

6-2016

# Evaluation of an In-Home Palliative Care Program's Management of Pain

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Evaluation of an In-Home Palliative Care Program's Management of Pain

By  
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Submitted in partial fulfillment  
of the requirements for  
the Department of Psychology

UNION COLLEGE

June, 2016

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## In-home management of pain 1

LAPORTE, MACKENZIE Evaluation of an in-home palliative care program's management of pain.

Department of Psychology, June 2016.

ADVISOR: Carol Weisse PhD

### Abstract

With the growing population of chronically ill patients wishing to receive care at home, care providers face unique challenges managing the pain of patients with quickly changing illness trajectories. Treating patients outside of institutionalized settings, where regular monitoring is standard, requires careful symptom management. This project was a retrospective review examining nurses' documentation of pain for patients enrolled in *Care Choices*, a new home-based palliative care program coordinated through a visiting nurse service and community hospital. The extent to which nurses documented patients' pain score, site, type and pain goal as well as nursing interventions and plan of care in *Allscripts electronic medical record* (EMR) was assessed over a 3-month period. Records from a total of 204 home visits were analyzed for 15 chronically ill patients. The results revealed inconsistent tracking of pain and variations by pain metric. Variable recording practices in the EMR made it difficult to determine whether pain crises were being managed within a desired time period. Aspects of the EMR with the ability to trend quantitative clinical data and chart patient pain goals were also underutilized. Ways of improving the tracking of pain management decisions in chronically ill populations are discussed.

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### Evaluation of an In-Home Palliative Care Program's Management of Pain

Due in part to medical advances, Americans are now living longer. The shift in the American demographic is largely due to the aging of the baby boomer generation; the population of individuals over the age of 65 is projected to increase from 13-20 percent by 2030 (Comlossy & Walden, 2013). Lengthening lifespans will likely come at a price, as many of the frailties associated with age will require more extensive care. As individuals age, roughly 80 percent will develop at least one chronic condition (Comlossy & Walden, 2013), including diseases like diabetes, cardiovascular disorders, arthritis, and cancer – all of which are commonly associated with chronic pain (Cherry et al., 2010). Unfortunately, 69 percent of the elderly will suffer from more than one chronic illness (Comlossy & Walden, 2013). In fact, an individual's risk of having multiple chronic conditions increases with age (Vogeli et al., 2007). The looming burden of a growing chronically ill population presents challenging health care needs, especially in terms of pain management, as many of the chronic illnesses experienced by aging adults are accompanied by pain.

Aging patients' complex health care needs complicate long-term pain management. For example, there may be distinct treatment approaches required for two different conditions, and these treatments could counteract one another, or worse present negative interactions to patients. For example, Sun and colleagues (2008) offer an example of the problems that can arise with comorbid conditions. In their case study, they describe a breast cancer survivor's struggle with pain management due to comorbid conditions. Along with breast cancer, the patient was diabetic; her diabetic neuropathy was often exacerbated by adjuvant chemotherapy treatments (Sun et al., 2008). With the

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increased incidence of comorbidities among the elderly, it can be difficult for practitioners to know which problem to address.

While patients with multiple chronic illnesses are difficult to treat because curative actions taken to care for one condition often interact with and exacerbate the symptoms of another illness, comorbid conditions can also increase the level of disability and the severity of symptoms associated with each individual illness. For example, Fried and colleagues (1999) observed greater physical disability, as measured by achieving activities of daily living, in individuals with multiple chronic conditions than in individuals with a single chronic condition despite controlling for the presence of separate diseases. Though the effect of individual diseases was controlled for, having a second chronic condition exacerbated the effects of each illness. Physically disabled individuals have been shown to experience greater pain than their non-disabled peers (Gayman, Brown, & Cui, 2011). Therefore, aging is associated with greater degree of comorbid illnesses and a greater risk of disability and pain that can lead to a greater complexity of care.

While many chronically ill people experience pain, failing to control it can present other health issues. For example, under-treatment of pain is linked to impaired mobility, sleep disruptions, medication dependence, and reliance on caregivers for daily activities (Siddall & Cousins, 2004). In addition, individuals with chronic pain are four times as likely as those without pain to experience depression or anxiety (Gureje, Von Korff, Simon, & Gater, 1998). Therefore, experiencing uncontrolled pain is associated with negative overall quality of life. Many of the symptoms associated with chronic pain can be debilitating and can lead to an exacerbation of existing conditions. While these

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issues are troubling for patients and caregivers alike, the increasing complexity of symptom management in the chronically ill has sparked a movement to focus care on comfort, especially with conditions for which there is no cure.

As a result of the changing demographics and rise in chronic conditions, there has been a movement toward palliative care. Palliative care, as defined by the World Health Organization (WHO), prevents and relieves suffering by early identification of illness, assessment and treatment of pain, along with other physical, psychosocial, and spiritual issues, in order to improve the quality of life in patients with life-threatening illnesses (WHO Definition of Palliative Care, 2002). Hospitals have begun offering palliative programs as a way of moving away from curative treatment toward comfort care (O'Brien, 2013). In-hospital palliative care can address health and treatment issues associated with chronic illness, including pain control and improved quality of life,

Palliative care clearly identifies pain control as one of its primary goals, and studies have shown that palliative care programs can achieve this objective. For example, Delgado-Guay and colleagues (2008) evaluated symptom distress and outcomes of Intensive Care Unit (ICU) oncology patients eligible for a palliative care consult. Symptoms were self-reported by patients using the Edmonton Symptom Assessment Scale (ESAS). Delgado-Guay and colleagues collected symptom data at baseline during the initial palliative care team consult and again upon follow-up, in order to monitor how pain symptoms changed as a result of interventions. Pain was reported by 84 percent of surveyed patients at the initial consultation. Interventions recommended by the palliative consultation team pertained to pain control through management of opioid analgesics (99%) along with use of steroids for pain (9%). Upon follow-up, 90 percent of patients

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reported improved pain. By evaluating how pain severity changed due to palliative care interventions, Delgado-Guay and colleagues found that a palliative approach to in-hospital care could decrease pain severity.

Additional studies have reported improved pain management by in-hospital palliative care programs. In a study of 1,450 cancer patients across thirty-two Italian hospitals, individuals were assigned to receive either standard clinical practice or early palliative and support care. Palliative care was delivered by a team, which included two physicians, two nurses, a psychologist, and volunteers. The goal of the delivery team was to deliver symptom management, psychosocial, spiritual, and emotional support to cancer patients and their families, and evaluation and management of pain was one of the targeted outcomes. Patients' most severe pain intensity in the twenty-four hours preceding an interview was measured using a four-point scale (0=no pain; 1=mild pain; 2=moderate pain and 3 = severe pain). Results indicated that the percentage of patients with no or mild pain was higher in patients receiving the palliative care intervention than in their peers receiving standard care. Also, patients receiving standard care were more likely to report moderate to severe pain than those treated with the palliative care intervention (Bandieri et al., 2012).

Furthermore, in-hospital palliative care programs reduce pain for every day patients spend on the program. The palliative care program evaluated by Ciemins and colleagues (2007) assessed and discussed patients' care goals, assessed pain symptoms, and reviewed the current treatment plan in order to make recommendations for future care. Pain was measured using the ten-point Edmonton Symptom Assessment Scale and assessed upon initial contact with the palliative care program, at day 1, day 2, day 3, and

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at discharge. Of the 48 patients evaluated, 33 percent were referred for pain and symptom management. While on the program, average pain scores decreased 86 percent (from an average score of 7.9 on initial contact to a score of 1.1 on discharge). Average pain score decreased each day on the program. Ciemins and colleagues' (2007) findings suggest that patients' pain improved after receiving inpatient palliative care. A palliative approach to care decreased patient pain each day spent on the inpatient program, indicating that palliative care can control and respond to daily symptom needs (Ciemins [et al.](#), 2007). Though the findings of both Delgado-Guay and colleagues (2008) and Bandieri and colleagues (2012) illustrated improved clinical outcomes associated with inpatient palliative care consults, Ciemins and colleagues (2007) suggest that in-hospital palliative care can respond to daily symptom changes.

Based on the findings of the above studies, in-hospital palliative care programs appear to manage the symptoms associated with comorbid conditions, like pain and decreased quality of life, well. As a result, palliative care has become entrenched within the American hospital system. Hospital-based palliative care and pain management programs were even included in the Joint Commission's accreditation process (Meghani, 2004). Development of in-hospital programs using a palliative approach has increased sharply in recent years. Morrison and colleagues (2005) collected data from the American Hospital Association Annual Survey on institutions that self-reported having a hospital-owned palliative care program. In fact, from 2001 to 2003, hospital palliative care programs demonstrated 67 percent growth. Since 2010, palliative care teams were available in 66 percent of American hospitals with more than 50 beds and 88 percent of hospitals with over 300 beds (Center to Advance Palliative Care, 2011). The growth in

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hospital-based palliative care programs has resulted in improved care for seriously ill patients and offers some hope regarding the care of this growing population of chronically ill individuals.

Though hospital palliative care programs are a step in the right direction, moving care of chronically ill individuals to the home is more desirable as hospitalization poses a significant risk to older individuals. Research suggests that elderly patients are particularly vulnerable and in jeopardy of contracting complications unrelated to the illnesses for which they are often hospitalized. For example, it has been shown that along with risk of nosocomial conditions, functional decline occurs by the second day of hospitalization and improves very little by time of discharge and, in many cases, elderly patients do not return to their home following hospitalization (Creditor, 1993). Risks of hospitalization include declining functional status and delirium, falls, medication toxicity, nosocomial infections, malnutrition, dehydration, immobilization, and pressure ulcers (bed sores) (Walsh & Bruza, 2007). However, keeping elderly patients out of the hospital allows for preservation of daily routines associated with wellbeing (Cohen, Boston, Mount, & Porterfield, 2001) and avoidance of an environment that disrupts sleep and mobility. Studies of sleep deprivation in ICU patients indicate that more severely ill patients experienced increased sleep fragmentation, while the abnormally bright and loud ICU environment also contributes to patient-experienced sleep deprivation (Pisani et al., 2015). Therefore, hospitalization of the frail elderly presents risks to their already complex health. In addition, many elderly individuals wish to receive treatment outside of a hospital (Townsend et al., 1990).

Treating chronically ill elderly individuals in the hospital has resulted in a

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disproportionate amount of patients dying there as well, counter to the desires of many patients. Approximately two-thirds of deaths occur in institutions, most commonly acute care hospitals (Higginson, 2002), despite the fact that dying individuals spend most of their final year at home (Thorpe, 1993). Palliative care seeks to provide holistic, whole-self treatment to address not only the physiologic aspects of chronic disease, but the psychological, social, and spiritual concerns as well. As such, meeting patients' preferences regarding where their palliative care is delivered falls under the umbrella of the palliative care mission. For patients that would prefer to receive treatment and care for chronic illnesses within their home, innovation of new ways to achieve quality care is imperative if healthcare is to serve an influx of aging patients with complex health needs.

Patients with chronic illnesses have expressed a desire to remain at home for treatment, despite the progression of their disease symptoms (Grande, 2013). With more patients suffering from multiple chronic illnesses that can render them homebound, movement towards in-home palliative care caters to the needs of an aging population. Studies have shown that palliative care can be provided in the home. For example, Brumley and colleagues (2007) evaluated rates of hospitalization in patients receiving typical in-home care and in-home palliative care. Participants were randomly assigned to either the control condition (standard homecare) or the experimental condition (an in-home palliative care intervention). As part of the palliative care approach, patients received pain management and other aspects of comfort care within their homes. Patients enrolled in the intervention could receive curative treatment in addition to comfort measures. Care was delivered through an interdisciplinary team approach, with the primary care team including the patient, their family, along with a palliative care

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physician, nurse, and social worker. Patients within the palliative care intervention evidenced fewer hospitalizations when compared with their peers receiving usual homecare (Brumley et al., 2007). Therefore, in-home palliative care successfully reduced hospitalizations in a patient population at elevated risks for nosocomial conditions once hospitalized.

In addition to reducing hospitalizations, in-home palliative care was evaluated to determine whether or not it could successfully manage patients' pain within the home. For example, Ornstein and colleagues (2013) assessed pain management in an in-home palliative care program. The severity of newly enrolled patients' pain symptoms was evaluated using the Edmonton Symptom Assessment Scale (ESAS). Patients were assessed at three time points: baseline, after three weeks, and then again after twelve weeks on the program. For patients with at least moderate pain symptoms at baseline, their pain significantly decreased (Ornstein et al., 2013). In this study, in-home palliative care was found to manage its patients' symptoms, particularly pain. However, it is worth nothing that in-home palliative care programs' success has relied on symptom assessment taken at set time points on the program (i.e. baseline, 1 month, 2 month, 3 months etc.). Though Ornstein and colleagues' research seems to indicate successful pain management, capturing pain severity at set time-points does not allow conclusions to be drawn about how well pain is managed in an on-going fashion. A specific pain score taken on one day does not necessarily indicate successful pain management when compared to baseline. Instead, measuring palliative care program's responsiveness to pain crises would be a better method of assessing whether an alternative approach is effectively managing symptoms that are fluctuating frequently as health declines.

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Assessing symptom management at set time periods is a common approach in studies evaluating the effectiveness of in-home care, but not all programs report decreases in pain metrics. For example, in a recent study by Pouliot, Weisse, Pratt, and DiSorbo (2015), patients' pain symptoms were assessed at three time periods upon enrollment in Care Choices, an in-home palliative care program offered jointly through the Visiting Nurse Services of Northeastern New York, and Ellis Medicine, a community hospital. Patients enrolled in the program were cared for at home by an interdisciplinary team composed of a medical director, nurse, social worker, chaplain, and home health. Using telephonic phone survey, data on symptom management and quality of life was collected. There were no significant difference in patient-reported quality of life and pain over the duration of time spent on the program. Average patient pain scores, as self-reported by patients and caregivers, were below five for recently admitted patients and dropped below 4 by the following phone assessment, though this change was not statistically significant (Pouliot et al., 2015). These findings suggest that *Care Choices* is maintaining its patients' symptoms, despite their worsening disease states. Yet, Pouliot and colleague's study presents a surface-level portrayal of pain management, as symptoms were measured at set time points and, therefore, do not capture the reality of on-going pain management.

Though pain levels showed no significant change from baseline to the time of a follow-up phone call, Pouliot and colleagues (2015) were unable to determine how well the patients' pain levels were being managed on a day-to-day basis. Instead, the study could only offer pain reports at predetermined time-points in "snapshots". Determining how well a program is managing pain crises and how well a program responds to

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Increases in pain severity by mobilizing interventions is a challenging task and requires a much more complicated assessment approach than surveying patients at select time points. By evaluating symptoms shortly after enrollment on the program as a baseline measure and then again after a month or more on a program, nursing actions taken to maintain a patient's pain level are not fully appreciated. In order to examine whether health care providers are undertaking appropriate interventions and actions, a different approach is warranted, especially given that the goal of palliative care is to adjust pain approaches as symptoms change. In order to assess how well pain management approaches are addressing pain episodes, one must take a closer look at the day-to-day nursing interventions and determine if these are controlling patients' symptoms.

Studies have attempted to assess symptom management in an on-going fashion by examining nurses' communication and documentation of pain. For example, in one study of patients being treated in Dutch hospitals, communication, quality of nurses' pain assessments and pain documentation between patients and providers were examined in order to assess patients' pain experiences. Two groups were assessed: a control group of patients given regular nursing care and an intervention group of patients that received care after nurses were trained through a pain monitoring program (PMP). Within the control group, patients were interviewed at the beginning of their admission and again at discharge. The intervention group's pain was assessed daily after nurses were instructed on the PMP. Patients were interviewed one month after the PMP took place. In both groups, self-report questionnaires were used to evaluate communication between patients and providers. Agreement between patients' and nurses' pain ratings was used to determine the quality of nurses' pain assessments. Information on documentation of pain

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was gathered from nursing records using methodology from Camp and colleagues' previous work. Researchers categorized nursing record information as related to the following variables: pain intensity, quality of pain, location of pain pattern of pain, situations that increased or decreased pain, verbal statements by patient, nonverbal observations about pain, and symptoms associated with pain, side-effects of pain medication, duration of pain, use and effect of pain medication, and other pain documentation (DeRond et al., 2000). Analyzing nursing documentation gives researchers a tool to evaluate the daily aspects of care that contribute to symptom monitoring. Investigating on-going pain management can provide an alternative way for organizations to evaluate their pain management practices outside of capturing pain severity at specified time points.

Managing complex health trajectories is at the forefront of healthcare innovation due to the foreseeable influx of patients with chronic illnesses associated with an aging population. The purpose of the current study was to examine whether an in-home palliative care program is effectively managing the pain of a chronically ill patient population. To do so, actual pain management practices were tracked in newly enrolled patients on the *Care Choices* program by conducting a review of nursing records in the electronic medical record, *Allscripts*. In order to gain a deeper understanding of the day-to-day management of pain across multiple patient visits, this study tracked pain score, site, type and pain goal along with nursing interventions and plan of care across multiple nursing visits to try and gain a better sense of responsiveness to pain incidents.

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## **Methods**

### **Sample**

A review of electronic patient records was completed on all patients in the *Care Choices* palliative care program who were first time enrollees between January 1st 2015, and March 31<sup>st</sup> 2015. Patients that were discharged from *Care Choices* and readmitted within the study time frame were not included in the sample. The admission criteria included: diagnosis of a serious illness (any disease at any age), evidence of symptomology (recent ER visit or hospitalization), desire to remain at home, and eligibility for Certified Home Health Agency (CHHA) admission. The sample included 204 medical records of 15 chronically ill patients (9 women; 6 men). All enrolled patients were from New York State's Capital district. The average age of the participants was 80.6 (range 49-97). Confidentiality of patient information was maintained throughout the study. The primary diagnoses within the patient sample are reported in table 1 (in cases where primary diagnoses changed during the course of treatment, the first diagnosis is included).

### **Measures**

Patient demographic and admission data included patient's identification code, date of birth, sex, and admission date. For each patient, the dates of all nursing visits within the duration of the study were recorded. Along with visit date, the type of visit was noted. Visits could be routine, unscheduled emergent visits (on-call), phone-calls, or interdisciplinary team meeting chart reviews. Other forms of in-home visits included start of care, recertification, follow-up, resumption of care, and discharge visits, along with

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visits for transfer of care to inpatient facilities. In addition to information regarding the visit date and type, the *Care Choices* nurse responsible for a visit was recorded.

The status of each patient's pain at the time of the visit was recorded as: no recent pain history or current pain, pain was well-managed at the time of visit, or pain required attention at the time of visit. Along with pain status, whether or not nurses documented the location of pain (*i.e.*, right shoulder) was noted. Additionally, whether or not nurses recorded the type of pain (*i.e.* neuropathic, arthritic, etc.) experienced by the patient at the time of visit was assessed. The severity of pain was measured using the numerical pain score (measured from 0-10) recorded by nurses. Each patient's desired amount of pain (numeric pain goal, measured on a 0-10 scale) was also tracked. In addition, whether or not there was documentation of an intervention designed to reduce or alleviate pain was measured by tallying the possible types of nursing interventions, discussed further in the procedure. Whether or not a physician was contacted in regards to the patient's pain was also assessed. Whether or not desired nursing pain outcomes were entered into *Allscripts* was also recorded by outcome type, including: having the patient or caregiver verbalize understanding of pain management and/or having the patient or caregiver demonstrate follow through with pain management. For any variable tracked, it was noted whether associated fields in the EMR were opened and data entry was incomplete, whereas fields were not opened, possibly for justifiable reasons.

### **Procedure**

All information was obtained retrospectively from *Allscripts*, the electronic medical record (EMR) used by the visiting nurse service and analyzed using the IBM Statistics Package of the Social Sciences (SPSS) Version 19 and Microsoft Excel for Mac

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2011. Data was collected from *Allscripts* for each visit by reviewing the clinical assessment, clinical note, and care plan fields.

Visit type was a field nurses selected upon initiating clinical documentation in a pain assessment. Therefore, the type of visit was generated along with a clinical assessment except when visits were carried out by licensed practical nurses (LPNs), which are not certified by the state of New York to document pain assessments. Phone calls and interdisciplinary team meetings' chart reviews were included as visits because, in each case, nurses were actively working to improve patient care. Thus, treatment recommendations provided over the phone or during interdisciplinary team meetings' chart reviews were considered pain management interventions. Nurses were identified by electronic signature within *Allscripts*. Information for pain status, pain site, type, and severity was identified by nurses' selections from a pre-set menu to document these fields and from nursing narratives. Similarly, nurses could record numeric pain goal by selecting pain intensity scores from the 0-10 pain scale within the clinical monitoring tool.

Unlike the pain assessments, nursing narrative was available within the clinical note and, to an extent, within the care plan. Nurses could select from preset options to record information within the care plan, but were able to incorporate an element of narrative due to modifiers, or notes added by nurses to provide clarification or additional information alongside the preset options. To evaluate whether or not pain status was documented within the clinical note, a search for phrases similar to "patient experienced pain" was conducted. Identifying interventions within the clinical note was largely up to the reviewer's judgment. Interventions were considered any nursing action intended to

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address a patient's pain and are listed by location within *Allscripts* in table 2. Categories were created upon review of all charts and examination of common factors shared by most interventions. As with clinical note status, determining whether or not a nurse documented informing a doctor of a change in the patient's condition relied upon phrases such as "spoke with a physician about patient X's uncontrolled pain." To evaluate desired nursing pain outcomes, many of the categories available for nurses to select and then modify within the care plan were grouped into major themes at the discretion of the reviewer. Themes for long-term desired nursing pain outcomes included: patients or caregivers verbalizing understanding of pain management practices and/or demonstration by patients or caregivers following through on care management practices. The reviewer also classified pain interventions within the care plan after chart review was completed for all patients and visits. Unlike with the clinical note, the care plan was not purely free narrative and many options were pre-set, with the potential for modification. Information on pain status, education, and goals, along with nursing interventions, was taken from three locations within *Allscripts*: pain assessments, care plan, and clinical note. In order to track from where in *Allscripts* pain management information was drawn, a variable was created to record the number of places pain control was documented within electronic nursing records for a given visit.

## **Results**

Initial analyses served to characterize the 204 *Care Choices* nursing visits from January 1<sup>st</sup> – March 31<sup>st</sup> 2015. Of the 204 visits, 148 were performed in the home (72.5%), 25 were IDG reviews (12.3%), 18 were phone calls (8.8%), and 13 were not categorized (6.4%). Phone calls comprised 18 of the 204 visits (8.8%). Out of 148 home

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visits, 96 were routine (47.1%), 23 were on-call visits (11.3%), and 29 were other (14.2%) visits that included: start of care, recertification/follow up, resumption of care, transfer to inpatient, or discharge visits. When examining visits by patient (n=15), patients received, on average, 14 total visits ( $M=13.6$ ; range 4-25), 10 in-home visits ( $M=9.9$ ; range 2-22), 6 routine visits ( $M=6.4$ ; range 1-16), 2 on-call visits ( $M=1.5$ ; range 0-5), 2 in-home visits that were neither routine nor on-call ( $M=1.9$ ; range 1-7), 2 IDG reviews ( $M=1.7$ ; range 0-5), 1 phone call ( $M=1.2$ ; range 0-6), and 1 visit that was not categorized ( $M=0.9$ ; range 0-5). The average number of days individual patients spent on *Care Choices* was 40.5 (range 4-85 days).

#### **Recorded Pain Metrics for In-home Visits (n=148)**

To assess how often patients were experiencing pain at the time of the visit, frequency analyses were performed on patients' pain status. Across all in-home visits, patients experienced some form of pain on 48 visits (32.4%). Records indicated that pain was well managed at the time of the visit in 29 visits (19.6%) and that pain required attention in 19 visits (12.8%). Out of 148 visits, no recent pain history and/or no current pain were reported in 82 visits (55.4%). For 3 visits, the pain experienced by the patient did not fit into any of these categories (2.0%). Information on patients' pain status was missing in 15 cases (10.1%) and for 9 patients (n=15, 60%).

In order to assess the severity of pain experienced by individual patients, frequency and descriptive analyses were performed on the highest pain score reported on a given visit. These analyses only assessed pain score for in-home visits (n=148). The average pain intensity recorded for each patient over the three-month time period is reported in table 3. The mean average pain intensity experienced by a patient was 1.06

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(range 0-8.5). Across all in-home visits, no pain (score of 0) was reported 70.3% of the time (104 cases).

To determine whether or not pain site was recorded during nursing visits, frequency analyses were performed on the location of pain. Pain site was recorded 41 times (27.7%); pain site was not recorded 92 times (62.2%); and information on pain site was not available for 15 visits (10.1%) and for 9 patients (n=15, 60.0%). One patient experienced multi-site pain during one visit. In order to evaluate whether or not pain type was recorded, frequency analyses were carried out on the type of pain experienced. The type of pain was recorded in 42 cases (28.4%), the type of pain was not recorded in 91 cases (61.5%), and information on pain type was not available in 15 cases (10.1%) and for 9 patients (n=15, 60%). To assess whether or not patients' numeric pain goals (0-10) were recorded, frequency analyses were conducted to see how often nurses recorded patients' pain goals within a clinical monitoring tool. Nurses did not record patients' pain goals using the clinical monitoring tool within *Allscripts* in 133 cases (89.9%) and fields within *Allscripts* needed to open the clinical monitoring tool were not active in 15 visits (10.1%). Additionally, to determine how often patients' pain goals were recorded frequency analyses were performed to see whether nurses recorded a numerical pain goal (0-10) within the patients' care plan fields. A numerical pain goal was recorded within the care plan in 7 cases (4.7%); no numerical goal was recorded within the care plan in 90 cases (60.8%); and fields within Allscripts needed to open this portion of the care plan were not active in 51 cases (34.4%).

Nurses' desired outcomes for patients' pain management were also evaluated by performing frequency analyses on documented nursing goals for patients' pain

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management objectives in order to determine how often nurses selected specific pain outcome(s) in *Allscripts* (i.e., patient/caregiver will verbalize understanding of pain management interventions and patient/caregiver will demonstrate follow through with pain management). One nursing pain outcome was recorded within the care plan 20.9% of the time (31 visits); dual nursing pain outcomes were recorded within the care plan 41.9% of the time (62 visits); and 8.1% of the time no nursing pain outcomes were selected within the care plan (12 visits). The field within *Allscripts* in which nursing goals for patients' pain management were recorded was not active within the care plan 29.1% of the time (43 visits).

### **Nursing Interventions**

To assess how often nurses recorded a need for education on pain management frequency analyses were performed on documented need for pain education during the clinical assessments (n=148). Nurses recorded that the patient or family needed ongoing education and reinforcement of pain management in 7 cases (4.7%); nurses recorded that the patient or family did not need education or reinforcement pertaining to pain management in 127 cases (85.8%); and no information was available to determine whether education or reinforcement was needed in 14 cases (9.5%).

To evaluate how often a nurse recorded that a doctor was informed of a change in the patient's pain status, frequency analyses were performed on physician notification of patient pain during in-home visits (n=148) and phone calls (n=18). Out of 148 in-home visits, physicians were informed of changes in patients' pain status 7.4% of the time (11 cases); physicians were not informed of changes in patients' pain status 91.9% of the time (136 cases); and no information was available to determine whether physicians were

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informed of changes in patients' pain status 0.7% (1 case) of the time. Out of 18 phone calls made, physicians were informed of changes in patients' pain statuses 44.4% of the time (8 cases) whereas 55.6% of the time (10 cases) no records indicated contact with a physician.

To determine how often nurses recorded responding to pain, frequency analyses were performed on pain interventions recorded within the clinical note for in-home visits (n=148), IDG reviews (n=25), and phone calls (n=18). Out of 148 in-home visits, interventions were recorded in 36 cases (24.3%) and were not recorded in 112 cases (75.7%). Out of 25 IDG reviews made, interventions were recorded in all cases (100%). Out of 18 phone calls made, interventions were recorded in 17 cases (94.4%) and no intervention was recorded in only 1 case (5.6%).

In order to evaluate how often pain interventions were recorded within the care plan, frequency analyses were performed on care plan pain interventions for in-home visits (n=148). Interventions were recorded 65.5% of the time within the care plan (97 cases), were omitted from the care plan 5.4% of the time (8 cases), and information was not available to determine whether pain interventions were documented in the care plan 29.2% of the time (43 cases).

### **Discrepancies in Recorded and Expected Frequencies**

To determine whether patients with recorded pain had interventions documented in the EMR, frequency analyses were used to track how often a need for pain management was recorded within pain assessments and how frequently a pain intervention was recorded within a nurses' clinical note narrative when there was a corresponding record of pain for in-home nursing visits (n=148). Of the 19 cases

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whereby nurses indicated patients' need of attention for pain, interventions were reported in the clinical note in 12 cases (63.2%) and no interventions were reported in the clinical note in 7 cases (36.8%). In cases where patients' did not have pain at the time of the visit or their pain was well managed (n=111), interventions were reported in the clinical note within 22 cases (19.8%) and no interventions were reported within the clinical note in 89 cases (80.2%).

In order to evaluate the number of nursing interventions that occurred in response to pain, we assessed the correspondence between frequency analyses performed on the status of patients' pain, as evaluated by nurses, and frequency analyses performed on recorded pain score for in-home *Care Choices* visits (n=148). Out of 82 cases in which no pain history and/or current pain was recorded, pain score was recorded above 0 (pain score=3) in 1 case (1.2%) and pain score was equal to 0 in 81 cases (98.8%). Out of cases in which nurses recorded well-managed pain or pain that needed attention (n=48), pain score was recorded as 0 for 21 cases (43.8%), pain score was recorded above 0 in 26 cases (54.2%), and pain score was not reported in 1 case (2.1%).

To evaluate whether or not a pain intervention was documented in both the care plan and the clinical note, a variable was created in Excel to group instances in which an intervention was reported in both locations, an intervention was not reported in either place, or in which an intervention was reported in one location but not the other.

Frequency analyses to determine whether pain interventions were reported within both the clinical note and care plan were performed for all nursing visits (n=204). Pain interventions were reported in both the clinical note and care plan in 32 cases (15.7%) whereas pain interventions were not reported in either the clinical note or care plan in 117

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cases (57.4%) and pain interventions were reported in either the clinical note or the care plan (but not both) in 55 cases (27.0%).

## Discussion

The goal of this study was to investigate pain management practices of nurses caring for seriously ill patients through an in-home palliative care program, *Care Choices*. In order to do this, pain-recording practices were tracked within the EMR *Allscripts*. To evaluate how well pain was managed, this study assessed patients' documented pain score, site, type, and pain goal. Additionally, nursing interventions and plan of care information were evaluated within the EMR. The clinical records of 15 chronically ill patients were evaluated for a total of 204 home visits spanning a period of 3 months. The results revealed that overall pain scores were low for most visits. Pain type and site were recorded frequently. However, results suggested inconsistent tracking of pain interventions and variations in recording by pain metric.

When evaluating nurses' records regarding patients' pain intensity, it was found that pain was infrequently experienced during in-home visits. For example, patients most often rated their pain intensity at the time of the visit as 0 out of 10 (where 0 is no pain and 10 is the highest level of pain possible). The mean average pain score reported by a patient was 1.06 (range 0-8.5). On most visits, patients reported that they experienced no pain or that any pain that they had was well managed. A prior study conducted on patients enrolled in *Care Choices* similarly reported low pain scores. Pouliot and colleagues (2015) found that average pain intensity was rated 3.30 shortly after enrolling in *Care Choices* and 2.30 upon follow-up. Low pain intensities were attributed to effective symptom management throughout time spent on *Care Choices* in their study.

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Although average pain intensity was low according to Pouliot et al. (2015), pain was assessed differently in the two studies.

In both cases, patients were asked to describe their pain intensity using a 0-10 scale; however, non-clinical volunteers interviewed patients over the phone in the study conducted by Pouliot et al. (2015), whereas the current study relied on data collected by nurses who asked patients during in-home visits to describe their pain intensity. Prior research by Guru and Dubinsky (2000) found that, when asked to assess patients' pain, physicians and nurses reported statistically lower pain ratings than those self-reported by patients. The lower scores found in this study could be attributed to nurse involvement when acquiring pain scores.

The current study also found that the location and type of pain (i.e., neuropathic, arthritic, etc.) experienced during visits was recorded frequently. Information on pain site and type was recorded approximately 28% of the time (pain site was recorded on 41 visits and pain type was recorded on 42 visits). However, the times when this information was omitted could have jeopardized clinical care. Clinical records are tools to maintain patient safety, continuity and care quality (Idvall and Ehrenberg, 2002). If information on the location and type of pain is not available, the clinical record is of limited use to future nurses investigating pain etiology and interferes with nurses' ability to stabilize ongoing pain. In palliative home care, continuity of care is even more challenging than in hospital settings because nurses do not round regularly. Furthermore, different nurses are often responsible for the same patient. Omitting the site and type of pain when documenting in-home palliative care visits prevents nurses who enter the home inconsistently and who care for patients who are also cared for by other nurses from having a complete history of

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prior pain. An incomplete or inconsistent health record could limit the ability of nurses to develop the most appropriate care plan.

Additionally, treatment decisions are complicated by cases of multi-site pain. In such cases, if pain site and type are not consistently reported, nurses may find it difficult to rely on past documentation to guide their decisions when addressing new pain crises. In the current study, multi-site pain was encountered 1.4% of the time (on 2 in-home visits). As comorbidities increase with age (Vogeli et al., 2007), palliative patients will likely encounter multi-site and multi-type pain, which will require appropriate documentation. In-home palliative care relies on well-documented pain metrics, like site and type, to ensure that nurses who round infrequently and see patients cared for by other providers have access to reliable pain histories, which becomes especially important with multiple pain sites.

One field that was consistently overlooked by nurses was one that allowed the tracking of pain goal. At the time of the study, nurses were unaware that the clinical monitoring tool was included within *Allscripts*; therefore the tool was not utilized. The clinical monitoring tool allows nurses to record both the intensity of pain that patients are currently experiencing and the desired pain intensity they would like to have. Asking patients about their pain goal allows nurses to identify patients' expectations regarding pain and allows nurses to address what treatments are possible and acceptable in order to achieve realistic pain management. If a patient expresses a strong personal desire to remain as awake and alert as possible, while still managing pain, they may have to accept more intense pain in order to avoid the sedative effects of opioid use. The clinical monitoring tool will allow nurses to integrate patients' pain expectations in their care

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plans.

By incorporating desired pain level into nurse assessments, the clinical monitoring tool will help providers to involve patients in their care. Care Choices should consider training nurses on the importance of reporting patients' desired pain and the use of the clinical monitoring tool to track patients' desired and experienced pain during in-home visits. However, adopting use of the clinical monitoring tool would build on nurses' existing documentation responsibilities within the clinical pain assessment. Systematizing use of the clinical monitoring tool in order to incorporate patients' personal goals into treatment planning could be useful in further developing Care Choices' role as a patient-centered provider.

Results from the current study also revealed that information within pain assessment fields (ie., pain site, pain type, pain intensity, etc.) was inconsistently recorded. Observed inconsistencies in recorded pain were characteristic of two patterns: missing and omitted data. The first pattern describing inconsistent reporting practices relates to missing information and refers to data that was not reported within an active field in the EMR, even though the nurse had completed other related fields. For example, pain site and type are both located within the same field in *Allscripts* and, by opening this field, a nurse is expected to fully report on each metric. Cases of missing information give an unclear picture of patients' pain to nurses reading the clinical record. The second pattern describing inconsistent reporting practices relates to information that was omitted and refers to data that could not be found within the EMR because the field containing that information was never activated or opened. A nurse may have omitted placing information within a field because the information window was not pertinent to the case

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at hand, or it is possible that the nurse was never prompted to open that field by the EMR dialogue. In addition, nurses may not have opened EMR fields because there were time constraints that prevented the nurse from being able to provide thorough reporting, as in situations in which patients were transferred to in-patient facilities. It is important to differentiate between missing and omitted fields because missing fields indicate failure of the nurse to complete pain documentation.

The current study also found inconsistent recording practices when nurses reported interventions. Interventions were primarily recorded within clinical notes and care plans in the EMR. The results of this study revealed that interventions were reported in either the care plan or in the clinical note, but not within both fields, 27% of the time. This made it difficult to piece together a complete picture of a patient's pain management. It is not reasonable to expect that insurers and other clinicians will peruse various fields within the EMR to try and locate information regarding pain management. If information about patient pain is difficult to track or locate, the clinical record cannot fulfill its role in optimizing patient care. Furthermore, in clinical interactions, other providers may not have time to search for information, thereby jeopardizing continuity of care. In these cases, the inability to locate information on patients' pain could result in wasted time on behalf of both the provider and patient, providers duplicating services, or delivery of contradictory instructions or orders. To ensure that clinicians and insurers understand the pain of the patient, clear clinical records should describe pain management unambiguously.

Clarity in a clinical record is also important because pain is a subjective experience. Due to the subjective nature of pain, "the investigator trying to measure [it] is

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in the position of the hunter who goes into the woods to find an animal no one has ever seen” (Turk, 1989). Nurses, occupying the role of pain-hunter, must communicate closely with patients to gain a better understanding of their pain. Once this is done, that understanding is lost if it is not further recorded through a shared clinical language in the patient’s record. In this sense, it becomes a nurse’s responsibility to translate from the patient’s language of subjective experience into a systematic dialogue of measures and treatment that other clinicians and professionals can reference. In this way, use of pain assessment tools, like rating scales for severity, aim to convert the subjective nature of pain into the objective (Malek & Olivieri, 1996). Records that include inconsistent or unclear information about pain further complicate the subjective experience of pain experienced by patients.

Unclear documentation practices are common and are attributed to “information overload”, in which providers, overwhelmed by the extent of information that can be recorded within an EMR, tend to stick to areas with which they are well-acquainted. By only completing familiar fields, providers tend to silo data in a way that limits the likelihood that information is shared with other clinicians (Clynch and Kellett, 2014).

Exclusively documenting the metrics that providers are comfortable with has implications on how frequently providers will reference the clinical record. For instance, Hripcsak and colleagues (2011) assessed EMR usage patterns by investigating the time spent authoring and viewing clinical documentation. Researchers recorded the rate and time of authoring and viewing clinical records and found that approximately 38% of nurses’ notes go unread by other EMR users. Nurses may not read future clinical notes when they have previously had trouble locating information.

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In this study, tracking pain-management practices through a clinical record review was a challenging task. Though nurses reported on different aspects of pain, the specific metrics and their location within the EMR were not easily accessed or consistently recorded. This was evidenced by interventions recorded sporadically throughout different sections of the EMR along with missing and omitted pain fields. Ineffective and unpredictable documentation of pain metrics and interventions have been reported in other retrospective record reviews of post-operative surgical patients' charts. For example, Coyne and colleagues' reported challenges in following pain management within the clinical record due to variations in documentation, which included: differing methods of pain assessment across nurse shifts and patients, along with selective recording of some aspects of pain, while others were missing from the clinical record. Although the problem described may be more characteristic of documentation than care delivery (Coyne et al., 1998), inconsistent recording of pain can hinder implementation of pain management practices.

Though a primary goal of palliative care is to treat pain crises, inconsistent and missing data made it difficult to determine how effectively Care Choices nurses were managing patients' pain. Future studies should consider how to best assess ongoing pain management, particularly in response to patients' pain crises. If pain intensity were consistently reported, nursing interventions designed to reduce pain could be associated with decreases in pain intensity. For instance, a recorded increase in pain intensity from the previous visit would be noted by future studies as a pain crisis. To determine whether the pain crisis was appropriately addressed, future studies could then investigate whether nursing interventions occurred on the date of the pain crisis in response to patients'

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elevated pain. In this way, nursing interventions on patient visits with increased pain would indicate that nurses recognized patients' pain crises and responded appropriately.

### **Limitations**

A number of limitations restrict the conclusions that can be drawn in this study.

One experimenter coded the data from the EMR without a check on the reliability of coding decisions. The current study was also limited by the use of a capture window treating all visits as "data points", even though the patients in the study sample varied in the length of time spent on the program, primary diagnosis, and other characteristics. For example, the number of days patients spent on *Care Choices* as of March 31, 2015 ranged from 4 to 85, with an average of 40.5 days spent on the program. If the study were to have designated its capture window as patients' first 10 in-home visits on *Care Choices*, nurses' reporting practices may have been more or less the same comparable, as a function of time on the program. Furthermore, the primary diagnoses of patients varied greatly (table 1) and may not have been representative of the wider *Care Choices* patient population. Similarly, if the study sample was selected based on patients' experiences with difficult to manage pain, more data directly relevant to nurses' responses to pain crises may have been available.

### **Conclusion**

The purpose of the current study was to examine whether an in-home palliative care program, *Care Choices*, effectively manages the pain of a chronically ill patient population. This was done by tracking pain management practices through a review of nursing records in the EMR. Pain score, site, type and pain goal, along with nursing interventions and plan of care, were assessed across multiple nursing visits in order to

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track day-to-day pain management practices. Results revealed frequent documentation of pain intensity, site, and type. However, clinical care was jeopardized in instances where either pain site or type was not recorded. During record review, a tool to track patients' desired pain goals was discovered. Though nurses were unaware of the clinical monitoring tool at the time of the study, use of the clinical monitoring tool to record patients' desired pain is recommended in order to incorporate patients' pain preferences into nursing care plans. Additionally, improving the consistency of recording practices within different fields of the pain assessment, along with the clinical note and care plan, is advised. As [result of inconsistent recording practices](#), it was difficult to determine the success of ongoing pain management interventions. Future studies should track nurse responsiveness, in the form of recorded nursing interventions, to elevated pain.

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**Table 1:** Primary diagnoses of patients enrolled in *Care Choices* (n=15, asterisks indicate two cases in which the primary diagnoses changed during the course of treatment).

<b>Primary diagnosis</b>	<b>Number of patients</b>
Cancer and All Neoplasms	3*
Circulatory System	2
Skin, Subcutaneous, Musculoskeletal System, and Connective Tissues	2
VXX Surgical Code	2
Endocrine, Nutritional, Metabolic, and Blood Forming Organs	1
Nervous System and Sense Organs	1
Respiratory System	1
Digestive System	1*
Genitourinary System, Including Pregnancy, Childbirth, and Puerperium	1
Injuries and Poisonings	1

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**Table 2:** Categories of pain intervention types, based on location within *Allscripts*, used to describe nursing actions taken during *Care Choices* visits.

Types of Pain Interventions		
Pain Assessment	Clinical Note	Care Plan
Recorded Patient or family need for ongoing education and reinforcement of pain regimen	Education Intervention Medication Intervention IDG Review Education on Medication Other (i.e., request for medical equipment, etc.)	Instruct in Limiting Activities that Increase Pain Instruct to Report Uncontrolled Pain Instruct in Stress Management/Relaxation Techniques Instruct in Prescribed Medication Techniques Assess/evaluate/teach pain management strategies

**Table 3:** Descriptive statistics for pain intensity scores (on a 0-10 scale) reported by each patient during in-home *Care Choices* nursing visits (n=148).

Pt.	Mean Pain Score	Min.	Max.	Number of Missing Pain Scores	Number of Omitted Pain Scores	Total Number of In-Home Visits
A	1.42	0	5	4	0	17
B	1.78	0	5	1	0	10
C	0	0	0	0	0	6
D	0	0	0	0	1	3
E	0	0	0	1	0	14
F	0.36	0	2.5	0	0	7
G	0.93	0	4	1	0	16
H	1.33	0	8	0	0	15
I	0	0	0	2	1	14
J	0	0	0	2	0	4
K	0.83	0	8.5	2	0	22
L	0	0	0	1	0	8
M	0	0	0	0	0	7
N	5.25	3.5	7	0	0	2
O	4	0	8	1	0	3
Mean	1.06	0.2	3.2	1	0.1	9.9

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