Disparities in Cancer Pain Assessment and Management among Ethnic Minorities

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### **Executive Summary**

Poor pain control impairs quality of life and functionality. Despite the increased knowledge of pain mechanisms, existing guidelines and improved methods to manage cancer pain, it remains inadequately treated, especially among ethnic minorities. A number of factors play role in the existing cancer pain management disparity: (a) language barriers between patients and providers; (b) providers' limited knowledge of cultural behaviors and pain expression; (c) providers' inadequate cultural competence awareness training; (d) providers' bias and stereotyping in clinical communication and decision-making; (e) reluctance to prescribe opioids; insufficient training and continuing education in cultural competence and chronic pain treatment; (f) underutilization of referrals to pain specialists; (g) poor provider to patient education and communication with ethnic minorities; and (h) high time pressure, cognitive complexity, and pressures for cost-containment (Stockler & Wilcken, 2012; Im, et al., 2009). Despite the accepted optimal pharmacotherapy, there is no systematic approach in pharmacotherapeutic cancer pain treatment.

The purpose of this project is to develop a pain assessment and management algorithm and guide for providers treating cancer patient's pain that provides an approach to pain assessment and management that is culturally sensitive and effective when considering pain treatment with ethnically diverse patients. This project's objectives are 1) identify existing barriers to pain management among ethnic groups at Mountain State Tumor Institute (MSTI) and St. Luke's inpatient Oncology (SL) in Boise, Idaho; 2) identify existing guidelines for pain assessment and management at the clinical sites and in the literature;3) develop an educational presentation with a downloadable educational model for nurses, and 4) present the educational session during the MSTI and SL staff meeting; 5) disseminate the presentation and the model through the St. Luke's online SumTotal Learning Center and Doctors of Nursing Practice Organization website.

The implementation phase included a literature review of pain assessment and management for minorities; palliative care experts' were consulted. A number of cultural barriers in pain management at clinical sites were identified. One of the major obstacles for providing a culturally appropriate cancer pain assessment was the lack of the current evidence targeting ethnic minorities. Salient points of pain assessment and management for ethnic minorities were gathered, outlined, and approved by the content experts. The project was presented and disseminated as above.

The purpose of the project was fulfilled and evaluated. Staffs' knowledge and competence in assessing and managing cancer pain of culturally diverse patient populations have significantly increased based on the post educational session evaluation. The message of reducing the burden of cancer pain and the disparities in healthcare delivery for ethnic minorities was recognized as an essential part in everyday practice. Future project development recommendations would include: 1) create a mandatory continuing education module "Cultural Pain Assessment & Management" for clinicians in various primary care settings; 2) create a continuing patient education module about the various Pain Assessment Tools, Pain Assessment & Management paths and algorithms; 3) research on patient perceptions of the various pain models; and 4) propose a culturally sensitive pain assessment & management protocol and/or guideline to be further maintained based on the latest evidence-based data & recommendations.

Disparities in Cancer Pain Assessment and Management among Ethnic Minorities

Problem Statement

Inequalities and inadequacies exist in treatment of pain for oncology patients in the outpatient setting, especially among ethnic minorities. As Stockler and Wilcken (2012) pointed out, these existing inequities in pain treatment lead to poor pain control in some cancer patients from minority populations (Stockler & Wilcken, 2012). They also noted that ethnic minorities are particularly prone to inadequate cancer pain management for a number of reasons, including low literacy rates, limited education, and restricted access to healthcare. Additionally, low socioeconomic status limits their ability to afford pain medication (Mossey, 2011). Multiple cultural and social factors in assessing and managing cancer pain may likely lead to adverse consequences for minority groups.

Major obstacles in adequate pain treatment stem from the sides of both provider and patient. Poor assessment of pain remains the most significant barrier in controlling patient pain (Stockler & Wilcken, 2012). Pain is the most common problem among oncology patients, and the one they most fear (McNeill, Reynolds, & Ney, 2007). Therefore, adequate cancer pain assessment, followed by appropriate treatment and continued evaluation are important goals for practitioners treating oncology patients (Stockler & Wilcken, 2012). Practitioners have to be aware of different cultural pain perceptions, beliefs, and behaviors in order to be both knowledgeable and objective in the assessment and management of culturally diverse patient populations (Rollman, 1998). According to Rollman (1998), practitioners have to understand that although pain intensity scale assessment is an important tool in their practice, patients' satisfaction with overall management is more important to the care of patients with various cultural backgrounds. In many cultures, disease and the pain associated with it, are part of life,

and therefore are usually accepted without seeking further intervention to relieve suffering (Callister, 2003). In order to effectively address pain, health care providers need to be respectful of cultural differences and strive for successful pain management; this includes not only elimination of physical pain, but also functional restoration of an affected body part. Better pain control and optimal functionality can ultimately lead to an improvement in patient's healing, mobility, and overall quality of life, as well as reduce pain's impact on society.

### **Clinical Significance**

Effective pain assessment and treatment can improve cancer patients' quality of life and decrease the number of inpatient admissions (Galal, El-Mesidy, Ali, & Al-Sirafy, 2010). This can be accomplished by increasing practitioners' knowledge and cultural competence of pain expression and meaning in culturally diverse patient populations (Narayan, 2010). It is believed that this knowledge can reduce the burden of cancer pain and the disparities in healthcare delivery for ethnic minorities. Practitioners' awareness and knowledge of cultural differences in pain perception may potentially improve assessment and management of pain and, likewise improve patient outcomes.

### **Objectives**

The purpose of this project is to develop and present a guide for assessing pain from a cultural perspective. The goal of this project is to improve the assessment and treatment of cancer patients' pain at Mountain State Tumor Institute Hematology/Oncology (MSTI) outpatient clinic and St. Luke's (SL) inpatient oncology unit.

This project included the following objectives:

1. Identify potential cultural barriers to pain management among ethnic groups represented in the location of the project.

- 2. Identify existing clinical guidelines regarding pain management among the three dominant ethnic groups at MSTI and SL.
- 3. Develop a guide to help health practitioners assess pain with a cultural perspective.
- 4. Present an educational session to explain the guide at MSTI and SL monthly staff meeting.
- 5. Evaluate the presentation and educational tool effectiveness with a Likert scale questionnaire by distributing a post-presentation evaluation.
- 6. Post the presentation and the education tool online through St. Luke's SumTotal Learning Center.
- 7. Disseminate the information related to this project through the online submission to the Doctors of Nursing Practice Organization's DNP Scholarly Projects (<a href="http://doctorsofnursingpractice.org/">http://doctorsofnursingpractice.org/</a>).

### **Literature Review**

### **Cultural and Ethnic Identity in Medical Literature**

According to the Institute of Medicine (IOM) report, *Unequal Treatment* (2003), healthcare providers must develop cultural competence to eliminate racial and ethnic disparities currently existing in healthcare (Smedley, Stith, & Nelson, 2003). Yet, in the medical literature, race and ethnicity have been poorly defined (Chávez & Guido-DiBrito, 1999). The main distinction between these two terms was historically based on the assumption that *race* was associated with certain biologic characteristics allowing division of humans into distinct groups, while *ethnicity* was perceived as variability between groups of people sharing similar culture, social behaviors, values, and beliefs (Culley, 2005). Categorizing people based on these criteria only, without considering socioeconomic class, geographic location, nationality, and language

may contribute to stigmatization and racism in healthcare (Moscou, 2008; Culley, 2006).

Labeling people by race or ethnicity can lead to discrimination. Smedley, et al. (2002) defines discrimination in health care "as differences in care that emerge from biases and prejudice, stereotyping and uncertainty in communication and clinical decision-making" (p. 160).

Race and ethnicity are routinely used as demographic variables in research and medical literature. Using physical features and genotypes as distinctive characteristics between groups, the U.S. population was divided to Europeans, Asians, Native Americans, Africans, and others "to describe populations, track disparities, identify risk markers for diseases, develop policies, etc." (Moscou, 2008, p. 94). In the U.S., more than 70% of entire population consists of White Americans, whose ancestors came to America from Europe, the Middle East, and North Africa (United States Census Bureau, 2011). White Americans historically inherited their "biological superiority" over minorities, who became undesirable within conventionally "white" society (Chávez & Guido-DiBrito, 1999). This outdated and limited concept of racial and ethnic categories to describe populations has strongly impacted our view of the world and human variants and cannot be used to reflect any overall culture people may have.

Although it is useful to know what beliefs and values may pertain to a certain culture, it is crucial for any healthcare provider to be aware of variations between and within cultures, and approach each patient in a way that individualizes care and respects individual perspective.

Various attitudes toward pain do not imply that certain rules and standards of care should be created to guide healthcare providers to treat one individual of a specific cultural group differently from another. Culture is constantly evolving; therefore the idea of transculturalism is fundamental to help providers to be aware of variations between and within cultures and to allow "others" to be seen in less non-discriminative ways (Culley, 2006). Transculturalism allows

practitioners to see culturally diverse groups as equal to each other despite the differences, which in turn, promotes delivery of care that is free of judgment, stigmatization, and racism.

Acknowledging and understanding cultural diversity in the clinical setting, and respecting individual's health behaviors and beliefs, assures the delivery of culturally competent healthcare (Campinha-Bacote, 2011). Recently, cultural competence has been broadened to include patient-centered care (Betancourt, Green, Carrillo, & Park, 2005). Patient centered care has several elements. It asks the provider to create understanding of patient's individual perspective in relationship to his/her health within their psycho-social context and come to a shared understanding of their problem and treatment thus forming a partnership between provider and patient (IOM, 2001). With this in mind, the patient's will is then integrated into decisions about his/her care, and promots individualized, rather than one size fits all, standardized healthcare to diverse populations (Betancourt et al., 2011).

### **Cancer Pain Management**

Cancer pain management is one of the most important goals during cancer treatment process. Successfully managed pain includes both the elimination of physical pain and restoration of function to the affected area reference. Pain control can eliminate needless suffering, prevent adverse clinical effects, improve overall quality of life, and reduce pain's impact on society.

Pain can be caused by cancer itself or by different cancer treatments, procedures, or comorbidities, and may even be the result of a combination of all the factors together (McNeill et al., 2007). According to Ward et al., (2004) ethnic minorities when compared to whites are at greater risk for developing malignancies and often receive a delayed diagnosis when cancer is more advanced, metastatic, or recurrent; these conditions typically causes more pain. Numerous

studies have suggested that ethnic minorities are especially prone to experience inadequate cancer pain treatment (Green et al., 2003; Ward et al., 2004). Research suggests that most individuals in minority populations are of a lower socioeconomic class, which puts these patients at risk for poor disease management primarily due to a limited access to care, and likely characterizes them as having low literacy, restricted financial resources, lack of insurance, and consequent cancer progression (Green et al., 2003; McNeill et al., 2007). In general, ethnic minority patients may have less access to healthcare and limited financial resources, and therefore have a decreased chance to prevent and detect cancer early, resulting in poorer prognosis and faster disease progression (Ward et al., 2004). Low literacy among this disadvantaged group of patients also plays a significant role in their health outcomes (Green et al., 2003). Disparities exist in pain prevention and its early detection, assessment, and treatment (Anderson et al., 2000; Ward et al., 2004). Among the numerous provider and patient related obstacles in adequate pain treatment, poor pain assessment remains one of the most significant barriers for patients to reach an adequate pain control (Stockler & Wilcken, 2012).

### **Cultural Perception of Pain**

Patients' cultural perception of pain can play a significant barrier in achieving pain control. In order to reduce disparities in cancer pain management, providers need to investigate every individual patient's understanding and attitude toward pain (Narayan, 2010). Ethnic minorities are more likely to receive inadequate pain assessment, have underestimated pain severity, and be prescribed with insufficient amount of analgesics to relieve their pain (Anderson et al., 2002). In a national study on ethnic difference and cancer pain Im et al., (2009) found that white patients controlled what treatment would be the most beneficial for them among diverse treatment options, whereas Hispanics, Asians, and African Americans (HAAs) tried to minimize

the importance of aggressive pain treatment and used natural remedies and approaches for pain control. White patients' attitudes toward cancer pain management were individualistic, whereas HAAs relied on their families to determine the pain treatment plan. These authors also found that white patients were also more in control of managing their pain, while HAAs tried to accept and tolerate as much pain as possible. In a different study by Chen, Tang, and Chen (2011), Asian patients' attitudes toward cancer pain were compared to those of Western patients. Asian patients believed pain is associated with cancer progression and is an inevitable part of the disease process. These authors found that unlike North Americans and Europeans, Asian patients were less likely to report pain and use analgesics due to a fear of opioid addiction, fear of injections, and developing side effects and tolerance, which could all create significant barriers in achieving pain control.

### **Provider-Related Barriers in Pain Control**

Cancer pain disparities may persist due to the provider-related barriers. McNeill et al. (2007) noted that "the poor are disproportionally more likely to be ethnic or racial minorities" (p.1122) and healthcare providers are more likely to stereotype poor people as substance abusers, which may affect the effectiveness and quality of pain assessment and treatment. In pain control research of ethnic groups, Fisch, Lee, and Weiss (2012) found that almost 70% of over three-thousand patients who participated in the pain control treatment reported having pain. This same study reported that almost one-third of these patients received poor initial treatment for their pain, which did not change in follow-up visits. All patients across ethnic groups identified broken communication with the healthcare providers as one of the main reasons for their poor pain management. In a similar study of ethnic difference and pain, Im et al. (2009) found that

white patients, unlike ethnic minorities, were in control of choosing the health care provider who would listen to them, and were not afraid to fire those who did not (Im et al., 2009).

Research of oncology pain management is lagging. Nearly two decades ago, the Eastern Cooperative Oncology Group (ECOG) conducted a survey on oncology pain management (Von Roenn, Cleeland, Gonin, Hatfield, & Pandaya, 1993). To date there have been no other attempts to assess if oncologists in the U.S. implement the best cancer pain management practice guidelines when treating cancer patients (Breuer, Fleishman, Cruciani, & Portenoy, 2011). The guidelines were established by the National Comprehensive Cancer Network (NCCN) in 1999 and have been used as the standard of care, which incorporates screening for pain presence, determination of pain intensity, systematic pain reassessment, and implementation of an algorithm that helps providers to make therapeutic decisions on the numerical pain rating (NCCN, 2013). Despite the existing guidelines and the accepted optimal pharmacotherapy, there is no systematic use of the guidelines and pharmacotherapeutic cancer pain treatment (Breuer et al., 2011). Breuer et al. (2011) noted that although oncologists consider themselves as less conservative in prescribing opioids compared to other medical providers, they are often reluctant to prescribe opioids because of the "excessive regulation" (p. 4772) that overly limit healthcare decision making. The providers are reluctant to contribute to drug abuse, addiction, and diversion and the possibility of being investigated or disciplined by a regulatory agency (Breuer et al., 2011). As a result, many patients with acute and chronic pain remain untreated or undertreated.

Other significant contributors to an inadequate cancer pain management include inadequate medical school training on cultural competence and chronic pain treatment, limited amount of Continuing Medical Education (CME) hours and low utilization of referrals to pain and palliative care specialists. Breuer et al. (2011) also found that healthcare providers often

lack knowledge in different pain medication treatment options, are not comfortable in prescribing opioids when needed, and lack initiatives to develop more efficient and standardized practices to improve cancer pain management treatments and patients' outcomes.

### **Patient-Centered Approach**

Cultural competence has often included the healthcare providers' knowledge in "traits approach;" (p.34) what to do or not to do while taking care of Hispanics, Asians, Jewish, or patients who are members of other racial and ethnic groups (Epner & Baile, 2012). However, this knowledge does not allow medical care standardization and results in stereotyping. As explained by Epner and Baile (2012) "patient-centered cultural competence" (p. 36) is a skill providers can possess in order to provide effective care for patients from different races, religions, socioeconomic statuses, and educational backgrounds in order to decrease health disparities. The definition of cultural humility may be a better fit in the understanding of culturally sensitive approach to each patient, because it incorporates a "lifelong commitment to self-evaluation and self-critique" in order to create a "clinical and advocacy partnerships between individuals and defined populations" (Tervalon & Murray-García, 1998, p.117). The word competency tends to reflect something rigid, set, defined, and not flexible. Therefore, competency may not be the right term to use along with culture because it is constantly changing. It is imperative for practitioners to have better awareness and knowledge in an individual patient's understanding and attitudes toward pain, and end of life decisions, but they should stay away from stigmatization and having a "recipe" for the treatment of specific cultural groups. Continuous education, life-long self-evaluation and reflection on one's own practice can make a culturally competent practitioner.

### Strategies for Improving Pain Assessment and Management

Many providers are aware of inequities in health care delivery; however, little is known about what strategies could significantly improve quality of healthcare delivery for ethnic minorities (Beach et al., 2006). Despite the existence of numerous educational programs and guidelines to properly assess and treat cancer pain (e.g. NCCN Clinical Practice Guidelines in Oncology: Adult Cancer Pain (NCCN, 2013); European Society for Medical Oncology (ESMO) Clinical Practice Guidelines: Management of Cancer Pain (Ripamonti et al., 2012); Agency for Healthcare Research and Quality (AHRQ): Cancer Pain Management (Bader et al., 2010)), many providers fail to adequately assess and, therefore, appropriately manage patients' pain.

Every provider has to understand that pain has a number of dimensions (social, psychological, physical, and spiritual) that are strongly influenced by culture. The multidimensional pain assessment is the first most important step in management of cancer pain (Narayan, 2010). It must take into account the type, onset, location, duration, intensity, radiation, and associated factors of pain, as well as concurrent comorbidities, and most importantly, the subjective perception of pain, which combines physical, cultural, and emotional aspects. Every patient is unique. Thus, pain assessment should include patient's experience of disease and pain as well as the patient's perceived pain management, followed by shared decision and adaptation of care to meet patient's wishes and expectations.

The pain scale is the most basic tool to assess patient's pain intensity. Types vary and may include verbal, numeric, visual (Wong–Baker FACES Pain Rating Scale), and observational discomfort in patients with any kind of visual, auditory, or cognitive impairment (Ripamonti, 2012). Although these tools have been translated to various languages, the translation may send a different message or distort a true original meaning and quality of pain, decreasing the validity of these instruments (Ripamonti, 2012). This author highlighted the importance of understanding

that the same word can have diverse meanings even within certain cultural groups that may consist of different subcultures and speak on numerous dialects. The Numeric Rating Scale (NRS), the Brief Pain Inventory (BPI), and the McGill Pain Questionnaire (MPO) have been extensively tested and translated to many languages (American Pain Society [APS], 2006; Narayan, 2010). These pain assessment scales are based on the patient's self-report of pain (Narayan, 2010). The mnemonic (COLDERRA) is based on asking the patient to (C) characterize the pain, describe its (O) onset, (L)s location(s), (D) duration, (E) exacerbating factors, if the pain is (R) radiating to other body parts, (R) relieved by any measures, and has (A) associated signs and symptoms. In addition, these tools are helpful in assessing response to treatment and the degree to which pain is affecting the daily living (Narayan, 2010). A number of pain assessment scales like NRS, BPI, and MPQ can be combined with other tools to improve accuracy of pain assessment. Narayan (2010) noted that a comprehensive pain assessment should also incorporate any unique cultural meaning of pain and treatment preference. This author suggested using the Explanatory Model Interview for pain assessment. Lasch (2000) noted that any explanatory model could be used to describe patient's interaction with the U.S. health system in terms of health and illness. The Explanatory Model Interview for Pain Assessment offered by Narayan (2010) included the following questions:

"What do you think is causing your pain? When did it start and what started it? What do you fear most about the pain? What problems does it cause? What have you used to help you with the pain? How does it help? Who else have you consulted about the pain (family member, traditional healer)? What treatments you think might help and who helps you when you have pain" (p. 43).

### **Strategies to Improve Cross-Cultural Pain Assessment**

There are a number of educational tools available for healthcare providers to improve patient assessment across cultures. Cultural competency is defined as a provider or organization's ability to "effectively meet the needs of patients from diverse social, cultural, and linguistic backgrounds" (Higginbottom, et al., 2011, p. 3). According to Higginbottom et al., (2011) continuous training, knowledge of various groups within the community, leadership, and willingness to serve the culturally diverse population can elevate the healthcare provider's ability to be culturally effective. One of the educational models used in practice is based on the LEARN mnemonic for (L) listen with sympathy and understand perception of pain, (E) explain your perception of patient's pain, (A) acknowledge differences and similarities, (R) recommend treatment, and (N) negotiate agreement (Berlin & Fowkes, 1983). Some additional models proved to be helpful in guiding providers towards a competent cross-cultural pain care include the Culturally Competent Community Care model (2001), and the Process of Cultural Competence in the Delivery of Healthcare Model (1994) (Higginbottom et al., 2011, p. 7). The Culturally Competent Community Care model is based on three constructs: cultural competence (caring, cultural sensitivity, cultural knowledge and skills), healthcare system ("place" for community healthcare), and health outcomes (incidence and prevalence rates). The idea is that positive change results when culturally competent care is provided (Kim-Godwin, Clarke, & Barton, 2001). The Process of Cultural Competence in the Delivery of Healthcare Model interprets cultural competence as the continuous striving of the healthcare provider to achieve the most effective professional interpersonal relationship with a diverse patient population, constantly integrating "cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire" (Campinha-Bacote, 2002, p. 181).

In addition to effectively assessing and managing patient pain, providers should be educated and made aware of steps to be taken to appropriately address diverse patient populations. In order to provide effective pain management plans and improve patients' outcomes, healthcare providers should identify those in need of pain assessment, ensure access to interpretation services, be aware of what pain medications patients are able to afford, offer additional pain management strategies (e.g., acupuncture, music and massage therapies, relaxation techniques, guided imagery, and more), educate patients to allow autonomy and active participation in pain management, and offer access to various services (social work, financial advisor, palliative care specialist, traditional ceremonies, etc.) (McNeill et al., 2007).

### **Theoretical Framework**

Poor pain management among ethnic minorities creates a significant barrier to patients' pain control, healing, and overall quality of life (Stockler & Wilcken, 2012). Knowles' *Principles of Andragogy* (1980) theoretical framework will guide this study in order to improve providers' cultural competence in assessment and management of cancer pain. Knowles' theory (1998) will be applied to the project implementation of staff education in order to enhance their ability to effectively assess and manage ethnically diverse patients' pain.

According to Knowles theory (1998), a number of principles should be incorporated into the adult learner education: 1) adult learners are self-directed; 2) they strive to gain a new knowledge; 3) they apply their life experience into their learning process; and 4) they are motivated to apply the newly gained knowledge (Knowles, 1998; Smith, 2002). In order for adults to readily start learning, they have to understand first in what way the new knowledge will benefit them. Adult learners expect "to be seen by others and treated by others as being capable of self-direction" (Knowles, Holton, & Swanson, 1998, p.65). Adult learners are task-oriented

and problem centered, which helps to enhance their learning process. Adults are more likely to be motivated by the internal factors, like increasing self-esteem and job satisfaction, rather than by the external factors (Knowles et al., 1998).

Knowles constructs of the adult learners, such as "need to know", "the learner's self-concept", "readiness to learn", "orientation to learning", "learner's previous experiences", and "motivation" were considered in the following ways. Prior to the presentation, staff was informed of it through both, email and "Weekly" MSTI/SL announcements. In the announcement message, the staff was informed about the topic and purpose of the presentation, outlining the benefits for those who attend the staff meeting. This assumed that voluntary education, compared to mandatory education, is much more in line with adult learners. During the presentation, adult learners' previous experience was helpful for the educator to practice clinical scenario/problem-solving exercise and enhance learning through group discussions. Questions and answers within the presentation assisted adult learners to apply their knowledge. Readiness was evaluated by pre- and post-tests. Real-life scenarios as examples provided adult learners with tools to apply the new knowledge in practice. Motivation was evaluated by willingness to attend the presentation.

### **Project Implementation and Evaluation**

The project methods, implementation and evaluation were carried out in several steps.

Existing barriers to pain management were defined from the literature and from conversations with experts in palliative care. A number of additional barriers in pain management at clinical sites (MSTI and SL) were identified and discussed. Salient points of pain assessment and management for minorities were gathered and outlined, and then presented to the content experts for their review and input. A set of guiding questions to assess and manage pain across cultures

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was composed from the above actions and compared to the best-evidence practice recommendations instead of comparing with local guidelines since these didn't exist. These were reviewed and edited by the content experts. The project was presented to the University of Utah College of Nursing committee on October of 2013 (Appendix A) and was approved for further development and implementation. An educational presentation that explained the use of these guidelines was developed and included a downloadable educational model. This was presented to providers at MSTI and SL monthly staff meetings on February 17<sup>th</sup>, 19<sup>th</sup>, and 20<sup>th</sup>, 2014. Each presentation lasted one hour. Each meeting was attended on average by 20 Registered nurses, 5 clinical assistive personnel, one Clinical Nurse Specialist, Departments Managers, secretaries, and Clinical Educators. Post-presentation evaluation was administered with a Likert scale questionnaire. The results showed a 35% increase in scores in comparison to the pretest. Staff noted a significantly increased confidence in taking care of non-English speaking cancer patients with the help of the newly developed and proposed resourced. The presentation and the education model were posted online through St. Luke's Intranet to further assist staff to provide culturally sensitive pain assessment in the future. Staff educators at the MSTI and SL Oncology Departments' and St. Luke's Education Department were contacted to consider posting the presentation on the educational internal website and convert it to a mandatory continuous staff education module. The information related to this project will be further disseminated through the online submission to the Doctors of Nursing Practice Organization's DNP Scholarly Projects (http://doctorsofnursingpractice.org/). Contact information will be posted online to network and contribute to the professional growth of the DNP community in the future. The final project defense was successfully carried out by the poster presentation (Appendix B) in March of 2014 in the University of Utah, College of Nursing.

### Results

The project objectives were addressed with the following details. A number of additional barriers in pain management at clinical sites (MSTI and SL) were identified and discussed with the stakeholders: 1) lack of standardized system-wide culturally sensitive pain assessment policy, guidelines, and recommendations; 2) limited staff cultural competence training and education; 3) lack of inpatient Pain Service and its limited outpatient availability and accessibility for oncology patients; 4) limited number of certified interpreters and their inadequate availability for oncology patients' continuous assessment and monitoring; 4) scarce budget allocation for various tools that can be helpful in providing adequate care to non-English speaking oncology patients (i.e., IPad with downloadable apps for live voice translation; visual analog and international pain assessment scales available in every patient room; etc.); 5) lack of research targeting local minority population in order to address their healthcare needs specifically related to cancer pain management.

Salient points of pain assessment and management for minorities were gathered and outlined, and then presented to the content experts for their review and input. A set of guiding questions to assess and manage pain across cultures was composed from the above actions and best-evidence practice recommendations were outlined in response to the lack of local guidelines. These were reviewed and edited by the content experts (Appendix C). Next, the educational presentation was created (Appendix D) with post evaluation form (Appendix E). Finally, the pain assessment and management algorithm (Appendix F) was created for nurses to guide them when taking care of non-English speaking patients.

The evaluation of the educational presentation indicated that the nursing staff's cultural awareness and competence increased. The nursing staff recognized the need for a standardized policy

to achieve consistent practice improvement while working with non-English speaking patients. In addition, the nursing staff identified the tremendous need for the Oncology Clinical Nurse Specialist (CNS) versus current department educator position. The Clinical Nurse Specialist is much more prepared professionally to conduct research, identify areas for improvement, coach and educate staff based on their knowledge deficits, and offer solutions to help nursing staff to assess and manage pain in non-English speaking oncology patients.

### Limitations

Any practice improvement and/or new policy development, implementation or change is an evolving process, requiring dedication, time, expertise and various resources. Lack of a previous standardized culturally sensitive pain assessment policy, guidelines, and recommendations to refer to made the implementation process somewhat challenging. However, time restrictions and pressure to accomplish the entire project as early as possible created the most significant stumbling block for project development.

### **Unintended Consequences**

After attending the staff educational session, MSTI and SL educators proposed to present the educational presentation to cancer patients at the monthly Lymphoma & Leukemia Society meeting, which was held on March 4<sup>th</sup>, 2014 at the MSTI Anderson Center. Twenty five patients and their family members attended the meeting. St. Luke's staff representatives included Bone Marrow Transplant patient navigator, Clinical Nurse Specialist, and an Oncology inpatient educator. The presentation was delivered with the emphasis on patients' education regarding different pain assessment tools, existing barriers to effectively assess pain and manage it, and what patients should be expected to report about their pain. Following the presentation, patients initiated a very thought provoking and engaging discussion. The overall consensus was the need

for continued education for both, clinicians and patients and the necessity for creating a culturally sensitive standardized pain assessment and management policy system wide.

### Recommendations

Following an extensive research using Medscape, CINHL, PubMed, UpToDate, and Cochrane databases, no existing policies and/or guidelines were found for cancer pain assessment and management among ethnic minorities. Therefore, the project should be continued and further expanded. There will be tremendous value in developing a detailed, system wide needs assessment for providers and oncology patients at St. Luke's to further identify the existent barriers and areas for improvement in order to achieve a better pain control for all patients.. The project can serve as starting point for further developments.

Future project development recommendations would include: 1) create a mandatory continuing education module "Cultural Pain Assessment & Management" for clinicians in various primary care settings; 2) create a continuing patient education module about the various Pain Assessment Tools, Pain Assessment & Management paths and algorithms; 3) research on patient perceptions of the various pain models; and 4) propose a culturally sensitive pain assessment & management protocol and/or guideline to be further maintained based on the latest evidence-based data & recommendations.

The replication of research strengthens the future project development recommendations. Therefore, further randomized controlled studies should be conducted to evaluate educational interventions to improve cancer pain assessment and management practices to improve ethnic minority population pain management outcomes. Furthermore, additional research is needed to evaluate long term effects of inadequate pain assessment and management in the ethnic minority cancer patient population. There may be a need for continuous surveillance to monitor practice

improvement and propose new policy implementation. Although the future development may take a number of years and is outside the scope of this project, the potential benefits could be of great clinical significance.

### **Conclusion**

Staffs' knowledge and competence in assessing and managing cancer pain of culturally diverse patients have significantly increased based on the presentation evaluation.. The message of reducing the burden of cancer pain and the disparities in healthcare delivery for ethnic minorities was recognized as an essential part in everyday practice. The project has definitively demonstrated the effectiveness of an educational presentation and its value in increasing nursing staff's knowledge and attitudes regarding cancer pain assessment and management in non-English speaking patients. As previously stated, additional studies will need to be conducted. One educational session may not be sufficient to change current practice and/or implement new practices. This project was one small step in creating awareness of individual variation in pain assessment, meaning and management and it is likely to improve future efforts to address the needs of ethnic minorities and cancer pain.

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### APPENDIX A

### **DEFENSE PPT PRESENTATION**

Disparities in Cancer Pain Assessment and Management among Ethnic Minorities

Laura Kogan, BSN, RN, SFNP

In partial fulfillment of the requirements for the Doctor of Nursing Practice degree October 10, 2013

### Background

- One in four deaths is caused by cancer
- □ More than 1.6 million new cancer cases expected in
- □ Inequalities and inadequacies in treatment of pain for oncology patients
- □ Ethnic minorities are especially vulnerable for undertreatment of cancer pain
- □ Poor pain control leads to adverse consequences and cancer progression

American Cancer Society. (2013). Cancer Facts & Figures 2013.
Retrieved from
http://www.cancer.org/research/cancerfactsstatistics

### Problem Statement

- □ Inadequate pain assessment and management for ethnic minority patients
  - Language gaps
  - Limited knowledge of cultural behaviors and pain expression
  - Providers' inadequate cultural awareness training
  - Providers' bias and stereotyping
  - Lack of handouts in appropriate languages and poor communication
  - High time pressure, cognitive complexity, and pressures for High time process...

    Cost-containment

    In E O, Len, I. H., Liu, Y., Lie, H. J., Gerren, E., & Chez, W. (2009). A National Color Forum on Efficie Difference in Cancer Pain Experience.

    Alwaing Research, 27 (2), 56-94.

### Purpose

to develop an educational model for clinicians treating cancer patient's pain that addresses an approach to pain assessment and management that is culturally sensitive and effective when working with ethnically diverse patients

### Significance

Practitioners' cultural awareness -better practice - better patient outcomes

- □ Improved quality of life
- Decreased readmissions to treat pain
- □ Reduced burden of cancer pain
- Decreased disparities in healthcare delivery for ethnic minorities

### Literature Review

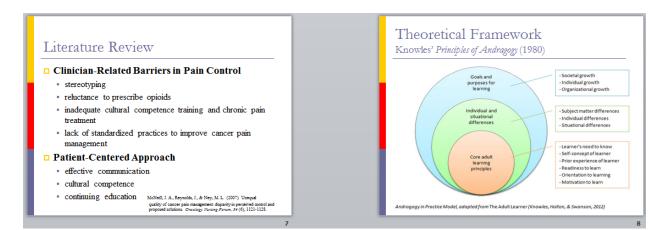
### □ Cancer Pain Management

- ethnic minorities are especially prone to experience inadequate cancer pain treatment
- · lower socioeconomic class, lack of insurance, limited access to healthcare

### Cultural Perception of Pain

- · minimized the importance of aggressive pain treatment
- accept and tolerate pain
- fear of opioid addiction

Anderson, K. O., Mendoza, T. R., Valero, V., Richman, S. P., Russell, C., Hurley, J. (2000). Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer*, 88(8), 1929-1938.



Implementat	ion & Evaluat	ion	Implementa	tion & Evaluat	ion
Objectives	Implementation	Evaluation	Objectives	Implementation	Evaluation
Identify existing barriers to pain management among the three dominant ethnic groups at MSTI and SL (Latino, Asians, and African-Americans).	Literature review of pain assessment and management for minorities. Interview experts in palliative care to identify cultural barriers in pain management at clinical sites (MSTI and SL).	Salient points of pain assessment and management for minorities gathered and outlined. Content expert review, edit, and approve.	Post the presentation and the education model onlin through St. Luke's SumTotal Learning Center	educators to assist. Contact	Verify with the appropriate departments that the presentation is online
Identify policies/guidelines for pain assessment and management at the clinical sites and in the literature	Compare local guidelines with the current evidence- based best practice general guidelines.	Content expert review, edit, and approve.	Disseminate the information related to this project	An online submission to the Doctors of Nursing Practice Organization's DNP Scholarly Projects (http://doctorsofnursingpra- ctice.org/).	Leave my contact information in order to network and contribute to the professional growth of the DNP community in the future.
Develop an educational presentation with a downloadable educational model for MSTI and SL	Presentation to clinicians at MSTI and SL monthly staff meeting.				

### Project Goals Acknowledgments PCNP Program Director: Dianne Fuller, DNP, APRN, FNP-C Executive Director MS and DNP Programs: Katie Ward, DNP, WHNP, ANP □ To expand the pain management Chair: Deb Penney, CNM, MS, MPH PhD(c) knowledge among staff Associate Clinical Professor debra.penney@nurs.utah.edu □ To improve cultural competence among Content expert: Dr. Lauren Clark, RN, PhD, FAAN, Professor Health Systems and Community Based Care Division Chair College of Nursing, University of Utah □ To decrease cancer pain burden among Lauren.clark@nurs.utah.edu ethnic minorities Resource consultant: Dr. Virginia LeBaron, PhD, APRN, FAANP Post-Doctoral Research Fellow Dana-Farber Cancer Institute/Harvard Cancer Center/University of Massachusetts Boston Virginia LeBaron@DFCLHARVARD.EDU

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### APPENDIX B

### **DEFENSE POSTER**



### Cancer Pain Assessment & Management in Non-English Speaking Patients

Laura Kogan, RN Family Nurse Practitioner Program



### AIMS/SIGNIFICANCE

### Aims/Objectives

- Improve pain assessment and management of cancerrelated pain for non-English speaking ethnic minorities.
  - Create an educational session for clinicians that addresses cultural varieties in pain assessment
  - · Educate hospital clinicians to use a cultural approach to pain assessment and management with the use of the algorithm and tool.

### Significance

Practitioners' awareness and knowledge of cultural influences and individual meanings and perceptions of pain may improve pain assessment and management and lead to improved patient outcomes.

### BACKGROUND

- caused by cancer in the U.S.
- management for oncology patients from ethnic minorities (America Cancer Society 2013; Cancer Facts & Figures 2015) No standardized pain assessment & management guidelines
- Ethnic diversity is increasing throughout the U.S. and in
- Oncology nurses lack a means of including individual

### PAIN ALGORITHM

### METHODS/RESULTS

- Methods Identify methods for pain assessment & management for nor English speaking patients Identify tools to assist nurses in applying cultural sensitivity is
- pain assessment & management Create an algorithm for pain assessment and manager identifies variations in individual pain interpretation and
- Disseminate information through educational sessions
- Results
  The algorithm and tool were developed and approved with the
- help of content experts

  The algorithm and cultural pain assessment educational sessions were presented at two hospital sites for oncology
- Evaluation: greater confidence of nurses in assessing and managing non-English speaking patients' pain by using the tool and algorithm
- The algorithm, tool, and PowerPoint were posted on the internal web system as a reference and continuing education

### FUTURE DEVELOPMENT

- Cancer pain is experienced by many patients; 1 in 4 deaths is
- Inequalities and inadequacies exist in pain assessment and
- exist for ethnic minorities.
- cultural variations in pain assessment & management

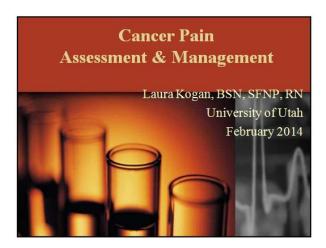
## Ton.

ASSESSMENT TOOL

- Create a continuing education module "Cultural Pain Assessment & Management"
- Educate other clinicians in various primary care settings using the Pain Assessment Tool & Pain Assessment & Management
- Educate oncology patients about the various Pain Assessment Tools, Pain Assessment & Management paths/algorithms, and receive their evaluation.
- Develop a culturally sensitive pain assessment & managemen protocol and/orguideline
- Continue to revise protocol/guidelines based on the latest evidence-based data & recommendations

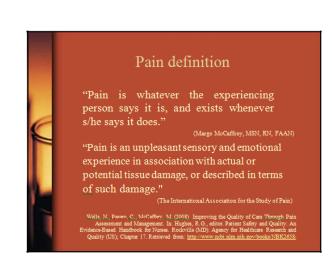
## APPENDIX C

## **EDUCATIONAL PRESENTATION**



# Understand various types & dimensions of pain Review primary causes of cancer-related pain Recognize effects of pain on cancer patients Understand culturally-sensitive patient care Describe methods of pain assessment in non-Englishspeaking oncology patients Familiarize with various pain assessment tools Differentiate between cultural competence, cultural humility, and culturally sensitive and individualized pain assessment Ultimately decrease pain burden among oncology patients and in particular, non-English-speaking oncology patients

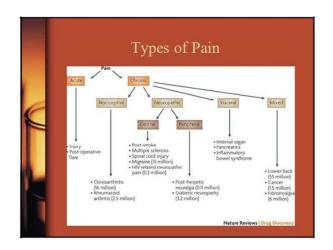
# Background One in four deaths is caused by cancer More than 1.6 million new cancer cases in 2013 Inequalities and inadequacies in treatment of pain for oncology patients Ethnic minorities are especially vulnerable for under-treatment of cancer pain Poor pain control leads to adverse consequences and cancer progression Marvices Carcar Society (2013) Cancer Facts & Figures 2013 Retrieved from http://www.cancer.com/sections/minks

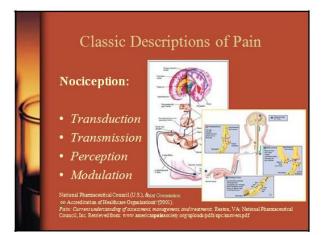


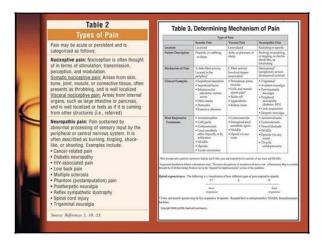


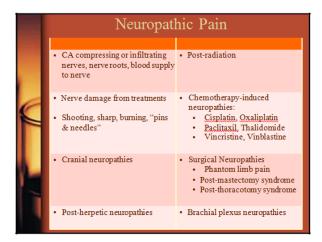


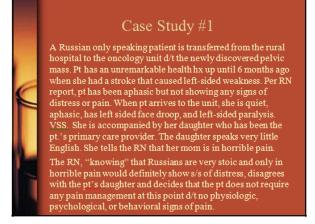


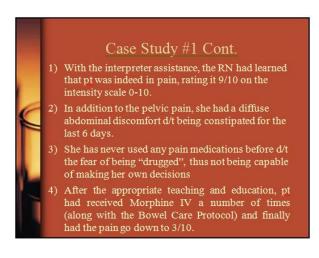








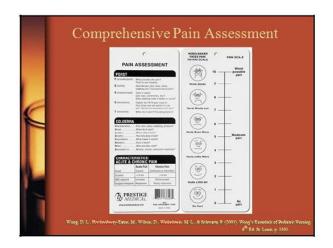


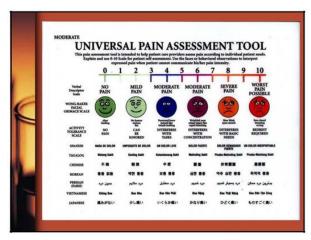


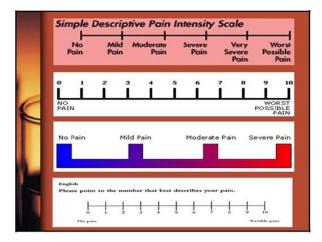


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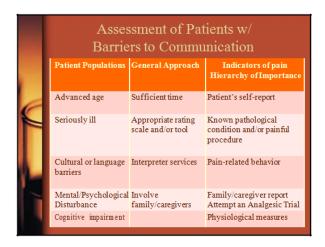


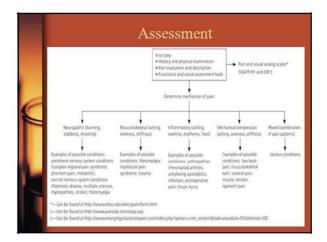














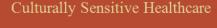
# Cultural Competence vs Humility

- A Stereotype is an ending point, no attempt is made to learn whether the individual in question fits the statement.
- A G eneralization is a beginning point, it indicates common trends, but further information is needed to ascertain whether the statement is appropriate to a particular individual.

Galanti G.A. (1991)

 Cultural Humility is a lifelong commitment to "selfevaluation and self-critique" to create a "clinical and advocacy partnerships between individuals and defined populations"

(Tervalon & Murray-García, 1998, p.117



- · Self-reflection
- Acquiring cultural knowledge
- · Facilitating client choice
- Communication
- Non-verbal communication strategies
- Developing an Approach to Care
- · Establishing mutual goals



#### Behavioral Directives for Nurses

- · Broaden your understanding of different cultures
- . Be sensitive to the nurse-client relationship
- Be aware of cultural differences in attitudes towards illness and care needs
- · Be non-judgmental
- · Advocate for client-centered care
- · Accommodate cultural preferences
- LEARN model
- · Utilize relevant cultural resources

Narayan, M. C. (2010). Culture's Effects on Pain Assessment and Management. AJN, 110 (4), 38-47.



# Culture....culture.... culture

http://www.nlm.nih.gov/medlineplus/languages/pain.html www.britishpainsociety.org/book\_pain\_older\_people.pdf http://depts.washington.edu/pfes/CultureClues.htm http://www.hrsa.gov/culturalcompetence/index.html http://ethnomed.org/



# What do you think would improve our practice?

- How can we empower patients to report their pain?
- How we can examine our own cultural beliefs and change them regarding pain?

#### Pain Management Practice Pearls

- The simplest dosage schedules and least invasive pain ma nagement modalities should be used first.
- Treatment of persistent or moderate to severe pain should be based on increasing the opioid potency or dose.
- Medications for persistent cancer-related pain should be administered on an around-the-clock basis with additional "asneeded" doses
- Opioid tolerance and physical dependence are expected with long term opioid treatment and should not be confused with addiction.
- The oral route is the preferred route of analgesic adminis tration because it is the most convenient and cost-effective method of administration.
- Because there is great inter-individual variation in susceptibility to opioid-induced side effects, clinicians should monitor for these potential side effects.



#### Cont.

- Monitor for side effects, esp. constipation -should be anticipated, treated prophylactically, and monitored constantly.
- An essential principle in using medications-to manage cancer pain is to individualize the regimen to the patient.
- Three major classes of drugs are used alone or, more commo nly, in combination to manage pain in the cancer patient: 1) NSAIDs and acetaminophen; 2) Opioid analgesics; 3) Adjuvant
- Most cancer pain can be managed by oral administration of drugs; however, difficulty in swallowing, gastrointestinal (GI) disturbances that render drug absorption unreliable, the amount of drug required, and many other factors may require alternative routes of administration. Consider using sublingual, PR or transdermal route as least invasive.



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# APPENDIX D

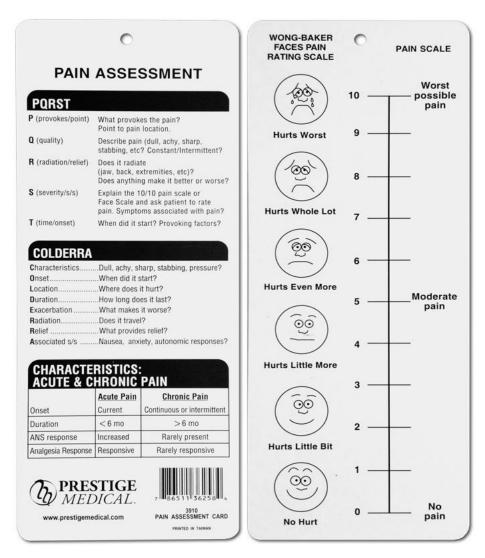
# PAIN ASSESSMENT AND MANAGEMENT ACROSS CULTURES GUIDE FOR NURSES

- Assess your own values and biases that underscore your approach and interventions, and their impact on the client
- Remember patients can have different behavioral/cultural responses to pain and different treatment preferences
- Use assessment tools in appropriate language (helpful links)

http://www.nlm.nih.gov/medlineplus/languages/pain.html http://depts.washington.edu/pfes/CultureClues.htm http://www.hrsa.gov/culturalcompetence/index.html http://ethnomed.org/

• Comprehensive culturally sensitive pain assessment

STEP 1 - use appropriate scale and COLDERRA or PQRST



Retrieved from: <a href="https://www.prestigemedical.com/ProductDetail.aspx?sku=3910">https://www.prestigemedical.com/ProductDetail.aspx?sku=3910</a>

#### STEP 2 – Assess cultural perception of pain

- 1) What do you call your pain? (e.g., ache, soreness, discomfort...)
- 2) What do you think is causing your pain?
- 3) When did it start? Why do you think it started when it did?
- 4) What do you fear most about the pain?
- 5) What problems does it cause you?
- 6) What does the pain mean for your body?
- 7) What have you used to help you with the pain? How does it help?
- 8) Who else have you consulted about the pain? Family members? A traditional healer? What do they know about your pain? What do you want them to know?
- 9) What treatments do you think might help you with the pain?
- 10) What cultural remedies have you tried to help you with your pain?
- 11) What are the most important results you hope to receive from the treatment?
- 12) Who helps you when you have pain? How do they help?
- Provide patient education materials in native language, when possible (e.g., the
  importance of controlling pain, the use of pain rating scales to report pain intensity, how
  to establish realistic pain relief goals, pharmacologic and non-pharmacologic
  interventions for pain) use the above helpful links
- Educate patients that:
  - (a) effective pain relief is important to treatment;
  - (b) their report of pain is essential;
  - (c) staff will promptly respond to patient requests for pain treatment.
- Continually evaluate and work to improve the quality of pain management.

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# APPENDIX E

### POST PRESENTATION EVALUATION FORM

	Poor	Fair	Good	Very good	Excellent
Introduction —         got the attention         topic is essential & relevant	1	2	3	4	5
<ul><li>2. Preparation –</li><li>preparation and practice apparent</li></ul>	1	2	3	4	5
<ul> <li>3. Organization –</li> <li>organized</li> <li>easy to follow</li> <li>included introduction, clear objectives, body, and conclusion</li> </ul>	1	2	3	4	5
<ul> <li>4. Creativity –</li> <li>• Interactive</li> <li>• Thought and discussion provoking</li> </ul>	1	2	3	4	5
<ul> <li>5. Meeting the objectives –</li> <li>Strong, supportive data &amp; materials included</li> <li>Concrete explanations and examples provided</li> </ul>	1	2	3	4	5
6. Please list two subjects discussed that were the most useful to you					
7. What did you gain/learn from the presentation?					
8. How do you think the presentation will help you in your work?					
9. How do you plan to use the information from the presentation?					
11. How do you expect to use the suggested resources, presentation, guide, and algorithm?					
12. What additional resources and/or steps would be also helpful for practice improvement?					

### APPENDIX F

# PAIN ASSESSMENT AND MANAGEMENT ALGORITHM FOR NON-ENGLISH SPEAKING PATIENTS

