treatment include care that is effective (as defined by the patient), efficient (delivered in a timely manner), and safe (reduced risk of respiratory depression, prevention and early management of adverse effects, and attention to methods to prevent diversion such as safe storage and disposal).<sup>[16]</sup> Desired patient outcomes and the nursing actions required to meet these outcomes will be explored for each of these recommendations.

### Education

**Patient Outcomes.** The summit participants concurred that successful educational efforts would result in improved pain and symptom management (.). The informed patient and family would report understanding of tolerance, dependence, misuse, and addiction, as misunderstandings regarding these effects of opioids lead to barriers to relief.<sup>[13]</sup> Better education will lead to a more comprehensive understanding of the plan of care and will enable patients and families to possess the knowledge and confidence to effectively and safely use tools to relieve pain. If education is effective, patients and family members will store and dispose of controlled substances safely. Educational efforts directed to professionals and the public will lead to fewer episodes where patients face stigma in reporting pain or receiving therapy using controlled substances.

**Table 1. Patient Outcomes and Nursing Actions for Improved Pain and Symptom Management: Education**

Patient/family outcomes—patients and families will:
Deny facing stigma in reporting pain.
Report appropriate understanding of tolerance, dependence, misuse, and addiction.
Understand the plan of care.
Possess the knowledge and confidence to effectively and safely use tools to relieve pain.
Store and dispose of controlled substances safely.
Nursing action—nurses will:
Assess patient and family fears, attitudes, and knowledge regarding pain and symptom management.
Address these barriers and provide education aligned with the patient's/family's needs.
Review discharge instructions with every patient/family including information about plan of care, prevention/management of adverse effects, safe storage, and disposal.
Educate public about evidence-based interventions to relieve pain and symptoms.

**Nursing Actions.** To achieve these outcomes, nurses must assess patient and family fears, along with their attitudes and knowledge base regarding pain and symptom management using pharmacologic, nonpharmacologic, and integrative therapies. Using this information, nurses can then address any barriers and provide education aligned with the patient's/family's needs. Throughout the course of care, the nurse should frequently review instructions with every patient/family. This information includes the plan of care, prevention/management of adverse effects, and particularly at discharge to home, safe storage, and disposal of controlled substances. Finally, public education around evidence-based interventions to relieve pain and symptoms can help inform and counter negative messages prevalent regarding opioids used for pain control. As nursing is regarded the most trusted profession, nurses are in a vital position to communicate and advocate to advance safe and effective pain control.<sup>[17]</sup>

### Clinical Care

**Patient Outcomes.** Excellent clinical care will result in patients being able to function at an optimal level in comfort, while experiencing improved quality of life (.). To achieve this goal, patients should expect and receive a thorough

pain assessment that includes level of intensity, function, and suffering. This assessment guides appropriate management that is nonjudgmental in its delivery. Another patient outcome of exceptional pain and symptom management is seen in patients spending more time at their homes (if that is their preferred setting of care) and fewer days in the hospital due to pain/symptoms. During the dying process, more patients will experience a comfortable death with decreased suffering. Throughout the process, patients and family members will encounter knowledgeable care attentive to the unique needs of special populations (eg, pediatrics, geriatrics, those with substance use disorder). Optimally, patients and family members will encounter seamless coordination of pain and symptom management without lapses across transitions.

**Table 2. Patient Outcomes and Nursing Actions for Improved Pain and Symptom Management: Clinical Care**

Patient outcomes—patients will:
Function at an optimal level in comfort, experiencing improved quality of life.
Receive a complete pain assessment that includes intensity, function, and suffering.
Receive nonjudgmental care.
Spend more time at home (if that is their preferred setting of care) and fewer days in the hospital due to pain/symptoms.
Experience a comfortable death with decreased suffering.
Encounter knowledgeable care attentive to the unique needs of special populations (eg, pediatrics, geriatrics, those with substance use disorder).
Encounter seamless coordination of pain and symptom management without lapses across transitions.
Nursing action—nurses will:
Improve awareness of the evolving components of a comprehensive pain assessment (ie, more attention on function and risk factors for adverse effects)
Improve education regarding multimodal therapies to relieve pain and symptoms, including pharmacologic, nonpharmacologic (eg, physical therapy, occupational therapy, mental health counseling), and integrative therapies (eg, music therapy, pet therapy, herbal/nutritional supplements, aromatherapy, acupuncture, Reiki therapy, massage, yoga, meditation, guided imagery, mindfulness and others) —basic education as well as CE (End-of-Life Nursing Education Consortium) —also rehabilitation principles (promote and prioritize function).
Associate appropriate knowledge and skills with pain and symptom management for special populations (eg, children are cared for by adequately trained pediatric providers).
Develop competencies regarding special populations (eg, pediatrics, the elderly, those with mental health or substance misuse disorders).
Advocate for access to comfort kits/easy access to medications needed during crises, use of standing orders, and availability of expert consultation.
Ensure care team communication.
Provide coordination of care/navigation to reduce fragmentation of care.
Create electronic health records that are seamless across practice settings.

**Nursing Action.** Further education of all nurses is needed so primary palliative care can be delivered in all settings. Optimally, this education is incorporated into the entry-level nursing curricula. Although integration of this content is gradually occurring, many still graduate from nursing programs having received little attention to palliative care principles. In addition, practicing nurses need continuing education regarding the importance of palliative care as essential for each patient's comfort. The attendees of the summit endorsed the End-of-Life Nursing Education Consortium as the exemplary program to deliver this education.

Summit participants agreed that improving the awareness of the evolving components of a comprehensive pain assessment (ie, more attention on function and risk factors for adverse effects) is needed within nursing educational efforts. Nurses also require education regarding multimodal therapies to relieve/reduce pain and symptoms,

including pharmacologic, nonpharmacologic, and integrative therapies. These nonpharmacological and physical approaches, although not usually totally effective by themselves, are frequently beneficial for the patients. Traditionally, they would be such approaches as rehabilitation, physical therapy, occupational therapy, and mental health counseling. These approaches are comparatively noninvasive and generally have less risk involved when compared with medications. Although applying these therapies may be more time consuming, the patient usually takes a greater active role. Expanded interventions include psychological approaches such as active listening, controlled breathing, distraction, and patient education. Additional effective approaches—often considered integrative or complementary—include music, pets, aromatherapy,<sup>[18]</sup> reflection,<sup>[19]</sup> and energy therapies.<sup>[20]</sup> Many times, basic palliative care techniques such as repositioning of the patient, warmth, cold, touch, and massage are effective and a great place to begin. Competencies yet to be developed include the care of special populations, such as pediatrics, the elderly, and those with mental health or substance misuse disorders, among others. Competencies in turn drive curricular development and implementation.

Access to comfort kits or medications needed during times of emergencies is essential. Standing orders also allow nurses to deliver care in a timely fashion during escalations in pain or other symptoms such as dyspnea, nausea/vomiting, anxiety/agitation, or hemorrhage. The availability of expert consultation is crucial, and providers caring for individuals in special populations must possess appropriate and relevant knowledge and skills in pain and symptom management specific to these populations.<sup>[21]</sup>

Communication emerged as a factor essential in relief/decrease of pain and other symptoms. Continued efforts to ensure timely, clear, and comprehensive care team communication are indispensable. This is especially important during transitions in care so that coordination will reduce fragmentation of care. Electronic health records have the potential to assist this seamless care across practice settings, yet more nursing input is needed in the development of optimal systems.

## Research

**Patient Outcomes.** With high-quality research to support interventions, patients will receive evidence-based primary palliative care to provide optimal relief of pain and other symptoms ( ).

**Table 3. Patient Outcomes and Nursing Actions for Improved Pain and Symptom Management: Research/Evidence Base**

Patient outcomes—patients will:
Receive high-quality, evidence-based primary palliative care in the relief of pain and other symptoms.
Nursing action—nurses will:
Build and contribute to an evidence base regarding pain and symptom research.
Propose research focused on better understanding from the patient/family perspective what well-managed pain/symptom management means in different disease processes.
Conduct studies to determine prevalence and undertreatment of pain and symptoms, particularly in the time of an opioid misuse crisis.
Advocate for increased research funding.
Contribute to the development of evidence-based guidelines.

**Nursing Action.** Nursing research is fundamental to the advancement of the science of palliative care.<sup>[22]</sup> Nurses should have the opportunity to build and contribute to an evidence base regarding pain and symptom research. In addition, focused research is needed to better understand the patient/family perception regarding what well-managed pain/symptom management means in various disease processes.

Current studies are necessary to determine the prevalence and undertreatment of pain and symptoms in illnesses commonly seen in palliative care. This is particularly important within the present opioid misuse crisis. Taking the data derived from this and other research, nurses can contribute to the development of evidence-based guidelines to guide clinical practice and policy. Finally, nurses must strongly advocate for increased research funding as continued limited support serves as a significant barrier both to advancement of the science and to the patient's comfort.<sup>[23,24]</sup>

## Policy/Regulatory

**Patient Outcomes.** With appropriate health care policies and regulation, patients and families will experience full access to primary palliative care, including evidence-based pain and symptom management ().

**Table 4. Patient Outcomes and Nursing Actions for Improved Pain and Symptom Management: Policy/Regulatory**

Patient outcomes—patients will:
Experience full access to evidence based pain and symptom management.
Nursing action—nurses will:
Realign regulatory standards and measures of outcomes with guidelines for safe and effective pain/symptom management.
Ensure full access to evidence-based care—palliative care, concurrent care, opioids, adequate staffing.
Advocate for third-party payor coverage of pharmacologic, nonpharmacologic, and integrative therapies.
Support safe disposal centers for medications, including controlled substances, within the community.
Authorize advanced practice nurses to function within their full scope of practice with prescriptive authority.
Advocate for system and policy reform.

**Nursing Action.** The opioid misuse epidemic is a serious public health problem. Unintended sequelae of policies designed to limit the extent of opioid misuse and deaths include reduced access of opioids for people with cancer or other life-threatening illness. Implementation of any new policy or regulation must carefully consider the potential for harm.<sup>[25]</sup> A realignment of regulatory standards and measures of outcomes must be considered during the development of guidelines to ensure safe and effective pain and symptom management. In complement to other interventions to reduce diversion and misuse, nurses should strongly advocate for implementation of safe disposal centers for medications, including controlled substances, within the community.

Of necessity, nurses must further advocate for full access to evidence-based care, including primary and specialist palliative care, as well as concurrent care. Lack of reimbursement for pharmacologic, nonpharmacologic, and integrative approaches serves as a significant barrier to quality palliative care. Nurse advocates need to focus attention on third-party payor coverage of these approaches. Finally, strong and continuous advocacy is an absolute necessity with reduced numbers of clinicians in the workforce serving as a barrier to access to care. Immediate regulations are needed to authorize advanced practice nurses to function within their full scope of practice with prescriptive authority ().

**Table 5. Pain and Symptom Management Resources<sup>a</sup>**

American Holistic Nurses Association
<a href="http://www.ahna.org/Home/Resources/Holistic-Pain-Tools">http://www.ahna.org/Home/Resources/Holistic-Pain-Tools</a>
<i>Holistic Nurses' Pain Relief Tools for Patients and Self-care</i> includes 59 references related to holistic pain relief.
American Society for Pain Management Nurses
<a href="http://www.aspmn.org/">http://www.aspmn.org/</a>
Position statements, publications, educational materials, and certification information
Center for Pediatric Pain Research
<a href="http://pediatric-pain.ca/">http://pediatric-pain.ca/</a>
Videos, blogs, educational materials, conferences, and other resources focused on pediatric pain
City of Hope Palliative Care Resource Center
<a href="http://prc.coh.org/">http://prc.coh.org/</a>
Numerous resources for pain, symptom management, quality of life, and cancer survivorship

Fast Facts—Palliative Care Network of Wisconsin
<a href="https://www.mypcnw.org/fast-facts">https://www.mypcnw.org/fast-facts</a>
Concise (usually 1–2 pages), practical, evidence-based summaries related to pain and symptom management issues in palliative care
International Association for the Study of Pain
<a href="https://www.iasp-pain.org/">https://www.iasp-pain.org/</a>
Educational materials, including FAQs related to the Global Year Against Pain (new topic each year—2017 is the Year Against Pain After Surgery)
National Cancer InstituteVCancer Pain (PDQ) (available in versions for health care professionals and for patients)
<a href="https://www.cancer.gov/about-cancer/treatment/side-effects/pain/pain-hp-pdq">https://www.cancer.gov/about-cancer/treatment/side-effects/pain/pain-hp-pdq</a>
Extensive, peer reviewed information regarding cancer pain; also available are summaries regarding other symptoms/adverse effects of cancer or its treatment with PDQs available on fatigue, gastrointestinal complications, and many other symptoms relevant to palliative care

<sup>a</sup>All Web sites accessed August 19, 2017.

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## Conclusion

Nurses in all settings have a vital role in providing pain relief and symptom management. The summit convened by the Hospice and Palliative Nurses Association and attended by leaders of 26 nursing organizations strongly endorsed the importance of nursing's role in pain and symptom management and developed a national agenda to advance primary palliative nursing. Although attendees acknowledged that palliative care requires multidisciplinary care, and nurses do not perform in isolation, the purpose of the summit was to focus on actions that individual nurses, along with nursing organizations, must take to relieve suffering. Patient outcomes and nursing actions include educational, clinical, research, and regulatory efforts. Through implementation of these actions, all nurses will be prepared to provide primary palliative care that is effective, efficient, and safe.

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