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Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to palliative care services for rural and non-rural populations

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Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to
palliative care services for rural and non-rural populations

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Abstract

The United States health system strives to improve the care patients receive while reducing healthcare expenditures. A significant portion of the nation's healthcare expenditure is spent on end of life care. Palliative care provides one solution to reducing healthcare expenditures while improving the patient experience. Reducing symptom intensity is one example of palliative care's success. A midwest palliative care program was tasked to gather quality data on the service's ability to manage patient symptoms.

The program selected the MD Anderson Symptom Inventory to improve symptom assessment and provide quality metrics for the organization. Additionally, research suggests rural populations have poorer access to palliative care services compared to non-rural patients. In response, a qualitative questionnaire was administered to rural and non-rural patients at consultation to gather information regarding barriers to palliative care services. Finally, the quality improvement initiative was evaluated for acceptability, feasibility, and sustainability. The scholarly project provided the organization characteristics of the population served, accurately assessed symptoms, and tracked performance of symptom management over time. The implications of this project is the MD Anderson Symptom Inventory provided a sustainable and feasible plan for a community based palliative care program to generate and gather quality data. The perceived barrier questionnaire revealed that patients experience symptoms for a long time prior to a palliative care referral and a knowledge gap exists regarding the role and existence of palliative care.

Executive Summary

A midwest palliative care program was tasked to gather quality data on the service's ability to manage patient symptoms. Therefore, the MD Anderson Symptom Inventory (MDASI) was administered to new home-based palliative care referrals to improve symptom assessment and provide quality metrics for the organization. Additionally, research suggests rural populations have poorer access to palliative care services compared to non-rural populations. In response, a qualitative questionnaire was administered to rural and non-rural patients at consultation to gather information regarding barriers to palliative care services.

Implementing the MDASI provided characteristics of the patient population's symptoms at consultation. The MDASI demonstrated that patients consulted for pain were in significant distress with an average pain rating of 7.93 out of 10 at consultation. However, patients who were consulted for pain and had a follow up interaction in 1 week had a mean pain improvement score of 6. The project design demonstrated that the MDASI is capable of measuring program effectiveness in managing symptoms over time. Upon evaluation of the scholarly project, it was learned that implementing the MDASI at consultation, 1 week after consultation, and 1 month after consultation was acceptable, feasible, and sustainable for the organization.

Immediately following the administration of the MDASI, 4 short answer questions were posed to patients during the consultation phone call. The 4 questions were analyzed for themes and patterns. Responses to the 4 short answer questions revealed that patients experience symptoms for long durations of time prior to receiving a palliative care referral. Additionally, patients reported a number of barriers to palliative care services. The most frequently reported barrier was a lack of knowledge of the existence and role of palliative care. In all, 17 of 25

patients did not receive palliative care sooner because of a knowledge gap. Of these 17 patients, 15 responded identically by saying, “I didn’t know about it.”

Patients learned about palliative care most frequently from a primary care provider (PCP). Specifically, 9 of the 25 patients learned about palliative care from a PCP. An analysis of co-occurrences deduced that 4 of the 5 patients that reported symptom duration in years learned about palliative care from a PCP. Oncologists were the second most frequent source of palliative care knowledge, educating 4 patients. Lastly, all patients responded, “no” when asked, “Do you believe where you live impacted your ability to receive palliative care?”

The qualitative analysis of patient perceived barriers to palliative care is consistent with the concerns already described in literature. Patients in both rural and non-rural communities suffer from unrelieved symptoms for long durations of time prior to receiving palliative care. The qualitative analysis was also consistent with literature that suggests a knowledge gap in rural and non-rural communities. Although this knowledge is not new, it validates the need for improved widespread education of palliative care’s existence and role.

Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to palliative care services for rural and non-rural populations

The goal of current healthcare reform known as the triple aim is to improve the health of populations, reduce cost, and improve the patient experience through quality care and improved patient satisfaction (Berwick, Nolan, & Whittington, 2008). The United States spends more money on healthcare than any other country yet our health outcomes are inferior to most developed countries (Bharadwaj et al., 2016). Moreover, in the United States there is a significant disparity in the allocation of healthcare resources among the population. In fact, in the United States two thirds of the nation's healthcare expenditures are spent on just 5-10% of the population. This disproportionate utilization of limited healthcare resources is largely accrued during end of life. Although only 5% of patients with Medicare die each year, end of life care accounts for roughly 25% of Medicare expenditures (Riley & Lubitz, 2010).

Background and Significance

Almost one quarter of seniors live with at least 4 chronic medical conditions (Chen et al., 2015). The final stage of life in patients with chronic conditions is often characterized by heavy and aggressive healthcare utilization. However, research demonstrates that aggressive medical interventions in the final weeks of a patient's life such as emergency department visits, hospitalizations, intensive care unit admissions, and chemotherapy administration are all associated with poor quality of life, poor quality of death, and perceived poor quality of end of life care by caregivers (Higgins, Garrido, & Prigerson, 2015; Hui et al., 2014). Palliative care can address this issue by providing guidance to patients and families to choose appropriate therapies that coincide with a patient's goals and wishes.

Palliative care is an interprofessional discipline that focuses on quality of life for patients with a life limiting illness by managing symptoms, facilitating communication, and guiding patients through medical decision-making (Hui et al., 2014). Quality palliative care is associated with reduced symptom burden, improved quality of life, increased patient and family satisfaction, cost avoidance, and reduced hospitalizations (Kerr, Tangeman, et al., 2014). Hospital systems have adopted palliative care programs in order to improve quality indicators and reduce costs. More recently, new recommendations encourage hospital systems to build and implement community based palliative care programs as an effort to involve palliative care earlier in a patient's experience with a life limiting illness (Kerr, Tangeman, et al., 2014). Earlier palliative care engagement guides proactive rather than reactive decision-making, assessment and treatment of distressing symptoms sooner, and improves quality of life. In fact, an outpatient palliative care referral has been observed as an independent factor for improved end of life care (Hui et al., 2014).

Problem Statement

According to a comprehensive organizational assessment, a midwest community based hospice and palliative care program had a strong desire to gather metrics of program performance in order to evaluate the organization's progress towards achieving the mission and vision. The purpose of this project was to implement and evaluate an evidence-based symptom inventory tool in a community based palliative care program.

Community based palliative care teams are known to reduce cost and improve quality of life by managing distressing symptoms (Brumley et al., 2007). These services however are unavailable to many rural communities (M. A. Bakitas et al., 2015). In this project, the patient population was divided between rural and non-rural areas. To investigate this concern,

additional focused assessment on the differences between rural and non-rural palliative care patients was completed to procure insights regarding perceived barriers to accessing palliative care services.

The Theory of Distressing Symptoms was used as a theoretical framework to guide the selection and implementation of the symptom inventory tool. Short answer questions were formulated to inquire about patient knowledge of palliative care services, establish the duration of time the patient experienced symptoms prior to referral, determine perceived barriers to accessing services, and perceptions of how demographics may impact access to services. Finally, the organization's acceptance of the implementation was measured through staff questionnaires.

The evidence for the chosen tool and a plan for implementation and evaluation was outlined and discussed. The Theory of Unpleasant Symptoms guided conceptualization of the symptom experience and the PARiHS model directed implementation of the quality improvement project. Finally, the project describes stakeholder support, presents a plan for project sustainability, examines the results and implications for practice, and outlines how outcomes will be disseminated. The examination of literature begins with a discussion of the Symptom Science movement because of Symptom Science's mission to expand symptom knowledge.

Symptom Science

The Symptom Science Model was created by the National Institute of Nursing Research to direct biobehavioral research, improve symptom management, and study tissue injury (Henly, 2015). The Symptom Science Model guides the description of complex symptoms, phenotypic characterization, and biomarker discovery for clinical application. The goal of this model is to

expand the understanding of symptoms and symptom management to improve outcomes and health-related quality of life (Cashion & Grady, 2015). The Symptom Science Model was created to make symptom research meaningful. Symptom Science researchers hope to further understand symptom clusters and the trajectory of distressing symptoms over time by forming interdisciplinary teams and encouraging cohesive methodology (Dodd et al., 2001).

Symptom assessment and symptom management is central to the role of nursing (Corwin et al., 2014). Nurses are well educated and are in an ideal position to analyze symptom triggers, reduce severity, and improve the symptom experience. However, the field of symptom science faces many challenges (Henly, 2015). Symptom research is challenging because it is difficult to generalize and compare across populations and research studies (Dodd et al., 2001). Moreover, literature on symptom management utilizes up to 47 different symptom measurement tools (Paice, 2004). The array of tools often measure different symptom clusters and use a variety of different scaling techniques. After addressing the problem of gathering quality and cohesive data, the final challenge identified by the Symptom Science researchers is knowledge dissemination. It is essential to expand understanding of the symptom experience to improve the care offered to suffering populations.

Symptom impact on health

Unrelieved symptoms significantly impact a patient's quality of life and ability to function (Cleeland et al., 2000). Unpleasant symptoms profoundly alters and limits activities, negatively impacts family relationships, impairs work productivity, and decreases quality of life (Dodd et al., 2001). Symptoms can also lead to the feeling of sadness, fear, vulnerability, and cause profound distress (Carlson, Waller, & Mitchell, 2012). For example, researchers suggest that unrelenting pain can lead to depression, anxiety, panic, social isolation, and spiritual crisis.

Unpleasant symptoms contribute to distress and are a major detriment to quality of life and functional ability (Cleeland et al., 2000).

A large symptom burden leads to poor quality of life in patients with a life-limiting illness. In 2016, there were approximately 14.5 million Americans fighting cancer (National Cancer Institute, 2016). Symptomology literature over the last decade consistently reports a high prevalence of symptoms in cancer patients in tertiary care, hospice, and community settings (V. T. Chang, Hwang, Feuerman, & Kasimis, 2000). Patients undergoing cancer treatment are known to report an average of 11 to 13 concurrent symptoms (Fan, Filipczak, & Chow, 2007). Researchers conducting a study in a Veterans Affairs hospital also reported a complex symptom experience, describing a median of 8 concurrent symptoms among cancer patients (V. T. Chang et al., 2000). The most consistent symptoms reported and identified were pain, fatigue, dry mouth, shortness of breath, and difficulty sleeping. Moreover, in these studies pain was never a solitary symptom. In fact, patients experiencing intense fatigue and pain were most likely to experience a multitude of other symptoms as well. Pain and fatigue were closely tied to the symptoms of dry mouth, dyspnea, fatigue, and weight loss (V. T. Chang et al., 2000).

Cancer and heart failure are the 2 most frequently represented diseases within the field of palliative care. Over 5 million Americans are diagnosed with chronic heart failure with a yearly incidence of at least 500,000 (Go et al., 2014). Like cancer, persons with end stage heart failure also have a high symptom burden (Adler, Goldfinger, Kalman, Park, & Meier, 2009). Patients with heart failure endure a mean of 9 symptoms concurrently. The most common symptom clusters noted in heart failure research are shortness of breath, fatigue, pain, drowsiness, and dry mouth (Bekelman et al., 2007). Heart failure may also lead to significant psychological,

physical, and economic burden. Thus there is a tremendous need for community based palliative care to relieve suffering and improve quality of life in this population.

Community Based Palliative Care Programs

Distressing symptoms are the most common reason patients seek healthcare (Xiao, 2010). Palliative care services significantly reduce unpleasant symptoms in patients with a life limiting illness (Bharadwaj et al., 2016). The initiation of palliative care within 48 hours of a hospital admission has been shown to decrease hospital length of stay by roughly 5 days, reduce overall hospital costs by as much as 40%, and has an insignificant impact on mortality rates. According to Bharadwaj et al. (2016) readmission rates are also significantly reduced at 30, 60, and 90 days following hospital discharge if palliative care is consulted early in a hospital stay. In addition, patients may require a hospital readmission and undergo unnecessary suffering (Chen et al., 2015). Hospital readmissions cause further distress and life interruption for both patients and caregivers.

Hospital readmissions are traumatizing to patients and are expensive and burdensome for the healthcare system. Financial penalties continue to climb for institutions with high readmission rates to provide incentives to improve care and reduce readmissions (Kripalani, Theobald, Anctil, & Vasilevskis, 2014). Moreover, readmissions cost the United States healthcare system 17.4 billion dollars annually in Medicare expenditures alone. Over one quarter of patients readmitted within 30 days of discharge are patients with heart failure. To address this issue research attempted to determine which interventions could reduce hospital readmissions for high-risk patients. Timely follow-up, medication reconciliation, patient education, home visits, and patient centered discharge instructions are interventions that significantly reduced hospital readmissions. All of these interventions improve the patient

experience and are at the core of community based palliative care services (Kerr, Tangeman, et al., 2014).

Outpatient palliative care services reduce hospitalizations and increase hospice utilization, which further reduces healthcare costs and improves quality care at the end of life (Blackhall et al., 2016). Kerr et al. (2014) found that an outpatient palliative care referral increased hospice admission by 45% as compared to a control group and increased the duration of hospice services by 25 days. In the same study, patients with an outpatient palliative care referral utilized fewer healthcare resources and saved an average of 11,724 dollars in the last 3 months of life. The cost of care for the treatment group in the final week of life was half of that for the control group. Increased hospice utilization is important for cost avoidance but it is also important for quality care (Higgins et al., 2015). Hospice focuses on preventing and relieving symptoms and prepares family and patient for the time near death (Lynn, 2001). According to Higgins et al. (2015) the duration of hospice care and location of death are the most significant factors for patient caregiver's perceived quality of end of life care. Hospice admissions within a week of a patient's death is associated with poor caregiver perceived quality of end of life care and can often be avoided with early outpatient palliative care involvement.

A primary objective of palliative care is the discussion, documentation, and fulfillment of advanced directives. In fact, patients receiving community based palliative care are 3 times more likely to complete advanced directives (Chen et al., 2015). Although hospice benefits have been a Medicare approved service for over 3 decades, hospice continues to be underutilized or initiated too late (Brumley et al., 2007). In 2007, 60% of deaths occurred in the hospital despite the fact that most patients wish to die at home (Brumley et al., 2007). In one study, improved advanced care planning with community based palliative care resulted in a reduction of hospital

admissions by 59% and shorter lengths of stay by over 5 days per patient (Chen et al., 2015). One hospital implemented an automatic palliative care referral system that triggered referrals for patients that were admitted with a life limiting illness. The hospital found that the automatic referral system significantly reduced aggressive end of life treatment and improved patient satisfaction (Maltoni et al., 2016). This research is consistent with other literature that demonstrates reduced aggressive end of life treatment improves perceived quality of end of life care (Higgins et al., 2015; Maltoni et al., 2016). Community based palliative care increases patient satisfaction, increases likelihood of dying at home, reduces overall cost of care, and promotes the fulfillment of healthcare end of life wishes (Brumley et al., 2007).

Oncology patients are the largest population of patients that utilize palliative care services. As cancer treatment has improved over time, the perception of cancer has changed: more recently cancer has become viewed as a chronic illness that is predominantly managed in the ambulatory setting. Therefore, the most ideal setting to provide palliative care for oncology patients is in the outpatient setting (Hui et al., 2014).

It is valuable to note that symptom burden, in both number and severity of symptoms is not related to the extent of one's disease (V. T. Chang et al., 2000). Therefore, patients with less advanced cancer in the outpatient setting may suffer from a similar symptom burden as those hospitalized for an advanced disease. Oncology patients in the outpatient setting may experience a multitude of symptoms that can be quickly resolved by palliative care engagement.

The impact of palliative care can be measured and identified quickly following a consultation. In one study, outpatient palliative care improved the patient's symptom experience within the first week of a palliative care consultation (Follwell et al., 2009). Palliative care services provided a 10% symptom reduction compared to baseline within the first week of

palliative care initiation. With continued palliative care involvement these results were sustained at 1 month. Patient satisfaction was significantly higher in the palliative care treatment group compared to the control group at 1 week and 1 month after the palliative care consultation.

Symptom reduction is important for quality of life but it may also be important to continue with treatment. Peripheral neuropathy, fatigue, intractable pain, and intractable nausea are all symptoms that can delay, halt, or result in dose reductions of chemotherapy or radiation. Changing treatment course may be necessary but can impact effectiveness of therapy, which can be fatal (J. Chang, 2000). Improving distressing symptoms that result in treatment delay or dose reduction is imperative to proceed with preferred treatment regimens.

Although, cancer and its treatment are distressing, palliative care can help reduce treatment distress. Rummans et. al (2006) studied quality of life in a cohort of patients undergoing radiation therapy for cancer. Quality of life was measured prior to and following radiation for a control group and a multidisciplinary treatment group. The multidisciplinary group included palliative care services. During the study, the control group had significantly poorer quality of life scores after radiation compared to baseline scores. After radiation, the multidisciplinary treatment group showed improved quality of life scores compared to the control group and compared to baseline (Rummans et al., 2006). This evidence suggests that quality of life can be sustained or even improved while undergoing cancer treatment with the involvement of a palliative care team and a multidisciplinary treatment approach. Palliative care services improve quality of life and should be available to all populations (M. Bakitas et al., 2009; Brumley et al., 2007; Hui et al., 2014).

Rural Populations

Rural areas are home to roughly 70 million Americans accounting for 23% of the United States population (Befort, Nazir, & Perri, 2012). Evidence suggests there is a disparity between rural and non-rural populations in referral and access to palliative care services (M. A. Bakitas et al., 2015). Patients residing in the rural setting have different demographics, perspectives on health, and social structures than those in urban settings. Rural populations are more likely to be older, less educated, poor, and diagnosed with cancer at a later stage (Hughes, Ingleton, Noble, & Clark, 2004). According to Hughes et al. (2004) rural patients typically have a different perspective on health and wellbeing. These patients are more likely to view health as the capability of being self-reliant with the ability to work. The culture of rural populations combined with poor access to healthcare services impacts the way rural populations view disease, life, and death.

Rural areas frequently have limited healthcare resources (M. A. Bakitas et al., 2015). Many rural hospitals lack palliative care programs and have little to no community-based services. Patients with cancer and other life limiting illnesses in rural areas may be unaware of services such as palliative care and may not have access to education regarding palliative care services. Evidence suggests that palliative care services are equally effective in reducing health care costs and promoting quality of life in rural areas as urban (M. A. Bakitas et al., 2015). Yet rural communities continue to be underserved.

Simply reproducing urban palliative care models may not translate into the rural setting. Researchers believe that palliative care implementation in rural areas may require unique implementation and practice models due to the unique challenges facing these programs. Rural community based palliative care programs often have scarce resources, a shortage of certified

palliative care practitioners, and small patient volumes (Ceronisky, Shearer, Weng, Hopkins, & McKinley, 2013). Additionally, researchers describe a knowledge gap regarding palliative care services in patients, providers, and communities (Hughes et al., 2004). Large stakeholder investment from rural communities and health settings will be essential to develop and implement new rural specific palliative care models in order for community based palliative care to become a reality in rural communities.

The caregiver structure is often different within rural populations as well (Hughes et al., 2004). Rural patients are more likely to receive care from a spouse because rural populations are more likely to be married than non-rural populations (Glasgow, 2000). Among informal caregivers, children are next in importance in providing care for parents. Although rural populations produce more children than non-rural it appears rural populations have less physical access to those children. Rural populations have less access to offspring and other young people because of the increased geographic mobility among young populations (Glasgow, 2000). Because of this phenomenon older people living in rural communities are more likely to receive non-kin assistance from other elders than older people in urban communities. Overall, older rural residents have stronger informal social support networks and receive more informal caregiving than urban populations. The differences in social structure and caregiving are important to identify when studying rural populations and potential barriers to accessing palliative care.

Common themes were discovered during the literature review of rural patients' access to palliative care services. Researchers report that patients residing in rural areas have less access to palliative care services than those residing in urban settings (M. A. Bakitas et al., 2015). Rural patients are referred to palliative care later than urban patients and spend more time with

unrelieved symptoms prior to attaining services. Ceronsky et al. (2013) and Hughes et al. (2004) have proposed that rural patients do not receive palliative care services in a timely manner due to scarce rural resources, lack of palliative care models specific for rural communities, lack of certified rural palliative care practitioners, poor sustainability of programs due to small patient volumes, and because of a knowledge gap of palliative care services in patients and communities. External barriers have been studied but little literature exists on patient perceived barriers to palliative care. It would be advantageous to learn how patients in the region of interest are learning about palliative care services, determine perceived barriers to services, and if patients believe region of residence influences access to palliative care. The community based palliative care team is missioned to improve the quality of life of patients with a life limiting illness in the region. The knowledge gap that exists in the region and nation is limiting palliative care from reaching patients who would benefit from thorough symptom assessment and effective treatment regimens. However, the symptom experience is complex and challenging to measure (Henly, 2015).

Measuring Symptoms

The study and description of complex symptoms and symptom clusters has long been a focus of nursing science (Henly, 2015). Despite current technological advances in symptom management, little has been done to improve symptom measurement (Dodd et al., 2001). A gold standard to measure the patient symptom experience does not exist. So as a result, measuring the subjective symptom experience is challenging, and continuing to seek an accurate and thorough symptom assessment is crucial to provide high quality care. Inconsistent and inadequate symptom assessments lead to unrelieved symptoms, which decreases quality of life and impairs physical function (Cleeland et al., 2000). Symptoms impact functional capacity and also can

interrupt treatment if severe enough. Thus, symptoms must be assessed accurately and frequently.

Symptom researchers believe that many symptoms are not adequately identified or treated (Cleeland et al., 2000). Due to the subjective nature of distressing symptoms many providers under appreciate patient's symptom burdens. Some assert that oncologists and healthcare professionals do not proactively assess symptoms and wait until symptoms are spontaneously reported (Kerr, Tangeman, et al., 2014). Many providers believe that patients will voluntarily report symptoms if they are truly distressing. However, patients often hesitate to report symptoms until severe and require emergency department evaluation or hospitalization (Kerr, Donohue, et al., 2014). Patients also under report symptoms because they want to be a "good" patient, are resistant to taking additional medications, or have difficulty admitting the disease may be progressing. Many patients do not want to bother providers and family members. Chang et al. (2000) claims patients may assume the provider already knows when the patient experiences symptoms and that reporting is unnecessary. These significant barriers underline the importance of a comprehensive symptom assessment tool and consistent follow up by providers (V. T. Chang et al., 2000).

Measuring What Matters

The American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association recently began a project to identify the most important quality measures in palliative care and hospice (Dy et al., 2015). With the goal to improve quality of life for patients undergoing treatment for a serious illness, the Measuring What Matters (MWM) project selected a set of measures proven to impact quality of care. The MWM team comprised of nurses and physicians and was able to identify 75 published measures relevant to hospice and

palliative care. The MWM project achieved consensus on 10 recommended measures which included: 1) comprehensive assessment; 2) screening for shortness of breath and development of a management plan; 3) screening for pain and providing treatment within 24 hours; 4) screening for nausea and constipation during initial consultation; 5) documentation of a discussion regarding psychological and emotional needs; 6) documentation of a discussion of spiritual needs and concerns; 7) completing documentation of surrogate decision makers; 8) documentation of a discussion regarding preferences for life sustaining treatments; 9) completion of the necessary documentation regarding end of life preferences for vulnerable elders; and 10) surveying patient and family satisfaction. The MWM project created a foundation to evaluate hospice and palliative care programs and established standards to promote program accountability.

Assessment tools assist programs in measuring what is important. In the next sections a variety of measurement tools are discussed.

Assessment Tools

A good symptom inventory is important to improve early symptom detection and treatment. Providers need a tool that can identify symptoms, determine severity, and that is sensitive enough to detect a response to treatment or changes in health (Cleeland et al., 2000). In conducting a systematic review of instruments, Paice et al. (2004) found 47 pain, symptom, and palliative care tools but reported that none were ideal. Creating a perfect symptom assessment tool is challenging due to the complexity and variety of symptoms a patient may experience. Making matters more challenging, symptom experiences are specific to the disease and individual. What may be an ideal symptom assessment tool for one palliative care patient may not be applicable to another. In the next sections, several common symptom inventories are discussed with their relative benefits and limitations.

Palliative Outcome Scale

The POS was developed to measure palliative care outcomes as a whole rather than by symptom management. The goal of the POS is to create higher standards of care by determining if patient and family needs are being addressed effectively and efficiently (Hearn & Higginson, 1999). According to the creators of the POS, it provides an efficient measurement tool designed to meet the need for a short and easy assessment of palliative care core quality measures. The POS consists of 10 Likert scale questions and 2 short answer opportunities. The symptoms measured include pain, nausea, coughing, constipation, anxiety, and psychosocial components. In addition to symptom measures, the POS poses questions regarding goals of care discussions and whether the patient feels needs are being addressed. The POS is validated and reliable for hospice and palliative care in the inpatient and outpatient setting (Hearn & Higginson, 1999).

The POS is the most well rounded palliative outcome scale that meets most of the MWM project points of focus. This assessment may be helpful in evaluating patient care but is not applicable at consultation. The scale takes roughly 8 minutes to complete but may require frequent clarification. Additional concerns regarding the POS are the questionable responsiveness to treatment and the low Cronbach's alpha score of 0.65 suggesting poor internal consistency (Paice, 2004). The POS measures a program's overall performance but is less effective in measuring a program's ability to manage patients' symptoms.

M.D. Anderson Symptom Inventory

The MD Anderson Symptom Inventory (MDASI) was created specifically for the oncology population. The MDASI measures the severity of 13 symptoms and 6 interference items on an 11-point scale (Cleeland et al., 2000). The tool measures pain, fatigue, nausea, disturbed sleep, distress, shortness of breath, remembering, appetite, drowsiness, dry mouth,

sadness, vomiting, and numbness or tingling. The interference items ask the patient how much the symptoms interfere with the patient's general activity, mood, ability to work around the house, relationships, walking, and enjoyment of life. The average completion time of the questionnaire is 5 minutes. The MDASI was created and validated to be administered over the phone or via interactive voice response. The tool is also psychometrically validated in 7 different languages. The test-retest coefficient for the MDASI is 0.75-0.96 and has been validated within the cancer population with a Cronbach's alpha of 0.85 to measure symptoms and 0.93 in the interference items (Paice, 2004).

The MDASI has been validated time and time again with a variety of cancer diagnoses (Cleeland et al., 2000) but the MDASI has not been specifically validated within the broad and expanding palliative care field. However, the symptom clusters of the MDASI are similar to those in the Edmonton Symptom Assessment Scale (ESAS) and other validated palliative care assessment tools (Paice, 2004). Additionally, the MDASI has a large operational and implementation advantage in that it can be administered and validated over the phone or through automated interactive voice response (Cleeland et al., 2000).

Cancer treatment guidelines recommend the regular assessment of the influence of pain on activities such as work, sleep, and social interactions (Cleeland et al., 2000). The interference items on the MDASI meet this guideline and were a significant contributor to the selection of the MDASI for implementation. The midwest palliative care team chose the MDASI as the symptom inventory of choice for this implementation project because of the ability of the tool to measure symptom clusters, the addition of the interference items, and the validation of administration over the phone.

Frequency of Administration

To determine frequency of MDASI administration for the project design a brief literature review was conducted. Upon review, there are no explicit recommendations for reassessment of symptoms in palliative care follow-up. There are however general guidelines for a variety of different patient populations. The Center for Disease Control and Prevention (CDC) recommends monitoring patients receiving chronic opioid therapy every 3 months (Dowell D, Haegerich TM, & Chou R, 2016). High-risk non-cancer patients receiving chronic opioid therapy should receive follow-up as often as weekly (Chou et al., 2009). All patients with cancer should be screened for pain and distressing symptoms at each point of contact (Ripamonti, Santini, Maranzano, Berti, & Roila, 2012). Measuring and identifying pain regularly is essential to effectively manage cancer pain. The exact symptom assessment intervals however, depend on severity of symptoms and patient setting (Walsh et al., 2008). Patients residing in the outpatient setting may require follow up by phone. Specific follow up recommendations do not exist for this population. However, theories are available to guide conceptualization of unpleasant symptoms to deepen the understanding of this phenomenon.

Theory of Unpleasant Symptoms

The Theory of Unpleasant Symptoms (TOUS) is a middle ranged theory intended for application by nurses and clinical researchers (Peterson & Bredow, 2009). The TOUS was the first symptom theory to describe multiple symptoms occurring simultaneously and to depict an interaction between them. The TOUS asserts that symptoms potentiate and catalyze one another and the treatment of one symptom will contribute to the management of another. The TOUS is a theoretical framework used to guide studies of patient's symptom experience. The framework

has been used to study symptoms associated with a variety of illnesses including cancers, chronic obstructive pulmonary disease, heart failure, transplant surgeries, and the postpartum period.

The Theory of Unpleasant Symptoms depicts antecedent factors, the symptoms themselves, and symptoms' impact on performance. In the TOUS, symptoms do not occur in a vacuum. The authors are aware that a patient's situation, environment, demographics, psyche, and physiology all impact the symptom experience. These influencing factors or antecedent factors are conceptualized into 3 categories: physiological factors, psychological factors, and situational factors. Each symptom is measured in multiple dimensions. The dimensions measured include duration, intensity, distress, and quality. The framework illustrates the interaction of symptoms in a stacked configuration. The final concept in the TOUS is performance. Lenz et al. (1997) asserts that symptoms affect performance and in turn performance influences symptoms and the antecedent factors. Appendix A presents a depiction of the theory's conceptual model.

The TOUS can be applied to rural populations. Rural populations have different social and physical environments (M. A. Bakitas et al., 2015). Rural populations also have different physiological characteristics. Specifically, rural populations are more likely to be diagnosed at an advanced stage of disease, more likely to be older, and often have different perceptions of health and illness (Hughes et al., 2004). Rural populations may also have unique antecedent factors and, according to the TOUS, different factors impact the symptom experience. The formation of questions posed to rural populations is guided by the antecedent factors depicted in the TOUS.

The MDASI was created to measure common symptom clusters that occur concurrently (Cleeland et al., 2000). Cleeland et al. (2000) asserts that multiple symptoms have a cumulative

effect on one another and on performance. Consistent with the TOUS, this author also emphasizes the importance of assessing multiple symptoms simultaneously to reduce patient distress. The symptom inventory assesses multiple symptoms on a 0-10 scale to assess intensity. The MDASI also assesses distress and performance through the interference items. However, the MDASI does not measure duration or quality of symptoms.

In summary, the MDASI is consistent with the concepts in the TOUS and serves as a sound measurement tool to measure multiple concurrent symptoms and the impact of symptoms on performance. A middle range theory has guided conceptualization of this project, a literature review was conducted to understand barriers to symptom assessment in those with life limiting illness, and the MDASI has been chosen to measure symptoms. The implementation model utilized to guide and support the implementation process will be discussed next.

PARiHS Implementation Model

The Promoting Action on Research Implementation in Health Services (PARiHS) implementation framework is a useful and practical guide for the implementation of evidence based practice (Rycroft-Malone, 2004). The PARiHS framework was created within the Royal College of Nursing Institute in the United Kingdom as an attempt to portray the complexity of change processes when implementing research based evidence into practice. The key factors within the PARiHS framework are evidence, context, and facilitation (Rycroft-Malone, 2004). Each factor in the framework is on a high or low continuum. Using the PARiHS framework and a variety of implementation attempts, Rycroft-Malone et al. (2004) assert that in order for implementation to be successful there must be clarity regarding the nature of evidence, a quality context, and skilled internal and external facilitation. The most successful implementations occur when scientific support is strong, the implementation contributes to patient satisfaction,

and when the professional team agrees on implementation strategies. Other factors consistent with successful implementation include strong leadership, a context receptive to change, and the presence of feedback systems with accountability.

Evidence

Evidence is “knowledge derived from a variety of sources that has been subjected to testing and has been found to be credible” (Rycroft-Malone, 2004, p. 311). Within the PARIHS framework evidence is not merely research driven, evidence also entails clinical and patient experience. There is considerable evidence of the importance of a consistent assessment of symptoms using a standard and validated measure within the palliative care population (Paiva et al., 2014). In existing research, consistent symptom assessment has a significant impact on patient experience and quality indicators (Paiva et al., 2014). The providers at the midwest palliative care program were aware of the importance of frequent and consistent symptom measurement; however, the previous clinical experience with administering instruments and gathering quality measures had been inconsistent. The providers had a negative clinical experience with measurements; viewing previous implementations as cumbersome and interruptive.

In summary, the evidence for the implementation project was high. The literature review was also consistent on the impact of frequent symptom assessment using a standard measurement tool on quality of care and on the patient experience (Paiva et al., 2014). However, the personal clinical experience of evidence was low. Overall, the evidence for the implementation project was moderate to high.

Context

Context refers to the environment in which the implementation is taking place. Contextual factors include the organization's culture, leadership, and evaluation. The midwest hospice and palliative care organization had a culture that was accepting of change especially when change might lead to actualization of the organization's vision. The organization underwent radical changes over the previous 5 years, increased patient census, and became fiscally sustainable as a result. The organization experienced and survived this change because of strong leadership. The leadership was supportive of the implementation process and was willing to contribute the necessary resources to sustain the project following the doctoral student's involvement. Evaluation was achieved both internally and externally. Internal evaluation occurred as the symptom inventory established a measure for provider effectiveness. The implementation of the MDASI allowed the organization to track symptoms and determine the effectiveness of symptom treatment regimens. Additionally, providers and organizational leadership evaluated provider based effectiveness in order to identify areas of opportunity for education. External evaluations included invested community stakeholders and may support government accountability in the future. The organization desired quality measures to present to donors, invested community stakeholders, and third party payers. The context of implementation in the palliative care program was high due to the positive culture of change, strong leadership, and internal and external evaluation.

Facilitation

Facilitation is a technique in which a person guides implementation and makes the implementation process easier for others. The facilitator's knowledge and skills play a key role in impacting the context. The facilitator's role is to help and support implementation by

providing advice, coordinating efforts between members of the healthcare team, and encouraging others to think critically to assess the achievement of goals. In this quality improvement project the doctoral student was the facilitator of the implementation of the project. The key functions of the facilitator role was to be the expert on the topic, to design evidence-based processes, to guide implementation, to evaluate effectiveness of implementation, and to impress the importance of continuing the project following student involvement. Thus there was significant investment of the facilitator for implementation of the project, and there was motivation for the facilitator to achieve the unified objectives.

Organizational Assessment

Organizational change is a type of chaos (Gleick, 1988). Systems alone are complex but change becomes even more complicated when humans are involved (Burke & Litwin, 1992). However, consistent patterns exist to draw conclusions, make predictions, and guide change within human systems. The Burke-Litwin Model was created through sound theory and research to evaluate organizations considering large changes. This model attempts to portray primary variables and the connecting linkages that should be considered when undergoing organizational change.

The Burke-Litwin Model of Organizational Change was used to guide research and interviews with members of the midwest palliative care program. The Burke-Litwin model predicts organizational performance and its capacity for change (Armenakis & Bedeian, 1999). This model focuses on organizational conditions and how elements of change impact different organizational variables. Appendix C depicts the model and shows the relationship between 12 organizational variables. Variables in the Burke-Litwin model include: external environment; mission and strategy; leadership; organizational culture; structure; management practices;

systems (policies and procedures); work unit climate; task and independent skills; motivation; individual needs and values; and individual and organizational performance. The relationships depicted in the model are either transformational or transactional. Transformational change most often occurs through interactions with environment forces. Transformational change requires behavioral and cultural change of the individuals and of the organization as a whole.

Transactional change occurs through short-term interactions between people and groups and often includes an exchange of information or services.

Burke-Litwin Assessment

The Burke-Litwin Model of Organizational Change was selected to assess the midwest hospice and palliative care team due to the model's ability to assess organizational performance, need for change, and capacity for change. The organization previously attempted to implement symptom inventory quality measures without success. The Burke-Litwin model was used to understand why previous implementation failed and how the organization managed change. The organizational assessment was completed through interviews with the Executive Director, Director of Business Development, Director of Quality and Education, Registered Nurse, and the Medical Director. The assessment of the organization begins by studying the external environment.

External Environment

According to Burke and Litwin (1992) the external environment is the most pivotal factor of organizational change. The external environment is the conditions and situations outside the organization's walls that impact function, vision, and performance. In the region alone there were 16 organizations that provided palliative and hospice care. According to the director of business, the palliative care and hospice field became dense and competitive in the geographical

area with non-profit organizations and for-profit organizations fighting for patients. At times the competition was not friendly. The organization could not be sustained without an adequate census of patients. Therefore, the intense competition impacted marketing strategies and overall functioning of the organization.

According to the Director of Business, stand-alone community-based palliative care programs were not easily sustainable under the current CMS reimbursement policies because programs are only reimbursed for consultations. Additionally, it was anticipated that reimbursement would continue to decline 1 to 1.5 percent in the next few years. The only financially advantageous feature of the palliative care program was a strategy to retain patients during their transition into the organization's hospice program.

The Hospice organization's geographical location in the midwest significantly impacted the organization's success. The people within the organization's region are known for their generosity and willingness to financially support organizations that benefit the community. The hospice and palliative care organization receives substantial donations every year to grow their budget and meet expenses. Without this generous financial community support, the organization would not be so financially secure.

The midwest palliative care program provided care within different facilities. The program served small community hospitals, assisted living facilities, and skilled nursing facilities. Each of these facilities had different policies, procedures, structure, culture, and climate. Whenever the organization's providers entered different healthcare systems, the providers had to adapt to the facility's expectations and requirements. It was necessary for the providers to adapt to new rules, documentation, understand chains of command, and communicate appropriately and effectively to best meet patient and organizational needs.

Working in different systems also mandated varying credentialing requirements. Therefore, each healthcare team member was credentialed to the highest level possible in order to meet the needs of each facility. The relationships with outside facilities were vital and the midwest hospice and palliative care organization devoted significant time and resources to continue forming and strengthening professional ties.

Mission and Strategy

Evidence suggests merely having a written mission statement is important to organizational effectiveness (Burke & Litwin, 1992). The declared mission states what is important to an organization and the strategy outlines how to fulfill the organization's mission and purpose. The Burke-Litwin model not only assesses the mission and strategy of an organization, but also assesses the employee's perception of these statements.

The midwest hospice organization's mission was to, "provide the most compassionate and highest quality end-of-life care through physical, emotional, and spiritual support." The vision was, "by delivering the highest quality of care for living, [the organization] is recognized as the most successful, preeminent hospice in [the state]." The organization's core values were "a passionate belief in: excellence, honest and integrity, sacredness of human life, and the unique contribution of each individual."

The mission statement, vision, and core values were clearly explained and discussed with all new hires. Most desks and bulletin boards around the headquarters had these statements displayed. The Executive Director and Director of Business believed the mission had formed the culture of the organization and they effectively retained the employees that had adopted the mission to guide daily work.

The hospice's mission statement, vision, and core values had key themes that form the backbone of the organization. During discussions with each member of the team the words "excellence," "highest quality," and "compassion" were regularly heard. The organization believed in the importance of an interdisciplinary team approach to provide holistic care to show compassion, and to treat and relieve suffering. The program hoped to reflect a spirit of caring that emphasized comfort and dignity for patients and families. The organization believed in the sacredness of life and respecting people of all cultures, lifestyles, values, and wishes.

The midwest palliative care team's Registered Nurse and Social Worker believed that the palliative care program and hospice shared mission statements, core values, and vision. However, the Director of Business said there was a different vision for the palliative care program. The lack of awareness of the palliative care program's mission and vision by the program's staff was a weakness of the organization. The uninformed team members suggested that the team had little to no contribution to the development of the vision and mission of the palliative care program.

Leadership

Leaders provide direction and serve as role models for employees (Burke & Litwin, 1992). This factor deals with leadership processes, leadership styles, and employee perceptions of the leadership. The midwest hospice and palliative care program as a whole believed that the team provided the highest quality, cost effective, and equitable care in the region. By delivering the best care, the organization hoped to become the most successful preeminent hospice and palliative care team in the region. The specific strategy to achieve this goal was developed by the Executive Director with the Director of Business. Prior to implementation the strategies were discussed with the Board of Directors. The strategies were highly protected and were not

discussed with the board or employees until time of implementation. The highly guarded behavior and lack of transparency from upper management was frustrating to staff. This process was non-negotiable and employees were given the opportunity to transition to new organizations if they could not accept the method of strategy development.

Prior to the tenure of the current Executive Director, the midwest hospice and palliative care organization was not financially sustainable. The organization needed dramatic change for survival. The current Executive Director had a reputation of success in these types of circumstances. It is reported that the Executive Director initially used a coercive leadership style. He demanded immediate compliance and made many large changes within the organization. After the organization recovered from crisis the leadership style transitioned to authoritative in nature. The Executive Director mobilized the team towards a common goal and mission. The Executive Director invited new hires to join in the journey if the applicant fits well within the organization. The expectations, mission, and leadership style was clearly defined for all new employees.

Organizational Culture

Organizational “culture is the collection of overt and covert rules, values, and principles that are enduring and guide organizational behavior” (Burke & Litwin, 1992, p. 532). An organization’s culture is an unspoken “meaning system” that is developed over time through an organization’s history. The midwest hospice and palliative care program’s history was rooted firmly in faith. The founders of the organization were affiliated with the Christian Reformed Church and felt a strong calling to treat and minister to the dying members of the community. Although the organization was not strictly faith based it claimed to be non-denominational and was committed to addressing the spiritual care needs of all patients and families. A Christian

faith was not a prerequisite to be employed at the hospice and palliative care organization but many healthcare professionals had a strong faith that guided their care and work. In the same way the organization ministered to all backgrounds and faiths while providing spiritual care desired by the patient and family.

According to the Nursing Educator and the Director of Business, the arrival of the Executive Director 5 years prior to this project triggered a large culture change. The Executive Director set clear expectations and created a list of rules for all employees to follow. There were 3 main themes throughout the employee manual that were required from all employees. First, “arrive to work on time, if not early, giving [the organization] 100% effort when you are working; second, stay focused, do not spend time on issues you have no control over; and third, get along with your coworkers.” Other topics included in the document were professionalism, effective communication, honesty, respect, and leading by example.

Structure

Structure is how people are arranged into specific areas and outlines responsibility, authority, communication, and relationships (Burke & Litwin, 1992). Structure articulates hierarchy and who communicates and answers to whom. The midwest palliative care program and the hospice program shared staff. The Registered Nurse and Social Worker were the only employees that were solely designated for palliative care program. The providers, Clinical Support Nurse, Patient Care Coordinators, Clinical Liaison, Community Liaison, Director of Business, Director of Quality and Education, Director of Counseling, Director of Finance, Billing Administrators, Director of Human Resources, and Executive Director were all shared between hospice and palliative care programs. This made an organizational diagram very complex. Nonetheless, the overall patient care team was very small and tightknit. The lines of

communication, authority, and personal responsibilities were clear to those within the organization.

Systems

Systems in the Burke-Litwin model represent the standardized policies and procedures that facilitate workflow and evaluation of outcomes (Burke & Litwin, 1992). This concept addresses factors from reward systems and evaluation of outcomes to goal and budget development.

The midwest palliative care team was the only community-based palliative care organization in the region with a physician-based model. This system revolved around the team of physicians that guided treatments and conducted consultations. Although this system and the roles of the supportive cast were clear the workflow, procedures, and policies regarding patient follow-up were ambiguous. There was no system, standard, or procedure that guided patient follow up. Furthermore, there was no consistent formal evaluation of outcomes. For 2 years the program used the Edmonton Symptom Assessment Scale (ESAS) to measure symptoms and monitor outcomes. The team did not believe the tool improved assessment or enhanced patient care and desired to adopt a new tool. During the summer of 2016 the team decided to use the Palliative Outcome Scale to measure quality data to evaluate the program's effectiveness. However, many providers found the tool cumbersome, the information derived irrelevant, and did not appreciate how the tool interrupted the natural workflow of the consultation. As a result many providers did not use the tool and outcomes were poorly evaluated by a standard measure. Although the midwest palliative care team was consulted most for symptom management, the organization had not consistently utilized a standard measure of symptoms. The lack of cohesion

and consistency made it difficult to determine effectiveness of the providers and of the program as a whole.

Management Practices

Management practices are how managers utilize resources to carry out the organization's mission and strategy (Burke & Litwin, 1992). This factor discusses behavior of managers and how they encourage employees to be creative and complete tasks and projects.

Each quarter the managers and directors met to determine and evaluate goals for each team. The goals had to surround 1 of 9 topic areas that contributed to meeting or exceeding the budgeted census. The 9 topics that guided the creation of goals included; business principles expertise, exceptional quality care, high customer satisfaction, long-term relationship building, targeting our audience, create synergy, educate for expertise, hire the best, and benchmarking. It was believed that goals guided by these 9 topics would contribute to the organization's mission of becoming the most successful and preeminent hospice in the state.

Each director managed the budget and determined department needs. Human resources were managed within close relationships. Each individual operated very autonomously but had support whenever needed. The roles and expectations of each staff member were clearly articulated and understood. Quick face-to-face meetings were encouraged and members of the team fed off each other's performance. The patient care managers were largely focused on determining patient needs and appropriate staffing oversight. These managers functioned more day-to-day while directors oversaw larger, more strategic issues. The managers matched supply and demand based on census. The unsteady and ever-changing utilization of nursing staff had a large impact on the work-unit climate.

Climate

The climate is the combination of impressions, expectations, and feelings of the staff and teams that impact relationships with peers, bosses, and other teams (Burke & Litwin, 1992). The work-unit climate was not always stable at the midwest palliative care and hospice program. Staff contentment seemed to rely heavily on patient census. The staff preferred to stay busy and active. However, during long periods of high census the climate could be tense and the staff had a tendency to feel overworked. A steady and manageable workload contributed to the highest employee morale. Within the palliative care team communication and workload were the 2 most significant factors impacting the work climate.

The leadership team was very open to change and appeared capable of effectively managing transitions. According to the Nursing Educator and Quality Director this was not true prior to the tenure of the current Executive Director. Change was reportedly once met with emotion and resistance. A number of employees who could not tolerate change decided to seek new employment opportunities. After a large leadership turnover the remaining team was excited about the trajectory of the organization. The team was capable of modifying practice and had become experts at adapting to the current situation or climate. The team's openness to change and the ability to be led created a positive working environment where creating the best patient experience was the focus.

Task and Individual Skills

Task requirements and individual skills are the knowledge, skills, and abilities required to complete a task and meet a job requirement (Burke & Litwin, 1992). This is often articulated as having an effective job to person match. According to the organization's goals and objectives,

“having the right people, in the right positions, doing the right things, at the right time, places the organization in the right direction.”

The interview process for new hires was long and consisted of 3 different reviews. An objective of the long process was that expectations were clear and the role understood. Another main objective of the arduous interview process was that there be a solid job-person match. The first interview was with the Human Resource Director. The next interview was with the manager and at least 1 member of the team. The final interview was with the Executive Director. The midwest hospice and palliative care organization preferred to recruit rather than post jobs online. Management team members were always looking for hard to fill positions and accepted applications even when positions were not open. This process focused on the long-term vitality of the organization and was proactive rather than reactive ensuring the right person for the right job.

Individual Needs and Values

Individual needs and values refer to the psychological factors that enhance an employee's job satisfaction (Burke & Litwin, 1992). This factor studies how employees derive worth from tasks and work. Each individual has a set of values and beliefs. When tasks are consistent and validate an employee's beliefs, work can be enriching to life.

All employees interviewed during the organizational assessment discussed the importance of alleviating suffering, providing quality care, and showing compassion. The Registered Nurse stated that she felt most fulfilled when developing relationships with patients and alleviating fear. The Marketing Director stated she felt most alive when overcoming obstacles and moving the organization forward. The Marketing Director also enjoyed communicating effectively to make complicated things easier. The Medical Director had a

mildly different perspective. The Medical Director felt most valued and appreciated when he was able to make a meaningful difference in a patient's life. A large reason the Medical Director transitioned from emergency medicine into palliative care was to have a gentler patient to doctor relationship. Whether through difficult discussions or optimal symptom management the Medical Director received fulfillment by leaving a meaningful impression in people's lives. From Marketing Director to Medical Director and Registered Nurse the needs and values were consistent. The employees of the hospice and palliative care program were most fulfilled through making a meaningful difference in people's lives.

Motivation

Motivation is the desire, incentive, or inspiration to complete a task (Burke & Litwin, 1992). Motivation is also described as the energy and power to achieve a goal in order to attain satisfaction. This intangible factor is often generated through values and beliefs. Therefore, there is significant overlap between employee's values and motivation.

Through interviews it was clear the members of the palliative care team were motivated to provide the highest quality care. However, each individual had more specific factors that served as motivation. For example, the Registered Nurse obtained the most satisfaction through impacting a patient's day-to-day life but was specifically motivated by completing individual tasks and completing a daily checklist. The Director of Quality and Education was motivated by working independently and utilizing a variety of skills to fulfill a large range of responsibilities. The directors were highly motivated by competition. The directors deeply desired to be the best hospice and palliative care team in the region and the competition inspired them to action and stimulates new initiatives and strategies.

Individual and Organizational Performance

The final factor of the Burke-Litwin organizational model of performance is a transactional factor (Burke & Litwin, 1992). Individual and organizational performance is the culmination of all other factors and examines the results produced by the organization.

The palliative care team used a variety of metrics to determine outcomes. Possible palliative care metrics were patient census, number of completed advanced directives, effectiveness of symptom management, patient satisfaction, number of patient hospital visits, and number of patients who transition to the organization's hospice program.

The organization was measuring patient satisfaction through an online survey sent out to all patients. Census, percentage of patients with advanced directives, and number of patients transitioning into hospice were monitored regularly. The organization was not however, monitoring other quality indicators. Measuring the organization's ability to manage symptoms was an area of opportunity as symptom management is the most common reason for a consultation with the midwest palliative care team. Unrelieved symptoms significantly impact a patient's quality of life and ability to function (Cleeland et al., 2000). Unpleasant symptoms profoundly alter and limit activities, negatively impact family relationships, impair work productivity, and decrease quality of life (Dodd et al., 2001). A good symptom inventory is important and should improve symptom detection and treatment. Thorough symptom assessment leads to more informed clinical decision making and more effective medication regimens. Due to reimbursement procedures nurses and providers are not reimbursed for follow up patient interactions. Within the reimbursement structure it becomes even more important to establish effective medication regimens that provide optimal symptom relief, which require less provider and nurse follow up. Reducing follow up interactions saves providers time and

decreases cost. Additionally, providing quality care generates positive word of mouth marketing, which should increase patient census. Providing quality care also increases retention of palliative care patients that transition to hospice care.

SWOT Analysis of Organization

The midwest hospice and palliative care team was studied analyzing strengths, weaknesses, opportunities, and threats (SWOT). A SWOT analysis provides a quick and succinct model to identify areas of high performance and opportunities for improvement. A SWOT analysis can help an organization capitalize on strengths and improve weaknesses.

Strengths

The midwest palliative care team had a unique physician-based model. The model ensured that patients saw a physician at the time of consultation and frequently during the first follow up. A physician-based model places a larger workload on the physicians and can be more expensive, but the organization believed this leads to the highest quality of care. There was also a culture of “going above and beyond” for patients. This became the palliative care team’s reputation in the community and the staff fed off of this culture. The palliative care team’s relationship with the hospice program expanded the services the palliative care program could provide. After hours the on-call hospice nurse provided 24-hour support to meet palliative care patient’s needs. The palliative care team had a fulltime social worker and if needed could access the hospice’s bereavement and pastoral care services as well. The team had a reputation of seeing patients quickly. In fact, it was common for patients to be seen the same day the referral was written.

The palliative care team covered a large area providing care in home and in facilities spanning 5 counties. The small team size was another strength of the midwest palliative care

program. Patients with complex diseases and multiple comorbidities were exposed to many healthcare professionals and a multitude of specialists. A small team streamlines communication and reduces the number of patient handoffs. Due to the small size of the team, the patients consistently talked to the same professionals who had developed a relationship and knew the patient's story.

Weaknesses

The midwest palliative care team's 2 largest weaknesses were poor focus on advanced directives and inconsistency in gathering quality data. During the spring of 2016, only a third of the palliative care patients completed an advanced directive. This statistic improved but more work needed to be done to assess and assure patient's wishes. The organization's difficulty gathering quality data had been discussed and was the focus of this quality improvement implementation project. An additional weakness identified by multiple members of the palliative care team was the underutilization of the social worker. Patients were not adequately screened to receive social work services. The social worker had the most available time compared to other members of the palliative care team.

The connection with the organization's hospice program was confusing to many prospective patients and families. The midwest hospice and palliative care team was not affiliated with a hospital or major healthcare system. Many prospective patients perceived this as a weakness as well. Patients with a terminal illness often utilize hospital services. Each time a patient is hospitalized and discharged communication must occur between the hospital system and the palliative care team. This transition of care creates opportunities for fragmented care and miscommunication. Medication reconciliation and updates in the patient's history must occur each time another entity initiates care. Variations in electronic health records make information

sharing even more challenging. Patients are often aware when care is poorly coordinated and poorly coordinated care increases the stress a patient experiences.

Opportunities

The most significant opportunity articulated by the palliative care team was supported in the literature. A knowledge gap existed among community members and even primary care providers (M. A. Bakitas et al., 2015). The organization was committed to allocating resources to provide education to the community and healthcare providers about the services palliative care could deliver. The organization believed there was strength in a physician-based model and boasted of quick consultations following referrals. However, there was poor community awareness about these strengths. This was a significant opportunity for the organization to move forward.

Threats

Hospice and palliative care services were available through many organizations for persons seeking these services. At the time of this project, a number of large hospital systems in the region were in the process of developing a community based palliative care program. In an already saturated market, referrals for the midwest hospice and palliative care team could diminish. Another hospice organization in the region offered unique services and was another competing organization. This other hospice program had a hospice facility for patients who were unable to die at home. And at this facility the other hospice organization had highly sought after designated Medicaid beds. The Medicaid beds were in high demand and many patients signed on with the other hospice organization in the hope of securing one of these coveted beds. In short, competition was the largest threat to the midwest hospice and palliative care organization.

SWOT of Proposed Intervention

Strengths

The midwest palliative care team identified the need for quality data regarding symptom experience. The organization was highly motivated to implement a symptom inventory tool to improve symptom assessment, improve clinical decision-making, determine effectiveness of treatment regimens, and gather data on provider effectiveness. The organization had a mission and strategy that strived for excellence, competitive leadership that wanted to be the best, a culture that accepted change, a system that needed quality data, and professionals that desired to improve performance.

Weaknesses

The organization had previously failed to implement and sustain previous attempts to assess patient symptom experience through surveys and questionnaires. These prior surveys failed because the tools were perceived as too time intensive, the information derived too irrelevant to the providers during consultation, and the tool interrupted the natural workflow of consultations. Another potential weakness was the lack of policy and procedures outlining timeframes for patient follow-up. The implementation strategy of this project created a new workflow and process requiring more frequent and structured patient follow-up.

Opportunities

Generating quality data is important to present to third party payers, the CMS, and invested community stakeholders. The midwest hospice and palliative care program received many sizeable monetary donations from persons who reside in the geographical area. According to the hospice leadership, their charitable donors desire to see impact from the donations provided. Generating and tracking quality data can also provide inter-provider accountability

and track the effectiveness of the prescribers. Overall, gathering quality data increases accountability to patients, government, charitable donors, the community, and workers within the organization.

Threats

The organization's prior failures to implement a symptom experience assessment tool, perceived lack of time during consultations, and the undefined follow up procedures were all possible threats to implementation. Additionally, there was no clear accountability or incentive to incorporate this procedure into practice. Implementation strategies were threatened until the palliative care team was able to observe a tool that has direct impact on patient care.

Key Stakeholders

The key stakeholders of the midwest hospice and palliative care team consisted of the 90 professionals, 200 volunteers, the Board of Directors, the charitable donors, the community, and the patients the organization serves. The organization had a large community support base consisting of volunteers and donors. According to the Executive Director, without the generosity of community donors the organization would not be sustainable. The palliative care program rendered services that cost substantially more than the organization received annually. In fact, the excess funds generated from the hospice program supplied for the financial losses of the palliative care program. The organization did not make the decision to provide palliative care services because it was fiscally advantageous, rather palliative care was provided because the organization believed that palliative care services were needed in the community to improve the quality of life for patients impacted by life limiting illnesses.

Project Plan

Purpose of Project

The midwest hospice and palliative care organization had prioritized the measurement of symptom experience but had been inconsistent in utilizing a tool during consultation and follow up. Therefore, the purpose of this project was to implement and evaluate an evidence-based symptom inventory tool with 4 additional short answer questions in a community based palliative care program. The symptom assessment tool provided a quality measure for the organization to assess outcomes. The short answer questions were used to identify trends and themes of perceived barriers to palliative care services by rural and non-rural patients. Finally, the organization's acceptance of the implementation was evaluated through staff questionnaires.

The proposed project had 2 objectives: 1) meet the organization's needs of generating quality data, and 2) improve understanding of rural populations and the challenges the population experiences in accessing palliative care services. The organizational objectives of this project were: 1) identify a symptom inventory tool that met the needs of the organization, 2) create an evidence-based project design with follow up recommendations, 3) guide implementation, 4) evaluate the protocol's effectiveness, and 5) provide recommendations to sustain the project. The objectives focused on rural populations included: 1) determine the duration of time a patient suffered from unpleasant symptoms prior to obtaining access to services, 2) identify patient perceived barriers to receiving palliative care, 3) determine what mode of communication was effective in educating the patient on palliative care, and 4) determine the patient's perceptions of geography and access to services.

Type of Project

This project was a quality improvement initiative. The project's primary objective was to implement a symptom inventory tool to provide quality data to track the palliative care program's effectiveness in managing patient symptoms. Another primary objective of the project was to gather insights regarding the impact of demographics on patient perceived barriers to accessing palliative care services. Therefore, an additional questionnaire was administered at consultation to identify themes for both rural and non-rural patients in palliative care barriers and utilization. A secondary objective of the proposed project was quality improvement through improved assessment. Frequent standardized assessment of patient symptoms has the potential to enhance provider effectiveness and improve patient care (Ripamonti et al., 2012).

Setting and Needed Resources

The midwest hospice and palliative care program was a non-profit, Medicare-certified, Joint Commission accredited hospice organization. The palliative care program was a member of the Center to Advance Palliative Care (CAPC). The hospice and palliative care team was located in the midwest but provided care in the home, clinic, and in many facilities across the region. The organization's service area spanned 5 surrounding counties.

The implementation of this quality improvement initiative required 900 dollars to purchase the MDASI in English and Spanish; this cost was absorbed by the organization. Additional needs for the proposed project included a phone to make phone calls, a computer, and secure email access to communicate about new consults and discuss follow up information.

Budget

The MDASI core inventory in English cost 100 dollars per healthcare provider. The midwest palliative care team requested a Spanish form of the symptom inventory as well, which

cost an additional 100 dollars per provider. The organization had 4 providers. With the addition of an administration fee the overall cost of implementation was 900 dollars. The MDASI was purchased by the organization in anticipation of long-term use.

Project Design

After thorough consideration of a handful of tools and an evaluation of the needs of the organization, the palliative care team chose the MDASI to measure symptoms and evaluate the palliative care team's performance. The doctoral student conducted phone calls to patients to administer the MDASI and the perceived barriers questionnaire. The perceived barriers questionnaire was administered following the administration of the MDASI during the first interaction only. The MDASI was administered: 1) within 48 hours of consultation to determine symptom burden, 2) 3-7 days after consultation, 3) every medication regimen change, 4) 3-7 days after a medication regimen change, and 5) 1 month following consultation. Rationale for patient follow-up was discussed in the "Measuring Symptoms" section. Start and stop times of MDASI administration was documented to determine administration time. Frequency of MDASI administration was also monitored. Following each phone call the completed MDASI was sent via email to the palliative care team's Registered Nurse for review and to upload the MDASI into the electronic health record. Any additional information regarding the patient was communicated to the team through the organization's encrypted email, over the phone, or face-to-face. A staff questionnaire was administered midway through the implementation project to all healthcare professionals within the palliative care program to evaluate objectives

The midwest hospice and palliative care team spanned 5 counties. According to the United States Census Bureau 2 of the 5 counties are considered rural (US Census Bureau, 2015). The remaining 3 counties the program served are considered non-rural. Patients that completed

the perceived barriers questionnaire were separated into rural and non-rural subgroups by county of residence.

Ethics and Human Subjects Protection

The Grand Valley State University Human Research Review Committee determined that this project was not human research. The project was a quality improvement initiative designed to improve symptom assessment, provide symptom management quality data, and increase understanding of patient perceived barriers to palliative care services. Similar to all quality improvement initiatives, patient data was collected and subject to confidentiality regulations. Data was maintained safely within the organization's offices. A door requiring keycard access, a locked office, and a password-protected computer protect patient data. The doctoral student obtained the patient's name and county of residence upon consultation. All patient identifiers were removed and sensitive information was translated into code. The patient-identifying key was stored on the organization's computers and was not removed from the site at any time. Information was shared between the palliative care staff using the organization's secure email account, over the phone, or face-to-face. During statistical analysis an encrypted thumb drive was used to transport data to the University's statistics department. After the scholarly project was uploaded into Scholar Works all information was given to the organization via encrypted email and information was deleted and destroyed.

Participants and Sampling

Participants included all English-speaking patients living at home or in assisted living facilities referred to palliative care services for symptom management. Additional inclusion criteria included the ability to self-report symptoms. Implementation began February 15, 2017 and ended April 7th upon completion of 25 qualitative questionnaires. Consults from skilled

nursing facilities or hospitals were not included in the sample. Patients in hospitals were excluded from participation because the scholarly project focused on the community-based patient population. Patients residing in skilled nursing facilities were excluded due to feasibility concerns. Based on the experience of the palliative care practitioners, they felt that many patients residing in skilled nursing facilities are unable to self-report symptoms due to cognitive abilities. Additionally, many of the skilled nursing facility patients do not have access to a phone. Therefore, administering the MDASI with patients would require time from the skilled nursing facility staff adding to the staff's workload. To fulfill the objectives of the project in implementing and evaluating a symptom experience tool, the palliative care practitioners wanted to avoid data that could confound the implementation. Persons in skilled nursing facilities will be considered at a later date.

Measurement

The MDASI was the primary measurement tool utilized in the proposed project. The answers to patient perceived barrier questions were synthesized to draw themes. Symptom scores were gathered and changes in scores monitored over time. The frequency of tool administration was counted, the amount of time used to administer the MDASI was calculated, and the project's acceptability by staff was measured via the "MD Anderson Symptom Inventory Implementation Questionnaire."

Steps of Implementation

The project commenced on February 15, 2017. All new referrals were called and surveys were administered. Patients were enrolled in the project on a rolling basis. On March 15, 2017 the "MD Anderson Symptom Inventory Implementation Questionnaire" was administered to determine the staff's opinions regarding the implementation and to guide a plan for

sustainability. The scholarly project ended data collection on April 7, 2017 upon completion of the 25th patient perceived barrier questionnaire.

Project Evaluation Plan

The project was evaluated in a number of ways. Frequency of tool utilization per patient and time to complete the MDASI were calculated. A staff questionnaire was administered on March 15, 2017 to all healthcare professionals within the palliative care program to evaluate objectives, determine workforce opinion, and to guide the sustainability plan. Questions in the staff questionnaire were posed in Likert format and are available in Appendix I. The questions asked the palliative care team: 1) whether the MDASI provided timely and helpful information; 2) contributed to assessment of symptoms; 3) effectively evaluated medication regimen effectiveness; 4) whether follow up intervals were practical and effective; and 5) whether the MDASI and protocol should be sustained in the organization.

Project Outcomes

Overall, 29 referrals were sent to the midwest palliative care program between March 15, 2017 to April 7, 2017. Of the 29 referrals, the MDASI was administered and completed by 19 patients and the qualitative analysis of patient perceived barriers was completed by 25 patients. Of the 19 patients surveyed with the MDASI, only 10 were consulted early enough in the quality improvement initiative to be followed for a month. However, among these 10 patients only 6 completed an MDASI at 1-month post consultation. Of the 19 patients referred for palliative care services 15 were referred for pain, 3 for shortness of breath, and 1 for fatigue.

Of the 29 patients referred for palliative care services, 5 were rural and 24 were non-rural. Approximately 72% of the perceived barrier questionnaire responders resided in Ottawa County. A pie chart of the counties represented in the qualitative analysis is available in

Appendix J. Of the 25 patients surveyed with the perceived barriers questionnaire 4 lived in an assisted living facility, during implementation 2 patients transitioned from palliative care into hospice care, and 2 patients deceased during the scholarly project. The qualitative questionnaire provided information regarding patient perceived barriers to palliative care services and the implementation of the MDASI provided population characteristics of patients referred for palliative care services.

MD Anderson Symptom Inventory Administration

Of the 19 patients that completed the MDASI, 15 patients sought consultation for pain management. The patients consulted for pain were in significant distress with an average pain rating of 7.93 out of 10 at time of consultation. However, the palliative care team was able to provide patients with considerable relief. Patients who were consulted for pain and had a follow up interaction in 1 week reported a mean 6-point improvement of pain. Appendix K presents a boxplot of patient reported pain at consultation, Appendix L presents a table of patient reported pain at consultation, and Appendix M presents a table of pain improvement measured with the MDASI.

The symptom cluster of pain, fatigue, and distress are frequently studied in literature. These symptoms as well as the interference of enjoyment of life inventory item were studied closer to learn patient characteristics and determine program effectiveness. Of the 19 patients that completed at least one MDASI the mean fatigue score at consultation was 6.74 out of 10 and the average distress score was 5.47 out of 10. On a scale of 0 to 10 patients were asked how much symptoms interfered with enjoyment of life. A score of 0 implied symptoms did not interfere at all and a score of 10 implied symptoms interfered with enjoyment of life completely.

The average response to the inventory item was 6.84 at consultation. Appendix N presents these symptom scores at consultation.

A key objective of the project was to provide a symptom inventory that gathered quality measures to monitor the program effectiveness in managing symptoms. During implementation 6 patients were followed for a month. Symptom improvement was studied in these patients at 1 week compared to baseline and 1 month compared to baseline. At 1 week the patients experienced: a mean improvement of pain by a score of 2.67; improvement of fatigue by a score of 1.17; improvement of disturbed sleep by a score of 0.83; and a decrease of symptom interference on enjoyment of life by a score of 0.67. At 1 month the symptom reductions observed were sustained and reduced further. In fact, at 1-month pain scores were improved on average by 3.5 compared to baseline; fatigue scores improved on average by 1.67; disturbed sleep scores improved by 3; and interference of enjoyment of life scores improved on average by 2 points. Appendix O presents a table of improvement of MDASI scores at 1-week compared to consultation and Appendix P presents a table of improvement of MDASI scores at 1-month compared to consultation.

The number of patients observed is far too small to imply significant results or draw generalizable information. The objective of the scholarly project was to create a means to generate and gather quality data. The organization needed a method to monitor program effectiveness in order to have reportable data. The results obtained during the quality improvement initiative provided evidence that the MDASI met the organization's objectives of generating quality data and tracking performance.

Patient Perceived Barriers to Palliative Care Services

Immediately following the administration of the MDASI, 4 short answer questions were posed to patients during the consultation phone call. A thematic analysis was conducted on the qualitative questionnaire to examine and record patterns observed in responses. The doctoral student transcribed responses during the phone call. During analysis responses were coded to determine frequencies and co-occurrences. Finally, themes were induced and patterns are discussed below.

How long have your symptoms affected your life? When reporting duration of time symptoms affected a patient's life, 5 patients reported duration in years and 20 reported duration in months (symptoms affected life less than 1 year). Of the 20 patients reporting duration in months, 3 patients reported that symptoms have affected life for years but clarified that symptoms have worsened within a time described in months. Additionally, 3 more patients that reported duration of symptoms in months clarified by saying, "pain got worse," "pain was up and down until," or "pain got out of control" prior to providing a duration of time in months. The 20 patients that described duration of symptoms in months reported an average duration of symptoms lasting 4.45 months prior to receiving a referral for palliative care. The 5 patients that described duration of symptoms in years reported an average duration of symptoms lasting 3.9 years prior to obtaining palliative care services. Interestingly, the 3 patients that suffered the shortest duration of time prior to obtaining a palliative care consult experienced an acute event that led to quick onset of symptoms and a quick referral.

What has kept you from receiving palliative care before now? A number of barriers were perceived and reported by patients. The most frequently reported barrier to palliative care was lack of knowledge of the existence and role of palliative care. In all, 17 patients did not

receive palliative care sooner because of this knowledge gap. Of these 17 patients, 15 responded identically by saying, “I didn’t know about it.” The remaining 2 patients said, “I never thought about it” and “I didn’t know where to start.” This is the strongest theme induced by the thematic analysis. The remaining themes were only shared by 1 or 2 responders. Of these, 2 patients did not seek palliative care sooner because patient and family wanted to manage symptoms through additional healthcare support such as home care or assisted living. Lastly, 2 responders reported there were no barriers. Both patients had a very short duration of symptoms and attained a referral and consult quickly.

All other barriers were only reported by a single patient. A patient admitted to under reporting symptoms to the primary care provider (PCP) and said, “I didn’t tell him how bad I was. There were a lot of things I didn’t tell him.” The patient stated that she had felt poorly for a long time. She finally received palliative care after honestly talking to her PCP about her symptom burden. The issue of under reporting symptoms was identified during the literature review and validates the need for a quality symptom assessment tool (Kerr, Tangeman, et al., 2014). A patient residing in a rural community received a palliative care referral from the treating oncologist. The patient stated that, “there was nothing the doctors could do for me.” This patient did not receive palliative care earlier because the oncologist wanted to be responsible for controlling the patient’s treatments and symptoms. This patient reported duration of pain affecting life in years and had a substantial symptom burden. Palliative care was not utilized sooner for 1 patient because family was not prepared to accept palliative care services. The patient’s wife admitted she was not ready for palliative care - as if accepting palliative care services was admitting defeat. When asked, 1 patient responded that palliative care services were not attained earlier because the patient lacked a PCP. As soon as the patient was able to

access a PCP a palliative referral was obtained. Lastly, a rural patient's PCP wrote a palliative care referral for the patient without notifying the patient and wife of the referral and without having a discussion about palliative care. The wife was upset about the consult and became defensive about the care she provides the patient. The wife argued that she provides adequate care for the patient and did not need help. After a long discussion about palliative care's role the wife believed palliative care was not needed or desired.

How did you learn about palliative care? Patients learned about palliative care most frequently from a PCP. Specifically, 9 of the 25 patients learned about palliative care from the patient's primary care provider. An analysis of co-occurrences deduced that 4 of the 5 patients that reported symptom duration in years learned about palliative care from a PCP. Although positive that patient's PCPs are educating patients regarding palliative care this co-occurrence would suggest that perhaps PCPs are waiting too long to consult palliative care services. Oncologists were the second most frequent source of palliative care knowledge, educating 4 patients. Education also came from home health nurses (3 patients); friends and family members (2 patients); in-patient non-palliative care healthcare staff (2 patients); other specialists (2 patients); in-patient palliative care team (1 patient); and on the phone with doctoral student (1 patient). A patient knew about palliative care already because she was once a hospice nurse. Patients were educated about palliative care from a multitude of different sources. No strong relationships were identified between barriers to palliative care and source of education about palliative care services.

Do you believe where you live impacted your ability to receive palliative care? All 25 patients responded "no" to this question. In addition to reporting "no," 2 patients believed living in an assisted living facility improved access to palliative care services and 1 patient

believed living in Ottawa County improved the patient's capability to know about and access palliative care services. Weaknesses of this question are discussed in the "Implications for Practice" section.

Characteristics of rural populations. Rural patients were highly hesitant to discuss health related information over the phone. Of the 5 rural patients referred for palliative care services, all were skeptical of the doctoral student's motives and only 1 patient was willing to participate in the MDASI. As discussed earlier, a rural patient declined palliative care after being referred to palliative care without a discussion with the PCP. This patient and wife were extremely skeptical of palliative care and perceived the referral as an insult to the spouse's ability to care for the patient. A couple patients refused to provide any information to the doctoral student. A patient refused to provide any information because "[He] never [discusses] personal information over the phone." The patient asked the doctoral student, "How can I know that you are who you say you are?" The next day the provider drove to the patient's home to conduct the consultation and the patient refused to let the doctor inside. The patient asked the physician to return another day. During a phone call the patient answered the phone and abruptly said, "You'll need to talk with my wife. She handles all of my medications." Before being able to respond the phone was handed to the patient's wife. After describing the importance and relevance of the symptom inventory the wife and husband refused to participate because, "it's been a long day and [the patient] isn't feeling up to it. We would rather share this information one time and directly to the doctor tomorrow." The wife argued that it did not make sense to tell multiple people the same story. During another phone call attempt to reach a rural patient, the mother answered the phone. The mother did not want the patient to be burdened by

the questionnaires and believed the information was too intimate to share over the phone without an established relationship with the staff or program.

Although, only 3 rural patients responded to the qualitative questionnaire of patient perceived barriers, 2 of them learned about palliative care during an inpatient admission. Also noteworthy, similar to information found during the literature review at least 4 patients had strong family support (Hughes et al., 2004). Early into each phone call with rural patients and family members it was clear that 4 patients received care from an informal caregiver. An individual had a very supportive mother and 3 patients had a highly invested spouse. The answers from the questionnaire were not thematically remarkable or different between rural and non-rural patients. The overall interactions however varied greatly between rural and non-rural populations. During implementation patients were not able to participate with the MDASI or the patient perceived barriers questionnaire for a number of reasons. However, only patients residing in rural communities refused to participate. The patients residing in rural areas were more skeptical of healthcare, hesitant to share information, and more likely to have an invested family member as the primary caregiver.

Evaluation of MDASI Acceptability

The scholarly project was evaluated in a number of ways. Frequency of tool administration per patient and time to complete the MDASI were calculated. A staff questionnaire was distributed to evaluate project objectives and to determine palliative care staff opinion regarding the scholarly project. The 10 patients consulted early enough in the quality improvement initiative to be followed for a month were observed for frequency of tool administration. The MDASI was administered to the 10 eligible patients an average of 2.9 times. The administration of the MDASI took an average of 6 minutes and 27 seconds with a median of

5 minutes and 55 seconds. The minimum administration time was 3 minutes and 1 second and the maximum administration time was 11 minutes and 25 seconds. According to Cleeland et al. (2000) administration of the MDASI requires an average of 5 minutes to complete.

Administration time was longer during the scholarly project. This difference in time to administer the MDASI is likely due to patient tendencies to share additional information beyond the questions of the symptom inventory. A frequency table of MDASI administration is available in Appendix Q and a descriptive table of time to administer the MDASI is available in Appendix R.

The number of patients observed is far too small to imply significant results or draw generalizable information. The objective of the scholarly project was to create a means to generate and gather quality data. The organization needed a method to monitor program effectiveness in order to have reportable data. The results obtained during the quality improvement initiative provided evidence that the MDASI met the organization's objectives of generating quality data and tracking performance.

The staff questionnaire was the final mode of project evaluation. All 5 palliative care team members completed and returned the survey. Responders included 2 physicians, 2 registered nurses, and 1 social worker. The staff as a whole agreed strongest that "the MDASI contributed to the assessment of patient symptoms" and "the MDASI was effective in evaluating medication regimen effectiveness/patient condition." The weakest agreement of the staff questionnaire was that "the administration and follow up intervals of the MDASI were practical and effective for patient care and monitoring." One respondent disagreed with this question and wrote on the survey, "frequency is an issue" believing the MDASI was administered too frequently. Other than this one disagreement response all other respondents agreed or strongly

agreed with each item on the implementation staff survey. The responses to the staff survey guided the sustainability plan and will be discussed below. Appendix S contains a bar graph depicting the means and standard deviations of responses to the staff questionnaire. In general, this project met the needs of the organization,

Sustainability Plan

The palliative care team struggled to consistently utilize prior quality measurement tools in place. Palliative care staff attributed the failed implementation attempts to the previously implemented tools. The providers believed the correct tool would be worth utilizing. To combat this barrier the palliative care team decided together to utilize and implement the MDASI. The perception of the tools was one barrier but another complaint regarding prior implementations was the disruption of the workflow during consultation. The palliative care providers were frustrated with the time to administer the tools and felt transitions prior and following the tool were cumbersome. To alleviate this barrier the providers themselves did not distribute the questionnaire or gather data.

During the implementation process the doctoral student completed the MDASI over the phone. Following the completion of the project the Registered Nurse continued to complete the MDASI over the phone. During the organizational assessment, multiple time-consuming responsibilities of the Registered Nurse were identified that could be completed by another employee. Many of these tasks did not require a Registered Nurse's knowledge or expertise. The doctoral student communicated to the organization that reallocating tasks would better utilize the Registered Nurse and was essential for the sustainability of this project. Instead of reallocating tasks, the organization elected to hire an additional fulltime Registered Nurse to improve the workload and ensure sustainability of the quality improvement project.

During implementation the Registered Nurses voiced concern regarding the workload of administering the MDASI prior to and following every medication regimen change. This concern resulted in a change in frequency of MDASI administration. Therefore, the organization agreed to administer the MDASI at consultation, 1 week following consultation, 1 month following consultation, and each month thereafter. The MDASI would continue to be administered and uploaded into the patient's electronic health record and the quality data would be maintained by the Director of Quality and Education. The Doctor of Nursing Practice (DNP) project is the culmination of the DNP education experience and is a final opportunity to learn, grow, and display the essentials in practice within a functioning organization. The DNP essentials utilized within this scholarly project are discussed below.

Doctor of Nursing Practice Essentials

The DNP essentials were established to outline fundamental curricular competencies in Doctor of Nursing Practice (DNP) programs (American Association of Colleges of Nursing, 2006). The achievement and growth of the 8 competencies are attained in a number of ways throughout the DNP program.

Essential I: Scientific Underpinnings for Practice

Essential I is the scientific underpinning for practice competency. This essential demonstrates an understanding of complexity of practice and the conceptual foundations of nursing (American Association of Colleges of Nursing, 2006). This essential was demonstrated in this project by the utilization of nursing theory as a conceptual framework for the phenomenon of unpleasant symptoms and through the utilization of an implementation model. Essential I was also fulfilled through the evaluation of symptom literature and, in response, the development of a

new strategy to assess and monitor patient's symptoms. Finally, this essential was demonstrated through evaluation of the implemented strategies.

Essential II: Organization and Systems Leadership for Quality Improvement

Essential II is the organization and systems leadership for quality improvement and systems thinking competency (American Association of Colleges of Nursing, 2006). Conducting an organizational assessment using the Burke-Litwin Model enacted this essential. This project also demonstrates essential II by providing a means of accountability for the organization's performance in managing symptoms. This quality improvement initiative provides quality data that can be monitored by the organization, reported to government agencies, and used for advertisement purposes. Throughout the implementation process the doctoral student enacted essential II through advanced communication skills and through leadership of the quality improvement initiative.

Essential III: Clinical Scholarship and Analytic Methods for Evidenced-Based Practice

Essential III is the clinical scholarship and analytical methods for evidence-based practice competency (American Association of Colleges of Nursing, 2006). This essential was demonstrated through critical appraisal of pertinent literature and by evaluating current practices within the organization. The organization's assessment techniques, processes, and follow up procedures were analyzed to guide the quality improvement initiative. The quality improvement initiative methodologies were also evaluated to promote effective, efficient, and equitable patient care, further utilizing essential III. The doctoral student was a collaborative consultant for the organization to improve symptom assessment and to provide quality data. Lastly, uploading the scholarly project into Scholar Works will enact essential III through disseminations of findings.

Essential VI: Interprofessional Collaboration

Essential VI is interprofessional collaboration for improving patient and population health outcomes competency (American Association of Colleges of Nursing, 2006). This essential was enacted by frequent communication with all members of the palliative care team. In addition, the doctoral student led the palliative care team in discussions of symptom management, available symptom inventory tools, and presented evidence of the importance of routine symptom assessment with a standard tool.

Essential VII: Clinical Prevention and Population Health

Essential VII is clinical prevention and population health for improving our nation's health competency (American Association of Colleges of Nursing, 2006). This essential was exhibited in a number of ways during the scholarly project. Palliative care's ability to accurately and thoroughly assess and treat symptoms improves the quality of life of this population (Hui et al., 2014). The purpose of this quality improvement initiative was to improve symptom assessment to further improve quality of life for the palliative care population. Determining barriers to palliative care and examining themes between rural and non-rural patients is another way this essential was enacted. Improved knowledge regarding barriers to palliative care can guide strategies to reach populations with poor access to improve population health and quality of life.

Essential VIII: Advanced Nursing Practice

Essential VIII is advanced practice nursing expertise competency (American Association of Colleges of Nursing, 2006). This essential was enacted through personal engagement with patients over the phone. During phone interactions the doctoral student assessed multiple symptoms, quality of life, and distress. Communications regarding symptoms and disease

progression required tact, discernment, and sensitivity. Over the phone the doctoral student needed to be perceived as professional, compassionate, and trustworthy. After multiple interactions, relationships were built with patients. Essential VIII was further enacted through educating the Registered Nurses on information learned during the quality improvement initiative. Lastly, this essential was enacted during the scholarly project by utilizing conceptual and analytical skills to evaluate and understand links in practice, populations, and policies.

Implications for Practice

Palliative care services are provided in an assortment of settings including hospitals, outpatient clinics, rehabilitation facilities, assisted living facilities, skilled nursing facilities, and inside patient's homes (Meyers, Kerr, & Cassel, 2014). Community-based palliative care is a comprehensive and multidisciplinary service that follows patients across the disease trajectory through transitions of care and a variety of healthcare settings (Kamal, Currow, Ritchie, Bull, & Abernethy, 2013). Community-based palliative care teams have the advantage of seeing a patient's environment to further individualize care and extend care to meet the need of patients with life limiting illnesses who are home bound. This home-based approach is an opportunity to reach rural populations and improve the care these patients receive.

A significant component of palliative care and its success on patient outcomes is the ability of the team to manage distressing symptoms (Hui et al., 2014). Unpleasant symptoms impact almost every facet of a patient's life and impairs functional capacity and increases patient's distress (Carlson et al., 2012; Cleeland et al., 2000). Patients struggling with a life threatening illness have a right to good symptom management. In order to provide the best care, symptoms must be measured regularly and accurately. A quality symptom inventory identifies symptoms, measures severity, and is sensitive enough to detect responses from treatment

(Cleeland et al., 2000). Although no symptom inventory is perfect, the MDASI best suited the needs of the midwest community based palliative care team.

Successes

The quality improvement initiative established and implemented a sustainable plan to obtain quality measures, improve symptom assessment, and standardize patient follow up procedures. By implementing the MDASI the organization can learn about its patient's characteristics, track provider effectiveness, and report the program's performance to community stakeholders.

The qualitative analysis on patient perceived barriers to palliative care is consistent with the concerns already noted in literature. Patients in both rural and non-rural communities are suffering from unrelieved symptoms for long durations of time prior to receiving palliative care. The qualitative analysis was also consistent with literature that suggests a knowledge gap in communities. The overwhelming majority of patients did not receive palliative care before referral because the patient or family "didn't know about it." Although this knowledge is not new, it validates the need for improved widespread education of palliative care's existence and role. The qualitative analysis also noted a difference in trust between rural and non-rural patients. Rural patients were less trusting, more skeptical, and more reluctant to discuss sensitive matters such as health without an established relationship. According to the literature, rural patients receive more informal support and caregiving than non-rural patients (Hughes et al., 2004). Prior to analysis the difference in caregiving was thought to be a result of limited resources. Perhaps the skepticism towards outsiders or strangers is also responsible for differences in caregiving structures between populations.

Difficulties

There were a number of challenges to overcome during implementation. The most consistent challenge was developing trust and establishing rapport with patients quickly over the phone. In most cases the doctoral student was the first palliative care team member to talk with the patient. It was the doctoral student's responsibility to create a positive first impression and establish a relationship. It may be uncomfortable to have intimate discussions regarding health, disease trajectory, and burden of symptoms. It can be even more uncomfortable to have such discussions with a stranger over the phone. Therefore, it was crucial that each patient was assured that the doctoral student was competent, trustworthy, and compassionate. At times fostering a quality relationship was more important than receiving quality data. When patients were resistant to providing sensitive information over the phone this hesitancy was respected.

Many patients were fatigued, distressed, and in pain. These patients have limited energy to offer. This was a significant barrier to participation. Additionally, many patients see a multitude of healthcare providers. Prior to provider visits patients are often required to fill out forms and questionnaires. Repeated web-based, telephone, and paper-based questionnaires can create survey fatigue (Olson, 2014). Providing relevance to the questionnaires and emphasizing the importance of the information obtained was challenging but essential to encourage participation. Still, many patients elected not to participate with the qualitative questionnaire and the MDASI. Patients' hesitancy to discuss personal information, the decision to decline participation due to fatigue and distress, and the overall number of home-based referrals contributed to the final challenge of obtaining a satisfactory sample size.

Strengths

The midwest hospice and palliative care organization has attempted to gather quality data in the past but had been unsuccessful for multiple reasons. This quality improvement initiative provided the organization an opportunity to trial a symptom inventory, observe the implementation protocol in action, and determine limitations and weaknesses prior to committing organizational time and energy. Following the implementation the organization had an opportunity to sustain the project or move in another direction. The organization has elected to continue the implementation but made a few adaptations to the follow up procedures as a response to information learned during implementation. Because of workload and logistical concerns the organization has elected not to administer the MDASI prior to and 1-week following medication regimen changes. The organization's ability to make necessary adjustments prior to adopting the protocol is a considerable strength and improves the likelihood of sustainability and a successful implementation.

Another strength of the scholarly project is the clarity of themes noted in the qualitative analysis of perceived barriers to palliative care. The analysis suggests patients suffer from distressing symptoms for an extended period of time prior to obtaining a palliative care referral. Additionally, the majority of patients did not receive palliative care services sooner because of a knowledge gap regarding palliative care's role and existence. This information provides urgency for educating the community about palliative care. The knowledge gleaned from this analysis can also guide marketing and education strategies. The questionnaire provided insights regarding how patients learned about palliative care and what prevented patients from accessing services sooner. The organization can utilize this information to determine what modes of

communication are reaching patients and perhaps develop strategies to educate prospective patients sooner.

Weaknesses

The scholarly project had a number of weaknesses. The first weakness was the number of participants reached for the quality improvement initiative. The organization experienced an uncharacteristically low number of community based referrals during the implementation period. The project also experienced a large number of patients electing not to participate as well as a large attrition rate following the first interaction. Of the 29 patients referred for symptom management, 10 did not participate with the MDASI at consultation. Patients did not participate with the MDASI because 1 was too weak, 1 was unable to communicate clearly over the phone, 2 were admitted to the hospital prior to consultation, 1 could not be reached despite many attempts, 1 passed away prior to consultation, and 4 patients refused. Although 10 patients did not participate with the MDASI, 6 of these patients completed the qualitative questionnaire or had family answer the questions on the patient's behalf.

A number of patients were lost to follow up after completing an initial MDASI. In all, 3 patients refused follow up surveys due to survey fatigue, 2 patients transitioned to hospice care, 2 patients deceased, and 5 patients only completed 1 MDASI because the scholarly project was completed prior to the 1 week follow up interaction.

Lastly, another weakness of the scholarly project was the missed interactions prior to medication regimen changes. On 2 occasions medication regimen changes were made prior to the administration of the MDASI. On 1 occasion a patient called the weekend on call nurse regarding a pain crisis. A medication regimen change was made over the weekend and the doctoral student was not notified until 3 days later. On another occasion the physician spoke

directly to the patient during a follow up interaction and made medication changes without notifying the doctoral student. Workload concerns and logistical issues such as these scenarios contributed to the organization's decision not to administer the MDASI during and after medication regimen changes.

Limitations

High attrition rates are a common occurrence when observing the palliative care population (Visser, Hadley, & Wee, 2015). Losing patients to follow up may be inherent of palliative care research but it is a limitation nonetheless. Improvements in MDASI scores at 1 week and 1 month can be noted compared to baseline. However, very little can be drawn regarding the program's effectiveness with a small sample size.

Limitations are also noted in the qualitative analysis. Question 1 of the questionnaire asks, "How long have your symptoms affected your life?" This question was intended to determine the amount of time a patient was appropriate for a palliative care referral prior to obtaining services. However, Question 1 of the questionnaire does not answer this intended question accurately. In fact, it is uncertain what can be deduced from this question. The question does not indicate how long symptoms have been poorly controlled, how long symptoms have interfered with daily activities, or the amount of time distressing symptoms has compromised quality of life.

The fourth question of the perceived barriers qualitative analysis was another limitation of the scholarly project. The final question asked the patient, "Do you believe where you live impacted your ability to receive palliative care." First, a significant weakness of this question is the close-ended format. A question that can be answered with a yes or a no does not provide means for an in depth qualitative analysis. Additionally, not a single patient believed location of

residence impacted the ability to access palliative care. This response did little to improve the understanding of barriers to palliative care services.

Clinical Implications

While the MDASI was moderately accepted by the organization facts for consideration are as follows. A difficulty faced during implementation was building a rapport quickly over the phone to make patients comfortable and willing to engage with the inventory and questionnaire. Although the doctors in the organization were resistant, the MDASI may be better received if the physician administered the first inventory face-to-face during the consultation. When determining who would administer the MDASI, the organization discussed the possibility of the Social Worker to decrease the workload of the Registered Nurse. Upon further consideration, the organization determined the clinical expertise of the Registered Nurse would improve the symptom assessment process. The frequency of MDASI administration was another topic of discussion. Midway through the implementation process the organization was considering administering the MDASI at consultation and at 1 month. The doctoral student encouraged the organization to consider administering the symptom assessment tool at 1 week as well. It was believed that the MDASI contributed to the assessment of medication regimen effectiveness and provided valuable follow-up information. It was also believed that administering the MDASI at 1 week standardized patient follow-up and guided medication regimen changes. Administering the MDASI during every patient follow up is supported by literature (Ripamonti et al., 2012). However, the organization did not believe administering the MDASI prior to medication regimen changes and following medication regimen changes was feasible or sustainable. Following discussions the organization decided to administer the MDASI at consultation, 1 week after consultation, and 1 month after consultation.

Dissemination of Outcomes

The doctoral student disseminated outcomes by presenting project results to the midwest palliative care team. The presentation focused on referral patient characteristics, the program's performance of managing symptoms, and information learned regarding palliative care barriers in rural and non-rural populations.

Conclusion

Palliative care services are provided in an assortment of settings including hospitals, outpatient clinics, rehabilitation facilities, assisted living facilities, over the phone, and inside patient's homes (Meyers et al., 2014). Community-based palliative care is a comprehensive and multidisciplinary service that follows patients across the disease trajectory through transitions of care and a variety of healthcare settings (Kamal et al., 2013). A significant component of palliative care and its success on patient outcomes is the ability of the team to manage distressing symptoms (Hui et al., 2014). Unpleasant symptoms impact almost every facet of a patient's life and impairs functional capacity and increases patient's distress (Carlson et al., 2012; Cleeland et al., 2000). In order to provide high quality care symptoms must be measured regularly and accurately (Cleeland et al., 2000). A proper symptom inventory will identify symptoms, expose severity, and will be sensitive to detect responses from treatment (Cleeland et al., 2000). Although no symptom inventory is perfect, the MDASI was deemed sustainable, feasible, and was accepted by a midwest palliative care team to assess patient's symptoms and to provide quality measures.

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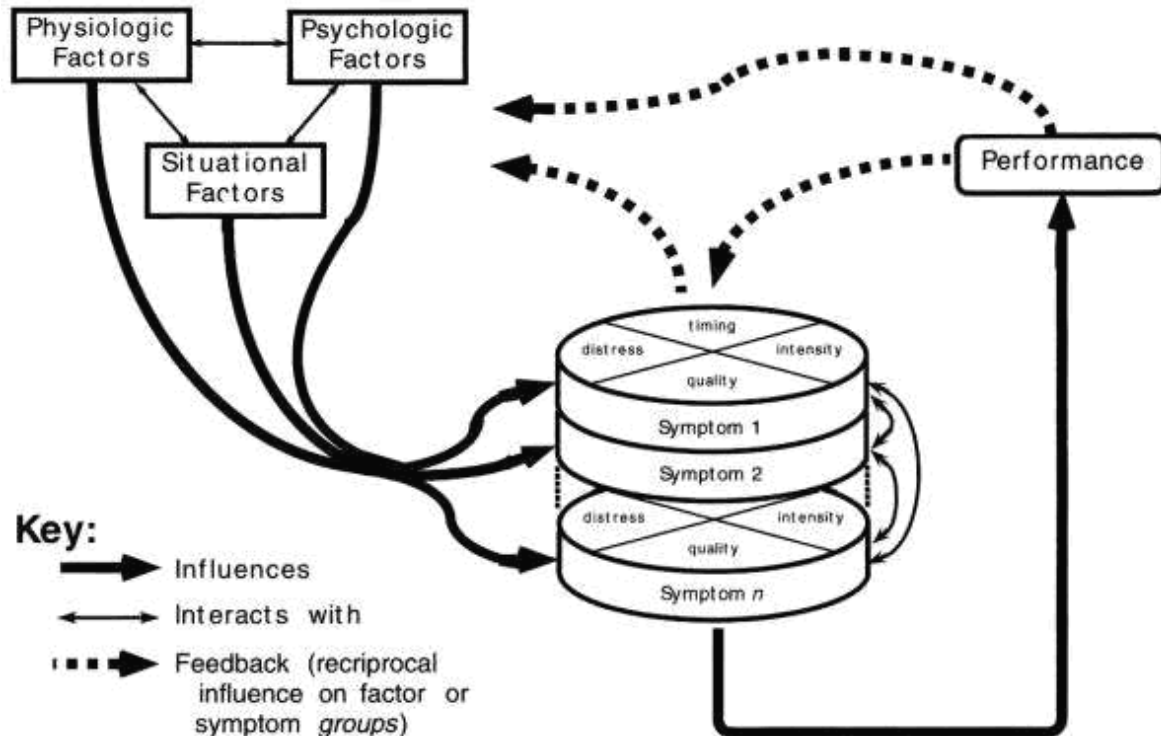
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<https://doi.org/10.1016/j.ejon.2010.05.011>

Appendix A: Theory of Unpleasant Symptoms

Theory of Unpleasant Symptoms



Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: an update. *ANS. Advances in Nursing Science*, 19(3), 14–27.

Used with permission. See Appendix B.

Appendix B: Theory of Unpleasant Symptoms Permission

Dear Daniel,

Your project sounds very interesting. If you plan to reproduce the figure in your project report, that is acceptable. If you were to use it in something you would sell, then you would need

permission from Springer Publishing Company. The publisher company holds the copyright; Linda and I do not.

Good luck with your project.

Sincerely,

Elizabeth Lenz, PhD, RN

Professor Emeritus

The Ohio State University

Sent from my iPhone

On Mar 16, 2017, at 3:18 PM, Daniel Johnson <johnsod3@mail.gvsu.edu> wrote:

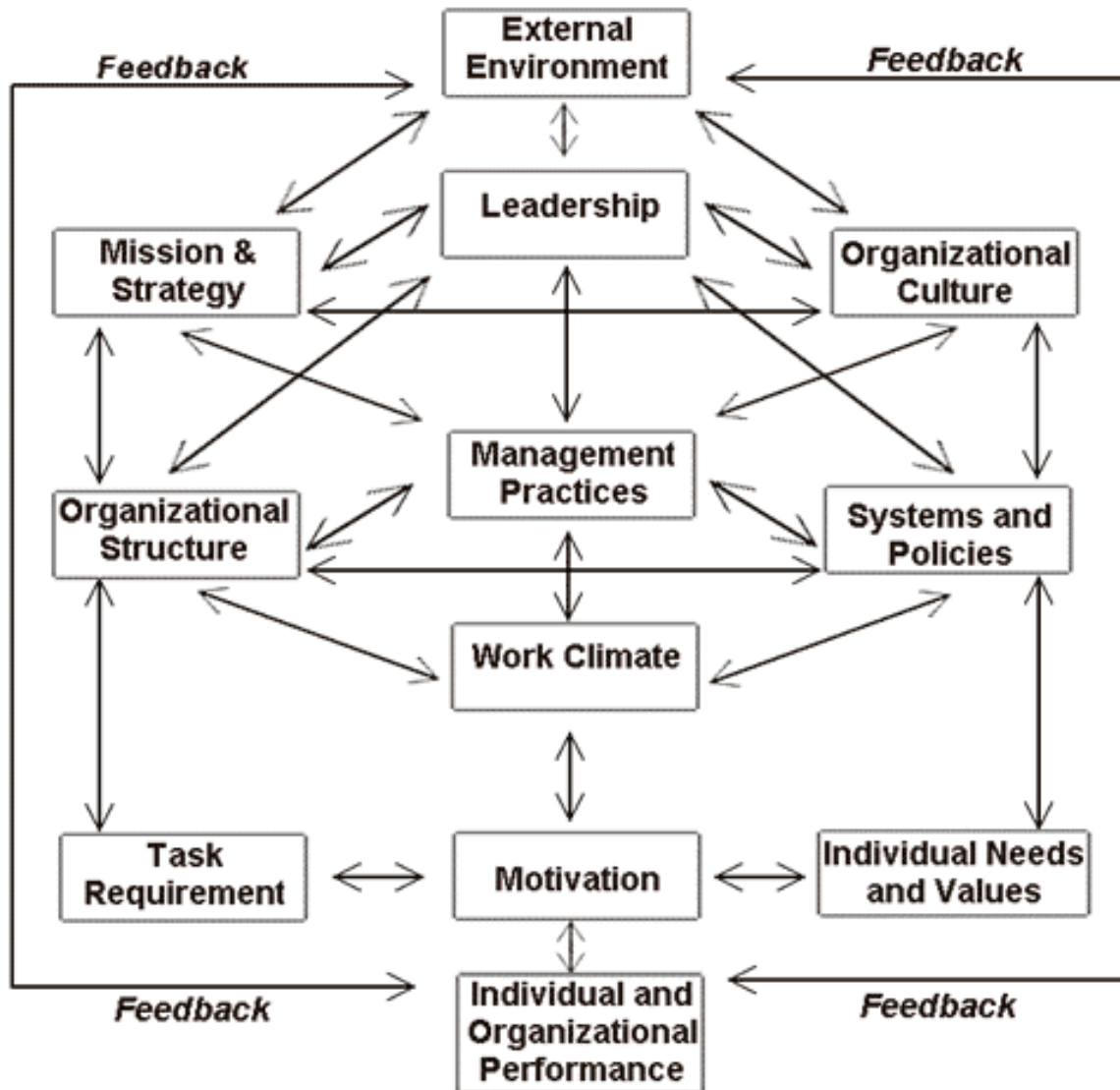
Dr. Lenz and Dr. Pugh,

My name is Daniel Johnson and I am a DNP student at Grand Valley State University in Grand Rapids, Michigan. I am emailing you to get permission to use your Theory of Unpleasant Symptoms for my scholarly project. My project is entitled, "Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to palliative care services for rural and non-rural populations." For this project I am implementing the MD Anderson Symptom Inventory in a palliative care program to create quality measures for the organization. I am also conducting a qualitative analysis of patient perceived barriers to accessing palliative care services. I would like permission to use the Theory of Unpleasant Symptoms as my theoretic framework. The project will be uploaded into ScholarWorks upon completion. Thank you for your attention and your time!

Daniel Johnson
DNP Student

Appendix C: Burke-Litwin Model of Organizational Performance and Change

Burke-Litwin Model of Organizational Performance and Change



Burke, W. W., & Litwin, G. H. (1992). A causal model of organizational performance and change. *Journal of Management*, 18(3), 523–545.

Used with permission. See Appendix D

Appendix D: Burke-Litwin Model Permission

Dear Mr. Johnson,

You have my permission to use the Burke-Litwin Model as a framework for your organizational assessment.

Good luck with the project.

W. Warner Burke

On Thu, Mar 16, 2017 at 3:34 PM, Daniel Johnson <johnsod3@mail.gvsu.edu> wrote:
Dr. Burke,

My name is Daniel Johnson and I am a DNP student at Grand Valley State University in Grand Rapids, Michigan. I am emailing you to get permission to use the Burke-Litwin Model of Organizational Change for my scholarly project. My project is entitled, "Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to palliative care services for rural and non-rural populations." For this project I am implementing the MD Anderson Symptom Inventory in a palliative care program to create quality measures for the organization. I am also conducting a qualitative analysis of patient perceived barriers to accessing palliative care services. I would like permission to use the Burke-Litwin Model of Organizational Change as the framework to conduct an organizational assessment. The project will be uploaded into ScholarWorks upon completion. Thank you for your attention and your time!

Daniel Johnson
DNP Student

--

W. Warner Burke, PhD
Edward Lee Thorndike Professor of Psychology and Education
Editor, *Journal of Applied Behavioral Science*
Box 24 Teachers College, Columbia University
525 West 120th Street
New York, NY 10027
(212) 678-3831

Appendix E: PARIHS Implementation Model Permission

Hello Daniel
Great to hear you are using PARIHS.

As the framework is published - as long as you reference it appropriately that's fine. If you want to reproduce one of the figures- depending on which one it is, you will have to seek agreement from the publisher.

Regards
Jo

Jo Rycroft-Malone
Pro-Vice Chancellor, Research & Impact
Professor of Implementation & Health Services Research
Bangor University

On 16 Mar 2017, at 19:26, Daniel Johnson <johnsod3@mail.gvsu.edu> wrote:

Dr. Rycroft-Malone,

My name is Daniel Johnson and I am a DNP student at Grand Valley State University in Grand Rapids, Michigan. I am emailing you to get permission to use the PARIHS framework for my scholarly project. My project is entitled, "Acceptability of the MD Anderson Symptom Inventory and qualitative analysis of barriers to palliative care services for rural and non-rural populations." For this project I am implementing the MD Anderson Symptom Inventory in a palliative care program to create quality measures for the organization. I am also conducting a qualitative analysis of patient perceived barriers to accessing palliative care services. I would like permission to use the PARIHS framework as my implementation model. The project will be uploaded into ScholarWorks upon completion. Thank you for your attention and your time!

Daniel Johnson
DNP Student

Date: _____

Institution: _____

Participant Initials: _____

Hospital Chart #: _____

Participant Number: _____

MD Anderson Symptom Inventory (MDASI) Core Items

Part I. How severe are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been **in the last 24 hours**. Please select a number from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	Not Present	As Bad As You Can Imagine									
	0	1	2	3	4	5	6	7	8	9	10
1. Your pain at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Your fatigue (tiredness) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Your nausea at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Your disturbed sleep at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Your feelings of being distressed (upset) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Your shortness of breath at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Your problem with remembering things at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Your problem with lack of appetite at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Your feeling drowsy (sleepy) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Your having a dry mouth at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Date: _____

Institution: _____

Participant Initials: _____

Hospital Chart #: _____

Participant Number: _____

	Not Present											As Bad As You Can Imagine	
	0	1	2	3	4	5	6	7	8	9	10		
11. Your feeling sad at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Your vomiting at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Your numbness or tingling at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Part II. How have your symptoms **interfered** with your life?

Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items **in the last 24 hours**? Please select a number from 0 (symptoms have not interfered) to 10 (symptoms interfered completely) for each item.

	Did Not Interfere											Interfered Completely	
	0	1	2	3	4	5	6	7	8	9	10		
14. General activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Mood?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Work (including work around the house)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Relations with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Walking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Enjoyment of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix G: MD Anderson Symptom Inventory Permission

From: symptomresearch

Sent: Thursday, February 16, 2017 7:01 PM

To: 'Daniel Johnson'; symptomresearch

Subject: RE: Order Form for Department of Symptom Research Assessment Tools

Hello,

I have attached the MDASI as you requested. Please note that:

- Your use of the MDASI is limited only to the study specified. To use the MDASI in additional studies, you must reapply online at www.mdanderson.org/departments/prg > Symptom Assessment Tools > The M. D. Anderson Symptom Inventory (MDASI).
- You are permitted to reproduce the copy of the MDASI that is included with this e-mail. However, you must not remove the copyright notice.
- The MDASI may not be modified in any way or translated into another language without the express written consent of the copyright holder; Charles S. Cleeland, PhD. Failure to comply may result in legal action. Permission to alter or translate the instrument may be obtained by contacting me at symptomresearch@mdanderson.org or by mail.

Please let me know if you have any questions. Thank you for your interest in the MDASI.

Regards,

Kristin VanHouten

Appendix H: Patient Perceived Barriers Qualitative Analysis

Date _____

County _____

Patient Perceived Barriers to Palliative Care Services

1) How long have your symptoms affected your life?

2) What has kept you from receiving palliative care before now?

3) How did you learn about palliative care and what they do?

4) Do you believe where you live impacted your ability to receive palliative care?

Appendix I: Implementation Staff Survey

Date _____

Professional's years of hospice and palliative care experience _____

MD Anderson Symptom Inventory (MDASI) Implementation Questionnaire

1) The MDASI provided helpful information at the right time.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

2) The MDASI contributed to the assessment of patient symptoms

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

3) The MDASI was effective in evaluating medication regimen effectiveness/patient condition

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

4) The administration and follow-up intervals of the MDASI were practical and effective for quality patient care and monitoring

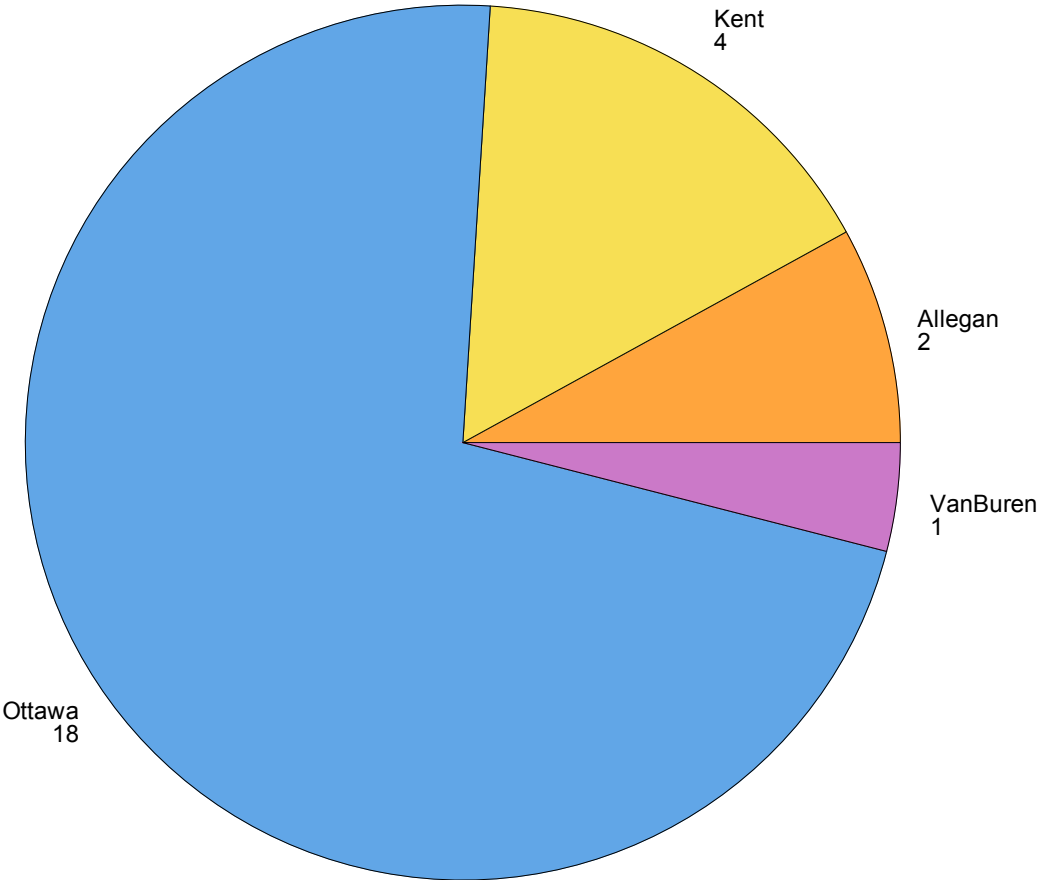
1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

5) The MDASI contributed to my practice as a healthcare professional and should be sustained

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

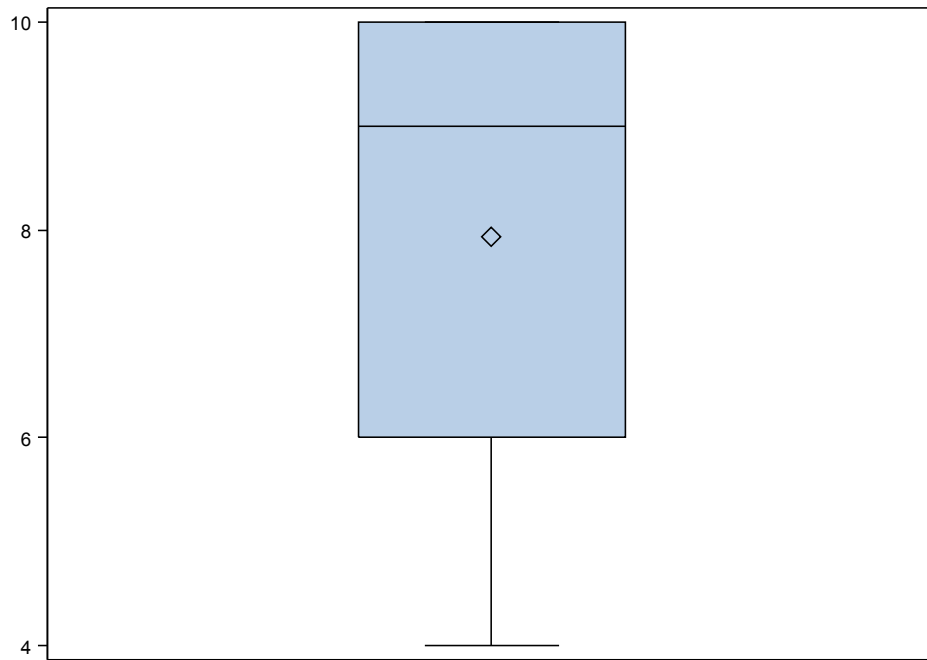
Appendix J: County of Residence of Palliative Care Program Referrals

County of Residence of Qualitative Analysis Respondents



Appendix K: Boxplot of Patient Reported Pain at Consultation

Boxplot of Pain at Consultation



Appendix L: Table of Patient Reported Pain at Consultation

Patient Reported Pain at Consult

N	Mean	Standard Deviation	Minimum	Lower Quartile	Median	Upper Quartile	Maximum
15	7.93	2.05	4.00	6.00	9.00	10.00	10.00

Appendix M: Pain Improvement Measured with MDASI

Improvement of Pain Scores at One-Week Compared to Pain at Consultation

N	Mean Pain Score Improvement	Standard Deviation	Minimum Improvement	Lower Quartile	Median	Upper Quartile	Maximum
7	6.00	2.52	2.00	3.00	7.00	8.00	8.00

Appendix N: Fatigue, Nausea, Distress, and Interference of Enjoyment of Life Scores at
Consultation

Fatigue, Nausea, Distress, and Interference of Enjoyment of Life Scores at Consultation

Variable	N	Mean Score	Standard Deviation	Minimum	Lower Quartile	Median	Upper Quartile	Maximum
Fatigue	19	6.74	2.10	3.00	5.00	7.00	8.00	10.00
Nausea	19	2.47	2.99	0.00	0.00	1.00	4.00	10.00
Distress	19	5.47	3.12	1.00	2.00	6.00	8.00	10.00
Enjoyment of Life Interference	19	6.84	3.10	0.00	5.00	7.00	10.00	10.00

Appendix O: Improvement of MDASI Scores at 1-Week Compared to Consultation

Improvement of MDASI Scores at 1-Week Compared to Consultation

Variable	N	Mean	Standard Deviation	Minimum	Lower Quartile	Median	Upper Quartile	Maximum
Pain	6	2.67	1.97	1.00	1.00	2.00	4.00	6.00
Fatigue	6	1.17	4.17	-4.00	-2.00	0.50	5.00	7.00
Nausea	6	1.00	5.37	-6.00	-2.00	0.50	3.00	10.00
Disturbed Sleep	6	0.83	5.31	-5.00	-5.00	1.00	6.00	7.00
Distress	6	0.50	5.36	-5.00	-5.00	0.50	3.00	9.00
Enjoyment of Life Interference	6	0.67	3.88	-5.00	-2.00	1.00	3.00	6.00

Appendix P: Improvement of MDASI Scores at 1-Month Compared to Consultation

Improvement of MDASI Scores at 1-Month Compared to Consultation

Variable	N	Mean	Standard Deviation	Minimum	Lower Quartile	Median	Upper Quartile	Maximum
Pain	6	3.50	1.22	2.00	3.00	3.00	5.00	5.00
Fatigue	6	1.67	1.51	0.00	1.00	1.00	3.00	4.00
Nausea	6	0.83	2.56	-1.00	-1.00	-0.50	3.00	5.00
Disturbed Sleep	6	3.00	4.00	0.00	0.00	1.00	7.00	9.00
Distress	6	0.83	5.88	-6.00	-4.00	0.00	6.00	9.00
Enjoyment of Life Interference	6	2.00	2.76	-1.00	0.00	1.50	4.00	6.00

Appendix Q: Frequency of MDASI Administration for Patients Referred Prior to March 16

Frequency of MDASI Administration for Patients Referred Prior to March 16

Number of Administrations	Number of Patients
1	10
2	8
3	6
4	4
5	1

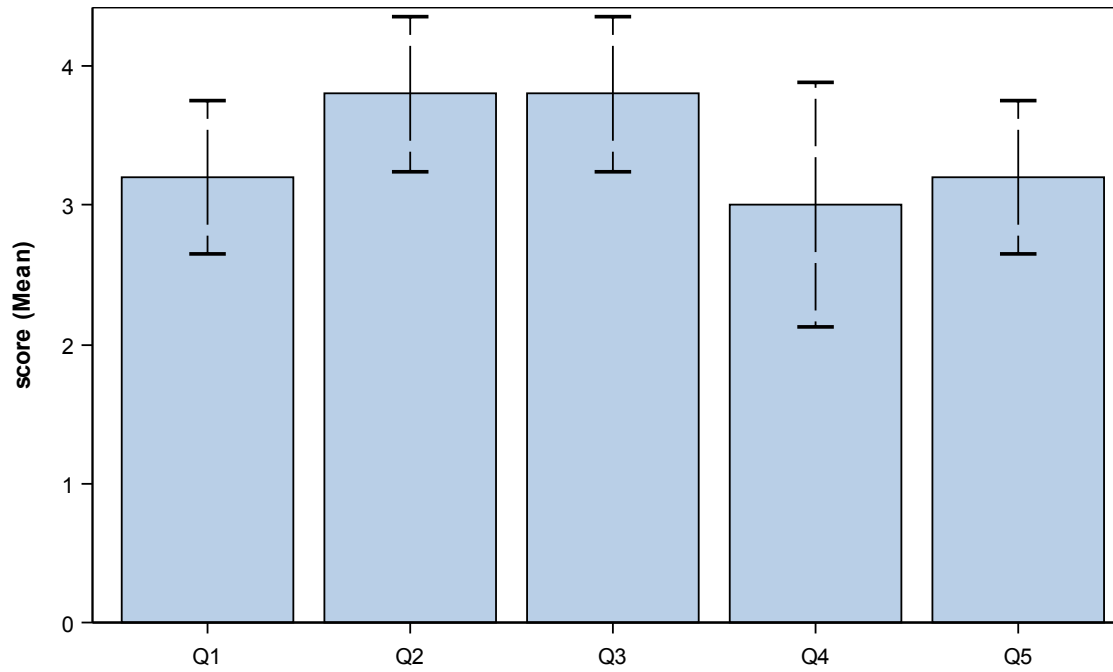
Appendix R: Time to Administer MDASI

Time to Administer MDASI in Minutes

N	Mean	Standard Deviation	Minimum	First Quartile	Median	First Quartile	Maximum
38	6:27	2:20	3:01	4:32	5:55	8:22	11:25

Appendix S: Implementation Staff Survey Responses

Means and Standard Deviations of Staff Responses to Implementation Survey



Appendix T: IRB Approval



DATE: February 13, 2017
 TO: Daniel Johnson, BS, BSN
 FROM: Grand Valley State University Human Research Review Committee
 STUDY TITLE: [1028150-2] Acceptability of the MD Anderson Symptom Inventory
 and
 qualitative analysis of barriers to palliative care services for rural and non-rural populations
 REFERENCE #: 17-142-H
 SUBMISSION TYPE: New Project
 ACTION: NOT
 RESEARCH EFFECTIVE DATE:
 February 13,
 2017
 REVIEW TYPE: Administrative Review

Thank you for your submission of materials for your planned research study. It has been determined that this project:

Does not meet the definition of covered human subjects research* according to current federal regulations. The project, therefore, *does not* require further review and approval by the HRRC.

Any research-related problem or event resulting in a fatality or hospitalization requires immediate notification to the Human Research Review Committee Chair, Dr. Steve Glass, (616)331-8563 **AND** Human Research Protections Administrator, Dr. Jeffrey Potteiger, Office of Graduate Studies (616)331-7207. See *HRRC policy 1020, Unanticipated problems and adverse events*. Exempt research studies are eligible for audits.

If you have any questions, please contact the Office of Research Integrity and Compliance at (616) 331-3197 or rci@gvsu.edu. The office observes all university holidays, and does not process applications during exam week or between academic terms. Please include your study title and reference number in all correspondence with our office.

*Research is a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge (45 CFR 46.102 (d)).

Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains: data through intervention or interaction with the individual, or identifiable private information (45 CFR 46.102 (f)).

Scholarly activities that are not covered under the Code of Federal Regulations should not be described or referred to as *research* in materials to participants, sponsors or in dissemination of findings.