

Chronic pain patient perceptions of primary care provider pain education

Angelina Gallegos

University of Hawaii at Hilo

October 29, 2020

Committee Chair:

Joan Thompson Pagan, Ph.D., NNP, MSN, RN

Committee Member:

Katharyn Daub, Ed.D., RN, CTN-A, CLNC, CNE

Abstract

Chronic pain in the U.S. affects millions of adults and the numbers are expected to continue rising, alongside rates of chronic disease which often accompany chronic pain. It has become increasingly complex to manage chronic pain which is only further complicated by the opioid epidemic. While the primary care setting is most often where chronic pain patients are treated, the focus is often primarily on the physical complaints. Current best practices suggests primary care provider education incorporate a biopsychosocial approach to support the best possible outcomes. Current evidence suggests that holistic primary care provider education is necessary to achieve optimal outcomes and efforts should be focused on improving self-management.

This project examined chronic pain management education delivery by primary care providers to identify potential gaps in education from the patient's perspective. A survey was developed with 40 items based on the Pain Assessment Screening Tool and Outcomes Registry (PASTOR), currently used by the military. The electronic survey was completed entirely online, with a total sample of 26 adult participants. The survey research revealed the largest deficits in pain education related to areas of behavioral change. The results indicated a need for improving education delivery to include a broader range of topics affecting chronic pain. Increasing knowledge of pain influencing factors can support more successful self-management in patients. The survey results informed practice improvement recommendations, using a two-pronged educational approach to improve chronic pain care education delivery in the primary care setting. Prong one was the development of a comprehensive patient pain education poster for primary care offices. Prong two was a provider education brochure detailing survey results and pain practice resources.

Keywords: *Chronic pain, patient perceptions, primary care providers, patient education, self-management, holistic pain management, integrative pain management.*

| | |
|---|----|
| CHRONIC PAIN | 3 |
| Abstract..... | 2 |
| Table of Contents..... | 3 |
| Chapter 1: Statement of Problem..... | 6 |
| Introduction..... | 7 |
| Problem Statement..... | 7 |
| Background and Significance | 9 |
| Goals of Project..... | 14 |
| Project Aims..... | 15 |
| Project Objectives | 15 |
| Chapter 2: Review of Literature and Conceptual Framework..... | 18 |
| Literature Review..... | 18 |
| Discussion..... | 27 |
| Conceptual and Theoretical Frameworks..... | 28 |
| Biopsychosocial Model..... | 28 |
| Complexity Model..... | 30 |
| Theory of Symptom Self-Management..... | 31 |
| Chapter 3: Project Design and Evaluation Plan..... | 33 |
| Methods..... | 33 |
| Participants..... | 33 |
| Project Site..... | 34 |
| Instruments..... | 35 |
| Data Analysis | 36 |
| Ethics..... | 37 |

Timeline..... 37

Human Subjects Protection.....36

Memorandum of Understanding.....38

Budget.....39

Expected Results.....39

Nursing Implications.....40

Chapter 4: Project Results42

 Data collection.....43

 Data findings.....45

Chapter 5: Recommendations and Conclusions57

 Results discussion.....57

 Discussion of data linked to specific aim and objectives of the project.....57

 Impact of results.....63

 Strengths & Limitations.....64

 Dissemination Plans.....65

References.....67

 Figure 1.....71

 Figure 2.....72

 Figure 3.....73

 Figure 4.....74

 Figure 5: PASTOR Pain assessment screening tool and outcomes registry.....75

 Table 1.....76

 Table 2.....77

Appendices.....78

 Appendix A.....79

 Appendix B.....80

 Appendix C.....82

 Appendix D.....83

 Appendix E.....90

 Appendix F.....91

 Appendix G.....92

Chapter One: Statement of the Problem, Project Aims and Objectives

Chronic Pain

Pain is a common human experience across the world, developing for a multitude of reasons. It can be encountered during any life stage but generally signals when something is wrong (IOM, 2011). Pain can be a natural warning signal helping to protect us so we can survive (IOM, 2011). According to the Institute of Medicine [IOM], (2011), pain is generally a unique experience because it involves individual biological, psychological, and social factors. Therefore, pain is experienced differently across different populations (IOM, 2011).

Ordinarily, pain begins as an acute response and can progress to chronic, depending on this range of factors. While serving a vital function, it can be considered maladaptive when persistent and lasting longer than anticipated (IOM, 2011). With a single root cause, the anticipated duration of pain can be projected and tends to resolve within a reasonably predictable time frame. According to IOM, (2011), though pain is a universal experience, chronic persistent pain development can often be avoided.

Chronic pain can be defined as pain lasting beyond the expected time frame, typically persisting beyond three months and longer than normal healing time (IOM, 2011). With chronic or persistent pain, abnormalities in pain processing can occur, resulting in changes to nervous system functions, including pain sensation, interpretation, modulation, and transmission, which could qualify it as a neurological disease (IOM, 2011). Considering the complex network of influencing factors involved with pain and its processing, the impact of chronic pain reaches far beyond physical symptoms.

Although millions of Americans are already affected by pain, its prevalence continues to rise and contribute to national rates of disability, morbidity, and mortality (IOM, 2011). The

IOM (2011) asserts that pain depends upon factors which include genetics, health status, brain pain processing, cultural, social and pain experiences in childhood including the context of cognitive and emotional pain occurrence. Thus, the most promising holistic approach recommendation is to comprehensively address chronic pain using a biopsychosocial, interdisciplinary approach (IOM, 2011). This paper intends to explore chronic pain patient education perceptions, relationship with their primary care pain provider, and perceived ability to self-manage.

Question and Statement of the Problem

Chronic pain is estimated to affect around 30% of the US population, making it a significant health care problem (Cheatle, 2016). The number of adults affected by chronic pain is greater than the total of heart disease, diabetes, and cancer combined (Steglitz, 2012). In other words, the number of Americans affected by chronic pain alone spotlights the importance of addressing this as a healthcare problem. The IOM report (2011) "*Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*" sought to find solutions for this national healthcare problem. The IOM report is one of the most comprehensive pain research works to date, which examined much data toward creating solutions for the current challenges in pain care.

The IOM (2011) asserts that a majority of pain care and management should occur through primary care and self-management. One of the IOM research finding recommendations was that pain care be customized based upon the individuals experience, with a recommendation to promote and enable pain self-management within the health care system (IOM, 2011). In other words, the current approach to pain care needs to be broadened and more holistically focused. The IOM (2011) points out that effective pain care begins with the patient and foremost

self-management, where the patient is empowered to self-manage before flare-ups occur, prevent further injury and be able to manage their pain.

Therefore, this Practice Inquiry Project (PIP) utilized a biopsychosocial lens to explore patient's perceptions of chronic pain education received from their primary care providers to identify gaps in pain education. Further data regarding relationship with provider and perceived ability to self-manage was collected; however, the primary focus was on identifying gaps in holistic pain education delivery. The project examined pain education provided in primary care to address educational gaps from the patient perspective. One question asked was in adult patients with chronic pain: what are the potential gaps, as reported by patients, in chronic pain education delivery from primary care provider(s), which might affect a patient's ability to self-manage? According to the IOM (2011), pain patients often do not have sufficient education, resources, or support to encourage or sustain active self-management practices. While every person is entitled to adequate pain relief, management, and optimal wellness, chronic pain complexities can make it more challenging to achieve and optimize the patient's pain relief without sufficient self-management ability.

The absence of a biopsychosocial approach may be one of the most significant barriers for patients to learn how to optimally manage or reduce their pain to a level consistent with their highest possible level of wellness. While many known barriers exist concerning effective and adequate pain management related to chronic pain, a holistic approach has the potential for powerful implications, as the IOM report discusses (IOM, 2011). Some known barriers are expanded upon and discussed within this paper; however, scant evidence-based research focuses solely on the patient's viewpoint of their healthcare delivery and impact. This project supports

the inclusion of the patient's voice and perspective as a resource for improving pain care education and self-management.

In recent years, the opioid epidemic and pharmacologic focus of symptom management has contributed to many gaps in pain care and education. Much of patient teaching time is focused on medication management, which may compel patients to attempt to self-manage without sufficient supportive education (IOM, 2011). In other words, if a patient is not receiving a comprehensive and holistic education for their chronic pain management, they may be navigating blindly without proper guidance from their healthcare provider. With the current state of pain management care focused on symptom management, pain care does not appear to be widely addressed with a holistic model or framework. Even more rare is examination or inclusion of the patient perspective with their pain care priorities and perceptions. This project would like to amplify patient voice and perspective, in large part, because they have acquired expertise which has primarily been gained through living with the experience of pain regularly. It is essential to bring that viewpoint more into the forefront of pain management conversations and use the gaps to improve current practice.

Background and Significance

More than a hundred million Americans are affected by chronic pain, which is why there is tremendous value to society and individuals to address it (IOM, 2011). Chronic pain and chronic disease often go hand in hand. Of the top ten leading causes of death seven are from chronic disease, and in 2010 half of the US adult population was afflicted by chronic disease (Fallon, 2015). Chronic pain rates are predicted to grow as Americans experience diseases associated with chronic pain such as cardiovascular disorders, diabetes, arthritis, cancer, and others (Cherry et al., 2010). The Centers for Disease Control and Prevention [CDC] (2020)

reported that one quarter of U.S. adults have two or more chronic diseases that contribute to the leading causes of death and disability. The IOM (2011) points out that prevalence of acute and chronic pain is likely to continue rising due to the relationship between high chronic disease rates and chronic pain. According to the IOM (2011), chronic pain has distinct pathology and can be considered a “disease in itself” with the nervous system changes and cognitive and psychological correlates. According to Ceko et al. (2020), studies have now demonstrated that some brain regions function differently in those with chronic pain versus those who are healthy.

The IOM (2011) describes pain as "a universal experience but unique to each individual" (See Figure 1). Chronic pain is abstract, as it has many variables, levels, and meanings. Chronic pain cannot be categorized neatly or sufficiently described as a single word since it is a complex process, and its description involves many layers and variables. A network of interconnected factors affects every individual pain experience, making it a complex condition to treat without approaching it holistically (See Figure 2).

Definitions

The International Association for the Study of Pain [IASP] (2019) defines pain as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage". The IASP (2019) definition seems to focus more on the physical attributes or contributors to pain. However, a more expanded definition of pain, offered by Gutiérrez Lombana and Gutiérrez Vidal (2012) explains pain as "a sensation affected by social, cultural, genetic, molecular, cellular, physiological, physical and psychological factors, all of them inter-related". With the sources and myriad of potential contributing factors, pain can be experienced very differently from person to person (IOM, 2011). The IOM (2011) suggests that pain is inclusive of and affected by all the factors previously discussed.

Chronic pain impacts quality of life, productivity, and is harmful (IOM, 2011). Higher costs, additional resources, unnecessary suffering can result with insufficient pain management or not addressing the whole person (IOM, 2011). The "prevention of chronic pain, from acute, depends on the initial treatment and insult, in addition to "patient-related risk factors" (HHSNPS, 2017). Chronic pain is one of the most frequent reasons adult seek medical care (Dahlhamer et al., 2018).

The IOM (2011) argues that self-management is the first step and repeated step in the pain relieving process. For those experiencing chronic pain, "self-management is a key treatment modality"(Lukewich, Mann, VaDenKerkhof, & Tranmer, 2015). Self-efficacy is closely intertwined with self-management. According to Keefe et al. (2008), one part of successful pain self-management requires some belief in their own ability to manage their pain. In other words, when the patient believes they can self-manage, they are more likely to be successful in doing so. It falls largely on primary care providers to provide the support and inspiration needed to begin empowering patients to successfully self-manage (IOM, 2011). Chronic pain self-management support needs to be prioritized by providers and pain patients to optimize outcomes (Luke, Mann, VanDenKerkhof, & Tranmer, 2015). However, given the many challenges in managing patients with pain, often the person in pain and their families carry "the burden of controlling pain" (IOM, 2011).

The IOM (2011) asserts the use of a strict biomedical medical approach is simply insufficient to address the complex nature of the pain experience. For those with persistent pain, a biopsychosocial and interdisciplinary approach offers the most potential for successful pain management along with an interdisciplinary team. The biopsychosocial model offers a holistic or whole-person approach. The biopsychosocial approach encompasses the combination of

"biological, psychological, and social, family, cultural contexts of pain", which is being used by most specialists treating chronic pain today (Gatchel et al., 2007). Dersh (2006) argues the failure to use a biopsychosocial approach will significantly increase prolonged disability in a number of chronic pain patients.

To maximize effective pain care, patients need a comprehensive assessment and sufficient education about the continually changing pain management process (IOM, 2011). As Kawl (2012) explains, patients are more likely to have a higher function and tend to use less pain medication when utilizing positive lifestyle changes and health-directed behaviors. Lee, Crawford, and Swann (2014) suggest that outcomes are maximized using complementary and integrative medicine (CIM) patient-centered therapies. Self-management supports a foundation for patients to navigate and actively participate in the optimal wellness level achievable.

One major challenge, affecting pain care, is the United States (U.S.) healthcare segmentation of care into specialties (IOM, 2011). With each specialty seeing patients with acute and chronic pain related conditions, the challenge is that pain is part of every speciality yet it "belongs to no one" (IOM, 2011). Essentially, there is nowhere patients can routinely go just for pain because patients usually see the specialist affiliated with their condition (IOM, 2011).

Once a patient reaches a point of severe and chronic pain, generally after dealing with a painful condition for years, they are unlikely to have access to a pain specialist (IOM, 2011). This circumstance is where primary care providers can embrace pain management training as equally as other areas of medicine (IOM, 2011). The IOM (2011) cautions that healthcare professionals lack education in evolving pain care plus pain prevention and treatment best practices. "Effective pain care involves many individuals, beginning with the patient and various treatments" (IOM, 2011). Even though there is increasing importance being placed on patient-

centered and collaborative primary care, it may still be in its infancy to some degree (IOM, 2011).

While national pain strategies and guidelines are continually being assessed and developed, they are often narrowly focused on pharmacologic management aspects and related complications. The need for education in using the biopsychosocial approach and deep understanding and empathy for chronic pain patients and their experiences is necessary for successful chronic pain management. Not only does comprehensive training matter, but the patient-provider relationship strength also influences the pain treatment effectiveness and progress made (IOM, 2011).

Impact

According to the IOM (2011), severe pain strongly influences every aspect of a person's quality of life, and insufficient treatment leaves the burden of pain control affects those in pain and their families most heavily. Since pain can be an “invisible kind of illness”, meaning it is not generally obvious to others, that even healthcare providers can have biases when treating chronic pain (IOM, 2011). This is particularly applicable to those living with pain for an extended time; even those close to the chronic pain patient might not be fully aware of the impact the pain has on the person (IOM, 2011).

The cumulative impacts of pain on individuals and society are too numerous to include in this paper; however, it is clear a consistent holistic, and individual approach to chronic pain management is desperately needed. Providing holistic and comprehensive education offers the patient an opportunity for effective and appropriate self-management of chronic pain, which may improve those individuals' lives and may reduce other impacts such as social and fiscal factors. Generally, when a person progresses to chronic pain, they are likely unaware of all the impacts

and toll it may take on their life if they are not sufficiently prepared for the challenges of living with chronic pain. Those with two or more types of chronic pain are reported to be nearly three times more likely to report a suicide attempt (IOM, 2011). In other words, the level of suffering from chronic pain is not always apparent by just physically looking at a person; it requires an in-depth assessment to determine risks. Notwithstanding, chronic pain can be a constantly evolving experience, with difficulty predicting, which is part of what makes its impact so great.

Project Goals

The overall goal of the project used a holistic framework to examine the chronic pain education delivered to patients by their PCP and identify potential gaps. This project examined patient perceptions of the holistic educational content delivered by their primary care provider, treating them for pain. The project intention looked toward examining what can be done to identify potential educational gaps and improve pain education practice. The gaps identified were then used to create a holistically focused chronic pain education poster, emphasizing its elements. The project utilized the most current evidence-based literature after building a foundation from a landmark study, the IOM (2011) report "*Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*" as a major resource.

The IOM report (2011) included strong recommendations for a biopsychosocial education pain program, which contributes greatly to exploring chronic pain patients' perceptions of education delivered by their primary care providers. The IOM (2011) recommendations support a biopsychosocial approach to more effectively manage chronic pain and achieve better pain outcomes, which result in lower health care costs plus the potential for better patient quality of life.

According to the IOM (2011), effective pain care begins with the patient. The chronic

pain survey utilized a biopsychosocial framework for patients to evaluate the pain education they received from their primary care providers, their relationship with their provider, and perceived ability to self-manage. The answers were then evaluated for potential gaps and the need for improvement in education delivery. Close examination of the patient's perceptions of chronic pain education delivered by their primary care providers with their perceived self-management ability offered insight into educational gaps needing further attention.

From a patient's perspective, identifying further gaps provides needed information to contribute to practice improvement using best practices with a biopsychosocial approach. The project survey intended to incorporate the patient's valuable voice and perspective as an essential part of improving chronic pain care and increasing patient-centeredness. The education gaps identified were then used to create an educational poster to improve future practice.

Project Aims and Objectives

The aims and objectives are as follows:

Specific Aim #1

Examine evidenced-based recommendations supporting effective holistic chronic pain care management.

Objective #1: Compare and contrast findings of effective chronic pain care models by reviewing current and landmark evidence-based research.

Objective #2: Identify potential facilitators and barriers to self-management.

Objective #3: Identify comprehensive chronic pain survey tools.

Specific Aim #2

Use an existing validated chronic pain survey tool framework to create a biopsychosocial survey to collect data from chronic pain patients about their perceptions of pain education delivered by

their primary care provider.

Objective #1

Use evidence-based literature to apply the Biopsychosocial framework to survey composition.

Objective #2

Incorporate factors identified in findings from evidence-based literature to survey questions, based on the Biopsychosocial approach recommendations.

Specific Aim #3

Recruit chronic pain adult patients with non-malignant pain and survey their perceptions of chronic pain management education by their primary care providers to identify potential gaps.

Objective #1

Adult participants will receive an electronic consent form, with a 5-point Likert scale format survey, with option to offer open-ended comments at the conclusion of the survey.

Objective #2

Determine potential gaps in education delivered in the primary care setting, as per patient report.

Objective #3

Synthesize data to determine which areas need more attention in patient education from a patient perspective.

Specific Aim #4

Create a chronic pain poster and provider brochure for chronic pain practice improvement, based on education gaps identified from the pain survey.

Objective #1

Use synthesized data to construct a pain education poster and brochure using the Biopsychosocial model.

Objective #2

Determine the most appropriate distribution pathway for poster based on cumulative data findings.

Objective #3

Distribute the poster and brochure to primary care practices on the island Maui.

Chapter 2: Review of Literature and Conceptual Frameworks

Chronic Pain Literature

Despite the rapidly growing body of knowledge related to chronic pain, the vast majority of literature remains focused on a pharmacologic approach with emphasis on the challenges of opioid management. Chronic pain management typically focuses on a single modality that may be costly, not maximally effective, or have undesirable side effects such as prescription medications or interventional procedures (Lee, Crawford, & Swann, 2014). With the epidemic proportions of opioid use and prescription drug misuse, much of the literature focuses on ameliorating that problem through guidelines and algorithms. Recent pain care models can be lacking the components needed for a truly comprehensive approach (Cheatle, 2016).

The needs and benefits of a multidisciplinary and multimodal holistic approach is clear when considering the complexity of chronic pain complex and its multifactorial disease process (IOM, 2011). An abundance of literature from many disciplines reflects the use of multimodal and multidisciplinary therapies, including recommendations for the benefit of non-pharmacologic interventions and self-care pain management practices independently; despite that, high-quality research of all these combined still appears to be sparse.

Numerous factors affect a patient's experience of pain and function, including medical, social, psychiatric, behavioral, and educational factors, which suggests that the approach to dealing with chronic pain incorporates a biopsychosocial approach; however, it is not routinely utilized (Peppin, Cheatle, Kirsh, & McCarberg, 2015). The IOM (2011) suggests there are a myriad of ways to address pain, and the medical model is too simplistic and limited. Therefore, one of the recommendations for chronic pain care is for most pain care delivery to be via primary care and self-management with individualization to the patient (IOM, 2011). The literature reviewed for

this paper examines patient perceptions about self-management promoting education, care received, and educational content delivered.

Databases

The databases selected to search for evidence included EBSCOhost, CINAHL Complete, Health Source: Nursing/Academic, Google Scholar, and Medline. The keywords used to conduct searches included chronic pain, patient perceptions, patient attitudes, patient perspectives, primary care providers, and patient education. Articles accepted were only those in English. Acceptable dates were 2010 to the present. The dates were chosen based on consideration for the inclusion of pioneering research from the 2011 IOM report.

Landmark Study

In 2010 the Department of Health and Human Services (HHS) and Institute of Medicine (IOM) entered an agreement to increase activity to address pain awareness as a public health problem in the United States (IOM, 2011). The HHS, via the National Institutes of Health (NIH), called for a study evaluating the pain science state, care, research, and education and to help advance the field with its recommendations (IOM, 2011). The IOM study began in 2010, involving a committee of experts from well over a dozen disciplines, pain sufferers and their advocates, to accurately assess the problem (IOM, 2011).

The landmark study by the Institute of Medicine [IOM] (2011), "*Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*", examines the problem, care, education, and research related to chronic pain (IOM, 2011). The IOM report is one of the most comprehensive collections of pain literature. Most pain literature since 2011 refers back to the findings and recommendations of the IOM report.

Inclusion Criteria

Given the vast body of literature and evolving practices related to pain and pain management, the search parameters were restricted to the adult population and focused on the most current evidence-based research, primarily of the last five years, with the inclusion of up to ten to allow for pioneering literature. Excluded articles were related to acute pain, malignant or cancer-related pain, perioperative pain, education delivery via technology, plus opioid abuse and management. Also excluded were articles focusing on providers from other disciplines, not meeting conventional primary care provider criteria, defined as Medical Doctor (MD), Nurse Practitioner (NP) or Physician Assistant (PA) (Medline, 2020).

The initial CINAHL advanced search revealed 4,396 articles on chronic pain and patient perceptions or attitudes or perspectives. The search criteria were refined to include only adults from age 19-64, all genders, all publication types, and all geographic locations with evidence-based selections only between January 2010 and January 2020, which revealed 1,106 articles. The addition of search criteria to focus on evidence-based research with the inclusion of primary care provider and patient education revealed only 16 articles, of which only 6 met all the inclusion criteria. The remaining articles were examined for patient perceptions, attitudes, perspectives, and beliefs of provider knowledge and education delivery regarding chronic pain management. All those meeting inclusion criteria were examined further for this project.

Swedish Long-Term Pain Study

A mixed-methods Swedish study explored patient and general practitioner (GP) perspectives about key factors affecting return to work in those with chronic pain (Lundberg & Melander, 2019). To narrow the study scope, the focus was mainly on motivational factors affecting return to work, emphasizing a push and pull framework (Lundberg & Melander, 2019).

Push and pull is a theoretical framework acknowledging patient and primary care provider perspective differences on motivation (Lundberg & Melander, 2019). In identifying differences in perspective, it can allow for providers to offer support that is patient-centered (Lundberg & Melander, 2019).

The Swedish study structured their findings into three categories of push and pull factors then examined the differences in responses between the patients and practitioners. In several instances, there were factors identified by the patient only group, which were not identified by the GPs. Lundberg & Melander (2019) propose that ability to motivate patients may be limited by being GP's being unaware of factors important to patients. This works in both directions, where the GP must also convey their viewpoints clearly so that the patient can understand their approach (Lundberg & Melander, 2019).

US Integrative Pain Management Study

In a mixed-methods quasi-experimental US study, pain experiences were examined using a psychosocial framework during a 12-week timeframe (Bruns et al., 2019). Participants were primary care patients with chronic pain who underwent a multimodal pain group incorporating four topics which were mindfulness or mind-body connection, physical movement education, and self-care techniques (Bruns et al., 2019). Also, participants could choose multidisciplinary treatments at various times in their week (Bruns et al., 2019).

Mounting evidence supports integrative treatment as efficacious, as they address psychosocial and biological aspects of pain (Bruns et al., 2019). In the 104 interviews of 41 participants, a baseline was established, plus three, and six-month follow-ups. Pre-study, the patients described a vicious psychologic cycle of pain, worsening with anxiety and movement,

along with pain not responding to increased medication management, which increased their sense of disempowerment and social isolation (Bruns et al., 2019).

Post-study, the patients reported many positive effects, such as decreased medication use, increased social connection, and a sense of psychological resilience (Bruns et al., 2019). The study reports that patients and providers prefer having pain management options to include complementary and integrative health (CIH) (Bruns et al., 2019). Overall, these findings support using a holistic pain management approach, which demonstrated positive outcomes for the patient included increased resilience and hopefulness (Bruns et al., 2019). Through a psychosocial approach, an opportunity ensues for patients to participate more fully in their self-care with the potential for improving their sense of resilience and social support engagement simultaneously (Bruns et al., 2019).

Canadian Equity-Oriented Health Care Study

A Canadian longitudinal two-year study examined the impact of equity-oriented health care (EOHC) delivery in primary care with the relationship between selected patient-reported health outcomes and patient perceptions of EOHC (Gilboe et al., 2018). EOHC is an approach that includes culturally safe, trauma, and violence-informed, and "contextually tailored care" (Gilboe et al., 2018). This study examined longitudinal data from primary health care clinics for 395 patients, drawn from a cohort of 567, over two years (Gilboe et al., 2018).

As Gilboe et al. (2018) discuss, reports of adverse health care experiences are linked to delayed care-seeking, including those with chronic illness or a history of trauma or violence (Gilboe et al., 2018). This Canadian study is among the first landmark studies to show that EOHC care delivery predicts better health outcomes for patients (Gilboe et al., 2018). It

demonstrates that EOHC can be a vehicle for enhancing patient confidence and comfort in their care and in preventing and managing their health problems (Gilboe et al., 2018).

Chronic pain is often concurrently experienced in those with mental health issues and a history of violence (Gilboe et al., 2018). EOHC places emphasis on creating contextually tailored care and a respectful, safe environment that helps support trust in the provider, a strongly associated key outcome in illness recovery (Gilboe et al., 2018). There are links to confidence in care and self-efficacy, which also may be aided by EOHC (Gilboe et al., 2018).

A path model was developed to examine self-reported physical and mental health and the influencing factors (Gilboe et al., 2018). Measurement was done using seven self-report scales including the Equity-Oriented Health Care Scale (E-HoCS), comfort & confidence with HCP, self-efficacy, quality of life (WHOQOL-BREF), chronic pain scale (CPS), PTSD civilian symptoms checklist PCL-C), depressive symptoms (CESD-R), discrimination experience, and financial strain index (Gilboe et al., 2018).

The EOHC study found that more extraordinary patient-reported experiences of confidence and comfort in health care services they received led to increased confidence in health prevention and self-management (Gilboe et al. 2018). Depressive, PTSD, and Quality of life improvements were predicted with higher confidence levels (Gilboe et al. 2018).

Canadian Self-Management Study

In another Canadian study, a focus group study of 50 participants, in a randomized controlled trial (RCT), was undertaken to understand factors important to pain patients with non-surgical lumbar spinal stenosis (LSS) (Lynch, Bove, Ammendolia, & Schneider, 2017). The RCT was designed to compare three non-surgical treatments, and the focus group was intended to reveal the participant's preferences, opinions, and experiences about the treatments they

received (Lynch, Bove, Ammendolia, & Schneider, 2017). This was a unique study given that previous thoughts and opinions of this population have been looked at but not previously in the context of an RCT (Lynch, Bove, Ammendolia, & Schneider, 2017).

The study results highlighted the participants' main treatment goal being pain reduction, often by any means possible (Lynch, Bove, Ammendolia, & Schneider, 2017). The data revealed three themes important to participants. These themes stemmed from the participant's desire to improve their condition and seeking the best ways to do so.

Self-management study theme one was the emotional response to their condition. Patients' primary emotions were frustration with the impact of their conditions on their lives, which was compounded when providers failed to provide adequate education on their condition (Lynch, Bove, Ammendolia, & Schneider, 2017). There was also an element of negativity and mistrust toward providers who felt withholding treatment or perceived as ineffective (Lynch, Bove, Ammendolia, & Schneider, 2017).

Self-management study theme two, the desire for education to improve quality of life, resulted in motivation to pursue information from any potentially promising source they felt could help (Lynch, Bove, Ammendolia, & Schneider, 2017). Though the sources varied from anecdotal to multidisciplinary professional medical advice, the participants were willing to consider any information that promised the potential of functional or pain improvement (Lynch, Bove, Ammendolia, & Schneider, 2017). However, there was a general preference toward professional medical advice but the uncertainty of navigating the information when opinions of medical professionals conflicted with one another (Lynch, Bove, Ammendolia, & Schneider, 2017).

Lastly, theme three uncovered the desire for individualized care based on lifestyle and self-management techniques (Lynch, Bove, Ammendolia, & Schneider, 2017). The participants identified a thirst for professional self-management teaching education, perhaps to reduce their reliance and financial strain potentially caused when pursuing multiple modalities (Lynch, Bove, Ammendolia, & Schneider, 2017). Again, frustration expressed regarding conflicting information regarding nutritional currency and inconsistent recommendations (Lynch, Bove, Ammendolia, & Schneider, 2017). These findings suggest that providing clear quality education with consistent, evidence-based recommendations, correcting misperceptions about a pain condition, and facilitation of self-management are needed by primary care providers (Lynch, Bove, Ammendolia, & Schneider, 2017).

UK Patient Perspectives Study

In another RCT in the UK, pain management in primary care was examined from the patient's perspective and the possible effects on the delivery of treatment. Semi-structured interviews were taken from a subsample of 44 participants from the RCT, recruited from 8 general practices in the UK. The study, reported to be one of the first of its kind, sought to explore participants experiences with illness and treatment through the lens of understanding how they influence accepting the intervention (Bee, McBeth, McFarlane, & Lovell, 2016).

The data from this study also revealed three themes. The first theme is illness context, which relates to chronic pain and related health services (Bee, McBeth, McFarlane, & Lovell, 2016). All participants reported having had discussions about their condition with their primary care providers but reported criticisms of the encounters such as the provider's failure to provide adequate resolve or explanation of the condition and or lack of provider empathy (Bee, McBeth, McFarlane, & Lovell, 2016). The participants also reported clinical consensus was lacking in

their chronic pain condition and the lack of personal understanding of their pain aggravation factors (Bee, McBeth, McFarlane, & Lovell, 2016).

The second theme is the identity context, which relates to the interchange of self and illness identities, behavioral pain responses, and the emotional response to the progression of symptoms (Bee, McBeth, McFarlane, & Lovell, 2016). While several factors were identified in this theme, the common narrative emerged: the psychological and social impacts of chronic pain (Bee, McBeth, McFarlane, & Lovell, 2016). The loss of roles and function were related to feelings of depressed mood, irritability, and frustration (Bee, McBeth, McFarlane, & Lovell, 2016).

The third theme related to the intervention context as it connects with experiences and preferences. The interventions using physical exercise or cognitive behavioral therapy separately or combined resulted in differing perceptions (Bee, McBeth, McFarlane, & Lovell, 2016). The perceptions ranged from negative to more accepting when provided simultaneously and suggests benefits may be maximized when combined (Bee, McBeth, McFarlane, & Lovell, 2016).

U.S. Self-Management Study

In one US study, patients with chronic musculoskeletal pain were asked for their comparative experiences with communication and self-support management from primary care physicians and nurse care managers (Mathias et al., 2010). The participants were a subset from a more extensive study, the SCAMP trial, testing stepped care approaches in patients with chronic pain and depression in primary care. While this scholarly project does not include care by nurse care managers, the study's findings related to primary care providers had commonalities with the other studies. This study's participants were divided into two focus groups, male (n=7) and female (n=11), and an experienced moderator facilitated sessions. While findings suggested

overall higher satisfaction with nurse care managers care than primary care providers, several themes arose, which are significant in regards to perceptions of primary care providers.

The participants identified areas they felt were lacking in primary care pain treatment by their primary care providers, which included poor perceptions of empathy or encouragement, listening skills, and medication over or under prescribing (Mathias et al., 2010). While some patients did express satisfaction with their PCP, the majority expressed some level of dissatisfaction with the pain treatment received in primary care (Mathias et al. 2010).

This study suggests systemic deficiencies are one of the main contributors to the problems identified. The broad scope of complex needs for chronic pain patients in the primary care setting may exceed what a PCP can provide (Mathias et al., 2010).

Discussion

The literature examined does highlight the different perspectives arising when comparing patient to provider perceptions in pain care. The perceptions that are important to patients may have some commonalities with provider priorities, but they are not always wholly aligned (Lundberg & Melander, 2019). This suggests that increasing understanding of patient perceptions of chronic pain can help providers become more effective. Patients need sufficient resources, education, and support to sufficiently self-man (IOM, 2011).

Biopsychosocial considerations arose as essential factors in the studies to understanding patient challenges and harnessing a holistic and expanded approach to increase patient's knowledge, confidence, and desire to employ self-management techniques. Patients have a relationship with their pain, and clinicians need to become engaged members of that conversation. Primary care is most frequently where pain is first reported in the health care system; therefore, primary care providers are "an early step in the pain care journey" (IOM,

2011). These studies suggest that providers' increased understanding is necessary to promote higher patient confidence, motivation, and ultimately outcomes.

All these findings underscore the importance of including patient perceptions into approaches to support optimal pain management and, ultimately, self-management support interventions. Keefe (2008) argues that self-management is almost always the first step in a person's journey to relieving pain". Whereas the IOM (2011) suggests that, whatever the cause or contributing factors, "the clinician must focus on the management of the painful condition, to assist in restoring the individual to a better state of health". It is critical that any information shared by the primary care provider be absorbed, understood, and meet the patient's individual needs to initiate and maintain a successful self-management plan. The literature examined supports the use of a biopsychosocial approach to improve pain education and self-management skills. According to Tranmer (2015), pain outcomes can be optimized via self-management education and building upon an individual's skill level.

Conceptual and Theoretical Frameworks

This paper's concept is primarily focused on chronic pain patient perceptions of pain education provided by their primary care provider. The concept of chronic pain itself is abstract. Chronic pain has many interwoven variables, with the levels of pain, function, and meanings being uniquely identified depending on the person affected. Chronic pain cannot be categorized or sufficiently described via one term since it is a complex process, and its description involves biological, psychological, and social factors.

Biopsychosocial Model

One framework used to guide this project is the Biopsychosocial (BPS) model. It is a means to understand "the patient's subjective experience as an essential contributor to accurate

diagnosis, health outcomes and humane care" and the multifactorial contributors to disease, illness, and suffering (Borrell-Carrió, Suchman, & Epstein, 2004). The most valuable contribution of BPS helps "broaden the scope of the clinician's gaze" (Borrell-Carrió, Suchman, & Epstein, 2004). The BPS framework "takes into account the rich range of potential causes, effects, and treatment strategies" (IOM, 2011) (See Figure 2).

Similar to other intense chronic conditions, pain has deep cognitive and emotional effects and is "much more than a biological phenomenon" (IOM, 2011). The IOM (2011) suggests that an interdisciplinary BPS approach offers the most promise for treating pain patients because of the psychological and cognitive effects pain produces. Successful treatment can include prevention, facilitation of self-care, and counseling, though costly procedures are often performed; however, to apply the proper treatments, the public and clinician perception of pain and its treatment must be changed (IOM, 2011). Applying the BPS model to pain care helps address the many facets of pain, such as the psychological, biological, social, and cultural influences on pain (IOM, 2011).

The BPS model supports efforts to increase providers' cultural competence to deliver competent but culturally appropriate care (IOM, 2011). Another way to apply the BPS model would be through addressing stereotypes, biases, knowledge gaps, and competencies in pain care by providing healthcare professionals with enhanced education and training about these barriers, which cause disparities in pain care (IOM, 2011). The IOM (2011) recommends improving data collection and reporting on pain, a population-based strategy for pain reduction, and its consequences. Further recommended is the creation of a comprehensive population health level strategy for pain treatment, management, and research, promotion of self-management, development of strategies to reduce barriers in pain care, educational opportunities in primary

care assessment and pain treatment, along with the revision of reimbursement policies to improve pain-based care.

In chronic pain medical decision-making, a patient's cultural and ethnic background, spirituality, age, and gender should be considered (Steglitz, 2012). The BPS model is one that can be applied to these issues. Borrell-Carrió et al. (2004) suggest adding reflective participation to the BPS model to shift from objective clinician detachment to care with greater caring and warmth. When a provider becomes more engaged with the patient priorities and unique pain factors, there may be more potential for increasing the patient's ability to self-manage (IOM, 2011). This would require that the pain management approach considers the uniqueness of an individual's contributing factors to inform the most appropriately focused care plan. Another model to help understand participation in care, causality, and dualism would be using the Complexity theory to help inform clinicians' actions (Borrell- Carrió et al., 2004).

Complexity Theory

Complexity theory is based upon complex structures interacting as constantly changing systems with accompanying feedback loops (Burnes, 2005). The complexity model is a nonlinear approach that evaluates a system with many parts, none having more importance than another. Cheatle (2016) defines complexity to be a large network of components with no central control but simple operational rules giving rise to sophisticated information process, complex collective behavior, and adaptation via evolution or learning, with no central control. For health care providers, this is crucial knowledge to incorporate into the care of patients experiencing chronic pain, as the chronic pain experience is very complex. "The complexity model evaluates and treats all of the domains that constitute the chronic pain experience, and the success of the model depends on each patient having a PCP and the pain physician serving as a true consultant"

(Cheatle, 2016).

Theory of Symptom Self-Management

Self-management is essential to chronic pain management outcomes (IOM, 2011). According to NINR (2020), self-management science supports individuals with chronic conditions and their caregivers through examining strategies to help them improve their health behavior, understand, and manage their illness. To facilitate better self-management, patients need clear, concise, and thorough education. Patients who actively participate in their own health care achieve better health outcomes and meet more of their health goals (IOM, 2011). One way to help patients support their own self-management and engagement in the self-management process is via holistic education delivery.

Another framework applicable to chronic pain management is the Theory of Symptom Self-Management (See Figure 4). Active participation in one's treatment was first described as self-management by Thomas Creer (Grady & Gough, 2014). Self-management (SM) can be incredibly empowering and help one gain more control over their symptoms. Since SM's initial descriptions as a concept were introduced, the descriptions evolved to now include five core SM processes, including decision-making, resource utilization, problem-solving, taking action, and partnerships with health care providers (Grady & Gough, 2014). Within this framework, the core components support a comprehensive approach to help patients become successful with their self-management.

According to Grady and Gough (2014), "self-management represents a promising strategy for treating chronic conditions moving beyond education to teaching individuals "to identify challenges and solve problems associated with their illness actively. Utilization of these frameworks with holistic assessment, comprehensive planning, and collaboration between

patients and providers optimizes the possibility of successful education delivery and success with chronic pain self-management.

Holistic Concept Map

Within the concept map, each concept component has its unique characteristics (See Figure 2). Many variables can act individually or simultaneously as a driving force, impacting how active a person might be in their self-management. For example, a person feels hopeless; they may not be motivated to participate, resulting in a worsening of their condition. Pain coping strategies vary, and motivation to engage in them is a key predictor of a patient's adjustment to pain (Kratz et al., 2010). The perception of control or self-efficacy is essential to confronting pain challenges and is believed to contribute to the successful navigation of pain (IOM, 2011). Goals of self-efficacy and self-management "reinforce the benefits that accrue" when people take an active role in their pain management (IOM, 2011).

Since this concept requires utilization of a holistic approach, these components may not reach their optimal level independently because there is a synergistic effect that comes from the integration of each component. The whole is greater because of the complexity of chronic pain and each individual's unique response to it. Through empowered self-management, optimal well-being can be realized and pain controlled sufficiently enough to allow the fullest life one can have.

Chapter 3: Project Design and Evaluation Plan

Methods

The project design was based on the application of survey research using a BPS model for pain management. The survey was the primary method to conduct a descriptive, cross-sectional study to evaluate chronic pain education delivery in primary care via the BPS model. The project integrated mixed methods to gather the research data. The primary method was data collection via utilization of online surveys, which provided an accessible and easy to use format for participants. The survey examined chronic pain patient pain perceptions of pain education delivered by their primary care providers, provider relationship rating, and perceived self-management ability to reveal potential chronic pain holistic education gaps.

Study Population

The selected population was a convenience sample of adults over age 18, with chronic pain of any type that was non-malignant, pain experienced greater than three months plus the ability to speak, read and write in English. The participants were self-selected through local advertisements via flyers and online flyer distribution (see Appendix A). Information provided to participants included a description of the survey elements, purpose of the study, along with informed consent (see Appendix B). Those meeting inclusion criteria were instructed to contact the student researcher to initiate survey participation, receive their personal consent copy, and survey access link. The participants were asked to email the student researcher, with their interest in the study, without any additional personal information. The only specific content requested to be included in the email was to label the subject line with “pain survey” to indicate their interest in participating in the survey. Upon receiving the email from the prospective participants, the eligible subjects were provided an electronic consent form copy for their records

and an online web link with instructions to access the online survey via Survey Monkey. All were notified that participation was entirely voluntary, and they could discontinue participation at any time they chose. The participant consent formalized with proceeding to survey participation.

Project Site

Initially the project site was intended for local community advertising for online participation. Therefore, preliminary recruitment included flyer postings in high foot traffic areas on Maui's island to increase visibility and awareness of the survey recruitment. No physical site was involved, as all data was gathered entirely electronically using the Survey Monkey online survey service. General recruitment started via print advertisement in the local community and some virtual flyers distributed via email. Advertising and recruitment flyers were displayed on local billboards in areas where chronic pain patients have frequented in the past or where eligible participants might potentially see them.

All recruitment activities were carried out in compliance with all local health and safety guidelines in effect for the State of Hawaii related to the COVID-19 pandemic. In the event an insufficient sample size would result from the community recruitment posters due to COVID-19 restrictions, an additional recruitment strategy was planned with the use of online technologies. Consequently, added steps were necessary to utilize online technologies. Further chronic pain patient recruitment was done via specific social media as a last resort since the local advertisements initially produced too few prospective participants. A description of the project with consent form was shared through email to ensure the information's visibility and personal receipt. Strict adherence to confidentiality guidelines, from any direct contact with the student

researcher, were maintained. The survey remained anonymous throughout the entirety of the project.

Instruments

The U.S. military is at the forefront of transforming pain management assessment and tools for holistically approaching chronic pain. The main instrument utilized for this project was a survey (see Appendix D) developed from a combination of previously validated tools used by the Defense and Veterans Center for Integrative Pain Management [DVCIPM] (see Figure 5). This project's survey was intended to assess perceptions of chronic pain provider education delivery components, through the patient perspective, get a rating of provider relationship, and perceived ability to self-manage, to identify pain education gaps for improving future practice.

This project required a comprehensive survey to determine perceptions of the chronic pain education components received from their primary care providers. The survey included several categories identified as relevant to holistic chronic pain management in previously validated tools to ascertain the degree of biopsychosocial education the participant has received. Surveys included 5-point Likert scales for participants to express their feedback. The secondary method offered an optional comment box to provide open-ended remarks for those participants who desired to share additional information not covered in the survey.

The project relied on current evidence-based literature to support the development of the chronic pain patient perceptions survey. The framework utilized for the survey was adapted from the Pain Assessment Screening Tool and Outcomes (PASTOR) obtained from the Defense and Veterans Center for Integrative Pain Management (DVCIPM), with permission to adapt the framework granted. The PASTOR tool was created as a survey to comprehensively assess a chronic pain patients state utilizing a Patient-Reported Outcomes Measurement Information

System (PROMIS) system with the use of instruments designed by the National Institutes of Health (NIH) (DVCIPM, 2010.); These previously validated tools incorporate the multitude of facets involved with a biopsychosocial approach.

The survey for this project incorporated the comprehensive PASTOR tool's domains as a framework to develop the comprehensive survey for patients to participate, as related to the range of primary care education topics delivered by their PCP (See Figure 5). The major PASTOR assessment domains included the areas of pain, physical, behavioral, and psychosocial factors involved with chronic pain screening (DVCIPM, 2010).

The survey created for this project focused on the broader categories used in PROMIS and PASTOR tools, for comprehensive survey data collection primarily in the area of holistic chronic pain education. The tools' collection highlighted components important to patient perceptions of primary care provider pain education, self-management perception, and gaps in knowledge.

Analysis

Ordinal survey data was collected, categorized and tabulated. Descriptive analysis methods were applied and analyzed utilizing Survey Monkey data, Excel spreadsheet program, and the JASP online statistical analysis program. Each question was analyzed for the mean, median, and standard deviations based on the Likert-scale items. Charts and graphs were prepared based on the data results. Future analysis using non-parametric testing may be applied.

Participation was anonymous for the online survey. The demographic information was collected for additional analyses, and any identifying information was kept entirely confidential and deidentified, if applicable, based on current guidelines and recommendations. The data were analyzed to examine the categories of education received, relationship with their provider,

perceived self-management skill, and potential gaps in these areas. The data were further examined for the largest educational deficit areas and those that may need to be addressed more frequently during primary care provider pain education.

Ethics

All ethical research principles and standards were followed throughout this project to maintain the ethical tenets' integrity while supporting the communication between the researcher and participants.

Timeline

Upon submitting application to the Institutional Review Board (IRB), an additional CITI program training for Information Privacy Security (IPS) certification was completed, to support project design specifications. Application processing was approximately one month to approval. The project implementation timeline was estimated at two to four weeks from receiving approval for human research from the IRB.

Week 1: IRB approval, survey construction and implementation.

Once the application approval was granted from IRB, the first week began with building the electronic survey version into survey monkey. Approved flyers were printed and photocopied for local distribution.

Week 2: Survey implementation and distribution.

Once the electronic survey was built, the printed and online materials were prepared for local distribution, based upon approved drafts; The project's survey implementation phase began. As previously outlined, the recruitment started with direct advertising in the community, with the addition of online outreach, to achieve an adequate sampling size. The participants were given

the option to fill out an online survey with the survey monkey direct web link, once contacting the researcher to indicate participation via email. The survey data was collected over two weeks.

Week 3: Completed recruitment, finalized data collection, and gift card distribution.

The survey concluded, and data collection was finalized. All participants were nominally compensated for their time with a ten dollar electronic gift card. Participant compensation was processed, then gift cards were delivered electronically via email, with participant approval confirmed via email.

Week 4-6: Data analysis

All data collected and analyzed for results. In the final weeks of the project, the data was fully compiled, analyzed, and organized for the final PIP presentation.

Week 7-8: Present data

The defense of this project will be completed with the final presentation of findings on or before November 15, 2020.

Protection of Human Subjects

All protections of human subjects were maintained per current guidelines and requirements of exempt approval. The project application for IRB was submitted in June 2020, with approval notification received on July 31. Upon IRB approval receipt, the project implementation and recruitment was initiated.

Memorandum of Understanding

A memorandum of understanding (MOU) did not apply to this project, as recruitment took place through local advertisement and remote recruitment via social media without any agency's direct involvement.

Budget

The project budget was estimated at \$750 (see Table 1). The projected expenses included costs related to recruitment advertisement, photocopying and printing, travel, online survey costs, participant compensation, in the form of electronic gift cards, and educational materials. The actual costs for all project-related expenses were \$525 in total.

Expected Results

Expected results were anticipated to reveal the potential gaps in chronic pain patient education from primary care providers via patient perception and report. Significant data findings were anticipated to identify gaps in holistically based education delivered, as reported by the patient, to suggest potential impacts of the educational gaps and where improvements could be made. Immediate outcomes included raising awareness of gaps in chronic pain management education in primary care, as reported by the patient, and potential communication topics to address with primary care providers to improve education delivery, relationship, and self-management potential for patients.

The intention with the expected results is to apply holistic chronic pain education gaps to construct an educational poster for patients. The poster design targeted primary care offices for use as a tool to display in patient view, enhancing self-management capacity. The poster supports increasing pain education knowledge while encouraging a more expansive dialogue about the many elements involved with chronic pain development, exacerbation, and self-management. For providers, the outcomes also include further education and self-awareness to help address the identified gaps; the poster can also be a tool for providers to engage and learn from as well.

Long-term goals include the development of additional tools that may assist the patient with starting conversations with their healthcare provider about using a holistic approach and

how to further engage or increase self-management support with their provider. Efforts to improve communication are often centered on provider training and provider-initiated therapeutic principles and relationship; however, patient training for enhancing communication and relationship with their provider seems to be missing from current approaches.

This project on chronic pain education patient perception supports the need for holistic pain education as the standard of care and some of the potential gaps between patients and providers, where the HCP is primarily responsible for facilitating the patient achieve a better outcome. Focusing on the patient's voice, their perceptions and insights inform can further support the need for improved education delivery and support of future patients.

Nursing Implications

The NINR (2010) reports self-management to be “a major part of the national nursing research agenda”. With increasing frequency, research demonstrates that “empowering patients to understand their conditions and take responsibility for their health” can improve outcomes with the use of self-management strategies (NINR, 2010). According to the NINR (2010), chronic disease limits the quality of life for those affected, nearly one in every two adults; Self-management research has enabled improved quality of life, despite these conditions.

The NINR (2010) self-management agenda model is focused on chronic disease care, which includes chronic pain, since pain is often be attributed to one or more chronic conditions. Chronic pain is widespread, and while some patients can be proactive and research some information on their own, not all can, nor do they know the most reliable sources outside of their HCP. Consequently, empowering patients to successfully self-manage requires clear, complete, supportive, and holistically focused education. HCP's are facilitators of patients' participation in their health management (Lukewich et al., 2015). Teaching chronic pain patients, using a

biopsychosocial model, and more effectively engaging and participating with their chronic pain treatment program will create enhanced capacity for self-efficacy and self-management.

The results of this project highlight the importance of pain education in the primary care setting and contributes to the national nursing research agenda toward expanding the research available on the topic of optimizing pain care. First and foremost, a collaborative approach is needed between healthcare practitioners and patients to support self-manage skills. Much more quality research is needed to improve chronic pain care, and nurses are already at the forefront by focusing on self-management research. This project encourages further examination of the patient's perspective to focus on patient-centered pain care truly and to be able to offer the appropriate stepping stones to help them more successfully manage.

The findings of this project help support the expanded education needed in chronic pain care and how nurses and other HCP's can take immediate action toward improving chronic pain outcomes. Perhaps one of the most important nursing implications for improving chronic pain education and practice may come from the increasing number of nurses becoming involved with the American College of Lifestyle Medicine (ACLM). The ACLM's mission (2017) focuses on healing and health improvement via promotion of behavior change, engaging the patient as a partner in care with the HCP guiding, supporting, and educating patients in the area of behavior change. The ACLM approach helps empower patients and healthcare providers to optimize outcomes. If every member of the health care team were to broaden their education scope, many lives might be improved for the better.

Chapter 4: Results

Frameworks

There were two main frameworks used to guide this project. The first was the theory of symptom self-management (TSSM) (Refer to Figure 4). The TSSM promotes increasing patient self-management through five core processes, which include problem-solving, taking action, decision making, resource utilization, and partnering with HCP's (Grady & Gough, 2014). According to Hoffman (2010), TSSM is affected by perceived self-efficacy and takes place through "self-directed action". For patients to take self-directed action, proper education and support resources are needed, which often start with their healthcare provider.

The second was, the biopsychosocial model which was utilized to examine a broader representation of the components influencing self-management capacity. Self-management was recommended by the IOM (2011) as one of the top priorities for supporting patients to have better outcomes when it comes to managing chronic pain. Borrell- Carrió et al. (2004) argued that the "patient's subjective experience" is a decisive contributing factor to humane care, health outcomes, and accurate diagnosis.

Previously tested for reliability and validity, an additional tool used to support the data collection for this project, was the framework from the Defense and Veterans Center for Integrative [DVCIPM] Pain Management Assessment Screening Tool and Outcomes Registry (PASTOR). The development of PASTOR came about to further pain research and "provide clinical outcomes data to improve evidence-making by providers" (USU, 2020). The four assessment domains included the areas of pain, physical, psychosocial, and behavioral categories, which the survey was based upon (see Figure 5).

The actual DVCIPM application of the PASTOR tool further subdivides and expands their survey, using computer-aided testing (CAT) to produce a nearly 30-minute survey which generates a comprehensive individualized chronic pain report for the clinician (USU, 2020). CAT is used to collect the survey data to generate a comprehensive report to help providers tailor chronic pain treatment and is currently in use by the DVCIPM for this purpose (USU, 2020). Therefore, this model utilized the PASTOR tool framework to elicit information from patients regarding primary care education topics delivered by their PCP.

Project Outcomes Evaluation

Data Collection

The IRB recommended not fully designing an electronic survey monkey form until they granted approval. Exempted IRB approval was granted mid-July, with notification approval received on approximately July 31, 2020. The implementation process began immediately upon receipt of approval notification, which included building the complete electronic survey into the survey monkey database.

All data collection was planned to be mainly via online communication, due to the COVID-19 pandemic; therefore, an online survey was the method for collecting the data. A total of 25 IRB-approved recruitment posters were printed for local advertisement (See Appendix A) with the survey recruitment language on one side and consent on the other side (See Appendix B). Posters were initially distributed only locally on Maui island, near places where chronic pain patients may frequent (i.e. Pukalani Superette market, next door to a PCPs and physical therapist [PT] offices). This generated very little response or interest during the first week and a half. The survey was then shared

electronically, with IRB approved email template, to the neighboring islands for distribution and finally online via Facebook (FB) to facilitate recruitment of a larger sample size.

The final recruitment included participants from a chronic pain FB group along with those who became interested through local print and email advertisements. The information flyers for the survey were distributed through local print and email advertisements, eventually with an additional posting of the flyers online to a chronic pain group. The online Facebook group, with over 100,000 followers, was a closed group called “Surviving Chronic Pain” for chronic pain sufferers. The site administrator was contacted regarding sharing the survey with their members, but kindly stated that they do not participate in any internal distribution to their group outside of support resources; however, anyone was invited to share relevant information and opportunity via their visitor page, rather than a group distribution or endorsement. They suggested submitting all pertinent details for the survey recruitment to a visitor’s page.

Once prospective participants established their survey interest via flyers and ads, they were instructed to contact the researcher on two occasions. The first time was to receive their copy of the consent along with the electronic survey monkey link. Then, participants were asked to recontact the student researcher, after survey participation, to grant permission to issue the electronic gift card via the email address they used for the survey link. After permission was confirmed, the participants were issued the electronic gift card sent to the email of their choosing. Participants reporting, they did not receive the card were instructed to check all their mailboxes including spam, and if necessary duplicate cards were re-sent with no difficulties.

The IRB recommended that where possible, no human contact take place for execution of the protocol, which created a limitation of this survey. The goal was to obtain a local sample size of 30

participants (N = 30) however due to planned deadlines for the survey, the final sample size was completed at 26 total participants (N = 26), which included online non-local participants. Given the pandemic impacts, many services (like PT) were not being scheduled as frequently and/or many people were self-quarantining at home, hence there was less foot traffic to be able to view the recruitment posters in the usual healthcare setting than would've previously been, therefore it was necessary to expand to non-local online recruitment.

Survey Data

The project survey design was a one-time 40 item questionnaire divided into four sections to include demographics, PASTOR assessment domains, PCP relationship, and self-management perception. The survey questions were placed in the form of statements from which a participant could answer on a five-point Likert scale. The Likert scale was included for ordinal data measurement collection from a total sample size of 26 participants. At the survey conclusion, one final question was offered as an open-ended space for free commentary. The survey was made available for two weeks locally and online for roughly two days.

The four sections were divided into basic demographics for question #1-6, with the sections as part A, B, and C. Part A, questions #7-23, were based on the PASTOR domains focused on pain scales, physical scales, psychosocial scales, and behavioral scales. Part B, questions #24-32, regarded the relationship with their primary care provider and Part C, questions #33-40, asked about chronic pain self-management. To conclude the survey, the additional comment box was offered to participants. They could share any feedback or comments related to chronic pain care education or anything they felt may be helpful, from their perspective, to enhance primary care providers' awareness.

While the survey provided rich data throughout, the main intent of this project was in identifying potential knowledge gaps in chronic pain education delivered by PCPs, as perceived by the patient. Therefore, part A of the survey is where the most detailed results reporting was focused.

Demographics

Initially, the time projected to take the survey was at 10-15 minutes though the typical time spent was around 7 minutes and 39 seconds with an average completion rate of 100%. The demographic information included 54% Female ($n=14$) and 46% Male ($n=12$) with ethnicities represented as 42 % Caucasian ($n=11$), 23% Asian ($n=6$), 19% Hispanic ($n=5$) and 8% Native Hawaiian ($n=2$), 4% African American ($n=1$, and 4% Rather not say ($n=1$), with none in the Other ($n=0$) category.

Figure 6. Gender Identification. Question 1 “What is your gender?”.

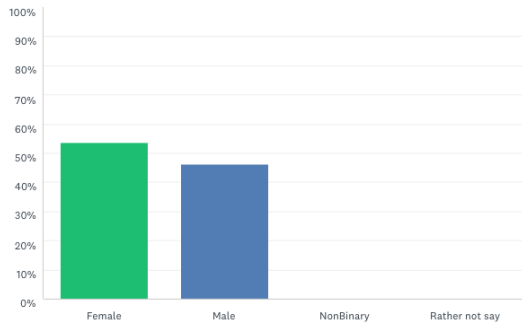


Figure 6. Participant Gender Identification.

Figure 7. Ethnicity. Question 2 “What is your ethnicity?”.

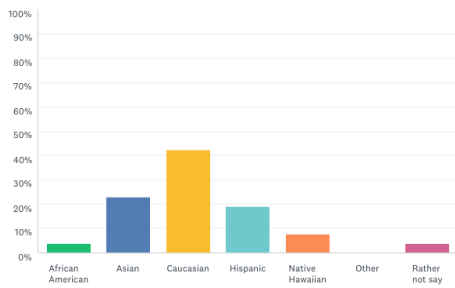


Figure 7. Participant Ethnicity.

The age group ranged from 18-60+, with 38% a median age of participants in the 40-49 age group ($n=10$). Interestingly, nearly 88% of participants ($n=23$) had some college background. The results revealed 50% with a college degree ($n=13$) and 38% a median educational level of at least some college ($n=10$).

Figure 8. Age group. Question 3 “What is your age group?”.

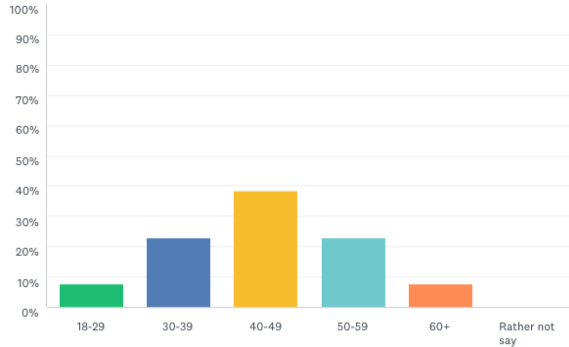


Figure 8. Participant Age group.

Figure 9. Educational level. Question 4 “What is your highest level of education?”.

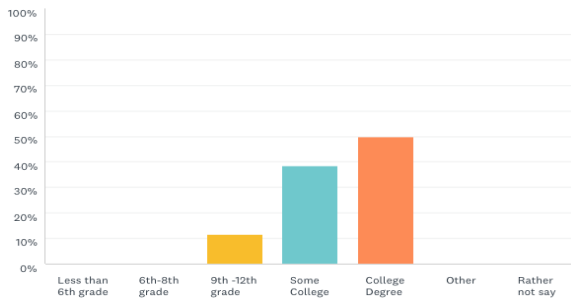


Figure 9. Participant Educational Level.

Figure 10. Primary language. Question 5 “What is your primary language?”.

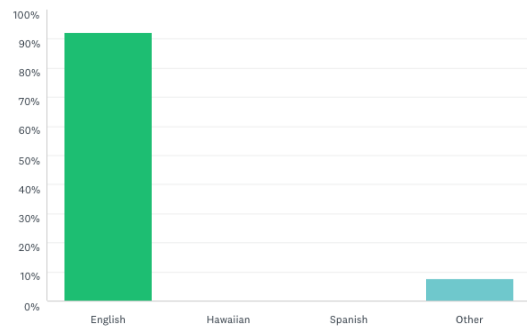


Figure 10. Participant Primary Language.

The primary care provider type reported most was by a medical doctor or doctor of osteopathy ($n=14$). Thus 54 % reported being cared for by an MD/DO ($n=14$), 12% by an Advanced Practice Registered Nurse [APRN] ($n=3$), 19% cared for by a PA ($n=5$), 12% cared for by a Naturopathic Doctor [ND] ($n=3$) and 4% by some other provider ($n=1$).

Figure 10. Primary Care Provider Type. Question 6 “What type of primary care provider do you regularly see for your chronic pain?”.

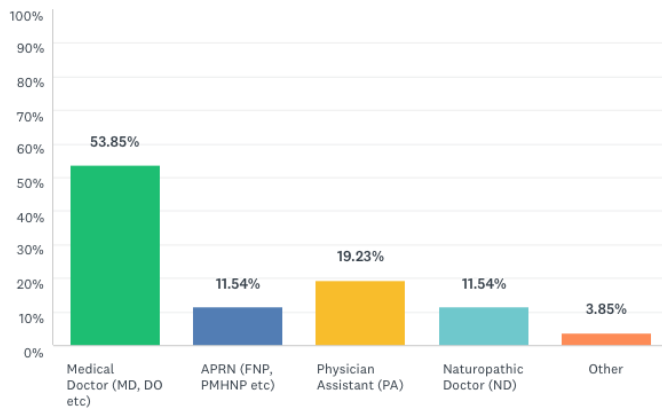


Figure 10. Participant Primary Care Provider Type.

Survey Part A. Part A of the survey asked about the type of chronic pain education delivered by primary care providers. The questions were in the form of statements from which the participants could choose five answers ranging from always, often, sometimes, rarely, and never. For purposes of this data analysis, the results reveal the knowledge gaps in the areas where participants selected rarely or never as topics that PCP discussed with them related to their pain. The highest chronic pain educational gaps according to participant perceptions were questions 11, 8, 15, 14, 19, and 22.

Question 11 addresses the topic of pain catastrophizing where 38% ($n=10$) report Pain Catastrophizing rarely or never discussed by PCP. Generally, pain catastrophizing refers to a mindset where there is a tendency to magnify the worst, feel helpless plus frequent negative rumination.

Figure 11. Pain Catastrophizing. Question 11 “My PCP has talked to me about how negative thoughts affect my response to pain” (based on Pain Catastrophizing scale).

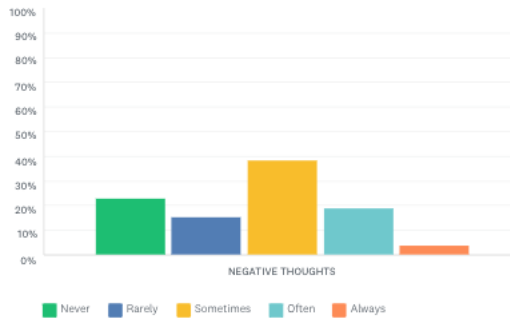


Figure 11. Participant Negative Thought Process Education.

Question 8 and Question 16 relates to Sleep and Sleep quality, where in either case, sleep was rarely or never discussed. Question 8 results revealed nearly 27% of the time the PCP rarely or never talked about how pain affects sleep ($n=7$). Question 16 showed that 28% of the time sleep quality and how it impacted quality of life was rarely or never discussed ($n=7$).

Figure 12. Sleep Education. Question 8 “My PCP has talked to me about how pain affects my sleep”(based on PROMIS sleep-related impairment).

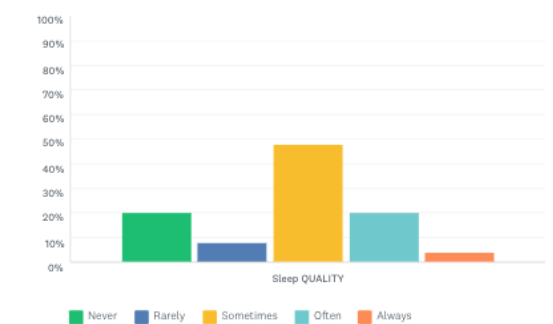
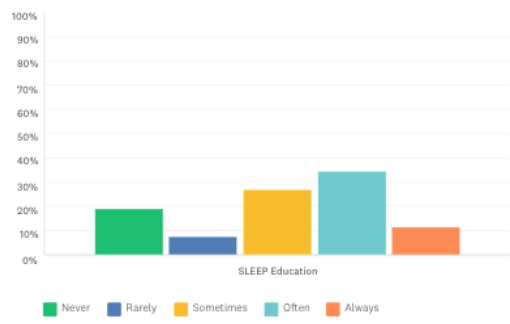


Figure 12. Participant Sleep Education.

Question 15 relates to Fatigue, where participants ($n=9$) reported the PCP rarely or never discussed the connection between fatigue and chronic pain. A 31% education deficit was noted.

Figure 13. Fatigue. Question 15 “My PCP has talked to me about fatigue and chronic pain” (based on PROMIS Fatigue).

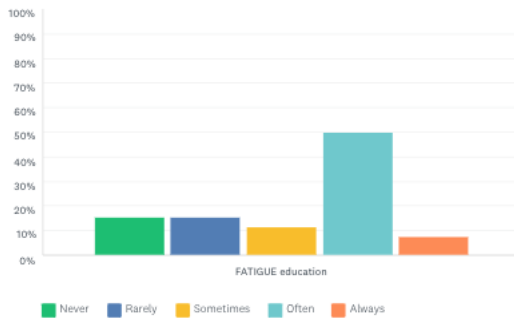


Figure 13. Participant Fatigue Education.

Question 19 relates to how Depression/Anxiety/Anger/PTSD affects or is involved with chronic pain. Participants ($n=9$) reported 31% of the time this topic was rarely or never discussed.

Figure 14. Mood. Question 19 “My PCP has talked to me about how anxiety, anger, depression, or PTSD might be affected or be involved with chronic pain (based on PHQ-9, GAD, Primary care PTSD screen and PROMIS anger).



Figure 14. Participant Mood Education.

Question 22 relates to Alcohol use and how it might affect chronic pain. Participants ($n=12$) reported that 46% of the time it was rarely or never discussed.

Figure 15. Alcohol Use. *Question 22 “My PCP has talked to me about how Alcohol use might affect my chronic pain (PROMIS Alcohol use).*

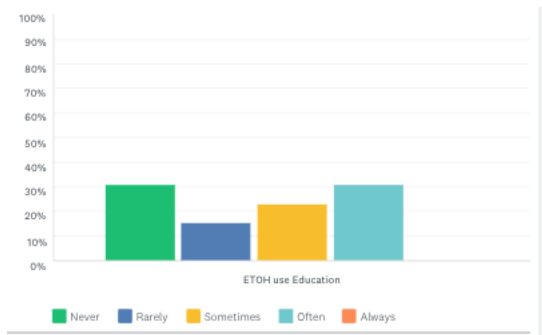


Figure 15. Participant Alcohol Use Education.

The next highest educational gaps were in the areas of the limitation of physical activity due to chronic pain. Question 14 relates to the discussion about specific body parts that may limit particular activities. Participants ($n=7$) report it was rarely or never discussed 27% of the time.

Figure 16. Body parts limiting activity. *Question 14, “My PCP has talked to me about what part(s) of my body limits my activity” (PROMIS Physical function).*

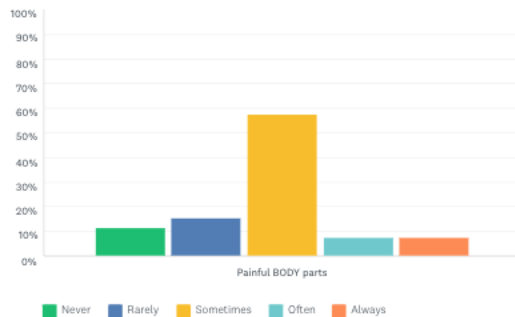


Figure 16. Participants physical limitation of body part education.

Question 17 relates to education regarding at least three activities that are important to the patient, that are affected by chronic pain. Participants ($n=6$) reported it was rarely or never discussed 23% of the time.

Figure 17. Pain impact on three activities. Question 17 “My PCP has talked to me about at least three activities that are important to me that are affected by my chronic pain” (3 Activities and Pain Impact Scale).

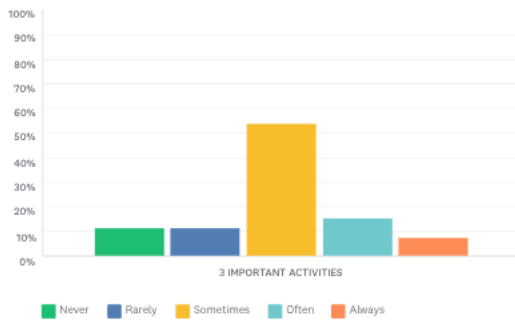


Figure 17. Participant 3 Important Activities valued.

Survey Part B. Part B of the survey examined provider relationship in question 24-32. The summarizing question shows that a large percentage of participants either agree or strongly agree with the statement they feel satisfied with their PCP’s pain treatment. Participants ($n=17$) reported feeling satisfied 65% of the time, while 31% ($n=8$) reported they were unsure.

Figure 18. Pain Treatment Satisfaction. Question 32, “I feel satisfied with my PCP treatment of pain”.

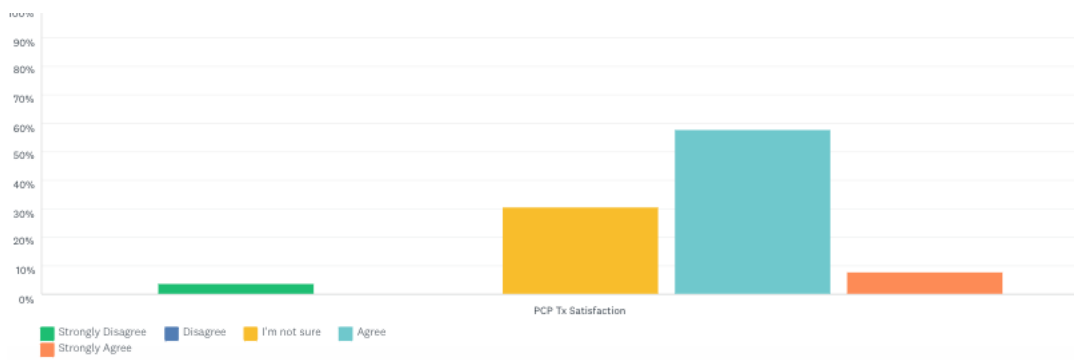


Figure 18. Participant Pain Treatment Satisfaction Response.

Survey Part C. Part C of the survey examined self-management perception in questions 33-40. In part C around 80% of participants ($n= 21$) either agreed or strongly agreed that they felt they could manage as well as most, (question 36). About 69% of participants ($n=18$) reported they felt they could handle self well with regard to chronic pain (question 35).

Figure 19. Self-management perception. Question 35 “I handle myself well with regard to my chronic pain”.

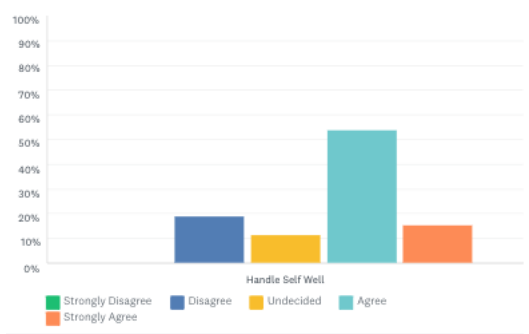


Figure 19. Participant Self-Management relation to others.

Figure 20. Self-Management Perception. Question 36 “I am able to manage things related to my chronic pain as well as most other people”.

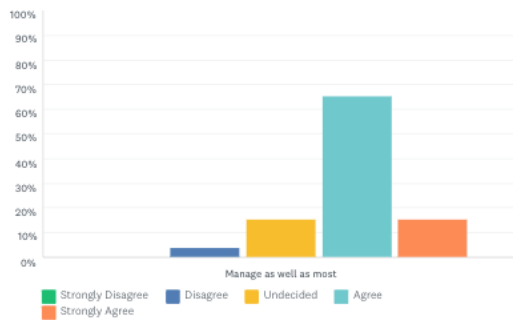


Figure 20. SM Perception relation to others.

Survey comments. The survey comment section was an optional question offering a space for participants to express any final thoughts they would like to share about survey topics

encountered. While the additional data was interesting and insightful, it was not the main focus of this project and was included for consideration for more in-depth future studies.

Figure 21. Participant Comments ($n=7$). Optional Remarks “From your viewpoint, is there anything you would like to share that may be helpful to primary care providers when taking care of persons with chronic pain?”

“For myself, I got used to my chronic pain.”

“Take time to assess.”

“It is hard to be firm in some of these answers because nothing is so black and white. I have run the gauntlet of many methods, medicines, therapies, even surgeries, doctors and healers and no one thing has specifically helped. My physical, mental and spiritual practices and studies have had the most positive effect but even those have certain limitations. My pain is relentless despite my personal reflections of the emotional, relational and familial healing kind. I feel I am at a very good place in my life with those things but the pain still does not let up or transform. My awareness of my part it what caused it and knowing that some things just are what they are for some who have emotional, chemical(whether through poisoning or drug) and/or genetic issues. I find benefit from my experience but I am still just suffering day in and out, hour for hour, minute to minute and it has been over 25 years of it. I have fibromyalgia but I also have now had 3 major spinal surgeries to install 2 lumbar fusions, 4 cervical fusions on the front of my spine and 5 cervical fusions on the back of my spine. I still suffer. I trained in a Taoist temple in china studying internal healing arts and taoist medicine and was worked on many times by my Master, the abbot of the temple, i worked with Native american healers, I have worked with many and Neither Medical, Mystical or Spiritual arts have healed me. My heart and spirit are strong and my will has intent but my body is weak and hurts many places all day everyday. It makes it hard to think, it makes it hard to sleep, it makes it hard to accomplish goals. I cultivate awareness in presence. It helps ease my mind and transform my thoughts, but in the end, the pain still is.”

“Address the current state of pain for relief then move on to the source.”

“If my PCP had ever asked me ANY of the questions that were listed in this survey, my quality of life most likely would have improved. Unfortunately they never have and are generally not helpful when it comes to pain management options or even being able to refer me to a pain management specialist.”

“Pills are not the way, though they can help bridge the difficulty of being in constant pain and finding other ways to manage. Consciousness cultivation and healing oneself and ones relation to and with others, is the only thing that brings any relief and if nothing more, brings wellness into the heart and mind.”

“I am lucky in that someone who works with my PCP has one of the same syndromes I have that causes ~60% of my chronic pain and it was through her advocating for me to my PCP that I was prescribed an emergency pain med. I asked many times to be referred to a pain clinic, they sent me to one within their network and the orthopedic doctor only discussed “mindfulness and meditation” with me over 3 visits and then I stopped going because I was extremely frustrated they couldn’t or refused to talk to me like an adult as to what my pain treatment options were. I have several conditions that cause chronic severe pain. None of these doctors or specialists have ever discussed pain management with me. It has always been me trying to advocate for myself and I am still struggling immensely to find any doctor who will talk to me about pain management options.”

Figure 21. Open comments from 7 chronic pain participants.

Conclusions and recommendations

When examining the data, the areas of holistic education topics were the main focus since chronic pain is such a complex process involving many variables. The survey data focus was on the questions where the patients perceived they either had rarely or never received education from their PCP most of the time. The highest educational gaps identified were, as previously mentioned, related to pain catastrophizing, sleep, fatigue, mood, and alcohol use, which a large minority of primary care providers never or rarely discussed.

When looking at such a large gap of information needed to empower chronic pain patients with improvement of their pain, it suggests we need to place much more emphasis on these topics in the primary care setting. Not only are the individual areas of education important but also the synergistic effect is even more powerful. Ideally, when patients present to their PCP with complaints of chronic pain, they should receive comprehensive information as a foundation to work from to achieve the best self-management outcome possible.

To address this, the recommendation used a two-pronged approach. First, an education poster designed to spotlight the lesser commonly known factors that can improve or worsen chronic pain. The poster items chosen were based on the areas that patients reported receiving little education about in their previous primary care visits. The chronic pain lifestyle poster was designed for placement in the primary care setting to help educate patients while they are waiting to see their provider and also to

support them in starting a dialogue with their provider should the PCP not have covered the topics. Secondly, while this project was focused on patient perceptions, to engage the providers in increasing education, an additional brochure was designed to share the survey results with them, provide additional resource links to the validated tools used for this project and encourage them to increase discussion of these topics along with displaying the posters within their offices.

Chapter 5: Recommendations and Conclusions

Results Discussion

Specific Aim #1

Examine evidenced-based recommendations supporting effective holistic chronic pain care management.

Objective #1: Compare and contrast findings of effective chronic pain care models by reviewing current and landmark evidence-based research.

Objective #2: Identify potential facilitators and barriers to self-management.

Objective #3: Identify comprehensive chronic pain survey tools.

Results. Evidence-based research about non-malignant chronic pain and primary care provider education was examined to support a biopsychosocial model approach recommended by the IOM. Pain management best practices suggest effective chronic pain care management be based upon a biopsychosocial model of care (Pain management Inter-agency task force, 2019). The IOM (2011) concluded a best practice for improving chronic pain outcomes is supporting the patient with self-management efforts, beginning in the primary care setting; this is where the vast majority of patients will be seen for their chronic pain complaints.

The literature reviewed supports further examination of the patient perspective, as this can help identify differences from providers, which allows providers to become more patient-centered in their approach (Lundberg & Melander, 2019). The complex factors involved in chronic pain response including psychiatric, behavioral, educational, medical, and social factors can act as a facilitator or barrier to self-management (Peppin, Cheatele,

Kirsh, & McCarberg, 2015). With the medical model approach being too simplistic, this can be one of the most significant barriers to chronic pain management (IOM, 2011).

Viewing pain through a wider lens, beginning in primary care, helps allow for individualization to the patient and increases the possibility of more successful self-management (IOM, 2011). The PASTOR tools were developed in response to this need and the framework was used in an abbreviated fashion to collect survey data from chronic pain patients.

Specific Aim #2

Use an existing validated chronic pain survey tool framework to create a biopsychosocial survey to collect data from chronic pain patients about their perceptions of pain education delivered by their primary care provider.

Objective #1: Use evidence-based literature to apply the Biopsychosocial framework to chronic pain survey composition.

Objective #2: Incorporate factors identified in findings from evidence-based literature to survey questions based on the Biopsychosocial approach recommendations.

Results: The goals of PASTOR help expand scientific understanding and inform changes to clinical workflow and practice, identifying previously helpful treatments, tailor treatments, engage in shared decision making, increase patient trust and empower patients while identifying barriers (USU, 2020). PASTOR framework was used to create a BPS survey for collecting chronic pain patient perceptions about education received from their PCP. A key component in helping patients self-manage includes a comprehensive assessment incorporating behavioral health approaches that examine potential comorbidities. According to the Pain management Inter-agency task force (2019), “patients with pain and behavioral health comorbidities face

challenges that can exacerbate painful conditions as well as function, QOL, and ADLs”.

Specific Aim #3

Recruit chronic pain adult patients with non-malignant pain to survey their perceptions of chronic pain management education by their primary care providers.

Objective #1: Adult participants will receive an electronic consent form, with a 5-point Likert scale format survey, with option to offer open-ended comments at the conclusion of the survey.

Objective #2: Determine potential gaps in education delivered in the primary care setting.

Objective #3: Synthesize data to determine which areas need more attention in patient education from a patient perspective.

Results. Chronic pain patient recruitment resulted in the enrollment of adult participants (N=26) with non-malignant chronic pain. The participants shared their perception of chronic pain education by their primary care provider, based on a biopsychosocial based framework. Participants had an excellent engagement with the survey questions and averaged 100% on answering all 40 questions. There was less participation from the optional comment area, which only seven participants chose to contribute their remarks to.

The data were examined for the areas with the highest education deficit, as perceived by patients within the BPS framework. The data showed the educational deficits greater than 25% of the time in quite a few categories. In other words, the PCP did not discuss factors patients could use to increase their self-management in several areas. This was reflected by participants in 11 out of 17 items, that 25% of the time or more, these topics were not being discussed. Therefore, the categories where providers could improve education delivery were highest in the behavioral assessment category; for example, up to 46% of the time, the PCP did not educate

about how substances can affect pain response. The next highest was in the category of pain catastrophizing, which acts to increase the biology of stress and can worsen pain. About 38% of the time, PCP's either never or rarely discussed this with patients. Behavioral health can "have a significant impact on treatment outcomes" (Pain management Inter-agency task force, 2019). Lastly, the physical changes to navigate when dealing with concurrent pain complaints such as. Survey was administered, perceptions collected, gaps in education determined, and data synthesized to create educational materials

Specific Aim #4

Create a chronic pain poster for chronic pain practice improvement, based on education gaps identified from the pain survey.

Objective #1: Use synthesized data to construct a pain education poster and brochure using the Biopsychosocial model.

Objective #2: Determine the most appropriate distribution pathway for the poster based on cumulative data findings.

Objective #3: Examine the potential distribution plan for future poster dissemination.

Results. Chronic pain poster created from data collected. The poster was inspired by the American College of Lifestyle Medicine (ACLM) lifestyle medicine pillars, as these are foundational practices when taking a patient-centered biopsychosocial approach. Lifestyle medicine examines the root cause of disease, is evidence-based, produces low cost, and highly beneficial outcomes, focusing on restoration of patient-centered health (Prather & Price, 2020). The lifestyle medicine pillars act as an umbrella to apply recommended education in areas identified within the survey. The pillars prioritize behavioral change for self-management.

Figure 21. Chronic Pain Self-management with use of Lifestyle Medicine

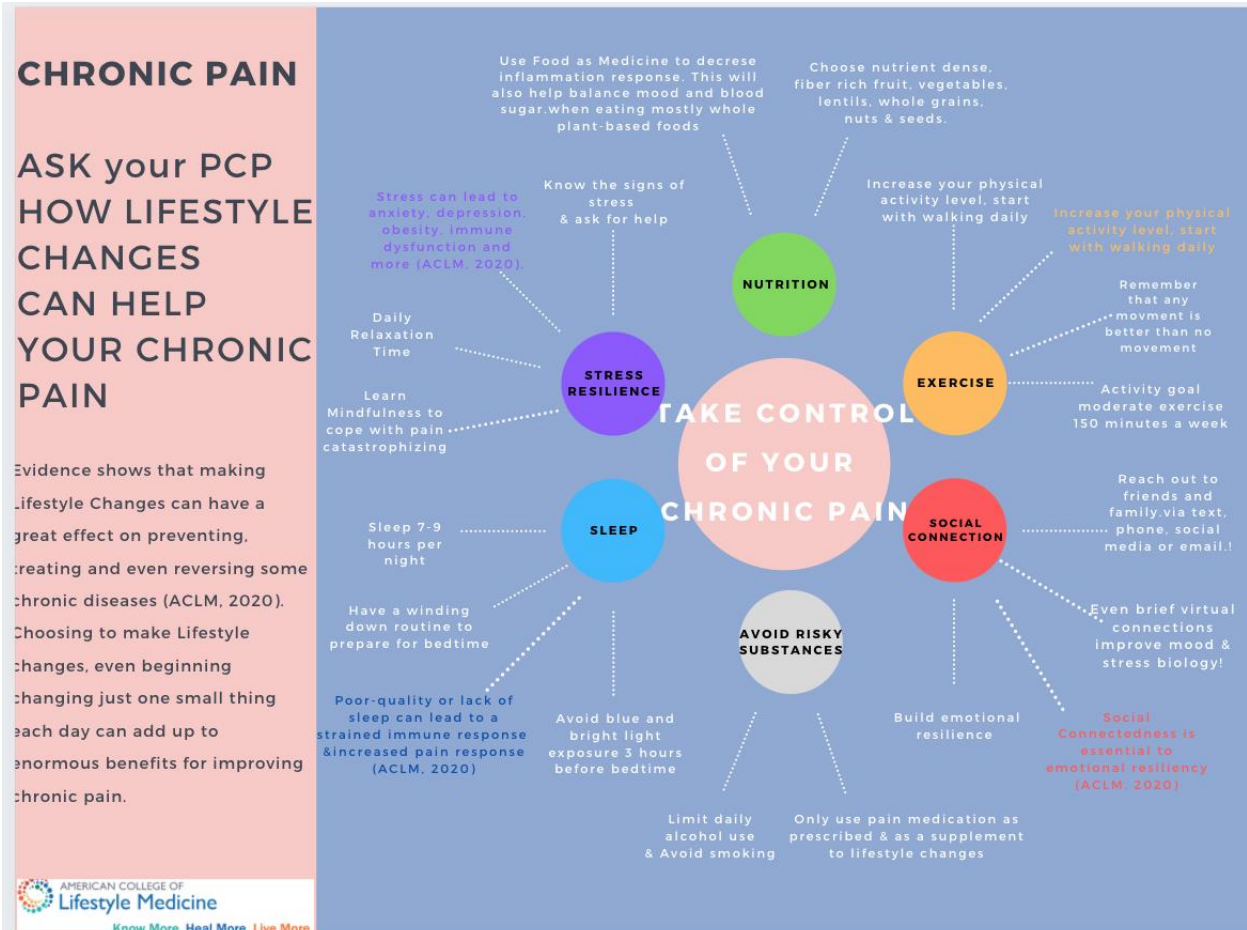


Figure 21. Chronic Pain Self-Managing Poster.

The poster for patients and a brochure for providers, will be distributed to primary care practices to help improve current pain education practice. The potential distribution plan includes disseminating the information to PCP offices with consulting and support services available to those practices wanting to expand beyond the educational posters and brochures.

“Evidence shows being mindful of your food choices, managing your stress, being physically active, avoiding risky substance use, getting plenty of sleep and having a

strong emotional support system in your life prevent, treat, and, often, even reverse chronic disease and select autoimmune conditions” (ACLM, 2020).

Figure 22. Chronic Pain Patient Perception Survey Results Brochure Page 1 and Page 2

RESOURCES

Defense & Veterans Center for Integrative Management (DVCIPM)

- Pain Assessment Screening Tool & Outcomes Registry (PASTOR)
- Joint Pain Education Program (JPEP)
- Patient Education Videos
- Provider-Focused Videos

Weblinks
<http://www.dvcipm.org/clinical-resources/joint-pain-education-project-jpep/pain-educational-videos/#dvprspatient>.

References
 Institute of Medicine [IOM]. National Academy of Sciences, Institute of Medicine, National Academies. Institute of Medicine of the National Academies, & Ebrary, Inc. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, DC: National Academies Press

United States Department of Health [USDOH]. (2019). *Pain Management best practices Inter-agency task force report*. Retrieved from <https://www.hhs.gov/about/news/2019/05/30/pain-management-task-force-issues-final-report-on-best-practices-for-treatment-of-pain.html>

SIX ESSENTIALS OF GOOD PAIN CARE

(DVCIM, 2020)

1. Educating the patient*
2. Educating the care team
3. Exploring Non-Pharmacological Methods to Pain Care
4. Safe Opioid Use
5. Bringing the Healthcare Team Together
6. Establishing Practical Metrics

OF THE SIX ESSENTIALS, EDUCATING THE PATIENT IS THE MOST IMPORTANT OF THESE. IT IS NEEDED TO CARRY OUT THE CARE PLAN BY ALL. (DVCIPM, 2020).

CHRONIC PAIN PATIENT SURVEY RESULTS 2020

OPTIMIZING CHRONIC PAIN SELF-MANAGEMENT

Survey of chronic pain patients identifying gaps in education for best practices to optimize patient self-management



Figure 22. Chronic Pain Patient Education Perception Survey Results Brochure

Impact of Results

The project results stimulated ideas about engaging chronic pain patients and providers to increase the range of dialogue about pain factors. Encouraging more conversations with their providers can lead to higher learning and empower patients to more confidently self-manage, ideally optimizing their maximum opportunity for increasing quality of life through better pain control outcomes.

Posters in the primary care settings could take this a step further in fostering and encouraging more conversations about the multitude of factors that affect chronic pain. More

discussions can help broaden and shift the conversations from solely pharmaceutical or physical derangement or complaint to a more holistic approach, which is what is recommended as a best practice by the IOM. In the future, depending upon the reach of the poster distribution, the posters can also be adapted to each geographical region to make them more culturally specific to where they are being distributed.

It is estimated that chronic pain affects at least one in five adults and costs over 560 billion dollars annually in disability programs, direct medical costs, and lost productivity (CDC, 2020). Use of Lifestyle Medicine (LM) offers an evidence-based, low-cost, accessible approach to answer this problem. “Lifestyle practices are among the nation’s most important health determinants” (ACLM, 2020). Based on the evidence-based literature examined for this project, the body of knowledge in using a patient-centered biopsychosocial approach needs to be expanded. This project contributes to that body of knowledge while offering tools for practice improvement. Utilizing the LM model to address chronic pain can maximize the opportunity for pain relief and self-management capability, confidence, and knowledge leading to improved health outcomes and lowers costs. This broader approach not only provides additional awareness but offers new strategies in which to become skilled in.

Strengths and limitations

The survey data collection provided abundant data that can be further expanded for future research projects. The volume of data collected was a strength to gain insights but limitation because there was far too much to explore fully within this project's context. This project helped reinforce the need for additional evidence-based data on using a more expansive approach to chronic pain than the medical model. While insufficient data supports a BPS approach, there is far less focused on what the patient thinks is important or

what the deficits might be for their needs. Lifestyle medicine works with patients to use shared decision-making as a foundational practice (ACLM, 2020), which further supports providers' opportunity to learn from them.

The project's limitations include the ongoing COVID-19 pandemic, small sample size, necessary online recruitment, potential sample bias due to majority of participants educational level and too vast a volume of data collected to be thoroughly analyzed in the scope of this project.

Dissemination plans

The final manuscript for this project will be submitted to the HOKU database at the University of Hawaii at Hilo for future reference. In the community, project findings shared with other PCP's first and foremost with distribution of educational literature, including survey findings, educational poster, and use of Lifestyle Medicine to help expand pain quality of life improvement practices. For primary care practices interested in improving pain self-management in their populations, further support could be provided to practices via the LM model to increase education delivery and self-management capacity in patients.

The educational primary care pain poster program may be expanded to include a mini-introduction online or a microlearning video to quickly increase understanding. Programs specifically developed for practices interested in having a chronic pain management specific program based on the practices current LM model. The practices can be supported to expand and adopt a new model, which includes shared medical appointments that allow for delivery of more quality education to more patients in less time and incorporates a multi-disciplinary team approach.

Other possibilities include subsequent data analysis for further study, possibly creating

variations of a chronic pain-specific protocol for future use, with LM's application. The development of a pain curriculum for PCP's to offer patients as a resource, additional future research in chronic pain EBP, and engaging an ACLM pain practitioner group are also possibilities. Overall, continued emphasis on use of the biopsychosocial approach, where the patient can be empowered to self-manage more successfully, supports further growth and opportunity for healthcare providers to embrace and expand upon chronic pain best practice.

References

- American College of Lifestyle Medicine. (2012). Lifestyle Medicine Standards. Retrieved from <https://www.lifestylemedicine.org/ACLM-Standards>
- Burnes, B. (2005). Complexity theories and organizational change. *International Journal of Management Reviews*, 7 (2): 73–90. doi:10.1111/j.1468-2370.2005.00107.x.
- Čeko M., Frangos E., Gracely J., Richards E., Wang B, Schweinhardt P., Bushnell MC. Default mode network changes in fibromyalgia patients are largely dependent on current clinical pain. *NeuroImage*. 2020; 216:116877. Retrieved from <https://www.nccih.nih.gov/research/research-results/study-provides-new-insights-into-changes-in-brain-function-in-fibromyalgia>
- Cheatle, M. (2016). Biopsychosocial Approach to Assessing and Managing Patients with Chronic Pain. doi: <https://doi.org/10.1016/j.mcna.2015.08.007>
- Dahlhamer, J., Lucas, J., Zelaya, C., Nahin, R., Mackey, S., DeBar, L., ... Helmick, C. (2018). Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults - United States, 2016. *MMWR. Morbidity and mortality weekly report*, 67(36), 1001–1006. doi:10.15585/mmwr.mm6736a2
- Grady, P.A., & Gough, L.L. (2014). Self-Management: A Comprehensive Approach to Management of Chronic Conditions. *American Journal of Public Health*. 104 (8), e25-e31.
- Gutiérrez Lombana, W., & Gutiérrez Vidal, S. (2012). Pain and gender differences: A clinical approach. *Colombian Journal of Anesthesiology*, 40(3), 207-212.
- Hoffman, A. J. (2013). Enhancing Self-Efficacy for Optimized Patient Outcomes through the Theory of Symptom Self-Management. *Cancer Nursing*, 36(1), E16–E26.

<http://doi.org/10.1097/NCC.0b013e31824a730a>

Institute of Medicine [IOM], National Academy of Sciences, Institute of Medicine, National

Academies. Institute of Medicine of the National Academies, & Ebrary, Inc. (2011).

Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research. Washington, DC: National Academies Press.

Institute of Medicine [IOM]. (2012). *Living Well with Chronic Illness: A Call for Public Health*

Action. Washington, DC: The National Academies Press. <https://doi.org/10.17226/13272>.

Kratz, A. L., Molton, I. R., Jensen, M. P., Ehde, D. M., & Nielson, W. R. (2011). Further

Evaluation of the Motivational Model of Pain Self-Management: Coping with

Chronic Pain in Multiple Sclerosis. *Annals of Behavioral Medicine*, 41(3), 391-400.

Doi:10.1007/s12160-010-9249-6

Lee, C., Crawford, C., & Swann, S. (2014). Multimodal, Integrative Therapies for the Self-

Management of Chronic Pain Symptoms. *Pain Medicine*, 15S76-S85

Doi:10.1111/pme.12408

Lukewich, J., Mann, E., VanDenKerkhof, E., & Tranmer, J. (2015). Self-management support

for chronic pain in primary care: A cross-sectional study of patient experiences and nursing roles. *Journal of Advanced Nursing*, 71(11), 2551-62

Mathias, M., Bair, M., Nyland, K., Huffman, M., Stubbs, D., Damush, T., and Kroenke, K.

(2010). Self-management support and communication from nurse care managers

compared with primary care physicians: A focus group study of patients with chron

musculoskeletal pain. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/20207325>

National Institutes of Health [NIH], US National Library of Medicine. (2016.). Chronic Pain.

Retrieved from <https://medlineplus.gov/chronicpain.html>

- National Institutes of Health [NIH], US National Library of Medicine. (2020). Choosing a primary care provider. Retrieved from <https://medlineplus.gov/ency/article/001939.htm>
- National Institute of Nursing Research [NINR]. (2020a). Self-Management: Improving Quality of Life for Individuals with Chronic Illness. Retrieved from <https://www.ninr.nih.gov/newsandinformation/iq/self-management-workshop>
- National Institute of Nursing Research [NINR]. Riegel, B. (2020b). At the Intersection of Self-Management and Symptom Science. Retrieved from <https://www.ninr.nih.gov/newsandinformation/newsandnotes/riegel-video>
- National Institutes of Health [NIH]. National Institute of Nursing Research [NINR], . (2010). Self-Management Fact Sheet. Retrieved from <https://www.ninr.nih.gov/sites/files/docs/ninr-focus-self-management.pdf>
- Peppin, J., Cheadle, M., Kirsh, K., & McCarberg, B. (2015). *The Complexity model: A novel approach to improve chronic pain care*. Retrieved from <https://academic.oup.com/painmedicine/article/16/4/653/2460532>
- Steglitz, J., Buscemi, J., & Ferguson, M. (2012). The future of pain research, education, and treatment: A summary of the IOM report "Relieving Pain in America: A blueprint for transforming prevention, care, education, and research". *Translational Behavioral Medicine*, 2(1), 6-8. Doi: 10.1007/s13142-012-0110-2
- The International Association for the Study of Pain [IASP]. (2018). IASP Terminology. Retrieved from <https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698>
- Uniformed Services University [USU], Defense & Veterans Center for Integrative Pain Management (DVCIPM). (n.d.). Pain Assessment Screening Tool and Outcomes Registry (PASTOR). Retrieved from <http://www.dvcipm.org/clinical-resources/pain->

assessment-screening-tool-and-outcomes-registry-pastor/

United States Department of Health [USDH]. (2019). Pain Management best practices Inter-

agency task force report. Retrieved from

<https://www.hhs.gov/about/news/2019/05/30/pain-management-task-force-issues-final-report-on-best-practices-for-treatment-of-pain.html>

Figure 1

The Picture of Pain

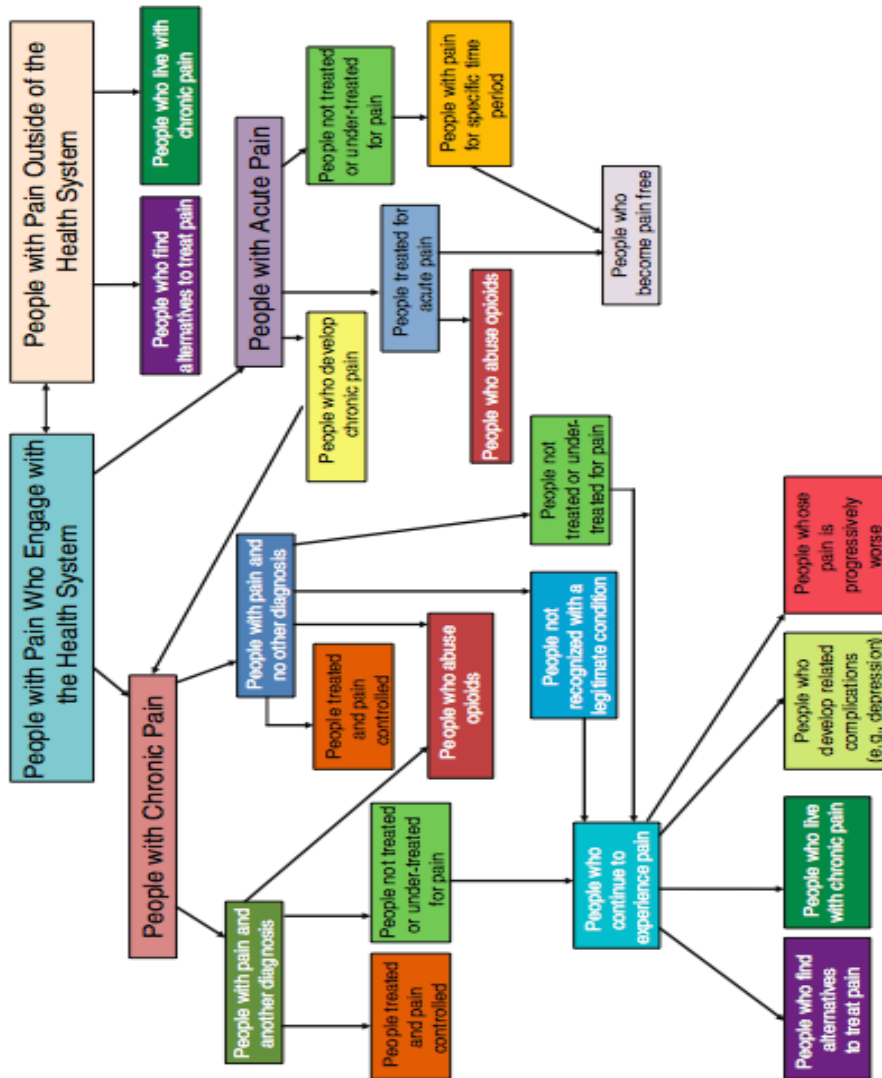


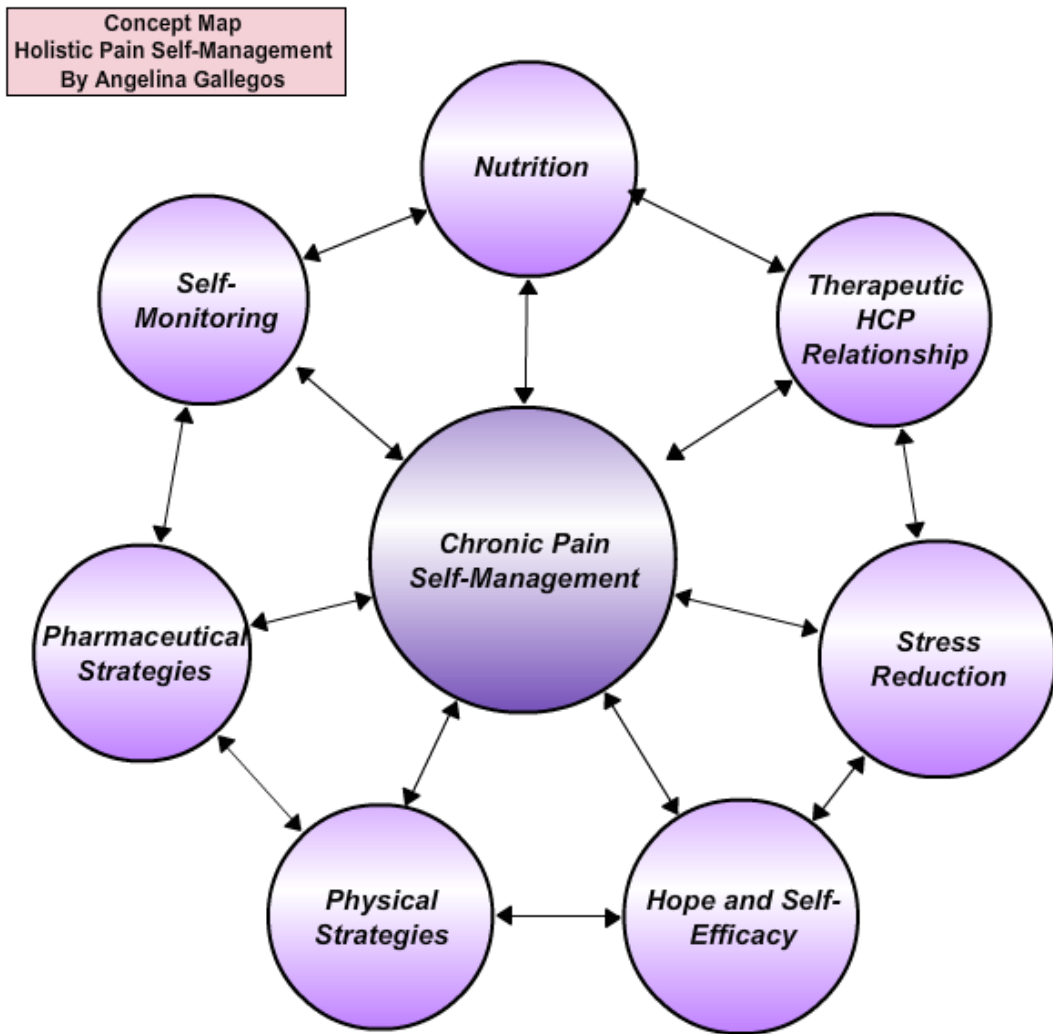
FIGURE 1-1 The picture of pain.
 NOTE: People can move between and among these groupings and can be in more than one group simultaneously. Similar colors represent similar endpoints (e.g., for those within or outside the health system, or for those with chronic or acute pain).

Note: The picture of pain illustrates the pathway(s) taken by pain patients inside and outside the health care system, with the color-coding signifying endpoints with similarities.

Reprinted from The Institute of Medicine [IOM], Institute of Medicine of the National Academies, & Ebrary, Inc. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, DC: National Academies Press.

Figure 2

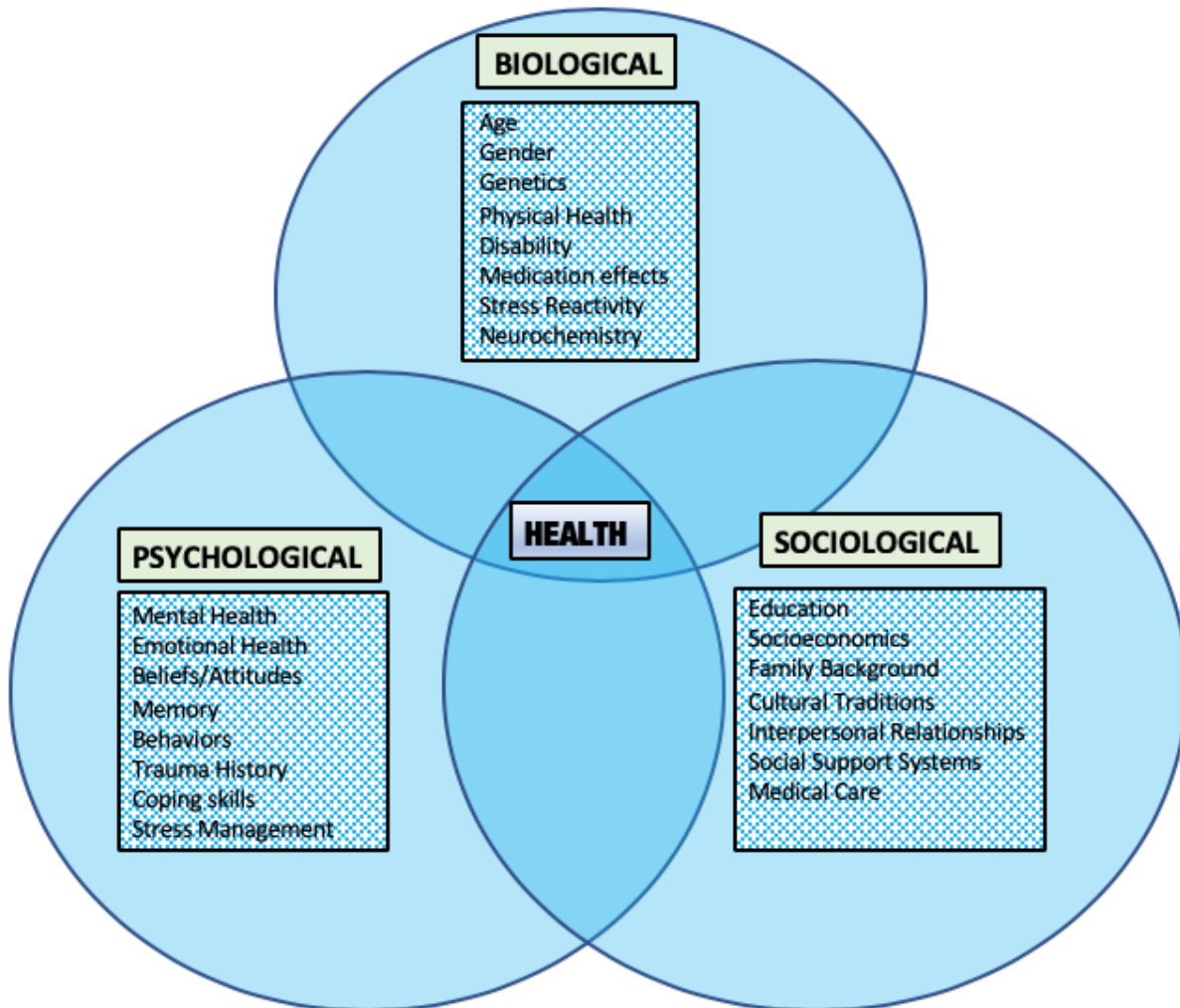
Concept Map for Holistic Chronic Pain Self-Management



Note: The concept map represents considerations that are fundamental to creating a comprehensive and holistic chronic pain self-management strategy.

Figure 3

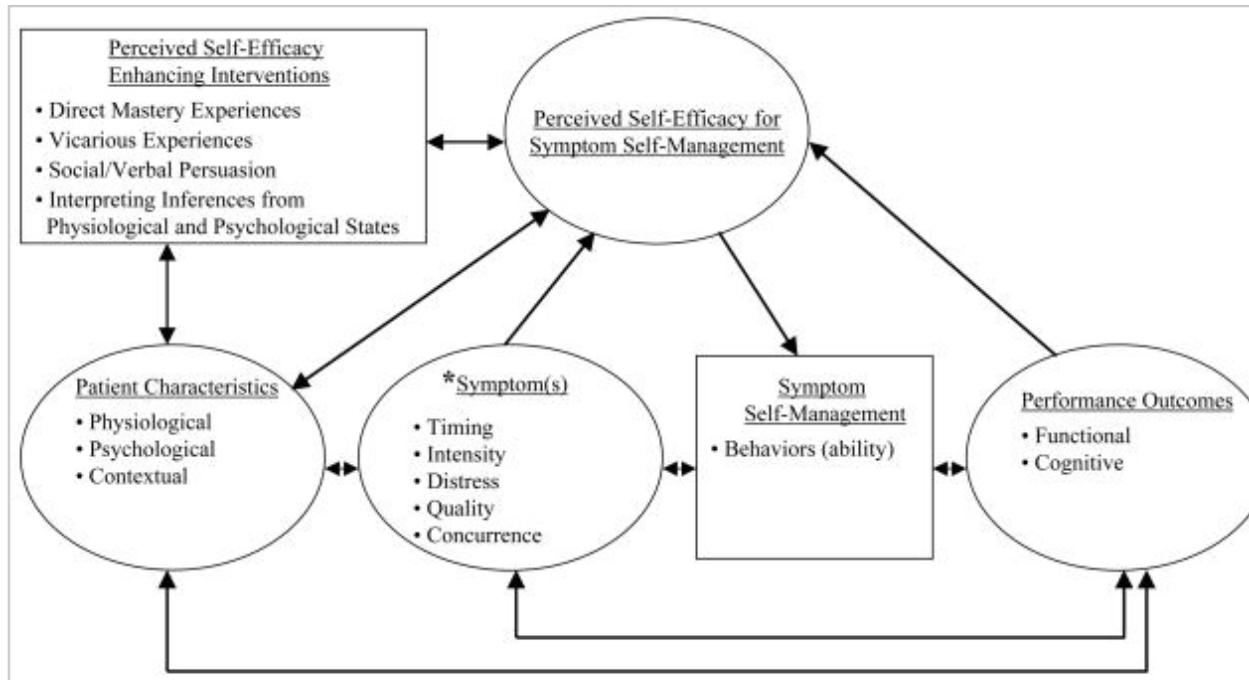
Biopsychosocial (BPS) Model



Note: Biopsychosocial elements which are essential to consider for an effective holistic chronic pain management approach.

Figure 4

Model for Theory of Symptom Self-Management (TSSM)



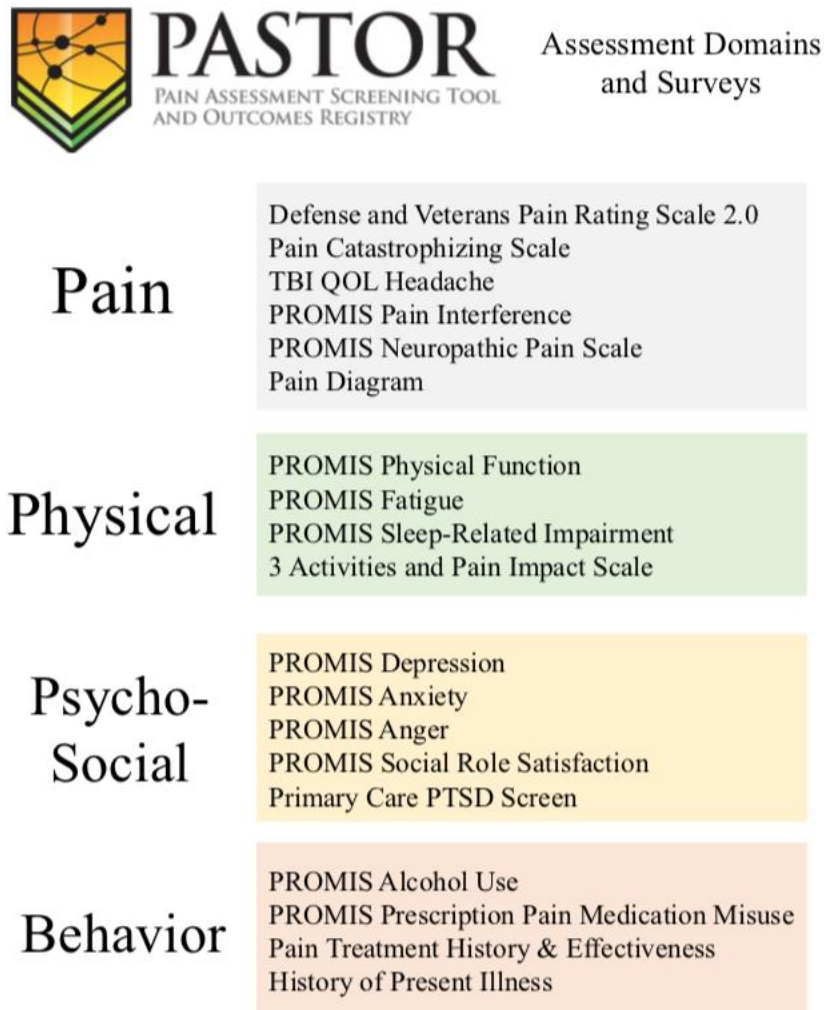
The Theory of Symptom Self-Management

❖ Square indicates an action.

❖ Oval indicates a state or trait.

Note: Model for Theory of Symptom Self-Management (TSSM) reprinted from Hoffman, A. J. (2013). Enhancing Self-Efficacy for Optimized Patient Outcomes through the Theory of Symptom Self-Management. *Cancer Nursing*, 36(1), E16–E26.

Figure 5
*Pain Assessment Screening Tool and Outcomes Registry (PASTOR),
 Assessment Domains and Surveys*



All PROMIS scales, except the Neuropathic Pain Scale, leverage Computer Adaptive Testing, whereby scales are typically completed in 3-8 questions.

Note: This is a model and tool created by the military to address pain management holistically in the military population. These domains have been identified as a cornerstone in treating pain comprehensively. Reprinted from Pain Assessment Screening Tool and Outcomes Registry (PASTOR), Assessment Domains and Surveys: PASTOR Provider Report_V6. Retrieved from http://www.dvcipm.org/site/assets/files/1078/pastor_provider_report_v6.pdf

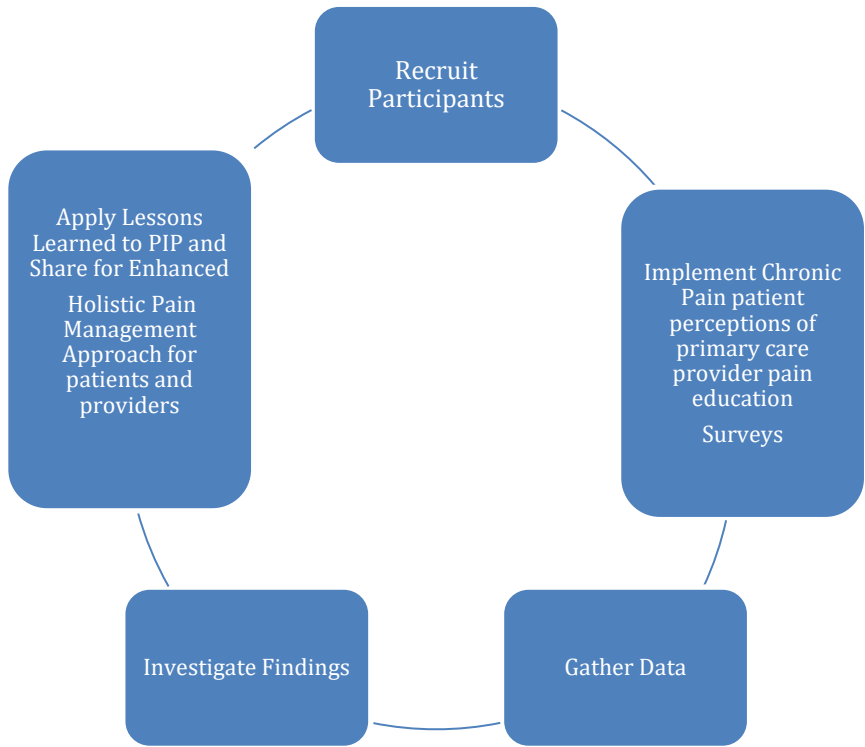
Table 1*Holistic Chronic Pain Project Management Budget*

| Anticipated Expense Details | Cost Estimate | Actual Cost |
|---|----------------------|--------------------|
| Recruitment Posters (Printer Ink & Paper) | \$75 | 100 |
| | | |
| Travel | \$25 | 15 |
| | | |
| Participant compensation: Gift cards @\$10/person x 30 persons | \$300 | 260 |
| | | |
| Online Survey Service -Survey Monkey | \$300 | \$85 |
| | | |
| Project Booklets/Brochure/Poster | \$50 | \$65 |
| | | |
| TOTAL | \$750 | \$525 |
| | | |

Note: These are the estimated expenses for this project focused on Chronic Pain.

Table 2

Holistic Chronic Pain Management Project Implementation



Note: This outlines the process for the implementation of this Chronic Pain project.

Appendices

Appendix A



Purpose: A University of Hawai`i student researcher will be performing this study to learn more about how chronic pain education affects patients with pain.

Study: We are looking for the first 30 eligible adults with chronic pain to participate in a survey that looks at *Patient beliefs about Chronic Pain information provided by their primary care doctor.*

Participants will be asked to:

- Consent to participation in the study.
- Complete an online anonymous survey one time.
- The survey will take around 15 minutes, depending on the person.
- Study volunteers will be compensated with a \$10 gift card.

If you would like to participate in the study OR have questions:

Email: agalleg6@hawaii.edu to receive the Survey Link.

Please Label Subject Line: "PAIN STUDY"

Or Call Angelina Gallegos at 808.463.9994

| | | | | |
|--|--|--|--|--|
| Chronic Pain Study agalleg6@hawaii.edu 808-463-9994 | Chronic Pain Study agalleg6@hawaii.edu 808-463-9994 | Chronic Pain Study agalleg6@hawaii.edu 808-463-9994 | Chronic Pain Study agalleg6@hawaii.edu 808-463-9994 | Chronic Pain Study agalleg6@hawaii.edu 808-463-9994 |
|--|--|--|--|--|

UH IRB Approval Date: TBA

Appendix B



University of Hawai'i
Consent to Participate in a Research Project
 Angelina Gallegos, Student Investigator
 Joan Pagan, Principal Investigator

Project title: Patient Perceptions of Primary Care Provider Pain Education

Aloha! My name is Angelina Gallegos and you are invited to take part in a research study. I am a graduate student at the University of Hawai'i at Hilo in the School of Nursing. I am doing a research project as part of the requirements for earning my graduate degree.

What am I being asked to do?

If you participate in this project, you will be asked to fill out a survey.

Taking part in this study is your choice.

Your participation in this project is completely voluntary. You may stop participating at any time. If you stop being in the study, there will be no penalty or loss to you.

Why is this study being done?

The purpose of my project is to learn more about the pain care patients receive from their doctor or primary care provider and how it affects them. I am asking for your participation if you are 18 or older, have experienced chronic pain (non-cancer related) for more than 3 months and can help share information about some of your experiences.

What will happen if I decide to take part in this study?

You will take a survey with 40 multiple choice questions one time. It will take about 10-20 minutes. The survey questions will be statements like, "My PCP has talked to me about how my pain affects my sleep", "My Primary care provider helps me understand my chronic pain", then you will choose if you agree or disagree with each of them. The online survey is accessed online and to I will provide you a link to participate.

What are the risks and benefits of taking part in this study?

I believe there is little risk to you for participating in this research project. You may become stressed or uncomfortable answering any of the survey questions. If you do become uncomfortable or stressed, you can skip the question or take a break. You can also stop taking the survey or you can withdraw from the project altogether.

There will be no direct benefit to you for participating in this survey. The results of this project may help improve how patients with chronic pain are supported in the future.

Confidentiality and Privacy:

I will not ask you for any personal information, such as your name or address. Please do not include any personal information in your survey responses. I will keep all study data secure in a locked filing cabinet in a locked office/encrypted on a password protected computer. Only my University of Hawai'i advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records. The University of Hawai'i Human Studies Program has the right to review research records for this study.

Appendix B



University of Hawai'i
Consent to Participate in a Research Project

Angelina Gallegos, Student Investigator
Joan Pagan, Principal Investigator

Project title: Patient Perceptions of Primary Care Provider Pain Education

Compensation:

You will receive a \$10 gift card for your time and effort in participating in this research project.

Future Research Studies:

Identifiers will be removed from your identifiable private information and after removal of identifiers, the data may be used for future research studies or distributed to another investigator for future research studies and we will not seek further approval from you for these future studies.

Questions: If you have any questions about this study that you would like answered at any time, please email agalleg6@hawaii.edu or call 808-463-9994. You may also contact my faculty advisor, Dr. Joan Pagan, at jniaukea@hawaii.edu or 808-932-7067. You may contact the UH Human Studies Program at 808-956-5007 or uhirb@hawaii.edu to discuss problems, concerns and questions, obtain information, or offer input with an informed individual who is unaffiliated with the specific research protocol. Please visit <http://go.hawaii.edu/iRd> for more information on your rights as a research participant.

***To Access the Survey:** Please go to the following web page: (surveymonkey.com-may insert link after IRB approval*). Once following the link, you will follow instructions for completing the survey. Going to the first page of the survey implies your consent to participate in this study.

Please print or save a copy of this page for your reference.

Mahalo!

Appendix C

Chronic Pain Project
TEMPLATE: EMAIL SCRIPT + Consent Form

Aloha,

As a University of Hawai'i Nursing School Student, I'm doing research about chronic pain for my final nursing school project. For this project, I need to recruit qualifying participants to take part in my research. The research consists of participation in an online survey, just one time. I would appreciate if you could pass this along to anyone you might know, who may be experiencing chronic pain and eligible to participate in the study. The criteria is below.

I'm looking to recruit around 30 persons to participate in the survey. Those eligible will be:

- Adults, over age 18
- Persons experiencing chronic pain (from any cause of chronic pain except for cancer related pain), for more than 3 months
- Persons who generally receives/seek care from their primary care provider (MD/NP/PA) for this pain.

The hope is to learn more about the kind of education being received from their primary care doctor, what the person experiencing pain has been taught about their pain and how it might affect how they feel about being able to manage their own pain.

Attached is a consent form which includes more of the details about the study and how to participate.

Anyone who would like to participate in the study or has any questions can contact me directly via Email: agalleg6@hawaii.edu or Phone: 808-463-9994.

Thank you so much for your help in passing this along to anyone who may be eligible to participate.

Thank you
Angelina

Angelina Gallegos, BSN, RN, RYT
UH Hilo Doctor of Nursing Practice Candidate
Email: agalleg6@hawaii.edu
Phone: 808-463-9994

Appendix D

Project: **Chronic Pain Patient Perceptions of Education by Primary Care Providers**
 Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval
 Angelina Gallegos, BSN, UHH

Demographics

This part of the questionnaire helps to understand who survey participants are as a group.



| Demographic & Provider Type | | | | | | | |
|--|--|---|--|---|--|--------------------------------|---|
| What is your gender? | Female <input type="radio"/> | Male <input type="radio"/> | NonBinary <input type="radio"/> | Rather not say <input type="radio"/> | | | |
| What is your Ethnicity? | African American <input type="radio"/> | Asian <input type="radio"/> | Caucasian <input type="radio"/> | Hispanic <input type="radio"/> | Native Hawaiian <input type="radio"/> | Other <input type="radio"/> | Rather not say <input type="radio"/> |
| What is your Age Group? | 18-29 <input type="radio"/> | 30-39 <input type="radio"/> | 40-49 <input type="radio"/> | 50-59 <input type="radio"/> | 60+ <input type="radio"/> | | Rather not say <input type="radio"/> |
| What is your highest education level? | Less than 6 th grade <input type="radio"/> | 6 th -8 th grade <input type="radio"/> | 9 th -12 th grade <input type="radio"/> | Some College <input type="radio"/> | College Degree <input type="radio"/> | Other <input type="radio"/> | Rather not say <input type="radio"/> |
| What is your primary language? | English <input type="radio"/> | Hawaiian <input type="radio"/> | Spanish <input type="radio"/> | Other <input type="radio"/> | | | |
| What type of primary care provider do you see for your chronic pain? | Medical Doctor (MD, DO etc) <input type="radio"/> | APRN (FNP, PMHNP etc) <input type="radio"/> | Physician Assistant (PA) <input type="radio"/> | Naturopathic Doctor (ND) <input type="radio"/> | Other <input type="radio"/> | | |

Project: Chronic Pain Patient Perceptions of Education by Primary Care Providers
 Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval
 Angelina Gallegos, BSN, UHH

PART A*:

Instructions This is a questionnaire designed to determine what type of education you have received from your primary care provider about your Chronic Pain.

- Each item is a belief statement with which you may ~~Agree~~ or ~~Disagree~~.
- Next to each statement is a scale which ranges from *strongly disagree* (1) to *strongly agree* (5).
- Please respond to each of the following items by choosing one option for each statement.
- Try to respond to each statement separately in your mind from each other statement. Choose your responses thoughtfully and make them as true FOR YOU as you can. Please respond to every statement.

| Section 1= Pain Scales | Always | Often | Sometimes | Rarely | Never | N/A |
|---|--------|-------|-----------|--------|-------|-----|
| DVPRS | | | | | | |
| My PCP has talked to me about how my pain affects my ACTIVITY level. | | | | | | |
| My PCP has talked to me about how my pain affects my SLEEP. | | | | | | |
| My PCP has talked to me about how my pain affects my MOOD. | | | | | | |
| My PCP has talked to me about how my pain affects my STRESS. | | | | | | |
| My Primary Care Provider (PCP) has talked to me about how negative thoughts may affect my response to pain (Pain Catastrophizing Scale) | | | | | | |
| My PCP has talked with me about how my Pain interferes with activities I liked to do (PROMIS Pain Interference) | | | | | | |
| My PCP has talked with me about what my pain feels like (pins/needles/stinging etc) (PROMIS Neuropathic Pain Scale) | | | | | | |
| | | | | | | |

Project: Chronic Pain Patient Perceptions of Education by Primary Care Providers

Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval

Angelina Gallegos, BSN, UHH

| Section 2= Physical Scales | Always | Often | Sometimes | Rarely | Never | N/A |
|---|---------------|--------------|------------------|---------------|--------------|------------|
| My PCP has talked to me about what part(s) of my body limits my activities (PROMIS Physical Function) | | | | | | |
| My PCP has talked to me about fatigue and chronic pain (PROMIS Fatigue) | | | | | | |
| My PCP has talked to me about the quality of my sleep and effects on my life (PROMIS Sleep-Related Impairment) | | | | | | |
| My PCP has talked to me about at least 3 activities that are important to me, that are affected by my chronic pain (3 Activities and Pain Impact Scale) | | | | | | |
| Section 3= Psychosocial Scales | Always | Often | Sometimes | Rarely | Never | N/A |
| My PCP has talked with me about how my chronic pain affects my ability to participate in my usual roles (PROMIS Satisfaction with Social Roles) | | | | | | |
| My PCP has talked to me about how Anxiety, Anger, Depression or PTSD might be affected or be involved with chronic pain (PROMIS Depression, PROMIS Anxiety, PROMIS Anger, Primary Care PTSD Screen) | | | | | | |
| Section 4= Behavioral Scales | Always | Often | Sometimes | Rarely | Never | N/A |
| My PCP has talked to me about how my chronic pain started (History of Present Illness) | | | | | | |
| My PCP has talked to me about treatments or things I have done that helped with my chronic pain | | | | | | |

Project: Chronic Pain Patient Perceptions of Education by Primary Care Providers
 Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval
 Angelina Gallegos, BSN, UHH

PART B*:

Instructions:

This is a questionnaire designed to determine how you feel about your relationship with your Primary Care Provider (PCP) when it comes to managing your Chronic Pain ONLY.

- Each item is a belief statement with which you may Agree or Disagree.
- Next to each statement is a scale which ranges from *strongly disagree* (1) to *strongly agree* (5).
- Please respond to each of the following items by choosing one option for each statement.
- Try to respond to each statement separately in your mind from each other statement. Choose your responses thoughtfully and make them as true FOR YOU as you can. Please respond to every statement.



| Section 1= Pain | Strongly Agree | Agree | I'm not sure | Disagree | Strongly Disagree | N/A |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----|
| I can talk openly to my PCP about my chronic pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| My PCP understands me | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| I trust my Primary care provider | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| My PCP and I agree on my chronic pain medical symptoms | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| My PCP and I make decisions together about my chronic pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| | | | | | | |
| My Primary care provider helps me understand my chronic pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| My Primary care provider listens to me | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| My Primary care provider really understands my problems with chronic pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| I feel satisfied with my Primary care providers treatment of pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | |
| | | | | | | |

Project: Chronic Pain Patient Perceptions of Education by Primary Care Providers

Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval

Angelina Gallegos, BSN, UHH

*Part B of this survey was developed from the patient-doctor relationship questionnaire (PDRQ-9) in primary care development and psychometric evaluation.
 Source: Validation of the Patient-Doctor relationship Questionnaire (PDRQ-9) in a representative cross-sectional German population survey.
 Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24637904>

PART C:
Perceived Chronic Pain Self-Management Scale

Instructions:

- This is a questionnaire designed to determine how well **you**, yourself, feel you manage your Chronic Pain.
- Each item is a belief statement with which you may ~~Agree~~ or ~~Disagree~~.
- Next to each statement is a scale which ranges from *strongly disagree* (1) to *strongly agree* (5).
- Please respond to each of the following items by choosing one option for each statement.
- Try to respond to each statement separately in your mind from each other statement. Choose your responses thoughtfully and make them as true FOR YOU as you can. Please respond to every statement.

| QUESTIONS | Strongly disagree | Agree | Undecided | Disagree | Strongly Disagree |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| It is difficult for me to find effective solutions for problems that occur with managing my Chronic Pain. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I find efforts to change things I don't like about my Chronic pain are ineffective. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I handle myself well with respect to my Chronic Pain. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to manage things related to my Chronic Pain as well as most other people. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I succeed in the projects I undertake to manage my Chronic Pain. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Project: **Chronic Pain Patient Perceptions of Education by Primary Care Providers**
 Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval
 Angelina Gallegos, BSN, UHH

| | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Typically, my plans for managing my Chronic Pain don't work out well. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| No matter how hard I try, managing my Chronic Pain doesn't turn out the way I would like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I'm generally able to accomplish my goals with respect to managing my Chronic Pain. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Part C: This survey scale was adapted from the Perceived Diabetes Self-Management Scale (PDSMS) which was made "Chronic Pain"-specific by replacing the word "condition" with "Chronic Pain" in each item of the PMCSMS.*

Diabetes self-efficacy was assessed by the 8-item Perceived Diabetes Self-Management Scale (PDSMS) which was made diabetes-specific by replacing the word "condition" with "diabetes" in each item of the PMCSMS.

The PMCSMS, in turn, was adapted from the PHCS (Smith et al. 1995), an instrument that has been shown to be reliable and valid in numerous investigations (e.g., Arnold et al. 2005; Samuel-Hodge et al. 2002). The responses for items range from 1 = "Strongly Disagree" to 5 = "Strongly Agree." Four of the items (#s 1, 2, 6, & 7) are worded such that high agreement signifies low self-efficacy or perceived competence. These four items are reverse-scored prior to being added to the other four items. The total PDSMS score can range from 8 to 40, with higher scores indicating more confidence in self-managing one's diabetes."

Key Reference

Walston, K.A., Rothman, R.L., & Cherrington, A. (2007). Psychometric properties of the perceived diabetes self-management scale (PDSMS). *Journal of Behavioral Medicine*, 30(5), 395-401.

Access & Cost Information This scale is free to use without permission and can be imported into your REDCap Project from the REDCap Shared Library

Project: Chronic Pain Patient Perceptions of Education by Primary Care Providers
Survey Questions Template -Will be Input into Survey Monkey after IRB Project Approval
Angelina Gallegos, BSN, UHH

| |
|--|
| OPTIONAL Feedback or Comments regarding pain care education |
| COMMENTS: |

Appendix E



University of Hawai'i Hilo
Doctor of Nursing Practice
Practice Inquiry Project
Scientific Review Committee Approval

Student's Name: Angelina M.Gallegos Date Submitted: 3/12/2020
Title of Proposal: Chronic Pain patients perceptions of
primary care provider pain education
Name of Committee Chair: Dr.Joan Pagan

Department Scientific Review Decision

Approved:

Not Approved: Comments:

Signature of SRC Chair: *Joan Pagan* Date: 3/18/2020

IRB

Date Submitted: _____

Committee: Social & Behavioral Biomedical

Type of Review (check one)

- Exempt
- Expedited
- Full Review

Approved

Not Approved

Comments:

Attach a copy of the IRB approval letter to this form

Appendix F



UNIVERSITY
of HAWAII
MĀNOA

Office of Research Compliance
Human Studies Program

DATE: July 14, 2020
TO: Pagan, Joan, PhD, University of Hawaii at Hilo, School of Nursing
 Gallegos, Angelina, BSN, University of Hawaii at Hilo, School of Nursing
 Rivera, Victoria, Dir, Ofc of Rsch Compliance, Social&Behav Exempt
FROM: Chronic pain patient perceptions of primary care provider pain education
PROTOCOL TITLE:
FUNDING SOURCE: None
PROTOCOL NUMBER: 2020-00522
APPROVAL DATE: July 14, 2020

NOTICE OF APPROVAL FOR HUMAN RESEARCH

This letter is your record of the Human Studies Program approval of this study as exempt.

On July 14, 2020, the University of Hawaii (UH) Human Studies Program approved this study as exempt from federal regulations pertaining to the protection of human research participants. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.104(d) 2.

Exempt studies are subject to the ethical principles articulated in The Belmont Report, found at the OHRP Website www.hhs.gov/ohrp/humansubjects/guidance/belmont.html.

Exempt studies do not require regular continuing review by the Human Studies Program. However, if you propose to modify your study, you must receive approval from the Human Studies Program prior to implementing any changes. You can submit your proposed changes via the UH eProtocol application. The Human Studies Program may review the exempt status at that time and request an application for approval as non-exempt research.

In order to protect the confidentiality of research participants, we encourage you to destroy private information which can be linked to the identities of individuals as soon as it is reasonable to do so. Signed consent forms, as applicable to your study, should be maintained for at least the duration of your project.

This approval does not expire. However, please notify the Human Studies Program when your study is complete. Upon notification, we will close our files pertaining to your study.

If you have any questions relating to the protection of human research participants, please contact the Human Studies Program by phone at 956-5007 or email uhrb@hawaii.edu. We wish you success in carrying out your research project.

UH Human Studies Program, Office of Research Compliance
 Office of the Vice President for Research and Innovation, University of Hawaii, System
 2425 Campus Road, Sinclair 10, Honolulu HI 96822
 Phone: 808.956.5007 • Email: uhrb@hawaii.edu
<https://www.hawaii.edu/researchcompliance/human-studies>
 An Equal Opportunity & Affirmative Action Institution



Appendix G



Completion Date 26-Mar-2019
Expiration Date 25-Mar-2022
Record ID 31018528

This is to certify that:

Angelina Gallegos

Has completed the following CITI Program course:

Human Subjects Research (HSR) (Curriculum Group)
Exempt Researchers and Key Personnel (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

University of Hawaii



Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w165ab534-3876-4f95-add9-49e50405f44b-31018528



Completion Date 23-Jun-2020
Expiration Date 23-Jun-2023
Record ID 37172066

This is to certify that:

Angelina Gallegos

Has completed the following CITI Program course:

Information Privacy Security (IPS) (Curriculum Group)
Exempt Researchers and Key Personnel IPS (Course Learner Group)
1 - Basic Course (Stage)

Not valid for renewal of certification through CME. Do not use for TransCelerate mutual recognition (see Completion Report).

Under requirements set by:

University of Hawaii



Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wa4f654ad-ca94-445d-8475-e61332bd92a0-37172066