EVIDENCE BASED PAIN MANAGEMENT TOOLS TO GUIDE THE MEXICAN AMERICAN FEMALE CANCER CAREGIVER

by

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EVIDENCE BASED PAIN MANAGEMENT TOOLS TO GUIDE THE MEXICAN AMERICAN FAMILY CANCER CAREGIVER

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ABSTRACT

Hispanics in the United States, the majority of which are Mexican American (MA), experience high cancer incidence and mortality. This often leads to home care by a MA female caregiver (MAFCG). MA cultural and linguistic views, combined with low literacy often found in this ethnic group, may affect health care learning contributing to health care disparities. Limited evidence exists about culturally sensitive cancer pain management in MAs. Within this honors project, the author’s aim was to answer the clinical question: What is the best (evidence-based) practice to promote comfort in MAs experiencing cancer-related pain? Research methodology included a structured integrative literature review process informed by Leininger’s Theory of Transcultural Nursing and theoretical and operational definitions of pain within the context of the MA culture. The author appraised citations for credibility, clinical significance, and applicability for inclusion in evidence to meet the study aim. Evidence supported development of a bilingual (English and Spanish) pain management script assessed by a bicultural consultant, tested with two to three MAFCGs, and delivered by promotoras-de-salud (Texas Certified Community Health Workers). Findings included MAFCG reception of the script as culturally relevant, “complete,” “very valuable,” and at a literacy level helpful to understand ways to manage a family member’s cancer-related pain. Additional MAFCG feedback prompted the author to develop two five-minute You-tube videos on cancer-related pain to improve information access and reinforcement in a low-literacy population that learns better through audio visual formats. Findings influence clinical practice by offering an evidence-based low-literacy script and video deemed helpful and culturally relevant by MAFCGs to increase their ability to promote pain management in a loved one with cancer. Increased caregiver
understanding may improve partnerships between caregiver, ill family member, and health care provider for culturally tailored care for MA families during cancer.

Keywords: MAs, cancer, pain, pain management, culturally sensitive/appropriate, health literacy.
Evidence Based Pain Management Tools to Guide the Mexican American Family Cancer Caregiver

Cancer is the second leading cause of death in the United States (U.S.). It is an illness that affects Americans of all races and ethnicities (Williams, Lantican, Bader, & Lerma, 2014). Hispanics are currently the fastest growing ethnic group in the U.S. By the year 2050 the Hispanic population is expected to reach about 106 million (Krogstad, 2014). The single largest subgroup from the Hispanic population is of Mexican origin (Williams et al., 2014). This Mexican American (MA) subgroup has cultural and linguistic views and needs that affect the management of cancer-related pain (Juarez, Ferrell, & Borneman, 1998).

Pain can affect all parts of an individual’s life and can delay healing (American Cancer Society [ACS], 2015). Pain can cause individuals to have trouble completing daily activities, eating, and sleeping. An individual experiencing pain can be very irritable and become easily frustrated, upset, and even angry. These factors can decrease quality of life of a patient and make it more challenging for the patient to achieve their health goals.

MAs approach pain with stoicism and prioritize family over cancer diagnosis and treatment, including pain management (Im, Guevara, & Chee, 2007; Juarez et al., 1998). The lack of pain expression and low priority can be interpreted by the health care professionals as the absence of pain and can contribute to unmanaged pain in MAs. In addition, MAs also rely on folk beliefs and nondrug interventions to manage pain which can go unreported to health care providers due to language barriers. The most common cited reason for noncompliance in pharmacological pain management treatment is the inability to understand instructions (Juarez et al., 1998).
In this paper, the author further describes disparities in pain management present in Hispanics, reasons for those disparities, and identifies culturally sensitive and appropriate methods to increase knowledge of pain management in the MA population. The author’s purpose was to develop a culturally sensitive and appropriate educational video that will increase MA caregivers’ ability to promote pain management in a family member with cancer. The author based the educational video on the best evidence-based practice of pain management for MA cancer caregivers. The author used materials developed in the culturally sensitive theory-based intervention Multidisciplinary Action Plan of Support (MAPS) module from previous research focused on the Mexican American Family Cancer Caregiver (MAFCG) to guide the script of the video (Cagle & Wells, 2016). The pain management MAPS module promotes caregiver health, minimizes negative caregiving outcomes, and supports caregiver role mastery to optimize care to a family member experiencing cancer-related pain.

**Statement of Clinical Question**

The findings stated above led the author to the clinical question: “What is the best evidence-based practice to promote comfort in MAs experiencing cancer-related pain?” The author presents evidence in this paper to develop an educational video for MA cancer caregivers to better understand and manage their family member’s cancer related pain. The video can then be used as supplement material in the MAPS.

**Theoretical Framework**

Madeleine Leininger’s Theory of Transcultural Nursing developed in the 1950s serves as the main framework for the clinical question stated above (Leininger & McFarland, 2002). This framework describes a holistic nursing perspective which considers cultural care, values, beliefs, and practices to achieve care that is culture-specific to promote health, well-being, or to help
people face health challenges (Leininger & McFarland, 2002). This theory guides nurses to address the medical priorities and the patient’s knowledge and cultural priorities, to create and follow an individualized plan of care for the patient; an approach that may support patient compliance with prescribed health care.

Pain is an unfavorable experience. Cancer-related pain adds stress to an already existing stressful situation, and can further delay the patient’s goal of reaching health or well-being. Pain is perceived differently by each individual, and culture plays a role in pain perception (Lewis, Heitkemper, Bucher, & Camera 2014). In MAs pain management is not a priority during cancer diagnosis and treatment possibly related to cultural practices as well as language barriers (Juarez, et al., 1998; Williams, Lantican, Bader, & Lerma 2008). Having unmanaged pain can result in negative consequences for the individual, including delayed healing.

One way to promote health or wellbeing of a population is through the concept of health literacy, “the ability to obtain, process, and understand basic health information and services to make appropriate health decisions” (U.S. Department of Health and Human Services [USDHHS], 2008, para. 1). According to the first National Assessment of Adult Literacy (NAAL), only 12 percent of U.S. adults had a proficient level of English health literacy (USDHHS, 2008). NAAL’s racial/ethnic graph shows Hispanics having the highest percentage of adults in the category of “below basic” understanding of health literacy at 41 percent (National Center for Education Statistics, n.d.). Using Transcultural Theory to guide this project, the author sought to identify cultural values, beliefs, practices, and health literacy levels specific to MAs, and determine the best practice to guide the family caregiver of an ill family member experiencing cancer-related pain (Cagle & Wells, 2010; Im et al., 2007; Juarez et al., 1998).
The author is guided by several key concepts to seek answers to the clinical practice question: “What is the best (evidence-based) practice to promote comfort in MAs experiencing cancer-related pain?” The key concepts for this project are MAFCGs, cancer, pain, pain management, culturally sensitive/appropriate, and health literacy. The author provides a theoretical and operational definition for each concept below.

**Mexican Americans (MAs):** For this project, men and women in the Dallas-Fort Worth area who express physical pain related to a cancer diagnosis or treatment define the population of “MAs experiencing cancer-related pain.” According to the State Cancer Profiles (n.d.) the incident rates of the counties in Texas vary greatly from as low as 150.4 to 640.2 per 100,000. Dallas county has an incidence rate of 349.7 per 100,000 and Tarrant county has an incidence rate of 331.8 per 100,000 indicating placement in the higher end of the spectrum of cancer incident rates for the state. The family caregiver (MAFCG) is the person (unpaid and untrained) who is the primary caregiver of the ill family member with cancer.

**Cancer:** Diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer, depending on the site, can cause almost any sign or symptom in an individual including, but not limited to fever, fatigue, weakness, and pain (ACS, 2014).

**Pain:** is a multidimensional and complex experience that causes human suffering and decreases personal quality of life (Lewis et al., 2014). Pain can be described broadly as physical pain and emotional pain. Physical pain results from body and emotional stimuli applied to the body and may result from environmental changes or cultural interpretation of pain. Pain for this project will be defined by Margo McCaffery’s (1968) definition as: “Whatever the person experiencing the pain says it is, existing whenever the person says it does” (McCaffery & Pasero, 1999, p.17). When pain is left untreated it can cause further physiological and emotional
problems such as a decrease in tissue healing and appetite, alteration of mood, increased susceptibility to infections, weakness, fatigue, decrease in motivation to continue treatment, insecurity and lack of control (Lewis et al., 2014). This project will define cancer pain as physical or emotional pain or a combination of both as defined and described by the person experiencing it. Evidence-based research demonstrates the most meaningful pain assessment tools for MAs include communication in the patient’s preferred language, use of a low health literacy level, one-to-one interaction, and the use of written tools (Cagle & Wells, 2010; Ezenwa, Ameringer, Ward, & Serlin, 2006; Im et al., 2007, Juarez et al., 2008, William et al., 2014).

Pain management refers to promoting comfort in MAs experiencing cancer-related pain as identified by the person experiencing pain. The patient will define what is “comfort” during the cancer experience.

Cultural sensitivity/appropriateness is respect for the patient’s values, beliefs, and practices (Leininger & McFarland, 2002). The health care team can deliver high quality care in the most efficient way to all patients with understanding that cultural factors affect the patient’s health beliefs, behaviors, and responses to medical issues as well as the differences that exist within cultures (Agency for Healthcare Research and Quality, 2014). For this project, cultural sensitivity/appropriateness is achieved through (evidence-based) research for the creation of a culturally and linguistically appropriate educational video to guide MA family caregivers to promote pain management in their family member experiencing cancer-related pain. A cultural consultant and promotoras-de-salud, Texas Certified Community Health Workers, reviewed the work by the author to assure the information is culturally sensitive and appropriate for use with MA patients and their caregivers.
Health literacy: is theoretically defined as having the ability to obtain, process, and understand basic health information and services to make appropriate health decisions (USHDHS, 2008). Operationally health (low) literacy refers to the Spanish speaking MAFCG or self-identified MAFCG who states she has trouble “understanding the doctor” to provide care for an ill family member at home.

Review of Literature

The author searched for evidence guided by key concepts from the clinical question as follows. The databases used in this search included CINAHL Complete, EBSCO (MEDLINE with Full Text), and PubMed. The first search consisted of “Mexican American AND Cancer” and produced 95 “hits” for CINAHL, 208 for Medline and 502 for PubMed. A “hit” in these databases is a match to the key words inputted. The author received one “hit” when using the search terms “Mexican American AND cancer AND pain management” in all these databases. This result indicates the literature gap that exists on managing pain in the MA culture. The search terms “Hispanic AND cancer AND pain management” yielded 75 articles from the databases. An inclusion criterion of publication within the last ten years narrowed the number of articles related to MA to eight. One of the articles used in this project did not meet publication criterion of being published in the last decade. Despite its 1998 publication date, this article fit the topic and provided consistent information. The articles most relevant to the proposed clinical question are described below in two categories, disparities in pain and interventions to promote comfort. The first category supports the gap in literature in pain management while the second category addresses the main clinical question of determining the best evidence-based practice to promote pain management. See Table 1.

Disparities in Pain
The first article, “Influence of Culture on Cancer Pain Management in Hispanic Patients” is a pilot questionnaire study with the purpose of describing how culture influences cancer pain management in Hispanics (Juarez et al., 1998). Researchers at City of Hope Medical Center developed and piloted The Hispanic Pain Experience Questionnaire to measure cancer pain and quality of life. Pain experts reviewed the questionnaire to evaluate cultural sensitivity. Seventeen subjects, mostly females who only spoke Spanish and had a mean education level of eight years, answered open-ended questions on perception and management of cancer pain. Four themes emerged: influence of culture, expressions of pain, managing pain/medications, and use of nondrug interventions. Of note, three more specific culturally defined findings were evident: MAs approached pain with stoicism, patients relied on folk beliefs and nondrug interventions to manage pain, and the most common reason for noncompliance of pharmacologic treatment was the inability to understand instructions. The findings suggest that attention to cultural factors is essential when assessing and treating cancer pain, written instruction in the patient’s preferred language is essential, and that communication with the patient and the patient’s family is crucial for effective pain management (Juarez et al., 1998).

Ezenwa, Ameringer, Ward, and Serlin (2006) conducted a systematic literature review of articles published from 1990 to 2004 to critically examine the research on racial and ethnic disparities in pain management. The authors focused on the magnitude of disparities and potential explanations for those disparities within the populations studied. Authors reviewed eleven studies and categorized information by type of pain: cancer pain, extremity fracture pain, and miscellaneous category. The sample size in articles ranged from 84 to 67,487 participants. The settings included variant outpatient units, emergency departments, community centers, and nursing homes. The findings of this systematic review revealed that studies have focused on
African Americans, whites or non-Hispanic Whites, Hispanics, and Asians, yet terms for these groups were neither well defined nor consistent across studies. The authors suggest that clarity and consistency among the terms race, ethnicity, and minority be used in future studies to promote specific descriptions of pain within cultural groups. Study findings describe consistent disparity related to minority status, although small in effect size. The study suggests further research to examine the differences that exist within the mentioned groups and to explain reasons for disparities across the groups (Ezenwa et al., 2006).

Im, Guevara, and Chee (2007), explored Hispanic patients’ cancer pain experience from a feminist perspective and in a qualitative online forum to find explanations for inadequate pain management. The study lasted six months and authors followed thematic analysis to process nine discussion topics and emergence of four themes. The themes included a lack of communication with healthcare providers related to under-medication and female gender roles which guided their pain behavior. The other two themes included patients placing a higher importance on family rather than pain management during cancer diagnosis and treatment and enduring inconvenient and unfair treatment in the U.S. healthcare system with a simultaneous appreciation of the treatment they were receiving. This study, along with that by Juarez et alm(1998), further described existing cultural factors to address to decrease the discrepancies that exist in pain management in Hispanics.

The fourth article titled “Racial and Ethnic Disparities in Pain: Causes and Consequences of Unequal Care” is a review that critically evaluated the recent literature, from 1990 to 2009, on racial and ethnic disparities in pain to determine measures to reduce and eliminate disparities in pain (Anderson, Green, & Payne, 2009). The study addressed the use of the terms race and ethnicity that have been used interchangeably and at times incongruent with the National
Institute of Health’s categories which thus complicates the literature review (Ezenwa et al., 2006). Anderson et al., (2009) differentiated the studies and placed them into pain categories of acute, chronic, cancer, and palliative pain. The authors stated there is a persistent disparity across the lifespan and treatment settings with minorities receiving less quality pain care than non-Hispanic Whites. To address this issue, authors recommended a “robust research program on disparities in pain” with the results “translated into practices and policies specifically designated to reduce and eliminate disparities in care” (Anderson et al., 2009, p.1198).

**Interventions to Promote Comfort**

Research by Williams, Lantican, Bader, and Lerma (2014) aimed at filling the gap in literature on occurrence and severity of symptoms of MA adults undergoing cancer treatments and the corresponding self-care to alleviate those symptoms. This cross-sectional study consisted of 67 patients who were currently receiving chemotherapy at a private cancer treatment center in El Paso, Texas. The authors used Therapy-Related Symptom Checklist (TRSC) a patient self-report instrument which lists 25 symptoms; it measures symptom occurrence and severity on a scale of 0-4, (“0” = no symptoms to “4” = very severe symptoms). Additionally, the participants used a Symptom Alleviation: Self-Care Methods (SA: SCM) tool to identify the self-care strategy used to alleviate the symptoms reported and whether the strategy offered relief.

All of the symptoms of the TRSC were reported at varying frequencies indicating the range of symptoms all related to cancer treatment. Of the 67 participants, 42 claimed to have a symptom severity of “0”, ten participants reported a symptom severity of “3”, and three reported a symptom severity of “4”. No statistics described which self-care methods worked although study results indicated 90% of the methods were effective and the medications and pain cream or patches were more frequently mentioned examples of self-care for pain. Williams et al, (2014)
thus argue that a systematic assessment and tracking of patient-reported symptoms is essential during therapy to enable providers to identify and prioritize symptoms. This tracking will also enable providers to determine needed interventions for best practice for each patient.

An additional study used qualitative research to evaluate an English and Spanish educational intervention (not specific for pain intervention) and determined that it improved quality of life and contributed to better patient outcomes (Juarez, Mayorga, Hurria, & Ferrell, 2013). Researchers used thematic analysis to analyze eight Latina breast cancer survivor interviews. This process yielded evidence that bilingual printed information along with verbal instruction from a bilingual and culturally competent health care provider who “can be effective in helping Latina breast cancer survivor’s transition successfully into survivorship, improve quality of life and contribute to better patient outcomes” (Juarez et al., 2013, p. 57). The article authors now implement some of the recommendations made by Anderson et al., (2009) and plan to evaluate the effectiveness to diminish disparities in care. By validating this intervention effectiveness, this study opens up opportunities for other areas of healthcare to adopt the interventions.

“Healthcare Literacy: Multiple Perspectives Grounded in the Experience of Mexican American Caregivers” (Cagle & Wells, 2010) described how limited healthcare literacy influences the caregiving experience of MAs. This article focused on three sequential studies: assessing the experience of MAFCGs, describing the quantity and quality of current caregiver educational materials, and assessing the needs of MAs from a healthcare providers’ perspective. The first study, a qualitative and quantitative study of 34 caregivers, identified the unmet learning needs of family caregivers’ caring for an ill family member at home. Caregivers spoke of specific unmet learning needs centered on how to care for the ill family member when they do
not want to take medications and eat due to cancer related side effects, as well as how to keep the patient comfortable at home over the treatment trajectory (Wells, Cagle, Bradley, & Barnes, 2008). The second study demonstrated that caregiver materials were scarce and when available, were at a higher reading level than needed by low literacy MAFCGs. This study also identified the caregivers’ preference for brochures with pictures in Spanish and English along with 91% of caregivers preferring a video format. The third study assessed health care providers and their understanding of the needs and experiences of MAFCGs. This article suggested the materials for MA with low literacy should consist of sixth to seventh grade reading level, use at least a 14-point font, simple language, active voice, use of metaphors and illustrative quotations, sentences with fewer than 10 words, emphasis on pictures and bullets, and the use of a “teach-back” method for clinical visits (Cagle & Wells, 2010).

The author used the following resource to classify the strength of the articles reviewed: The Johns Hopkins Evidence-Based Practice Research Nursing Evidence Appraisal (Dearholt & Dang, 2012). This appraisal classifies the quality of evidence into three categories: high quality, good quality, and low quality. High quality is characterized as consistent, generalizable results with a sufficient sample size for the study design, adequate control, definitive conclusions, and consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence. Good quality is characterized as reasonably consistent results with a sufficient sample size for the study design, some control, and fairly definitive conclusions. Low quality is characterized as little evidence with inconsistent results; insufficient sample size for the study design; conclusions cannot be drawn. The author further followed this resource to categorize the strength of studies in five levels according to the type of study. Level I includes experimental study, randomized control trial (RCT) or meta-analysis of RCT, Level II includes
quasi-experimental studies, Level III includes non-experimental studies, qualitative study, or meta-synthesis, Level IV includes opinion of nationally recognized experts based on research evidence or expert consensus panel, Level V includes opinion of individual expert based on non-research evidence. In reviewing the articles, the author identified a literature gap in the available health information materials and interventions that are culturally sensitive and appropriate for MAFCGs to promote pain management in their loved one. See Table 1 for the strength and quality of the articles used in this literature review.

**Methods**

The author followed a methodological approach to address the clinical question. The process included an informed sequence of steps: a) literature review of key concepts, b), critique of literature to determine reliability, validity, strength, and quality, c) evidence summary with recommendations for clinical practice, d) development of learning modules (in English and Spanish) to guide MAFCGs to address pain management in their ill family member experiencing cancer-related pain, e) review of module and supporting documents by a MA bilingual/bicultural consultant for cultural appropriateness, f) production of contextual notes of the pilot session using the module with MA women (promotoras-de-salud) in one-to-one intervention role-play sessions with a lay caregiver, g) refinement of the materials to guide the script for a video based on feedback, and h) preparation of two five-minute videos (one in English and one in Spanish) on basic pain management care for implementation with MAFCGs in future studies. The author’s final products from this honors project include a culturally sensitive and appropriate pain management module for low-literacy MAFCGs. The module includes written materials to guide promotoras-de-salud to teach caregivers, handouts, and a video as an audio/visual reinforcement tool of key pain management concepts. See Appendices to review project outcomes.
The author used this literature to develop a culturally appropriate and sensitive pain management module along with handouts for the MAPS module of pain management used in the research study, “Part III: Meeting Information and Coping Needs of Mexican American Family Cancer Caregivers: Pain and Nutrition management Project Development and Feasibility Study”. The author wrote the materials in English and translated to Spanish to best serve the needs for pain management in MAs as identified by the literature. Once the materials were created, two promotoras-de-salud and a cultural consultant assessed them for cultural appropriateness and sensitivity. Next the author revised and edited the materials based on the input from the promotoras-de-salud and the cultural consultant, and the learning module was assessed for feasibility (the ease of use, understandability, and perceived appropriateness for the MA low literacy population) to assist MAFCGs to promote pain management in their loved one experiencing cancer-related pain.

The feasibility was determined using a research based strategy on becoming stronger in a one-to-one role playing session in which promotoras-de-salud delivered the pain management module to MAFCGs, which in this project were Texas Christian University (TCU) housekeepers (Wells et al., 2008). The author recruited TCU housekeepers at the end of the day time shift in a break room used by the housekeepers. The author observed the sessions, which were delivered by the promotora-de-salud in the MAFCG’s preferred language, and created contextual notes throughout the sessions. A group open-discussion was held after the sessions to assess effectiveness and feasibility of pain management script. The author wrote contextual notes during and after reflection of the role-play sessions. (See Appendices E and F). The participants found the script to be culturally relevant, “very valuable”, and at a literacy level helpful to understand how to better manage cancer-related pain. The author sought accuracy of contextual
notes, as well as further feedback of the pain management modules and handouts via promotoras-de-salud meetings held post-session.

After receiving TCU Institutional Review Board (IRB) approval the author proceeded with the development of a culturally sensitive and appropriate video. The author used the contextual notes, discussion, and feedback from the promotoras-de-salud and participants as a guide for edits and refinement of the MAPS learning module and resulting handouts (See Appendices B-I). The author created two video scripts, one in English and one in Spanish, based on the edits and the literature review which supports the idea that MA and low literacy populations learn best by visual and auditory means. Furthermore, Professors, Dr. Wells and Dr. Cagle, a promotora-de-salud and a cultural consultant reviewed the content for cultural appropriateness and sensitivity.

The video script focused on broad information in low literacy to manage pain as well as on one of the handouts created for the MAPS session (See Appendix J). The handout is a chart that allows the MAFCG to help their loved one keep track of any pain they are experiencing, when they experience it, what makes it better or worse, and what problems it presents in their loved one (See Appendix G). The author translated this handout in Spanish (See Appendix H). The videos resulting from this script can be further tested for feasibility and effectiveness in MAFCGs.

**Conclusions and Implications**

The author described evidence that demonstrates the literature gap present in pain management in MAs with cancer. Research demonstrates disparities in pain management in Hispanics including MAs (Ezenwa et al., 2006; Im et al., 2007; Juarez et al., 1998). Other studies demonstrate the positive patient outcomes and effects of utilizing bilingual and culturally
sensitive education and other interventions in different areas of oncology (Juarez et al., 2013; Williams et al., 2014). Health care literacy in the MA population is one of the challenges prevalent in our society that influences the quality of health care for that population (Cagle & Wells, 2010). To address the cancer pain management challenge, culturally sensitive and low literacy materials presented in personalized health care encounters preferred by MAFCG must exist to improve health care of MA patients with cancer. The pain management video for delivery by a promotora-de-salud to a MAFCG is guided by evidence-based practices to promote pain management in MAs experiencing cancer-related pain as well as the need for intervention tools to guide the MAFCG role. The video with the previously created MAPS Pain Management module and handouts considers participants’ low health literacy and limited English proficiency and addresses health disparity that currently exists in cancer-related pain management in MAs. Researchers can determine feasibility and usefulness of the video within the MAPS Pain Management module with implementation in future studies with MAFCGs.
References


APPENDIX A

Table 1- Literature Review

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<thead>
<tr>
<th>Study</th>
<th>Strength</th>
<th>Quality</th>
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</thead>
<tbody>
<tr>
<td>“Influence of Culture on Cancer Pain Management in Hispanic Patients” (Juarez et al., 1998)</td>
<td>Level III</td>
<td>High</td>
</tr>
<tr>
<td>“Racial and Ethnic Disparities in Pain Management in the United States” (Ezenwa et al., 2006)</td>
<td>Level V</td>
<td>High</td>
</tr>
<tr>
<td>“The Pain Experience of Hispanic Patients with Cancer in the United States” (Im et al., 2007)</td>
<td>Level III</td>
<td>High</td>
</tr>
<tr>
<td>“Symptom Monitoring, Alleviation, and Self-Care Among Mexican Americans During Cancer Treatment” (Williams et al., 2014)</td>
<td>Level II</td>
<td>High</td>
</tr>
<tr>
<td>“Survivorship Education for Latina Breast cancer Survivors: Empowering Survivors Through Education” (Juarez et al., 2013)</td>
<td>Level III</td>
<td>High</td>
</tr>
<tr>
<td>“Healthcare Literacy: Multiple Perspectives Grounded in the experience of Mexican American Caregivers” (Cagle &amp; Wells, 2010)</td>
<td>Level III</td>
<td>High</td>
</tr>
</tbody>
</table>

Note. The author used the John Hopkins Evidence-Based Practice Model and Guidelines tool to determine the strength and quality of the studies included in Table 1.

APPENDIX B

MAPS Pain Management Module Script (English and Spanish)

Multi-disciplinary Program of Support (MAPS) for Mexican American Family Cancer Caregivers

Promoting Patient Comfort during the Cancer Experience

English Version

Step 1 Introductions

CHW says: “Hello Señora ___________________. I am ______________. It is good to see you. How have you been since the last time I visited? How is _______________ (ill family member) doing?

“I am happy to be here once again. As I have mentioned before I am a Certified Community Health Worker, also known as a promotora de salud. This means that I am very fortunate to work with people from my own culture to talk about ways to promote their health and cope with illness. In my previous visits we discussed that this program is designed to help MA cancer caregivers to gain skills and knowledge to provide care to their loved one with cancer.”

Paso 1 Introducción

CHW: “Hola Señora ______________.” Yo soy ______________. Me da gusto de volver a verla. ¿Cómo ha estado desde la última vez que la visite? ¿Cómo está su ser querido?

“Estoy muy contenta de estar una vez más aquí con usted. Como le he dicho yo soy una promotora de salud, certificado, también me llaman promotora. Esto quiere decir que afortunadamente tengo la oportunidad de trabajar con gente de mi propia cultura para hablar sobre las diferentes maneras de promover la salud y ayudarles a enfrentar diferentes enfermedades. En mi última visita, le explique a usted, que este programa está diseñado para darle apoyo a los cuidadores primarias de familia mientras cuidan a su ser querido.

“The remainder of the sessions will occur in the clinic or in your home, your choice, and you will receive calls in between the face-to-face sessions. The purpose of these sessions is to help you, the caregiver, care for yourself so you can care for your loved one with cancer.”

“The last time I visited, we spoke about stress related to being a caregiver and ways to decrease some of that stress to allow you to have a more comfortable caregiving experience.”

“How has the last session helped you?”

“For session three of the program, I want to discuss pain with you and ways that you, as the caregiver, can help your loved one control any pain they may experience. This will increase their comfort level and overall wellbeing. We believe that when the patient is most comfortable the caregiver (you) do better, too. When you do better, the patient will also do better.”
“If you have any questions through this session, feel free to ask me.”

“Las sesiones que quedan se llevaran a cabo en la clínica o en su hogar, como usted prefiera y recibirá llamadas entre las visitas. El propósito de estas sesiones es para ayudarle a usted, el cuidador primario, cuidarse a sí mismo (a).”

“La última vez que la visité, hablamos sobre el estrés que puede aparecer al ser el cuidador primario y sobre diferentes maneras de disminuir el estrés para que usted pueda estar más cómodo (a) al cuidar de su ser querido.”

“¿Cómo le ha ayudado la última sesión?”

“Para esta tercera sesión vamos a hablar sobre dolor y sobre las maneras que usted pueda ayudar a controlar el dolor que pueda sentir su ser querido. Al controlar el dolor su ser querido podrá estar más cómodo y más saludable. Nosotros creemos que entre más cómodo este el paciente el cuidador primario, usted, se sentirá mejor. Cuando usted se siente bien el paciente se sentirá mejor.”

“Si tiene alguna pregunta durante esta sesión, no dude en preguntarme.”

**Step 2 Facts about Pain**

“Let’s begin with some facts about pain.”

**CHW gives the handout to the caregiver and indicates where the facts about pain are located.**

“Vamos a comenzar con unos datos sobre el dolor.”

**La Promotora le entrega al cuidador primario el folleto y le indica la parte sobre los datos de dolor.**

“Not everyone that has cancer experiences pain. Those who have pain can have different types of pain during treatment. Different types of cancer medicine help patients control those kinds of pain.”

“Reporting pain and wanting to get relief is not a sign of weakness. It is a sign of wanting to feel better and wanting to stay active.”

“Pain can make people feel and act different. This is why having pain is not seen as normal. People with pain can experience fatigue, depression, anger, anxiety, loneliness, and even stress.”

“Pain is experienced differently by each person. Only the person experiencing the pain knows the severity of it. The person in pain should be the one reporting it to their doctor, nurse, or other health care provider. If you, as the caregiver report it to the doctor or nurse, it is best if you use the patient’s own words to describe their pain.”
“Pain, with the proper treatment, can be controlled.”

“No todos los pacientes de cáncer sienten dolor. Los pacientes que sí sienten dolor pueden sentir diferentes tipos de dolor durante el tratamiento. Diferentes tipos de medicina ayudan a controlar los diferentes tipos de dolor.”

“Reportando el dolor al doctor y querer disminuir o controlar el dolor no es una señal de no ser fuerte. Al contrario, es una señal de querer mejorar la salud y de querer mantenerse activo.”

“El dolor puede hacer que las personas se sientan y piensen diferente. Esto es una señal de que el dolor no es algo normal. Las personas que tienen dolor también pueden sentirse cansado, deprimido, y enojados y pueden tener ansiedad, soledad y estrés.”

“El dolor es diferente en cada persona. Solo la persona que tiene dolor sabe que tanto dolor siente. Así que la persona que debería de reportar el dolor al doctor, la enfermera, u otro miembro del equipo de salud es el paciente. Si usted, como cuidador primario, reporta el dolor al doctor o a la enfermera será mejor si usa las palabras exactas que usa el paciente para describir su dolor.”

“El dolor, con el tratamiento adecuado, puede ser controlado.”

**Step 3 Types of Pain**

“As I mentioned before, there are different types of pain. Pain can range from mild to moderate and severe. It can also be described into categories such as acute, chronic, and breakthrough.”

**CHW indicates where this information is located on the handout.**

“Como ya mencioné, hay diferentes tipos de dolor. El dolor puede ser leve, moderado, o severo. El dolor también puede ser agudo, crónico, o súbito.”

**La promotora indica el lugar de esta información en el folleto.**

“Acute pain is pain that appears quickly and lasts a short amount of time.”

“Chronic pain is pain that does not go away or pain that appears frequently.”

“Breakthrough pain is intense pain that occurs in a person even if they are taking medicine properly. This pain can occur with or without a motive.”

“Dolor agudo es dolor que aparece rápidamente y dura poco tiempo.”

“Dolor crónico es dolor que a veces no desaparece o dolor que puede aparecer con frecuencia.”

“Dolor súbito es un aumento de dolor fuerte que puede aparecer en una persona, aunque esté tomando medicina para el dolor. Este dolor puede ocurrir con o sin motivo.”
Step 4 Pain Medicine

“We have discussed some facts about pain and types of pain. Now let’s discuss some facts about pain medicine.”

La promotora indica el lugar en el folleto donde está esta información.

“Many people hesitate to take prescribed pain medicine out of fear of becoming “addicted”. In reality, cancer patients who take medicine as directed by their doctor, in the right amount and at the right time, rarely become addicted.”

“Pain medication, like Advil or Tylenol, can be obtained at drug stores without a prescription, but the patient must inform their doctor before taking any other pain medication to avoid any unnecessary side effects or outcomes.”

“Pain medication can have some side effects which can include: constipation, fatigue, nausea, and vomiting. It is very important to notify the doctor if any side effects occur while taking pain medication. This information will allow the doctor to take appropriate action to control pain without side effects.”

“The best way to make use of pain medicine is to take it as ordered by the doctor and to report to the doctor whether the medication helped control the pain and whether the medication caused any side effects.”

“Varias personas no desean tomar medicinas para el dolor por miedo de hacerse adicto a la medicina. En realidad, los pacientes de cáncer que toman las medicinas como se las receta el doctor, en la cantidad y en el tiempo correcto, raramente se hacen adictos.”

“Medicina para el dolor, como Advil y Tylenol, pueden ser comprados en una farmacia sin receta, aun así, el paciente debe de hablar con el doctor antes de tomar cualquier otra medicina de dolor para evitar que ocurran efectos secundarios u otras complicaciones.”

“La medicina para el dolor puede tener efectos secundarios como: estreñimiento, cansancio, náuseas y vómito. Es muy importante que si algunos de estos efectos secundarios ocurren mientras el paciente tome la medicina, el doctor sea notificado. Con esta información el doctor podrá tomar la acción correcta para continuar el control de dolor sin efectos secundarios.”

“La mejor manera de sacar provecho a la medicina de dolor es tomándola como la receta el doctor, reportando al doctor si la medicina ayudo a controlar el dolor, y reportando efectos secundarios si ocurren.”
Step 5 Other Methods to Relieve Pain

“Although pain medication is one of the treatment options more often used to control pain, there are other methods used to relieve pain such as physical therapy, acupuncture, meditation, and other forms of relaxation such as the breathing exercises we tried last time I visited.”

“Aunque la medicina para el dolor es uno de los tratamientos más usado para controlar el dolor hay otros tratamientos que pueden ser usados para aliviar el dolor como la terapia física, acupuntura, meditación y otras formas de relajación como los ejercicios de respirar que practicamos la última vez que visité.”

“Physical therapy is a treatment option which can include massage, heat or cold compressions, and/or exercise to help relieve pain and promote comfort.”

“Acupuncture is the use of thin needles at different pressure points in the body to help relieve pain and promote comfort.”

“Meditation is a practice which trains the mind to relax thus diminishing pain and promoting comfort.”

“Patients with pain can try these and other treatment options, to find a treatment they feel comfortable with and works best at relieving their pain.”

“La terapia física es un tratamiento que puede utilizar compresión caliente o frío, masaje, ejercicio para ayudarle a sentirse mejor.”

“La acupuntura es el uso de agujas delgadas en diferentes puntos de presión en el cuerpo para aliviar el dolor y promover la comodidad.”

“La meditación es una práctica que entrena la mente a relajarse. Esto ayuda a disminuir el dolor y promover la comodidad del paciente.”

“Las personas con dolor pueden utilizar estos tratamientos, y otros, para encontrar el tratamiento que los haga sentirse cómodos y que les ayude más a disminuir el dolor.”

Step 6 Communicating with the Health Care Team

“We have covered different parts of pain. One of the most important things in regards to pain is that the doctor receives the adequate information from the patient, your loved one.”

CHW hands the caregiver the second handout which consists of a table to record the information about pain and the pain rating scale.
“Hemos hablado sobre diferentes cosas relacionadas al dolor. Una de las más importantes es que el doctor reciba la información sobre el dolor del paciente, su ser querido.”

La Promotora le entrega el segundo folleto al cuidador primario. El segundo folleto tiene la tabla para anotar la información del paciente relacionado al dolor y la escala de dolor.

“There are 6 different things that should be reported to the doctor or nurse. Where is the pain? What kind of pain is it? How strong is the pain? When did the pain start? How long does the pain usually last? What makes it better or worse? Does the pain affect daily activities?”

“The answers to these questions can be written out in a table.”

“Hay 6 cosas que deben ser reportadas al doctor o a la enfermera sobre el dolor. ¿En dónde está el dolor? ¿Qué tipo de dolor es? ¿Qué tan fuerte es el dolor? ¿Cuándo empezó el dolor? ¿Cuánto tiempo dura el dolor? ¿Qué mejora y que empeora el dolor? ¿Tiene el dolor efecto en sus actividades diarias?”

“Las respuestas a estas preguntas pueden ser escritas en una tabla.”

CHW points out the table on the second handout.

“This can make reporting the pain to the doctor or nurse easier.”

“Most of these questions have an easy answer. The question that tends to give people a hard time is measuring the strength of the pain.”

“In doctors’ offices there will often be a pain scale. Although there are different types of pain scales the one from 0 to 10 is very widely used. In this scale 0 is used to indicate no pain, 5 indicates moderate pain, while 10 indicates the most severe or worst possible pain.”

CHW points out the 0 to 10 scale on the second handout and the faces scale.

La promotora le muestra la tabla en el segundo folleto.

“Esto hará más fácil reportar el dolor al doctor o a la enfermera.”

“Muchas de estas preguntas son fácil de contestar. La pregunta que puede ser más trabajosa para responder para algunas personas es de cómo medir que tan fuerte está el dolor.”

“En las oficinas de doctores hay escalas de dolor. Aunque hay diferentes tipos de escalas de dolor hay una que es usada mucho. La escala es la del 0 al 10. En esta escala el 0 significa que no hay dolor, el 5 significa dolor moderado, mientras que el 10 indica dolor severo o el peor dolor que se pueda imaginar.”

La Promotora le muestra la escala de 0 al 10 en el folleto al igual que la escala de las diferentes caras.
Step 7 What the Caregiver can do to Promote Comfort.

“Before we talk about things that you, as the caregiver, can do to help control any pain your loved one may experience, are there any questions about what we have talked about?”

“As the caregiver it is important to remember that each person has a different pain tolerance and each person experiences pain differently. It is also important to remember that pain is whatever your loved one says it is, and this is the information that needs to be reported back to the doctor, nurse, or other health care professional.”

“The following are different things that you, the caregiver, can do to promote comfort in your loved one, with respect to pain they may experience.”

CHW identifies these tips in the second handout.

Paso 7 Lo que puede hacer el cuidador primario para promover la comodidad

“Antes de hablar sobre las cosas que usted, como cuidador primario, puede hacer para ayudarle a su ser querido a controlar dolor que pueda sentir, ¿tiene algunas preguntas de lo que hemos hablado el día de hoy?”

“Al ser el cuidador primario es importante recordar que cada persona tiene un diferente nivel de tolerancia al dolor, así que cada persona siente el dolor diferente. También es importante recordar que el nivel de dolor es lo que diga su ser querido, y esta es la información que debe de ser reportada al doctor, enfermera, u otro profesional médico.”

“Las siguientes son diferentes ideas de lo que usted puede hacer para promover la comodidad de su ser querido al sentir dolor.”

La promotora indica la parte de los consejos en el folleto.

“Observe your loved one for signs of no pain relief, such as grunts or not wanting to change posture.”

“Help remind your loved one of when and how to take pain medication. If there is ever a question about how a medication should be taken do not hesitate to contact the doctor, nurse or pharmacist and ask.”

“Keep a list of all the medications your loved one takes and indicate which ones are for pain. This can help the doctor have a better look at the treatment for pain, the patient follows at home.”

“Observe your loved one for signs of confusion or dizziness, especially when beginning to take a new medicine, as these are common side effects of medications and should be reported to the doctor or nurse.”
“Encourage activities that your loved one enjoys doing. This can help distract the mind from the pain, which can promote comfort. These activities can be things like reading, going out for a walk, playing board games or putting puzzles together. What are some things your loved one enjoys doing?”

“Other things you can do for your loved one is to remind and encourage them to write down the pain in the pain chart and to discuss it with his doctor or nurse.”

“Remind your loved one that addiction will not occur if the medications are taken as prescribed by the doctor.”

“Remind your loved one that pain is not a sign of weakness and that pain control is part of the patient’s rights and part of their treatment.”

“Ensure that you, as the caregiver, are well taken care of. The healthier you are, the easier it will be to help your loved one keep pain under control.”

Would you be able to incorporate some of these ideas into the care you provide for your loved one?

“Observe a su ser querido por señales que indica que no tiene alivio de dolor como gruñidos o no querer mover el cuerpo.”

“Recuérdelé a su ser querido de cómo y cuándo tomar su medicina para el dolor. Si tiene alguna pregunta de cómo tomar la medicina no dude en llamar al doctor, enfermera, o farmacéutico para preguntar.”

“Mantenga una lista de las medicinas que su ser querido toma, e indique las medicinas para el dolor. Esta información le puede ayudar a su doctor a ver el tratamiento que su ser querido esté practicando en casa.”

“Observe a su ser querido por señales de confusión o mareo especialmente cuando empiece a tomar una medicina nueva, porque estos son efectos secundarios comunes y deben de ser reportados a su doctor o enfermera.”

“Anime su ser querido a hacer actividades que le gusten. Esto puede ayudar a distraer la mente de su ser querido cual puede promover la comodidad. Las actividades pueden incluir cosas como leer, ir a caminar, jugar con juegos de mesa, o armar rompecabezas. ¿Cuáles son unas actividades que le gustan hacer a su ser querido?”

“Otras cosas que usted puede hacer para su ser querido es recordar y animar a su ser querido a escribir su dolor en la tabla y a hablar con su doctor o su enfermera sobre el dolor.”

“Recuérdelé a su ser querido que la adición no ocurrirá si se toma las medicinas como le indica el doctor.”
“Recuérdale a su ser querido que el dolor no es una señal de ser débil y que es su derecho y parte de su tratamiento.”

“Asegúrese de que usted, como cuidador primario, se esté cuidando bien. Entre más saludable esté usted más fácil será ayudar a su ser querido a estar cómodo y a tener el dolor controlado.”

“¿Podrá usar algunos de estos consejos en su vida al cuidar a su ser querido?

**Step 8 How the Pain of a Loved one can Affect the Caregiver**

“During the majority of this session we have focused on how to help your loved one to identify, report, and alleviate pain. Now let’s talk about how you, as the caregiver, can also experience pain.”

“You can also feel pain during the time your loved one is going through treatment. You can feel emotional pain from seeing your loved one endure their pain.”

“You also need to pay attention to this pain. This pain can be alleviated or controlled as well.”

**Pasó 8 Como Afecta el Dolor de un Querido al Cuidador**

“Durante la mayoría de esta sesión nos hemos enfocado en cómo ayudar a su ser querido a identificar, reportar y aliviar el dolor. Ahora vamos hablar de dolor que puede sentir usted como el cuidador primario.”

“Usted también podrá sentir dolor durante el tiempo que su ser querido esté en el tratamiento. Podrá sentir dolor emocional al ver a su ser querido soportando dolor.”

“También debe prestar atención a este dolor. Este dolor también puede ser aliviado o controlado.”

“These are some of the things that you can do to alleviate or diminish emotional pain you might feel:

- Talk to other people about your emotions. You can talk to family or friends with which you feel comfortable with, a religious leader, a counselor or social worker, or your doctor or nurse.

- You can join a support group for caregivers. These are groups of people that meet to share their experiences as they are experiencing a similar situation. There you can share your experience as well as listen to other people’s experiences and you can exchange tips with one another.
-Stay active. Participate in activities you enjoy doing like reading, going to the movies, or exercising.

-Ask for help when you need it. Yes you are the caregiver, but this does not mean that you have to do everything by yourself all the time.

“Remember that it is important for you to rest too. The healthier you are the more you will be able to take care of and help your loved one.”

“Estas son unas cosas que usted puede hacer para aliviar o disminuir el dolor emocional que usted puede sentir:

-Hable con otras personas sobre sus emociones. Puede hablar con familiares o amigos con quienes usted se sienta cómodo(a), con un líder religioso, un consejero o trabajador social, con su doctor o enfermera.

-Únase a un grupo de apoyo para cuidadores. Estos grupos son personas cuales se reúnen para compartir sus experiencias por estar pasando por una situación similar. Allí podrá compartir su experiencia al igual que escuchar la experiencia de otras personas y se podrán ofrecer consejos unos a otros.

-Haga actividades que le guste hacer a usted como leer, mirar una película, hacer ejercicio.

-Pida ayuda cuando lo necesite. Si es usted el cuidador primario, pero esto no quiere decir que usted tiene que hacer todo solo (a) todo el tiempo.

“Recuerde que es importante que usted también descanse. Mientras más saludable esté usted mejor podrá cuidar y ayudar a su ser querido.”

Step 9 Questions and Answers

CHW says: Our session is almost over. Are there any questions you have for me about our discussion today?

Are there other family members you will share this information with?

What do you think was the most helpful information from this session?

Paso 9 Preguntas y Respuestas

“Nuestra sesión ya se está terminando. ¿Tiene algunas preguntas sobre los temas que hablamos hoy?”
“¿Hay otros familiares con los que compartirá esta información?”

“¿De esta sesión que información le ayudó más?”

**Step 10 Conclusion**

CHW will

- plan a time to call the caregiver to see if the caregiver has questions about this session.
- schedule a time for Session Four
- thank the caregiver for the opportunity to discuss this information
- remind the caregiver to take care of herself so she can take care of her loved one, and remind the caregiver that if there are ever any questions about pain or pain medication to contact the doctor or nurse without hesitation.

**End of Session Three**

**Paso 10 Conclusión**

La Promotora hará lo siguiente:

- planificar un tiempo para hacer una llamada con la cuidadora en dos semanas para saber si tiene alguna pregunta sobre la sesión
- planificar el día y la hora para la Sesión Cuatro
- recordarle a la cuidador/a de cuidarse a sí mismo/a para que así pueda cuidar a su ser querido
- Recuerde a la cuidador/a que si tiene alguna pregunta sobre dolor o la medicina para el dolor que llame al doctor o a la enfermera

**Final de Sesión Tres**
APPENDIX C

Pain Management Fact Sheet for MAPS Pain Management Module (English and Spanish)

Facts about Pain
- People experience pain differently.
- Reporting pain and wanting pain relief is not a sign of weakness.
- Pain can make people feel and act different.

Types of Pain
- **Acute**: appears quickly and lasts a short amount of time
- **Chronic**: does not go away or appears frequently
- **Breakthrough**: occurs in a person even if they are taking medicine properly. It can occur with or without motive.

Pain Medicine
- Addiction is very unlikely to occur if the medicine is taken as directed by the doctor.
- The patient should inform the doctor of all the medicine they are taking at home, including over the counter pain medicine.
- Side effects of pain medicine include constipation, fatigue, nausea and vomiting. These should be reported to the doctor immediately.
- The best way to use pain medication is as prescribed by the doctor.

What the caregiver can do to promote comfort
- Observe your loved one for signs of no pain relief, such as grunts or not wanting to change posture.
- Remind your loved one of when and how to take pain medication. If there is a question about how a medication should be taken contact the doctor, nurse, or pharmacist. Phone numbers here: __________
- Keep a list of all the medications your loved one takes. Let’s list them on the back of this form now:
- Observe your loved one for signs of confusion or dizziness, especially when beginning to take a new medicine.
- Encourage activities that your loved one enjoys doing. List some activities here: _________________
- Remind and encourage your loved one to write down the pain in the pain chart and to discuss it with his doctor or nurse.
- Remind your loved one that addiction will not occur if the medications are taken as prescribed by the doctor.
- Remind your loved one that pain is not a sign of weakness and that pain control is their right and part of their treatment.
- Ensure that you, as the caregiver, are well taken care of. The healthier you are, the easier it will be to help your loved one keep pain under control.” (Remember the Stress Coping Guide from another session.)
APPENDIX D

Pain Management Fact Sheet for MAPS Pain Management Module (Spanish)

Datos del Dolor
-El dolor es diferente en cada persona.
-Reportando el dolor y queriendo alivio no es una señal de no ser fuerte.
-El dolor puede hacer que la persona actúe diferente y se sienta diferentes.

Tipos de Dolor
-Agudo: Dolor que aparece rápidamente y dura poco tiempo.
-Crónico: Dolor que a veces no desaparece o dolor que puede aparecer con frecuencia.
-Súbito: Aumento de dolor fuerte que puede aparecer en una persona aunque este tomando medicación para el dolor.

Medicina Para el Dolor
-La adicción en pacientes de cáncer es muy rara si la medicación se toma como la receta el doctor.
-El paciente debe de informar a su doctor de todas las medicinas que estén tomando en casa incluyendo medicina de dolor sin receta.
-Efectos secundarios de la medicación pueden incluir estreñimiento, cansancio, nausea, y vómito. Esto se debe a reportar al doctor inmediatamente.
-La mejor manera de usar medicina es como se lo indique el doctor.

Lo que puede hacer usted, el cuidador, para promover la comodidad
Observe a su ser querido por señales de no tener alivio como gruñidos o no querer cambiar de posición.
Recuerde a su ser querido de como y cuando tomar su medicina. Si hay alguna pregunta de como tomar una medicina llame a su doctor, enfermera, o farmacéutico. Número de teléfono ____________
Mantenga un lista de todas las medicinas que toma su ser querido. Podemos escribirlas atrás de este papel.
Observe a su ser querido por señales de confusión o mareo especialmente cuando comience a tomar una medicina nueva.

Anima a su ser querido a hacer actividades que le gusten. Actividades que le gusten: ______________
Recuerde y anime a su ser querido a escribir su dolor en la tabla de información y a hablar con su doctor o enfermera sobre el dolor.
Recuerde a su ser querido que la adicción es muy rara si se toma la medicación como se lo indique su doctor.
Recuerde a su ser querido que el dolor no es una señal de no ser fuerte y que es su derecho controlarlo y parte de su tratamiento.
Asegúrese de que usted, como el cuidador, se cuida. Entre mas saludable esté usted será mas fácil ayudar a mantener el dolor de ser querido bajo control. Recuerde que ya aprendió maneras de controlar el estrés.


APPENDIX E

Contextual Notes – Validation of Pain Module

August 13, 2015 – TCU Bass Building 3001, 0430-0830

I met with Carolyn Spence Cagle (CSC) at 4:00pm in the atrium of Bass Building to greet the five expected TCU housekeepers (caregivers). I recruited the housekeepers on 8/6/2015 in the basement of Moudy South in between shifts (most of the housekeepers’ first language is Spanish; other groups of housekeepers can be recruited in a similar matter at other buildings at TCU).

At 5:30pm only one of the five housekeepers had arrived, Susana (S). S expressed that she was disappointed that no one else had come out to take advantage of this opportunity, nor informed that they would not be able to make it. S seemed like she was in her early 40s. She was well dressed and was eager to participate. Throughout the session S listened intently, smiled, and asked questions to clarify the information. There was occasional crying when speaking of the recent diagnosis of cancer in her husband. In June her husband had a small growth under the skin removed from the groin area. S and her husband were informed that it was cancer and since then he has gotten a CAT scan but results will be delivered within the next week. S also told the promotora, Maria Quinteno (MQ), in the session that her father had died from stomach cancer a few years ago, and S, herself had a non-malignant tumor removed from the left side of her brain over a year ago. S is extremely interested in a nutritional module as she feels it is her duty to take better care of her husband and her family and she can do this by helping them eat healthier.

The second participant, Marlin (M), is the son of one of the promotoras, Maria. He is a student at El Centro College in Dallas who wants to become more knowledgeable about the health care field. Marlin noted that he has no history of family cancer but has heard of neighbors and friends dealing with cancer.

When S arrived I went upstairs with her to begin the informed consent process. When I presented the consent to S, she asked if there was a Spanish version of the consent form. S – “It takes me a while to read and understand information I read in English.” (Maybe in future studies it would be best to create a consent form in Spanish) I proceeded to read the consent form in English and then translate the information verbally to Spanish. After consent forms were signed by S, she got up for refreshments and proceeded to speak with the promotoras MQ and Gaby Hernandez. Jo Nell Wells (JNW) then introduced me to Marlin. I read over the consent form in English with Marlin without any complications.

Panera sandwich boxes, fruit, ice tea, and water available to all participants throughout session.
After JNW gave an overview of the night she emphasized that any notes and anything said within the session will be kept confidential and anonymous. Then JNW read the case scenario in English, which was the role-play scenario used in the promotoras session. (JB assisted with translation to S, as needed). 2 groups were formed to test the script. The first group consisted of the promotora, Maria, S, CSC and JB. The second group consisted of the promotora, Gaby Hernandez (GH), M, and JNW.

Session- 6-7:15pm - CSC/Maria/Susana/JB

In the session Maria used note cards she had created from the MAPS module sent to her – she later explained that the cards made it easier for her to follow through the session as it gave her flexibility to go back and forth between topics according to the necessity of the patient, in this case Susana. A lot of time was allotted to handouts especially the first one: “Facts about pain, types of pain, pain medicine, what caregiver can do to promote comfort”. Maria and Susana both seemed comfortable throughout the session. Susana got teary eyed from time to time but was comfortable enough to ask questions and Maria used real life examples from her life and Maria’s past medical history to ensure she had understood the content.

Maria began the session by role playing and “knocking on the door” as if to be entering Susana’s home. She then introduced herself to Susana by shaking hands. She also gave Susana a journal with colorful flowers on the front and a pen and told her to feel free to write any questions or comments in it as the session continued. She told her that the journal would be hers to keep and would not be shared with anyone unless she decided to share it. (Later Maria mentioned that this strategy was one she had gained from the previous module testing on stress) Susana smiled as she received the gift. She didn’t write in the journal through the session but she did use the pen to write and mark on some of the handouts used.

The second handout, “Information to share with your doctor or nurse about pain/comfort level” was very appealing to Susana. She really liked that there was a way she could track all the information that should be delivered to the doctor. The third handout was introduced after the second handout was explained. Susana asked questions about the second handout and Maria responded by writing down examples of things that can be written in the second handout. She emphasized that it was important to write down what the patient said in regards to the pain as well as to write down any changes, Susana, as the caregiver observed in her family member.

The session ended at 7:10, as Maria asked if Susana had any other questions and completed the scenario by stating when the follow up call would take place and when the next visit by would occur.

Comments:
Susana connected with the handout on various types of pain as she noted that her husband was afraid of addiction to pain medicine as he had advised her not to take so many medications after she had surgery to remove her tumor. She also expressed the
feeling that it was now her duty to take care of him since he had taken care of her after her surgery. (Susana had a prior personal experience with health care providers and pain, did this play a factor in her willingness and eagerness to learn more about pain and how to manage it better?)

During my initial contact with Susana (recruitment) she mentioned that she was the one who was setting up appointments and making sure her husband attended them and did as he was told by the doctor, reinforcing the idea that women are the gateway for families into the health care system.

Throughout the session Susana referenced God “Si Dios quiere”, “Bendicion de Dios”, translating to “God willing” and “Blessing from God” when speaking about the session and how it would help her. Maria would respond with references to God as well which seemed to comfort Susana especially at times when she got teary eyed. She also referenced the strengths she has as coming from God, “Dios me ha dado mucha fuerza” (Maria individualized this module to Susana’s perspective/strength which I think is important to note as it further supports the caregiver.)

Maria used her time wisely throughout the session as she asked questions about the material she had presented to ensure that Susana had grasped the idea and could answer questions. (Example: Maria asked what type of pain would fall under acute and Susana responded with “pain that happens suddenly and for a short time, like a headache”)

**Feedback with full group 7:25-8:30pm**

**Marlin**

- Fluent English speaker
- Noted that he felt comfortable with Gaby. Gaby (promotora) was very informative, relaxed and knowledgeable and gave him time to ask questions.
- “I learned to be better prepared as caregiver, and important ways to care for someone who has pain.”
- What was good about the module and the script M – “Gaby gave good examples, she was sort of a counselor more than a teacher, she let me go back and ask questions about the material, she emphasized to always talk to the doctor about what is going on with the patient”

**Gaby**

- Noted that she did not use the script word for word, but rather paraphrased the material into something Marlin would easily understand
- Some of the words changed included “physical therapy” to “therapy”
- When asked why Gaby responded “you have to consider who you are talking to, consider what their education level is, what their maturity level is”
- Noted that her approach to Marlin was different then if she would have done her session with Susana – “I asked questions at the beginning of
the session that were relevant to him and not necessarily related to cancer in order to gain his trust.”

- Noted that she wrote the script out in her own notes, in which she bolded some of the main topics addressed. Since she had studied the notes prior to the session she used the words in bold as key points to drive the conversation (session) between her and Marlin into the next section of the script. – “this gave me flexibility so if Marlin had a question I could go back to that section to readdress it and still come back to the topic we had been discussing.

**Pain Tool:** A specific question was asked in regards to the pain scales (“Universal Pain Assessment Tool,” Visual Analog”, and “Distress Thermometer”) and which was the most effective. Both Marlin and Susana agreed that the “Universal Pain Assessment Tool” was the most effective. Marlin – “I did not like the line one, because there were no levels of pain, it doesn’t really explain anything; the one with the thermometer seems like a survey you have to answer” Susana agreed “It shows you the faces as the pain increases with the numbers.” Later on Maria explained that she did not spend much time on the other 2 tools – “I did not want to add to her anxiety by giving her too many scales to look at”

**Maria**

- “The notecards make it easier for me to move through the material. If Susana has a question about something we already talked about I can just pull that particular notecard out and go over that material”
- Noted that the journal and pen were talked about in previous stress module so she thought it would be helpful in this session as well.
- Believes overall the material is ready to use. Noted that Acupuncture can be taken out as S did not know what it was when she first mentioned it and it can be an expensive treatment. Also noted that “physical therapy” is more commonly referred to as “masaje” instead of “terapia fisica” in Spanish.

**Susana**

- Noted that she was grateful for being invited to session. She felt she received “lots of help” and was grateful for the “opportunity to learn” She reflected “I learned different ways to alleviate pain, when to take medications, and the chart (referencing to “Information to share with Doctor…” ) is very important to communicate with the doctor” She also stated that Maria’s real life examples allowed her to fully grasp the concept of what to write down.
- When asked about the length of the session S responded – “The length seemed fine, I could have kept on going with the discussion”
- S- “As an employer for TCU I am grateful they give us opportunities to learn”

**Edits on Handouts**
• First Handout “Facts about Pain, Types of Pain, Pain Medicine, What
caregiver can do to promote comfort”
  o Gaby – “This information is useful for everyone not just for those
dealing with cancer.”
  o Gaby – “handout has valuable information but it is too much content
on one page” (Maybe splitting up the content on 2 worksheets
instead of one or shortening the content on the worksheets) “Avoid
duplicating content on handouts” (Going back and editing this
handout might reduce the content and make it more visually
friendly)

• Second handout “Information to share with Doctor…”
  o Gaby - could add some more information in the columns: include
what patient is doing at the time of pain in the date/time column,
where is the pain? (Noted that at the clinic she works at there is a
similar tool used to track blood glucose readings in diabetic patients
and the doctors love the tool because it gives them a quick way to
assess patient’s history)
  o Maria - add a part in the script (or when explaining the chart) to
assess that the caregiver knows what daily activities are and what
their family member’s daily activities currently are (maybe give
examples of how these daily activities can change in perception to
pain, Maria gave examples when explaining this part to Susana)
Contextual Notes – Additional Feedback about Pain Module from the Promotoras

September 23, 2015 – Northside Community Health Center-Promotora Gaby

I met with Gaby at the Northside Community Health Center on September 23rd, 2015 at 4:30pm to discuss any suggestions or edits Gaby had about the pain module after its validation on August 13th, 2015 at Texas Christian University.

Gaby discussed how she approached the MAPS modules when they are given to her:

- Gaby reads through the module and makes her own notes on the modules. The notes include things like: similar words or phrases that can be used in case the caregiver does not understand the ones used in the script as well as examples she can refer to.
- A few days before validation of the modules Gaby goes back to re-read the module and her comments and adds any additional comments she believes she might need.
- Gaby explained that some of the comments she makes on her notes she does based on prior experience. She works with the Mexican American (MA) population very closely, particularly in managing diabetes, thus she has insight information on vocabulary that this population might not be too familiar with, even at a low literacy level.

General suggestions/comments Gaby had about the MAPS Pain Module:

- “Be very friendly, overly nice” - ‘the caregiver chooses to let you be a part of their family when they agree to be a part of this study, so you should be very nice and respectful to the caregiver and their loved one throughout the whole session’
- Stay away from using “ensenar”, “to teach”. Instead use “platicar”, “to talk”. “To teach” tends to imply that you, the promotora, or the health care provider, is above or more important than the patient. Using “to talk” indicates that you are on their level. (I will take a look at the MAPS Pain Module and try to replace ensenar with platicar if possible.)
- Gaby wrote out “identificar = esto es lo que hay que buscar” in case there was a question about what that meant. (Identify = this is what we need to look for).
- Gaby wrote in various pages, “Reportar” and “Preguntarle a su doctor”. She stated that these were reminders to herself that although she has medical experience if the caregiver asks specific questions she needs to tell the caregiver to report those findings to her doctor or ask her loved one’s doctor about it.
- She suggested adding in the conclusion “preguntar y hablar es la base de estar bien informado para estar tranquilos”. “Asking and talking is the base of being well informed in order to be calm.” (I will try and incorporate this into an updated version of the MAPS Pain Module).
Gaby believes that only the Universal Pain Assessment Tool should be used to discuss the pain, as it not only provides numbers, but faces and words that all connect with each other.

- She suggested to simplify the MAPS handout to have less writing on it as she feels that it looks too cluttered and thus the MA caregivers might not find it appealing or useful. (I will look at the MAPS handout and see if there is editing I can do to simply the look of it.)
- She also suggested adding a column of “where the pain is located” in the chart used to track information about pain. (I will add this information to the chart.)
- “I feel happy to participate in the sessions. I know the information is out there but I think it needs to be made more accessible to Spanish speakers especially in cities like Fort Worth where there is a large population who only speak Spanish.”

October 1st, 2015- Starbucks-Promotora Maria

I met with Maria at a Starbucks in Arlington, halfway between TCU and Maria’s home at 6:00pm to discuss any suggestions or edits Gaby had about the pain module after its validation on August 13th, 2015 at Texas Christian University.

Maria discussed how she approached the MAPS modules when they are given to her:
- Maria reads through the module and then from the module makes her own note cards. These flash cards are written down in the steps that the module is originally written in. “The cards let me go back to material easily if the caregiver has a question about something I mentioned earlier in the session.”
- A few days before validation of the modules Maria goes back and reviews her flashcards to make sure she has all the information that is on the module.
- Maria also makes additional notes in her flashcards to make things a little more interactive. Example: after explaining the different types of pain she has a note to ask the caregiver to give an example of what an acute pain would be. (This teach back method can be incorporated in future MAPS modules)

General suggestions/comments Maria had about the MAPS Pain Module:
- The chart that asks about the pain the family member is experiencing is very important. One thing that can be added are examples so that when you go over the chart with the caregiver they can have something to look back at when filling it out with their loved one. Maria recalls that in her session with the caregiver she used the example of having a headache when explaining the chart.
- Maria explained that some of the extra notes she makes on her note cards are not extra things she says during the session but rather reminders for her about what comes in the next step of the module. “Words or phrases I write help me remember what I am going to talk about next.”
- “I am very happy to have met Dr. Wells and be a part of this project. I don’t think the professors realize the magnitude that these projects have. In the MA community word spreads quickly, and by educating the caregivers, which are usually the females in the household, you are really educating families and
communities. The information they have shared with me is very valuable and should be made more public."
# APPENDIX G

**Pain Chart (English)**

**Chart with information about pain to share with your doctor/nurse**

<table>
<thead>
<tr>
<th>Time &amp; Date</th>
<th>What kind of pain? Where?</th>
<th>How strong is the pain?</th>
<th>When did the pain start?</th>
<th>How long did the pain last?</th>
<th>What makes it better/worse?</th>
<th>Does the pain affect daily activities? List examples</th>
<th>Was pain medicine taken? If yes, how did he/she feel after?</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:00am March 2, 2016</td>
<td>Sharp Pain in the lower back</td>
<td>5/10</td>
<td>After the usual morning walk</td>
<td>2 hours</td>
<td>Sitting made it worse, laying down made it better</td>
<td>Sitting down to eat was hard, so was sitting and watching tv</td>
<td>Yes, the medicine prescribed by the doctor was taken and after 30 minutes the pain went down to 3/10.</td>
</tr>
</tbody>
</table>
APPENDIX H

Pain Chart (Spanish)

Tabla con información de dolor para compartir con su doctor/enfermera

<table>
<thead>
<tr>
<th>Fecha Y Hora</th>
<th>¿Qué tipo de dolor? ¿En dónde está el dolor?</th>
<th>¿Qué tan fuerte es el dolor?</th>
<th>¿Cuándo empezó el dolor?</th>
<th>¿Cuánto duro el dolor?</th>
<th>¿Qué mejora y que empeora el dolor?</th>
<th>¿El dolor afecta sus actividades diarias?</th>
<th>¿Tomo medicina para el dolor? Si la tomo, como se sintió después?</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:00am 2 de marzo del 2016</td>
<td>Dolor agudo en la espalda baja</td>
<td>5/10</td>
<td>Después de caminar en la mañana</td>
<td>2 horas</td>
<td>Estar sentado empeora el dolor. Estar acostado mejora el dolor.</td>
<td>Sentar a comer fue difícil y doloroso, al igual que sentar a ver la tele.</td>
<td>Tomo la medicine que le receto el dolor y después de 30 minutos el dolor bajo a 3/10.</td>
</tr>
</tbody>
</table>
Universal Pain Assessment Scale

PAIN MANAGEMENT FOR CANCER CAREGIVERS

APPENDIX J

Pain Management You-Tube Script

Pain Management for Mexican American Cancer Caregivers – YouTube Script

English

This video is available at _________________________.

Hello my name is ______________ and today I am going to share with you ways you, the caregiver, can help your loved one manage their cancer-related pain.

First let me explain that pain is not a sign of weakness and it is your loved ones’ right to have pain treatment. Pain that your loved one may have can be managed. This does not necessarily mean that the pain will completely go away, but it means that if we all do our part we can help lessen the pain your loved one feels and make them more comfortable. By making them more comfortable your loved one will be able to rest and have energy to eat and do other activities. This will help them on their path to feeling better.

Now I’ll tell you how we can manage their pain.

The first step to managing your loved one’s pain is informing the doctor of any pain your loved one may be feeling.

This chart can be used as a tool to write down some information that your doctor may need in regards to the pain your family member is feeling. Now let’s spend some time going over some of the things on the chart, so you can use it later.

The first column in the chart asks you to record the time and date your family member feels pain. This helps the doctor know how often your family member is in pain.

The second column allows you to record where the pain is located. Pain can occur in one particular place - like the lower back - or several places at the same time. The chart also allows you to list the kind of pain your loved one has – the pain may be dull or sharp, or it may be acute (lasting a short time or with activity) it can also be chronic, pain that lasts and does not go fully away. Place the word that your loved one uses to describe the pain in the second column.

The next question is very important. It asks to measure the strength of your loved one’s pain. Using this Universal Pain Assessment Tool shown, your family member can rate their pain. A rating of 0 means “no pain”, 5 means “moderate pain”, and 10 means the “worst pain possible”. The Universal Pain Assessment Tool is used by many doctors to determine the rate of pain in different people. The important thing to remember is that your loved one needs to rate their pain, not you as the caregiver. Your loved one is the best person to rate their pain because they are the ones feeling it.
The next two questions on the chart ask what things make the pain better or worse. Some examples are: laying down makes the pain better while walking makes the pain worse.

The last column asks information about ways the pain affects daily activities. This question seeks your loved one’s view on everyday examples. If your family member likes to take walks but cancer pain prevented them from taking a walk that would be written in this column. Or if your family member likes watching movies but pain did not allow that, this would be another everyday example to write in the column.

It is important that you share this information with your doctor to help develop a plan to best manage your loved one’s pain.

A popular way to manage pain includes the use of pain medicine. Here are some important things to know about taking pain medicine.

- Addiction to pain medicine in patients with cancer is very unlikely if your loved one takes the medicine in the way the doctor directed.
- It is important for your loved one to inform their doctor of all the medicines they take at home including over the counter medicine and herbs. An easy way to do this is to create a list with this information and take it to each health care appointment. This will help the doctor determine the appropriate medicine to manage your loved one’s pain.
- Pain medicine can have side effects such as: constipation, fatigue, nausea, and vomiting. Report these and any other side effects to your loved one’s doctor.

There are also other, more general things that you as the caregiver, can do to manage your loved one’s pain and promote their comfort.

- Observe for any signs of confusion or dizziness in your loved one, especially when beginning to take a new medicine you can record this on your pain report table.
- Encourage activities that your loved one enjoys.
- Remind your loved one that pain is not a sign of weakness and that pain control is their right and part of their treatment.
- Remind your loved one of when and how to take their pain medicine.
- Remind and encourage your loved one to fill out the pain chart and discuss it with their doctor or nurse.
- Last ensure that you, the caregiver, are well taken care of. Remember that the healthier you are, the easier it will be to help your loved one keep pain under control.
Este video está disponible en _______________________.

Hola mi nombre es __________ y hoy voy a compartir con usted, unas maneras de como usted, el cuidador, puede ayudar a controlar el dolor relacionado al cáncer de su ser querido.

Primero déjeme explicarle que todos sufren de dolor en algún tiempo de su vida. Este sufrimiento no es una señal de debilidad. Su ser querido tiene derecho a recibir tratamiento para el dolor y así mejorar su vida. Su ser querido puede controlar su dolor durante la enfermedad de cáncer. Controlar el dolor no quiere decir que el dolor se desaparecerá por completo, si no que si todos nosotros (sus doctores y, enfermeras, usted como cuidador y su ser querido) hacemos nuestra parte podemos ayudar a disminuir el dolor que sienta su ser querido y lo haremos sentir más cómodo. Al hacer más cómodo su ser querido el podrá descansar y tendrá más energía para comer y hacer otras actividades. Estando más cómodo su ser querido estará en camino a sentirse mejor.

Ahora le diré como usted, el cuidador, puede controlar el dolor de su ser querido.

El primer paso para controlar el dolor de su ser querido es informándole a su doctor de cualquier dolor que sienta su ser querido. El doctor no podrá ayudar a su ser querido sin esta información.

Quiero compartir con usted una tabla de información puede ser utilizada para escribir información sobre el dolor que siente su ser querido. Esta tabla le ayudará al doctor a decidir cómo controlar el dolor de su ser querido. Ahora vamos a repasar unas de las cosas en la tabla para que usted la pueda usar después.

La primera columna de la tabla pide la hora y la fecha en cual su ser querido siente dolor. Esto le ayuda al doctor a saber que tan seguido su ser querido siente dolor.

La segunda columna pregunta en donde está el dolor. Dolor puede ocurrir in un solo lugar – como en la espalda- o en varios lugares al mismo tiempo. La tabla también le permite describir que tipo de dolor su ser querido tiene. Este dolor puede ser lento o agudo, si empezó rápidamente y duro poco tiempo, o si es crónico y no se retira. Ponga la palabra que su ser querido usa para describir el dolor en la segunda columna.

La siguiente pregunta es muy importante. Le pregunta que tan fuerte es el dolor de su ser querido. Usando el instrumento universal en la tabla, su ser querido puede calificar su dolor. Una calificación de 0 significa que “no hay dolor”, 5 significa “dolor moderado”, y 10 significa “peor dolor posible”. Este instrumento es utilizado por doctores para determinar qué tan fuerte es el dolor en personas. Lo importante es que su ser querido debe de calificar el dolor no usted. Su ser querido es la mejor persona de calificar el dolor porque él es quien siente el dolor.
Las siguientes dos columnas preguntan que mejora y que empeora el dolor. Unos ejemplos son: acostándose ayuda el dolor mientras caminar empeora el dolor.

La última columna pregunta si el dolor afecta actividades diarias. Aquí puede poner ejemplos diarios. Si a su familiar le gusta caminar y el dolor de cáncer no lo deja caminar escriba esto aquí. O si a su familiar le gusta mirar películas, pero el dolor no lo deja, escriba esto aquí.

Es importante compartir esta información con su doctor para ayudar a que ellos desarrollen la mejor manera para controlar el dolor de su ser querido.

Una manera popular de controlar el dolor es con medicina. Estas son unas cosas importantes que debe de saber acerca de tomar medicinas para el dolor.

- La adicción a la medicina en pacientes de cáncer es muy rara si su ser querido se toma la medicina como lo dirige el doctor.
- Es importante que su ser querido le informe a su doctor de todas les medicinas que tome en casa, incluyendo medicina sin receta u otros remedios caseros. Una manera fácil de hacer esto es de tener una lista con esta información y llevarla a todas las citas de su doctor. Esto le ayudara al doctor a decidir que medicina ayudaría a controlar el dolor de su ser querido.
- Medicina para el dolor puede tener efectos secundarios como: estreñimiento, cansancio, nausea, y vomito. Reporte estos efectos secundarios y cualquier otro que sienta su ser querido a su doctor.

Hay otras maneras, más generales que usted como cuidador, puede hacer para ayudar a controlo el dolor que siente su ser querido y promover la comodidad.

- Observe a su ser querido por señales de confusión o mareo especialmente cuando comience a tomar una medicina nueva. Puede escribir estos cambios en este lugar de la tabla.
- Anime a su ser querido a hacer actividades que le gusten.
- Recuérdele a su ser querido que el dolor no es una señal de ser débil y que es su derecho controlarlo y parte de su tratamiento.
- Recuérdele a su ser querido de cómo y cuándo tomar su medicina.
- Recuérdele y anima su ser querido a escribir su dolor en la tabla de información y a hablar con su doctor o enfermera sobre el dolor.
- Y, por último, asegúrese de que usted, como el cuidador, se cuide. Entre más saludable este usted, será más fácil ayudar a mantener el dolor de su ser querido bajo control.