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The Impact of Intensive Case Management on Hospice Utilization

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ABSTRACT

THE IMPACT OF INTENSIVE CASE MANAGEMENT ON HOSPICE UTILIZATION

Objective: The purpose of this study is to examine if patients enrolled in multi-disciplinary intensive case management program (ImPACT) alter the patient's end-of-life path or setting of death.

Methods: The quality improvement project is a quantitative retrospective study that compared patients receiving standard primary care vs intensive case management (ImPACT) during 2/2013-1/2014. It is a secondary analysis of a larger study of a quality improvement evaluation that took place at the Veterans Administration facility in Palo Alto, Ca.

Results: Among the 82 patients who died, 19 were enrolled in ImPACT for approximately 249 days compared to 63 who received standard care. The patients had more than 10 chronic conditions with the average age of 71 years. There was a statistically significant relationship between the ImPACT patients and hospice utilization. 74 % of the ImPACT patients enrolled in hospice care vs 45% of the standard care group. There was no significant relationship between the days on hospice between both groups. However, the majority of the ImPACT patients died on inpatient VA hospice (50%) or home (26%) compared to standard care in which 27% died on inpatient VA hospice and 34% died at home.

Conclusions: This study was the first to examine if intensive case management (ImPACT) would alter the patient's end-of-life path or setting of death. ImPACT was successful in promoting hospice referral compared to patients receiving standard care.

THE IMPACT OF INTENSIVE CASE MANAGEMENT ON
HOSPICE UTILIZATION

by

Debra Lowry Hummel, MSN, ARNP-C

A project

submitted in partial

fulfillment of the requirements for the degree of

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APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the master's degree.

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DEDICATION

This doctoral project is dedicated to my mother, Dr. Lois Lowry, who was the quintessential life long scholar. Without her words of encouragement and belief in me, I would not be where I am today.

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First, I would like to thank my three children, Hans, Katharina, and Lukas for their love and support throughout my doctoral program. You gave me the strength, love, and patience to get through this program. This project would also not have been possible without the support of my boyfriend, Tommy Lin, I share this achievement with you.

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CHAPTER 1: INTRODUCTION

In the United States, greater than one in four individuals have multiple (>2) medical chronic conditions (MCC) and the incidence of MCC increases with age (U.S. Department of Health and Human Services [HHS], 2010). Multiple chronic conditions is defined by HHS as chronic conditions encompassing medical, cognitive, and mental health conditions that last greater than a year and can occur concurrently. As a patient's number of chronic illnesses increases, the individual experiences a higher risk of mortality, decreased functional status, decreased quality of life, prolonged hospitalizations, unnecessary ER utilization, and over all increase in poor health outcomes (Anderson, 2010; HHS, 2010; Lee et al., 2007). Chronic illness is defined as an illness that is not self-limiting, long in duration, is slowly progressive, and hinders quality of life, productivity, and functionality of the patient (Institute of Medicine [IOM], 2012). These include, but are not limited to Alzheimer's disease and dementia, arthritis, asthma, atrial fibrillation, cancer, chronic kidney disease, chronic obstructive pulmonary disease, depression, diabetes, heart failure, hepatitis, HIV/AIDS, hyperlipidemia, hypertension, ischemic heart disease, osteoporosis, schizophrenia and psychotic disorders, and stroke (Centers for Medicare & Medicaid Services [CMS], 2016).

MCC patients encounter poly-pharmacy, symptom burden, juggling multiple medical appointments, and overall complex medical regimens. Psychosocial issues and mental health conditions are prevalent in MCC patients (Hasselmann, 2013; Hong et al., 2014). Psychosocial challenges such as homelessness, lack of social support, and financial barriers further complicate chronic disease management (Hasselmann, 2013; HHS, 2010).

The medical complexity encountered by the patients with MCC can be overwhelming. Studies have examined the patient's perspective of managing MCC in which requesting easy access to providers, clearly communicated care plans, care coordination, a direct and convenient phone line, frequent caring contact with providers, and feeling listened to are valuable characteristics (Bayliss, Edwards, Steiner, & Manin, 2008; Bennett, Coleman, Parry, Bodenheimer & Chen, 2010; Noel, Frueh, Larme, & Pugh, 2005). Noel, Frueh, Larme, & Pugh (2005) studied patient's perspectives on managing MCC within the VHA primary care clinics in a qualitative study. Among the sample of sixty patients, common themes identified were the impact on the patient's functional status and physical symptoms, psychological manifestations such as depression, anxiety, loneliness, anger, negative impact on relationships, inability to enjoy or partake in work and leisure pursuits, medication compliance, poly-

pharmacy, and health-care providers lack of communication are the most concerning and problematic for patients.

The associated economic burden on the U.S. healthcare system with MCC is a grave concern. Studies have noted that only five percent of the patients drive over fifty percent total healthcare spending (Agency of Healthcare Research and Quality [AHQR], 2010; Brown, Peikes, Peterson, Schore, & Razafindro, 2012; Hasselman, 2013; IOM, 2013). Not surprisingly, the patients with MCC account for the majority of inpatient and outpatient medical services, increased number of prescriptions, and home health care needs (AHQR, 2010). The greater the number of chronic conditions the patient has, the higher the healthcare costs (AHQR, 2010; Hasselman, 2013; HHS, 2010).

In congruence with the private sector, within the Veterans Health Administration's (VHA) five percent of the patients generate approximately half of the health care expenditures (Zulman et al., 2013). Despite the VHA's effort to implement a primary care provider and provide patient-centered medical home (PACT or Patient-Aligned Care Team) for all patients, patients with MCC account for disproportionate amount of costs (Yoon, Scott, Phibbs, & Wagner, 2011; Zulman et al., 2013). More than three-quarters of the VA population have more than three chronic conditions and almost fifty percent have more than five chronic conditions

(Zulman et al., 2013). The most prevalent chronic illnesses include hypertension, ischemic heart disease, diabetes, chronic renal failure, low back pain, depression, post-traumatic stress disorder, alcohol, and substance abuse (Yoon et al., 2011; Zulman et al., 2014).

High utilizing MCC patients have complex medical and psychosocial issues and therefore, need more comprehensive and frequent health care services that intensive case management programs can provide. The philosophy of intensive case management is accessibility and frequent contact with a holistic, patient-centered approach with the goals of care coordination, addressing medical and psychosocial complexities, illicit health goals, and behavior change (Bayliss et al., 2008; Hasselman, 2013; Hong, Siegel & Ferris, 2014; Robinson, 2010; Sweeney, Halbert & Waranoff, 2007).

Studies suggest that improved clinical outcomes and potential cost savings may be achieved with multidisciplinary intensive case management that focuses on improving physical and mental health function and decreasing symptom burden of the medically complex patient (Bayliss et al., 2008; Hasselman, 2013; Hong et al., 2014; Sweeney et al., 2007). However, very few ambulatory intensive case management programs within the U.S. have studied their impact on hospice utilization, goals of care, and end-of-life planning.

Statement of the Problem

In the United States, MCC account for seventy percent of deaths in which heart disease and cancer attributed to almost fifty percent of the deaths and eighty three percent of health care costs (CDC, 2015; Dorr, Wilcox, Brunner, Burdon, & Donnelly, 2008; IOM, 2012). Despite the increased mortality rates with chronic illness, intensive primary case management programs have focused on decreasing healthcare utilization and costs, and seldom focus on the patient's end-of-life "goals of care", advanced care planning, or timely hospice referral. Advanced care planning encompasses end-of-life choices, delegating a healthcare durable power of attorney, and making decisions about medical treatments and interventions near one's end-of-life (Billings & Bernacki, 2014; Bischoff, Sudore, Miao, Boscardini, & Smith, 2013). Advanced care planning can occur at any age, in any state of health, and be an ongoing conversation between the provider, patient, and family members (IOM, 2014).

Advanced care planning was recognized as an important issue in ninety percent of the 18 and older population, yet less than thirty percent have completed an Advanced Directive or have had a "goals of care" discussion with their provider (The Conversation Project, 2013). In 2012, California Healthcare Foundation surveyed almost 2,000 adult Californians

on their views of end-of-life discussions. More than seventy-five percent of the respondents would like to discuss end of life wishes, however more than ninety percent stated that no provider brought up the issue or the respondents felt they had other things to worry about (41%) or didn't want to think about death or dying (26%) (California Healthcare Foundation [CHCF], 2012). For those who have proactively discussed end-of-life "goals of care" with their provider also tended to prefer comfort care and Do Not Resuscitate wishes. The majority of the respondents were familiar with hospice (73%), seventeen percent were knowledgeable about palliative care, and only thirteen percent were familiar with the Physician Orders for Life Sustaining Treatment (POLST) (CHCF, 2012).

The Institute of Medicine Dying in America consensus report (2014) discovered improving care and services for patients and families resulted in a higher quality of life and may positively impact the health care system. The report recommends care coordination, patient centered care, advanced care planning, and shared decision making with goals of care. Providing families the end of life resources, promote quality of life, and holistic patient and family centered care that honors the patient's desires and goals should be a national priority (IOM, 2014).

The purpose of the capstone project is to examine if patients enrolled in multi-disciplinary intensive case management (ImPACT)

program alter the patient's end-of-life path or setting of death. It is hypothesized that due to the trusting relationship created, identifying the patient's values and beliefs, and discussing their care preferences with the team will facilitate hospice referral. The research question for this capstone program is "Are patients enrolled in intensive case management more likely to be referred to hospice compared to patients receiving standard primary care at the Veteran's Administration, Palo Alto?"

CHAPTER 2: LITERATURE REVIEW

Conceptual Framework

The Health Belief Model (HBM) and Wagner's Chronic Care Model (CCM) are the conceptual models that will be providing the framework for the capstone study. The HBM meets the patient where they are in order to create value driven goals or what really matters to the patient. The CCM identifies six interrelated factors in chronic care management to assist the patient to be proactive in their health and the healthcare team to be patient-centered. In this chapter I will discuss the HBM and CCM in relation to chronic illness and intensive care coordination.

Health Belief Model

The HBM posits that a patient will be motivated to change behaviors if they believe that they are susceptible to an illness (Carpenter, 2010; Finfgeld, Wongvatunya, Conn, Grando, & Russell, 2003). The model can predict a patient's motivation to change behavior based on the patient's perception of illness severity. The negative outcome of an illness must be perceived as severe in order to change behavior (Carpenter, 2010; Rosenstock, Strecher, & Becker, 1988). The benefits must outweigh the barriers or costs for effective behavior change to occur (Carpenter, 2010; Elder, Ayala, & Harris, 1999; Finfgeld et al., 2003; Rosenstock et al., 1988).

The Health Belief Model combines the concepts of illness perception with social cognitive theory of self-efficacy and the trans-theoretical stages of change (Whitehead, 2001). It is a linear, uni-directional model based on the individual's beliefs, emotions, attitudes, and cognitive changes (Fingeld et al., 2003). HBM postulates that readiness to change is based on six concepts: perceived susceptibility, perceived severity of an illness, perceived benefits, perceived barriers, cues to action, and self-efficacy (Fingeld et al., 2003; Glanz, Burke, & Rimmer, 2015).

Figure 1. Health Belief Model

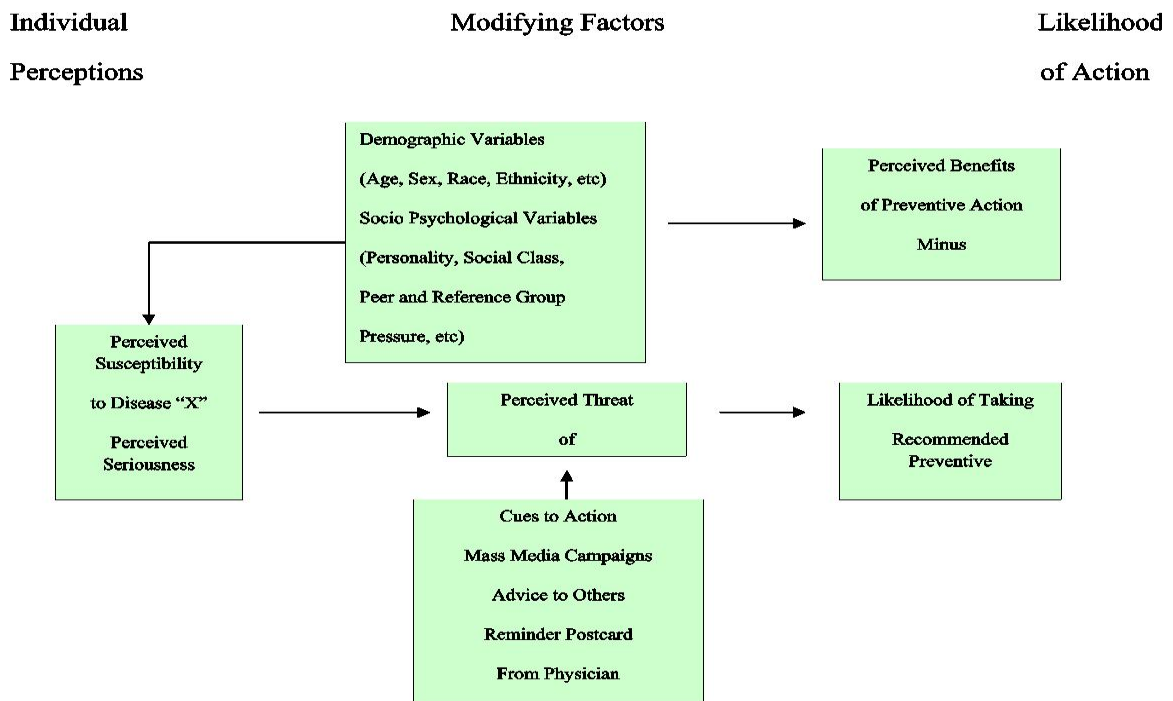


Figure 1. The Health Belief Model. Source: Rosenstock, I.M. (1974).

Historical origins of the health belief model. *Health Education and Behavior*, 2(4), 328-335.

Perceived susceptibility is defined as the individual's belief of developing an illness or co-morbidities of an illness (Janz & Becker, 1984; Rosenstock, 1974). This perception can range from total denial to imminent risk of developing an illness (Finfgeld et al., 2003). A common perception of patients is if they don't feel "sick" or "bad" then they don't need to take medications. Many times the medications have side effects and the patient feels worse with treatment than without. This perception is the core of medication non-adherence or non-compliance. In other words, the patient does not perceive themselves as ill or susceptible to illness due to their lack of symptoms, therefore will not take medications or change lifestyle habits.

Perceived severity refers to the consequences of having or not treating an illness (Finfgeld et al., 2003). It is the person's emotional response to how the illness will affect them, their family, their work-life, and social relationships (Janz & Becker, 1984; Rosenstock et al., 1974). Perceived severity of an illness can promote behavior change or can immobilize a patient by being in denial.

Perceived benefits are how the person believes behavior change will decrease severity or susceptibility to illness and how these changes outweigh perceived barriers of inconvenience, pain, costs, and emotional response (Finfgeld et al., 2003; Glanz et al., 2015). For behavior change to transpire, the potential benefits need to outweigh the costs (Janz & Becker, 1984). This can be performed with motivational interviewing in order to assist patients in exploring their values, conflict, and ambivalence between their desired, and actual behavior (Rollnick, Miller, & Butler, 2008). Perceived barriers and readiness to act can create conflict or indecision. At this juncture is when behavior change begins.

Cues to action are an important concept in behavior change. Overt messages of healthy behaviors by media and friends play an important role in behavior change, since the individual's beliefs are influenced by societal norms and pressure (Elder et al., 1999; Janz & Becker, 1984; Rosenstock, 1974). Shared medical appointments and chronic disease management classes can motivate individuals to adopt healthy behaviors due to the peer-to-peer relationship (Raue et al., 2010).

Self-efficacy is defined as the individual's confidence in their ability to meet their goals and achieve certain behaviors regardless of challenges or barriers (Glanz et al., 2015; Jang & Yoo, 2012). This can be based on past personal accomplishments, observation of other's success, verbal

persuasion, and physiological and mental health states (Jang & Yoo, 2012; Rosenstock, Strecher, & Becker, 1988). Overall, the HBM meets the patient where they are, helps identify health beliefs, perceptions, barriers to their health, resulting in predicting behavior change. The following section discusses the Chronic Care Model that provides a framework to guide healthcare systems to improve care of patients with chronic illnesses.

Chronic Care Model

The Chronic Care Management Model (CCM), developed by Ed Wagner, provides a framework for implementing patient-centered primary care to patients with chronic illnesses (Bodenheimer, Wagner, & Grumbach, 2002; Coleman, Austin, Brach & Wagner, 2009; Glasgow, Orleans, & Wagner, 2001). The model purports to change the primary care model from reactive, acute care to pro-active, community centered, and planned evidence based care. CCM has been integrated into many diverse health care systems, national quality improvement initiatives, and the framework for creating patient centered medical homes (Coleman et al., 2009; Glasgow et al., 2001).

The chronic care model identifies six essential factors in management of chronic illness. These factors are community resources, health care system, self-management support, delivery system redesign,

decision support tools, and clinical information systems (Bodenheimer, 2003; Bodenheimer, et al., 2002). The collaboration of these elements creates a synergistic relationship between the pro-active patient, the knowledgeable provider, and an easily navigated health care organization.

Figure 2. The Chronic Care Model

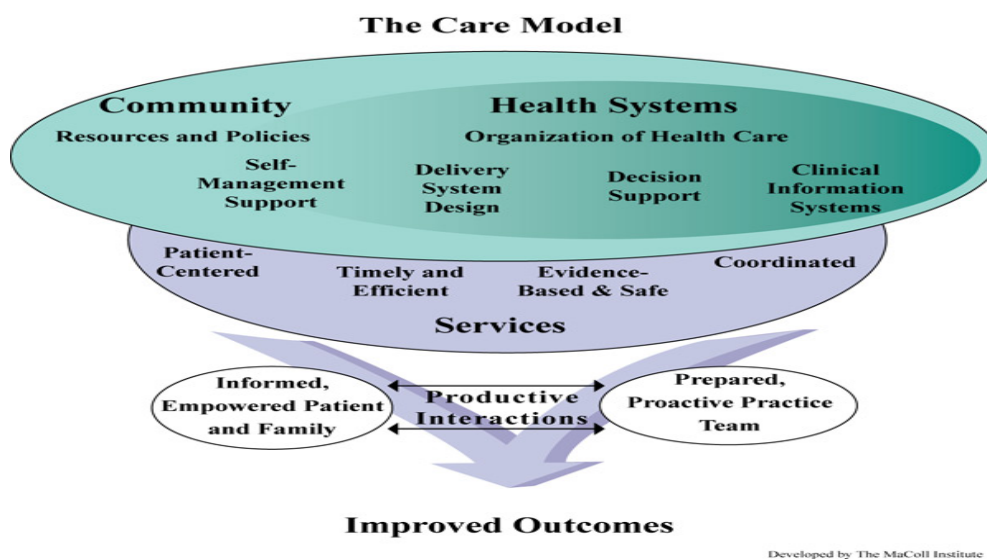


Figure 2. The Chronic Care Model. Source: Improving Chronic Illness. (2015).

The chronic care model. Retrieved from <http://www.improvingchroniccare.org>

Community resources and health care systems are the overarching concepts that connect the other four components of self-management support, delivery system redesign, decision support tools, and clinical information systems. Community resources are integrated into the

patients' care by incorporating partnerships between the organization and community centers, education classes, and home care agencies (Bodenheimer, 2003). These services can fill the gap in care of the chronically ill and vulnerable populations.

The health care system needs to have a paradigm shift to create a patient-centered culture, be receptive to change, and develop innovative strategies to promote and improve chronic illness care (Bodenheimer, 2003). Leadership at all levels of the organization play an integral part in promoting chronic care management and system change (Bodenheimer, 2003; Glasgow et al., 2001). Communication and data-sharing between and within organizations to enhance care coordination is to be developed. Constant evaluation of mistakes and errors need to be analyzed in order to make change and continue to provide safe and high quality care (Improving Chronic Illness, 2015).

Self-management is the most important concept of the chronic care model. It promotes and empowers the patient's role in managing their health with self-care, knowledge, problem-solving, and goal setting (Bodenheimer, 2003; Glasgow et al., 2001). Self-management support involves collaborative efforts of patients and providers to work together to create treatment plans based on the patient's goals (Bodenheimer et al., 2002; Improving Chronic Illness, 2015).

Delivery system design consists of defining team member's roles to provide pro-active care to patients. The design provides the structure of the team to ensure that the patients are provided with intensive case management and follow-up at regular intervals (Bodenheimer, 2003; Improving Chronic Illness, 2015).

Decision support tools consists of evidence-based guidelines and information to guide the patient's care and provide information for the patient to encourage their cooperation in care (Bodenheimer, 2003; Improving Chronic Illness, 2015). Provider education and training in motivational interviewing and behavior modification methods and strategies will foster the patient-provider relationship and treatment plan. Collaboration between specialties with offering alternating visits between the providers, shared visits, and co-attending medical visits further enhance chronic care treatment and outcomes (Glasgow et al., 2001).

Clinical information systems organize and provide current patient information in order to implement effective and efficient care (Improving Chronic Illness, 2015). The data-base can serve as a reminder for patients and providers, track biologic markers of chronic illness, share information between providers and patients, and track populations needing additional care.

The Health Belief Model and Chronic Care Model provide a framework for chronic care management. The premise of the two models support patient-centered care focusing on what is important and matters most to the patient. This perspective of care is crucial and valuable in discussing the patient's end-of-life issues and "goals of care" which results in better patient satisfaction and quality of life with MCC patients.

Review of Literature

Chronic conditions account for the majority of the healthcare burden in the United States and the concept of acute, reactive care does not adequately address the multiple complexities of patients with MCC. As a strategy, care coordination was developed in the 1990's to address disease specific chronic illness and there is a plethora of research studies on disease specific care (Bodenheimer, 2003). However, the advent of intensive ambulatory care coordination for patients with MCC is a relatively new strategy and not extensively studied. Further, no ambulatory intensive case management programs have examined the impact of hospice utilization, goals of care, and end-of-life planning with MCC.

For the review of literature, a systematic review for observational and controlled studies in the United States from the years 2005-2016 was conducted using the search engines EBSCO, CINAHL, and PubMed using the terms "intensive ambulatory care", "care coordination", "advanced care

planning”, “hospice”, and “chronic illness”. There were sixteen quantitative and two qualitative studies in the following literature review. The literature review is organized into four sections: care coordination and chronic illness, hospice barriers and chronic illness, care coordination and hospice utilization, and gaps in the literature.

Care Coordination and Chronic Illness

Care coordination has been identified by the Institute of Medicine as a national priority to enhance healthcare quality of those with chronic illness (IOM, 2012). Care coordination is defined as *“the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care”* (McDonald et al., 2007).

Interdisciplinary care coordination programs greatly benefit patients with chronic conditions. There were two qualitative studies that address the patient’s perspective of coping with chronic illness (Bayliss et al., 2008; Noel et al., 2005). Trusting collaborative relationships, more time, frequent follow-up, and patient-centered care are common features desired by

patients with chronic illness and are the core interventions of interdisciplinary care coordination teams. Bayliss et al. (2008) performed a qualitative study exploring the perspectives of elderly patients with multiple chronic illnesses who were apart of a Health Maintenance Organization. The randomly selected sample consisted of patients older than 65 years of age with at minimum diagnosis of diabetes, osteoarthritis, and depression. The majority of the sample had over 10 chronic illnesses. Themes extracted from the interviews included requesting easy access to providers, frequent contact, communicated care plans, one identified point of contact for care coordination, and a desire to have their perspectives listened to. Overall, the patients felt that a caring demeanor and time to be listened to were valuable characteristics of their medical providers.

Noel et al. (2005) performed a nationwide qualitative study exploring the needs and preferences of patients with multiple chronic illnesses at eight Veteran's Administration primary care clinics. Common themes extracted were not enough time to discuss all the multiple issues with the provider and disagreements on what problem or illness was the most important to address. Overwhelming disease management or medication plan, lack of knowledge or skills to manage the complexity of their health concerns, desire for more frequent follow-up, and difficulty navigating the

healthcare system were other common themes from patients with multiple chronic illnesses.

New and innovative models of care are needed to address this growing epidemic of chronic illness and escalating health care costs. Care coordination programs in a variety of settings and patient populations have been studied and evaluated over the last decade with mixed outcomes in cost reduction and healthcare utilization. Cost containment was the primary motive of the various studies evaluating intensive care coordination for patients with MCC. Only three quantitative studies addressed end-of-life planning as an outcome as a result of intensive primary care coordination programs (Douglas, Daly, Kelley, O'Toole, & Montenegro, 2007; Engelhardt et al., 2009; Sweeney et al., 2007).

Sweeney et al. (2007) examined the effect of intensive case management on survival and health care costs in a prospective cohort study comparing patient-centered management (PCM) to standard health maintenance organization management (HMO) care. Patient-centered management consisted of care coordination, home visits, regular contact with the patients to elicit goals, assist with end-of-life planning and education, and symptom management. The intent-to-treat method was used to evaluate the PCM group (n=358) to the HMO group (n=398) over 18 months. The patient centered management group was noted to

improve symptom management, decrease hospital admissions by 38%, decrease hospital length of stay by 36%, and emergency room utilization by 30%. Hospice utilization increased by 62% and home health care increased by 22% in the PCM group. The authors examined life span and did not note a difference between the HMO and the patient centered group (Fisher exact test, $P=.80$; Mantel-Haenszel test, $P= .73$).

Douglas et al. (2007) examined cost and quality of life outcomes of intensive case management on the critically chronically ill patients in a randomized trial comparing the intensive case management group with a control group for an eight-week period ($n=334$). In the intensive case management group an Advanced Practice nurse met with the patients in hospital, 48 hours post discharge, at home with in 48 hours, and then weekly home visits. The intervention consisted of care coordination, emotional support to patient and family, end-of-life counseling, medication reconciliation, and health monitoring. The control group received usual care. The results were not significant for quality of life outcomes nor costs. However, there was a decrease in hospital readmission rates for the intervention group.

Engelhardt et al. (2009) evaluated a structured time limited advanced illness coordinated care program to a control group. The program implemented health counseling, patient education, and care

coordination in a 6-session model. The sessions consisted of three domains, 1) health/illness topics and symptom management 2) coping and psychosocial aspects of managing chronic illness 3) care giver support. The intervention group noted improved communication and symptom management ($P=.02$), increased spiritual well-being ($P=.03$), and the care givers reported higher level of emotional and spiritual support. Most importantly, there was an increase and more timely completion of advanced directives and goals of care discussions in the intervention group.

Successful care coordination programs are multidisciplinary teams that are patient focused. There are two quantitative studies that explored the common themes of successful intensive care coordination programs (Berry, Rock, Houskamp, Brueggerman, & Tucker, 2013; Brown, Peikes, Peterson, Schore, & Razafindro, 2012). The studies noted that interdisciplinary teams illicit what matters most to patients, create goals of care, identify the patient's barriers and fears, and foster a trusting relationship.

Berry et al. (2013) evaluated intensive care coordination pilot program of the most complex patients in their healthcare system. Gunderson Health in Wisconsin is an independent integrated health care organization that has implemented an extensive care coordination program

for their most one to two percent most complex patients. This program exemplifies a successful interdisciplinary care coordination program. The teams consist of nurse and social work dyads who have frequent face-to-face contact with the patient and family, co-attend medical appointments, perform community visits, enhance the communication between the patient and providers, and provide assistance with transitions of care. The core components of the care coordination are the relationships formed between the team and patients. They are the first to notice patient changes in condition, educate the patients and family members on the disease trajectory and management, and assist with social work or community resources. The team is proactive in their care, anticipate needs, and incorporate a macro perspective level of care. Due to the care coordination program, Gunderson health decreased unscheduled hospitalizations and emergency department utilization by 50%, decreased length of hospital stay by almost 40%.

The importance of relationships between the care coordination team and patients was also noted in a large study by Brown et al. (2012), who evaluated fifteen Medicare coordinated care programs throughout the United States. The most successful programs had monthly face-to-face encounters and frequent virtual encounters. Relationships and open trusting communication were the key components whether between the

providers and patients or between the primary care provider and specialty care provider. Patient education on self-care management, symptom management, and behavior modification were an integral part of the programs as well as timely transitions of care between healthcare settings, such as palliative care or hospice.

In conclusion, limited inquiries are available evaluating intensive care coordination programs. Many programs originated studying the high utilizing medically complex patient in relation the healthcare utilization and costs but seldom focused on end-of-life planning. Patients with MCC are at high risk for mortality, yet the programs have not studied this. Many programs are still struggling with sustainability, identifying the complex patient, and interventions of intensive care coordination.

Hospice Barriers and Utilization in Chronic Illness

Patients with more than one chronic illness have increased steadily over time. According to the Centers for Disease Control and Prevention (CDC, 2015), approximately half of the U.S. population has more than one chronic disease and one in four people have more than two chronic diseases. To no surprise, patients with MCC have higher needs, higher mortality risk, and higher healthcare costs. The mortality rate is staggering with MCC. According to the World Health Organization (WHO) the mortality from chronic disease has surpassed death from infectious

disease. In 2010, 48% of the deaths were a result of heart disease and cancer (CDC, 2015). In 2013, over 80% were 65 years or older who died on hospice care with primarily a non-cancer diagnosis (National Hospice and Palliative Care Organization [NHPCO], 2014). However, discussing end of life “goals-of-care” and Hospice referral is rarely implemented.

Hospice is a service that provides comfort care to patients with a terminal condition with less than six-month life expectancy (NHPCO, 2014).

Several barriers to hospice utilization were identified in the literature. The most common barriers are primary care providers not feeling confident in predicting less than six month survival in patients, lack of end-of-life training, lack of knowledge, provider attitudes, providers belief that the patient and family are unwilling, and difficulty differentiating between palliative care and hospice (Billings & Bernacki, 2014; Clemins, Stuart, Gerber, Newman, & Bauman, 2006; Feeg & Elebiary, 2005; Hamlet et al., 2010; Snyder, Hazelett, Allen, & Radwany, 2012; Tang, French, Ciper, & Rastogi, 2012).

Snyder et al. (2012) surveyed 158 primary care providers (PCP) in North East Ohio to evaluate their knowledge, attitudes, experience, advanced care planning, and hospice and palliative care utilization. Overall, almost 100 percent of the PCP's felt comfortable discussing advanced care planning however, only 43 % actually discussed end-of-life

goals of care. Barriers identified by the PCP were lack of time, felt it was the specialist role, or perceived that the families were not ready to discuss end-of-life matters. Surprisingly, fifty percent of the PCPs could not differentiate between palliative care and hospice care.

Tang et al. (2012) performed a retrospective study examining hospice utilization and length of hospice services at the Veteran's Affairs North Texas Healthcare System between 2001-2010. The greatest barrier to hospice utilization were providers not feeling confident estimating a person's survival of less than 6 months. The PCPs had a more difficult time estimating survival in non-cancer diagnosis than the Oncologists who tended to refer to hospice much earlier. There were significant differences on the length of hospice services depending on the type of referral. Oncology referrals had mean hospice stay of 35 days, primary care and other specialty clinics had means length of utilization of 19 and 23 days respectively. The overall hospice utilization increased over time, which is in conjunction with the national data. However, the length of hospice stay noted no difference over time.

Patients with MCC have multiple medical and psychosocial complexities that make it challenging to predict the trajectory of the disease or mortality. Hospice was utilized more readily in cancer patients than with MCC. Thomas, O'Leary, and Fried (2009) examined hospice

utilization among providers and patients with advanced cancer, chronic obstructive pulmonary disease (COPD), or heart failure. Not surprisingly, hospice was discussed with 46% of the cancer patients, 10% of the COPD patients, and 7% of the heart failure patients. This was attributed to the provider's uncertainty of a patient's life expectancy. However, hospice discussions did increase hospice utilization.

In summary, patients with MCC are medically and psychosocially complicating. The disease trajectory and mortality of MCC is challenging to predict therefore, hospice is rarely involved. The most common barrier to hospice is the provider not feeling confident in predicting death.

Care Coordination and Hospice Utilization

Hospice utilization has steadily increased over the years. In 2014, approximately 1.6 to 1.7 million patients received Hospice services in contrast to 1.4 million patients in 2010 (NHPCO, 2015). Care coordination has been the primary intervention within palliative and hospice programs. However, there have been a sparse number of research studies that examined the relationship of primary care intensive care coordination teams and Advanced Care planning and hospice utilization. There are four quantitative studies that evaluated care coordination for the advanced and critically ill patients (Beyea, Fischer, Schneck, & Hanson, 2013; Clemins et al., 2006; Hamlet et al., 2010; Spetell et al, 2009).

Spetell et al., (2009) performed a retrospective study examining if case management impacts hospice and acute care utilization in patients with advanced illness. A historical control group was compared to three groups; case management (n=3491), enhanced benefit (n=387), and Medicare (n=447). The case management group received intensive case management; the enhanced group received intensive case management in addition to more liberal hospice requirements of death prognosis within 12 months. The Medicare group followed the Medicare hospice guidelines of less than six-month survival and received case management. Case management consisted of frequent phone contact from a RN, identified goals of care, provided education on end-of-life planning, and assisted with hospice care coordination. Hospice utilization was increased with the case management group in contrast to the control group (enhanced case management 69.8%, control 27.9%, $p < .0001$; Case management 71.7%, control 30.8%, $p < .0001$). The number of days on hospice was increased in each group in comparison to the control (enhanced case management 36.7 days, control 21.4 days; case management 28.6 days, control 15.9 days). In contrast, the percentage of acute care stay was decreased in comparison to the control group (enhanced case management 16.8%, control 40.3, $p < .0001$; case management 22.7%, control 42.9%, $p < .0001$; Medicare case management 30%, control 88.4%, $p < .0001$). Case

management was beneficial in increasing hospice utilization by almost 70% in comparison to the control group. Removing the strict hospice guidelines did allow for earlier hospice referral but it was not significant in comparison to the case management alone group.

Clemins et al. (2006) performed an observational retrospective study examining the outcome of Advanced Illness Management (AIM) program on hospice utilization in the San Francisco bay area. The program consisted of integrating palliative care into home-health care with a focus on education, symptom management, goals attainment, and advanced care planning to chronically ill patients with a projected less than 6 month survival. The intervention group (AIM) (n=140) was matched by symptoms and survival prognosis to two control groups. The control group was apart of the AIM home health agency (n=66) and the other at another home care agency (n=227) in order to reduce bias. The AIM program noted a 27% increase in Hospice compared to the same home health agency and 67% to the other home care agency. There was a significant increase in African-American patients referred to hospice with the AIM program ($p<0.01$).

Hamlet et al. (2010) also studied chronically ill patients with less than a 1-year survival on telephonic end-of-life counseling. The sample (n=43,497) was apart of two randomly assigned Medicare Health Support

pilot programs that integrated end-of-life counseling in the care coordination program compared to a control group. The nurse had one or more successful phone encounters during the 12-month period. The study did not note a significant increase in hospice referral or length on hospice between the intervention group and control. However, there were cost savings of \$1913 between the two groups with a total cost savings of \$5.95 million. Perhaps if there was more frequent follow-up and relationships established, hospice utilization would have been statistically significant.

Community Care of North Carolina (CCNC) partnered with the North Carolina Department of Health and Human Services for Medicaid patients. The CCNC serves 1.1 million patients and 4500 primary care providers. Beyea et al. (2013) examined the outcome of palliative care education with 510 case managers associated with CCNC in order to facilitate timely hospice and palliative care referral and discuss advanced care planning. This initiative originated and expanded the traditional chronic care management programs to incorporate more care for the chronically ill Medicaid patients in North Carolina. Due to the palliative care education, the referrals to palliative care and hospice increased from 8% to 155%. However, there was no significant difference of non-dual Medicaid patients enrolled in hospice within 90 days of demise. This could be due to the small sample size.

In summary, care coordination is commonly embedded into palliative care and hospice. Due to the hospice criteria of death prognosis within 6 months, programs have been created to provide care coordination for the frail elderly and critically ill patients. The studies have mixed outcomes if there is an increase in hospice referral as a result of care coordination.

Summary

Management of patients with MCC has gained momentum over the last several years. Historically, chronic disease management was disease specific and did not adequately address the complexity of MCC patients. The patients with MCC have complex medical, behavioral, and social needs that require time, creativity, and continuity of care that the current primary care system is not designed for. They are at a higher risk for mortality, emergency room, and hospital encounters. Many have underlying mental health and psychosocial complexities that further puts them at risk.

As a result, an intensive ambulatory care coordination programs using the Chronic Care model framework has evolved as a solution to decrease healthcare costs and better manage MCC. Common components of intensive ambulatory care coordination programs are trusting relationships, frequent encounters, more time caring for patients with a patient-centered approach, and providing wrap around support for

the patient. However, very little research has been conducted evaluating intensive ambulatory care programs, interventions, or patient populations. The programs that have been studied primarily focused on cost and utilization of healthcare services and often had mixed results. There is a gap of knowledge regarding hospice facilitation and early end-of-life planning as a result of intensive ambulatory care coordination despite the fact that patients with MCC are at a higher risk for mortality. To date there are no research studies that have exclusively examined hospice utilization with intensive ambulatory care coordination embedded in primary care.

The premise of this capstone project is to examine if patients enrolled in multi-disciplinary intensive case management (ImPACT) program alter the patient's end-of-life path or setting of death. It is hypothesized that due to the trusting relationship created, identifying the patient's values and beliefs, and discussing their care preferences with the team will facilitate hospice referral.

CHAPTER 3: METHODOLOGY

Project Design

This capstone quality improvement project is a quantitative retrospective study examining hospice referral for individuals enrolled in the ImPACT program who died between 2/2013-1/2015. It is a secondary analysis of a larger study of a quality improvement evaluation that took place at the Veteran's Administration (VA) facility in Palo Alto, California from 2/1/2013-6/30/2014 (Zulman et al., 2014). The purpose of the capstone project is to examine if patients enrolled in a multi-disciplinary intensive case management (ImPACT) program alter the patient's end-of-life path or setting of death. It is hypothesized that due to the high-touch patient-centered philosophy of the program, the trusting relationship created, and identifying the patient's values, beliefs, and care preferences would more likely facilitate a hospice referral. The research question for this capstone program is "Are patients enrolled in intensive case management more likely to be referred to hospice compared to patients receiving standard primary care at the Veteran's Administration, Palo Alto?"

Setting

The study took place at the VA in Palo Alto. The patients were a selected subset of the primary care medical patient home (PACT) that

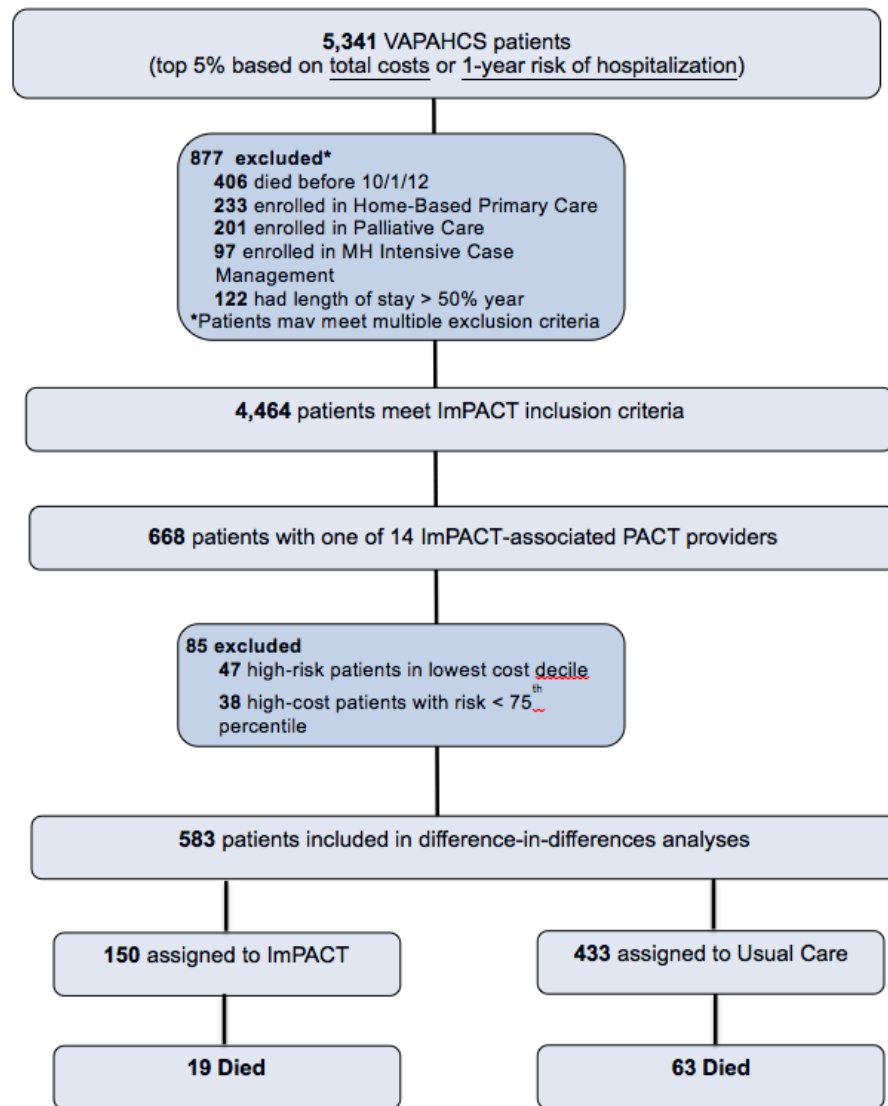
serves over 18,000 veterans.

Patient Population and Sample

The ImPACT program was implemented for Veterans receiving care at VA Palo Alto. The patient criteria was designed to identify high-risk, high-need ambulatory care patients that were 1) >18 years of age, 2) their primary care provider is one of 14 ImPACT-affiliated PACT providers with 3 or more half-days of clinic per week, 3) encounters were predominantly outpatient during the eligibility period and 4) their total healthcare costs were in the top 5% during a 9-month eligibility phase (10/1/2011-6/20-2012) or if their risk for one-year hospitalization was in the top 5% based on a Care Assessment Need (CAN) score of 95 or greater (Zulman et al., 2014). The CAN score is the percentile risk of a hospitalization within one year and ranges from 0 indicating low risk to 99, the highest risk of hospitalization (Wang et al., 2013). The exclusion criteria were designed to eliminate already existing intensive case management such as enrollment in Home-Based Primary Care, hospice care, or Mental Health Intensive Case Management. Among the patients meeting criteria, 150 randomly selected veterans were assigned to the pilot ImPACT group and 433 veteran's received standard PACT care (See Figure 3). In this secondary analysis, the analytic cohort consisted of those who died

between 2/2013-1/2014. The patients were identified through the VA's electronic health records.

Figure 3. Patient Recruitment



Ethical Considerations

This specific quality improvement project was approved by the Institutional Review Board at California State University, Fresno in addition

to the broader quality improvement project's IRB at Stanford University.

The data was obtained from the electronic medical record and in order to maintain confidentiality, all identifiable information was removed. The data was stored in a password protected electronic record in a password protected computer. There was no psychological, social, physical economic, nor legal risk involved with this quality improvement study.

Intervention

In February 2013, the Palo Alto VA implemented an outpatient intensive management pilot program (Intensive Management Patient-Aligned Team or ImPACT) for high-risk and high-cost patients with the goal of coordinating their healthcare, preventing hospitalization, unnecessary emergency room utilization, and reducing health care costs. However, an unanticipated and notable observation made by the clinical team was that the intervention improved end of life preparation and was in alignment with patient's goals of care.

The ImPACT multi-disciplinary team consisted of a full-time Nurse Practitioner, Social Worker, Recreation Therapist, and Administrative Coordinator in conjunction with a quarter-time Physician Champion. The team's interventions consisted of coordinating the patient's care, addressing their medical and psychosocial complexities, assisting with end-of-life planning, eliciting health goals, and developing multi-faceted

strategies and solutions to the patient's medical conditions and symptom burden. The ImPACT team did not replace the existing primary care teams, but rather augmented the care by providing a more patient-centered, high-touch approach. High-touch approach is providing frequent interactions either face-to-face or by telephone. Aspects of the ImPACT clinic that were unique compared to the standard primary care (Patient-aligned Care Team or PACT) care was 1) 24/7 direct phone line to a physician or nurse practitioner 2) multidisciplinary comprehensive intake focusing on patient's goals and barriers to care 3) mutually created care plan between ImPACT and the patient 4) frequent follow up per patient's acuity and needs, 4) health education and coaching 5) co-attend medical appointments 6) early identification of social work needs 7) collaboration with the inpatient team when the patient was hospitalized 8) community reintegration.

The ImPACT team worked with a holistic and patient-centered focus. A comprehensive assessment included hearing the patient's story, asking what matters most to them, what their concerns are, and how they foresee their medical condition to be in 6 months to a year from now, who their support system is, and to review and update their Advanced Directive (AD). A thorough chart review was performed by the Nurse Practitioner to identify patterns in the patients care, hospital and emergency room

utilization, specialty care, Advanced Directive (AD) discussions, and possible compliance issues such as no-showing appointments or not taking their medications as prescribed. The patients were discussed at weekly interdisciplinary team meetings to create patient-centered care plans and follow-up plans based on acuity.

The acuity is color coded as red, yellow, or green. Red represents poorly managed chronic conditions with increased symptom burden, poor compliance with medications and treatment, poor health behaviors, untreated mental health condition, social isolation, unstable housing or psychosocial issue, and frequent ER visits and hospitalizations. Patients with red acuity require weekly calls, all medical appointments to be co-attended, monthly medication reconciliation, and home visit. Yellow acuity represents patients with poor chronic disease self-management but medically stable, elderly, recent hospitalization, unstable mental health condition but is being treated, stable housing, and has support network. Yellow acuity patients require monthly encounters either face-to-face or via telephone, specialty appointments co-attended, monthly medication reconciliation, and proactive management of their conditions. Green acuity is the lowest risk for an emergency room encounter or hospitalization. The medical conditions are stable and patient has insight on their medical conditions and health behaviors, displays proper medication management,

housing is stable with a good support network, and actively engaged with mental health. Green acuity patients require encounters every 2-3 months via telephone. Recreation therapy is actively involved at this point to reinforce health behaviors. Due to the complexity of the ImPACT patients, their acuity is constantly changing based on the medical and psychosocial conditions.

After the comprehensive intake, the team performed frequent face-to-face or telephone encounters per acuity color. The patients with the highest acuity had weekly encounters either face-to-face or virtually. Those with lower acuity would have regular monthly encounters. The frequent encounters using motivational interviewing and a patient-centered focus helped to foster a trusting relationship between the ImPACT team and patient. Community visits were performed to those patients that needed to improve insight and or patient engagement. Care coordination, identifying gaps in care, completing an Advanced Directive, providing a medication calendar, referring to appropriate services such as mental health, substance abuse treatment, neuropsychological testing, or physical therapy were the primary interventions.

Over time, the team developed an intimate perspective of the patient through the patient sharing their story, values and beliefs. This allowed the team to advocate for the patient, discuss the patient's care preferences

with medical providers, be proactive and identify changes in their conditions or social situations in order to prevent an emergency room visit or facilitate a Hospice referral. The trusting relationship formed was the crux of the intervention of the intensive case management team. Goal setting, behavior change, goals of care discussions, maintaining stable psychosocial issues, and overall positive change in the patient was created and sustained as a result of the relationship created.

Data Collection

This is a retrospective review of patient data from the sub-cohort of the ImPACT study of those who died during 2/2013-1/2015 at the Veteran's Administration Palo Alto. The data was collected by chart review from the electronic health record (CPRS). When the information regarding location and circumstances of death was unknown in the chart, data collection was supplemented by phone calls to the next of kin. The chart review consisted of date and place of death, hospice utilization, and length of time engaged with ImPACT. The author was the primary investigator in addition to two other chart reviewers. Any disagreements of data, was presented to a fourth independent reviewer to reach consensus. A chart review protocol was written and adhered to in order to obtain consistent data from the chart reviews. All of the identifiable information was removed from the data and entered into an excel spreadsheet and SPSS

22.0 software that was stored in a pass-word protected computer.

Data Analysis

IBM SPSS Statistic 22.0 was used for data analysis and descriptive analysis of demographic characteristics. Stata v13 and t-tests were used to analyze the demographic and patient characteristics. A chi-square test of independence was performed to assess the relation between hospice referral and ImPACT care.

CHAPTER 4: RESULTS

The purpose of the capstone project is to examine if patients enrolled in multi-disciplinary intensive case management (ImPACT) program influences end-of-life care. It is hypothesized that the program's emphasis on developing trusting relationships, identifying patient's values and beliefs, and incorporating patient preferences into care plans will facilitate hospice referral and the end-of-life care in less intensive settings. The research question for this capstone program is "Are patients enrolled in intensive case management more likely to be referred to hospice compared to patients receiving standard primary care at the Veteran's Administration, Palo Alto?"

IBM SPSS Statistics 22.0 (IBM Corporation, Armonk, New York) was used for data analysis. Independent sample *t* test was used for continuous variables of age, number of conditions and CAN score. The chi-square test was used for dichotomous/ categorical variables of gender, patient characteristics, geographical information, and hospice data. All data was numerically coded in regard to sample, hospice referral, and location of death. The author partnered with a statistician to run the statistical analysis.

Demographic Characteristics

Among the 82 patients who died during 2/2013-1/2014 and were included in the analytic cohort, 19 were enrolled in ImPACT (mean enrollment 249 days) and 63 received standard PACT care. As shown in table 1, there were no significant differences in age, gender, geographical location, or ethnicity between ImPACT and standard care groups.

Table 1

Characteristics of ImPACT vs. Usual Care patients who died

	ImPACT (n = 19)	Standard Care (n=63)	P-value‡
	n (%)†	n (%)†	
Age, mean (SD)	76(12.6)	71.6 (13.4)	0.21
30-50	0 (0)	3 (5)	
51-64	3 (16)	20 (32)	
65-74	6 (32)	15 (24)	
75 +	10 (53)	25 (40)	
Gender			
Male	19 (100)	61 (97)	0.43
Female	0 (0)	2 (3)	
Patient Geographical Indicator			
Urban	17 (89)	57 (90)	0.81
Rural	2 (11)	5 (8)	
Unknown	0 (0)	1 (2)	
Race/Ethnicity			
White, Non-Hispanic	10 (53)	43 (68)	0.18
Black, Non-Hispanic	4 (21)	4 (6)	
Hispanic	0 (0)	3 (5)	
Other	5 (26)	13 (21)	
Chronic Conditions, mean (SD)	12 (3.0)	11 (3.6)	0.58
0-6	0 (0)	5 (8)	
7-9	4 (21)	13 (21)	
10-12	10 (53)	18 (29)	
13 or more	5 (26)	27 (43)	
Homelessness (ICD-9 60.0)	1 (5)	11 (18)	0.187
CAN Score, mean (SD)****	96.6 (4.3)	95 (5.5)	0.39

‡P-values reflect t-tests for continuous variables (Age, Number of Conditions, CAN Score) and chi-square tests for dichotomous/categorical variables (Gender, Patient Type, Patient Geographical Indicator).

****Care Assessment Need Score

Clinical Characteristics

Over ninety percent of the patients were male and over sixty percent were over 65 years of age with the mean age of 71 years. ImPACT and standard care patients had high numbers of chronic conditions with a mean (SD) 12(3) and 11.5(3.6) conditions respectively. Almost 80% of the ImPACT group and 72 % of the standard group had greater than 10 chronic conditions. Hypertension, coronary artery disease, diabetes mellitus, hyperlipidemia, and kidney disease were the most prevalent medical conditions. Over 50% of both groups had at least one mental health comorbidity. Depression, post-traumatic stress disorder, alcohol dependence, and substance abuse accounted for the most common mental health diagnosis. There were few significant differences between the most common conditions confirming that the two groups were comparable clinically (Table 2).

Table 2

Chronic condition diagnoses among ImPACT vs. Usual Care patients who died

	ImPACT (n=19)	Usual Care (n=63)	
Medical Conditions	n (%)	n (%)	P-Value (Chi- square)

Cancer			
Cancer	11 (58)	22 (36)	0.10
Cardiovascular			
Hypertension	17 (89)	50 (79)	0.32
Coronary Artery Disease	11 (58)	24 (38)	0.13
Heart Failure	10 (53)	26 (42)	0.38
Arrhythmia/Conduction Disorder	12 (63)	33 (53)	0.41
Cerebrovascular Disease	5 (26)	10 (16)	0.30
Vascular Disease	9 (47)	24 (38)	0.47
Endocrine/Metabolic/Nutrition			
Diabetes Mellitus	8 (42)	27 (43)	0.95
Lipid Disorders	14 (74)	38 (60)	0.29
Overweight/Obesity	5 (26)	10 (16)	0.30
Thyroid Disorders	2 (11)	9 (14)	0.67
Gastrointestinal			
Esophageal/Gast/Duod Disorders	13 (68)	32 (51)	0.17
Liver Disease or Hepatitis C	3 (16)	17 (27)	0.32
Mental Health			
Any Mental Health Condition	10 (53)	37 (59)	0.64
Depression	6 (32)	22 (35)	0.78
PTSD	2 (11)	10 (16)	0.56
Anxiety Disorders	1 (5)	9 (14)	0.29
Bipolar Disorders	0 (0)	4 (6)	0.26
Personality Disorders	0 (0)	1 (2)	0.58
Schizophrenia	1 (5)	1 (2)	0.36
Psychotic Disorders- Other	0 (0)	11 (18)	0.05*
Alcohol Use Disorders	2 (11)	13 (21)	0.32
Drug Use Disorders	1 (5)	14 (22)	0.09
Musculoskeletal			
Spine Disorders	8 (42)	23 (37)	0.66
Joint Disorders	11 (58)	32 (51)	0.59
Musculoskeletal Conditions- Other	8 (42)	34 (54)	0.36
Neurologic			
Traumatic Brain Injury	0 (0)	2 (3)	0.43
Dementia	5 (26)	5 (8)	0.03*
Spinal Cord Injury or Paralysis	2 (11)	2 (3)	0.19
Peripheral Nerve Disorders	3 (16)	10 (16)	0.99
Nervous System Sx/Disorders- Other	9 (47)	25 (40)	0.55
Renal/Urinary			
Renal Failure or Nephropathy	10 (53)	25 (40)	0.32
Kidney/Ureter/Urinary Conditions	9 (47)	37 (59)	0.38
Respiratory			
Chronic Obstructive Pulmonary Disease	4 (21)	15 (24)	0.80

Asthma	0 (0)	4 (6)	0.26
Respiratory Conditions- Other	14 (74)	40 (64)	0.41
Hematologic/Immunologic			
Anemia	5 (26)	33 (52)	0.046*
Thrombocytopenia	2 (11)	9 (154)	0.67
Coagulation and Hem Disorders	1 (5)	5 (8)	0.70
Hematologic/Imm Conditions- Other	4 (21)	15 (24)	0.80

1. Samples include patients who were alive and present as of 2/1/13. Chronic conditions were identified using WHEI Handbook.

* p less than 0.05

Hospice Utilization

A greater proportion of the ImPACT sample were enrolled in hospice supporting the hypotheses that patients receiving ImPACT care are referred to hospice more readily. Specifically (see table 3), 74% of the patients enrolled in ImPACT were more likely to be referred to hospice compared to 45% receiving standard care. A chi-square test of independence revealed a significant relationship between enrollment in hospice and ImPACT care ($\chi^2 (2, 82) = 4.995, p = .025$).

Table 3

Percent of Patient Enrollment into Hospice by Case Management

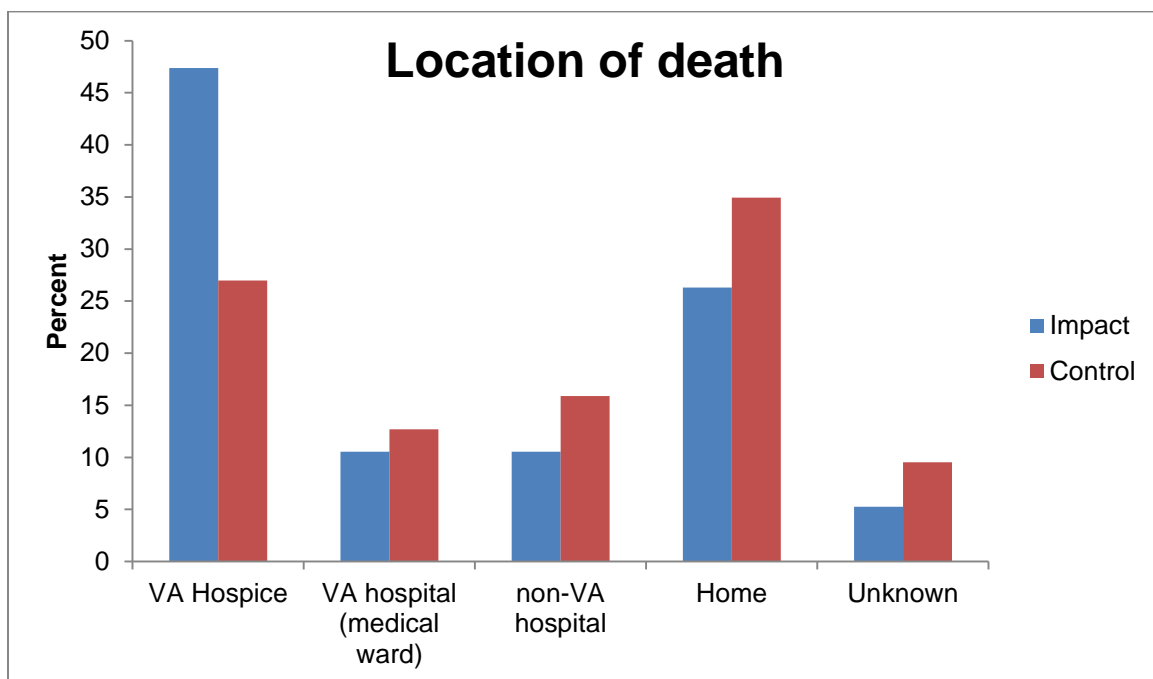
Group (N = 82)

CASE MANAGEMENT	% REFERRED TO HOSPICE

CONTROL	44.4%	P=0.025
IMPACT	73.7%	

Among those enrolled in hospice, the mean (SD) number of days patients spent in hospice was 48(53) and 78(131) for the ImpACT and standard care group respectively. There was no significant difference noted between the number of days on hospice between ImpACT and standard care using an independent samples *t* test ($t(38.88)=1.07$, $p=0.290$). The age of death between both groups was 72 years of age for ImpACT and 76 years of age for those receiving standard care. As noted in figure 4, for those patients whose location of death could be confirmed, almost 50% of the ImpACT patients died on inpatient hospice compared to 27% receiving standard care. The ImpACT patients were admitted to inpatient hospice when they were actively dying. For the patients that died at home, 26% were ImpACT patients and 34% were the standard care patients. The location of death was not known in seven cases. A small percentage (10%) of both groups died on the VA wards with comfort care without hospice.

Figure 4. Location of Death



CHAPTER 5: DISCUSSION

Intensive ambulatory multi-disciplinary case management programs have evolved as a solution to the healthcare burden and costs with MCC patients, yet none have examined end-of-life planning or hospice referral as an outcome. Patients with MCC have an increased burden on the healthcare system, higher risk of mortality, and higher healthcare costs (AHQR, 2010; Anderson, 2010; HHS, 2010; Lee et al., 2007). These patients have complex medical, behavioral, and social needs that require time, creativity, and continuity of care that the current primary care system is not designed for. The core components of intensive ambulatory care coordination programs are trusting relationships, frequent encounters, more flexible time caring for patients with a patient-centered approach, and providing wrap around support for the patient (Bayless et al., 2008; Hasselman, 2013; Hong et al., 2014; Robinson, 2010; Sweeney et al., 2007). Identifying the patient's "goals of care" and end of life wishes can be easily discussed due to the relationship formed between the patient, family, and case management team.

This quality improvement study was the first to examine if patients enrolled in an intensive ambulatory case management (ImPACT) program would alter the patient's end-of-life path or setting of death. It was hypothesized that due to the trusting relationship created, identifying the

patient's values and beliefs, and discussing their care preferences would facilitate hospice referral. The hypothesis was supported that ImPACT program did promote hospice referral more readily. The core essential activities of ImPACT were listening to the person's life story, identifying their beliefs, values, and concerns, frequent encounters, and acting as an advocate for the patient. Trusting relationships were formed which facilitated open and frank discussions on the patient's end-of-life wishes and goals of care. ImPACT would advocate for the patient to ensure his treatments were in alignment with their goals. Secondly, due to the frequent interactions, changes in the patient's condition were noted sooner, facilitating an earlier hospice referral or treatment course.

Limitations

There are several limitations to this quality improvement study that must be acknowledged. This study was conducted over a short period of time of two years; therefore the sample size was small. The sample was comprised primarily of males and not ethnically diverse due to the fact only one Veteran's Administration facility was evaluated. Additionally, the study was limited in only examining the high-risk most costly Veterans at the VA Palo Alto.

Implications for Nursing Practice and Conclusion

This study makes several important contributions to nursing practice and the existing literature. This study did find a significant association between intensive case management and hospice. It was hypothesized that the trusting relationship formed and frequent encounters between the patient and care coordinator facilitated honoring the patient's wishes and end-of-life care. There are no studies that specifically evaluated end-of-life care and hospice use as an outcome of ambulatory intensive care coordination programs.

The common denominator to successful case management programs is the nurse's role. Advanced practice nurses (APN) possess unique skill sets and are educated to care for patients as a whole, encompassing the bio-psycho-social-spiritual aspects of the individual (Stephens, 2012). Patients with MCC have multiple physical and psychosocial complexities that result in increased healthcare burden, costs, and ultimately, mortality. The current disease specific model of healthcare does not address the multitude of issues patients with MCC encounter (Leppin & Montori, 2015). The development of APN run intensive case management programs is a solution to providing holistic patient centered care to patients with MCC. The APNs are ideally suited to provide patient centered care and help identify the values, beliefs, and concerns of the patient, create realistic goals, and educate about the

disease trajectory. The trusting relationship established allows for frank and open discussions about the risk of mortality and morbidity associated with MCC. The APN is in the ideal role to prepare the patient and family about the trajectory of the disease, complete an Advanced Directive and POLST, and facilitate hospice.

Characteristics of the MCC patients are medically and psychosocially complex. There are very few research studies that have examined patient characteristics or collaborative interventions of intensive case management programs. Clearly there are opportunities to further study these programs. The APN is the perfect candidate to create evidence-based protocols and guidelines for intensive case management programs working with MCC patients and teach others to learn and implement innovative ways of patient centered care.

Conclusion

My project is unique in that very few intensive case management programs have studied the impact on hospice utilization, goals of care, and end-of-life planning. The project's results substantiate that MCC patients would benefit from intensive care-management, earlier palliative, and hospice services. Studies have indicated that there is significant cost savings with utilizing intensive case management as well as better end-of-life preparation and knowledge, improved functional and symptom

management, and decreased symptom burden. However, more research is needed to study and evaluate the effectiveness of intensive ambulatory care management for the chronically ill.

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APPENDICES

APPENDIX A: DATA COLLECTION PROTOCOL FOR PATIENTS THAT DIED

Chart review:

Check for the following notes: Advance Directive Discussion and Advance Directive scan, referrals to hospice/palliative care and information regarding patient death

1. Open CPRS, select correct patient (using SSN)
2. Record the DOD that pops up on screen alert in Date of death column

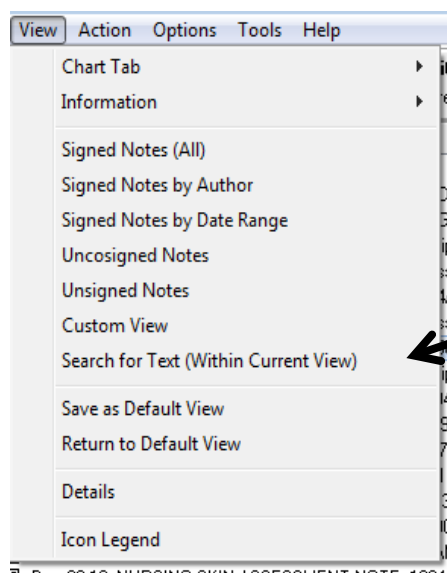
Checking for referral to hospice or palliative care:

1. Go to “Consults” tab
2. Check for referrals to hospice or palliative care by consults titled: “NDR HOSPICE/ HOME HOSPICE/PALLIATIVE CARE”

For more details or if no information in consults:

1. Go to the Notes tab
2. Click on “View” tab, click on “Custom View”. Add another zero in order to

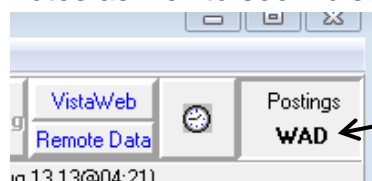
return 1000 notes:



3. Check for information in the search results that indicate how long patient was in hospice, if applicable, is hospice was home or inpatient (VA), and where they died
4. To check for hospice or palliative care notes specifically (if too many other notes at end of life):
 - a. Click "View"
 - b. "Search for Text (within current view)"
 - c. Search "hospice"
 - d. Also search "palliative"
5. Each entry will be reviewed a second time for accuracy. Once your list is complete, send to Cindie and she will assign to another research team member to verify.

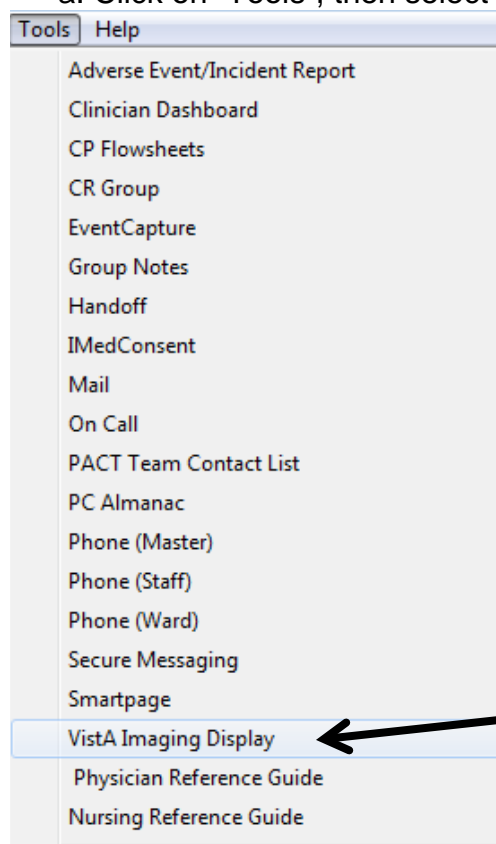
Checking for advance directive:

1. Check postings in top right corner for "Advance Directive Discussion"- double click to open the note and verify the date discussion took place. Sometimes this is not the discussion, so check the "Advance Directive" notes as well to see if discussion took place under the other notes.



Crisis Notes, Warning Notes, Directives	
Goals Of Care Discussion	Jul 10,13
Research Study Subject (tpl) 14097	Mar 15,07
Research Study Subject 14097	Dec 15,06
Research Study Subject 14097	Nov 17,04
Advance Directive Discussion 18832	Aug 08,13
Advance Directive Aug 31,09	
Advance Directive Jun 06,02	

2. To open the scanned advance directive:
 - a. Click on "Tools", then select "VistA Imaging Display"



- b. Sort by Note title (Click on Note title box) to view all Advanced Directives

Item	Site	Note Title	Proc DT
	PAL		12/14/2011 00:01
	PAL		09/16/2009 00:01
	PAL		04/08/2005 13:00
	PAL		04/08/2005 13:00
	PAL		04/08/2005 13:00
	PAL	ADVANCE DIRECTIVE	06/18/2014 10:10
	PAL	ADVANCE DIRECTIVE	11/26/2008 14:53
	PAL	ANESTHESIA RECORD 23445	04/14/2014 12:27

- c. Double click on the document to view it in the reading pane below.
- d. To scan through additional pages (so you can see signed date), click on the icon to the second right:



3. Document in excel the dates the document was signed or discussions took place

Mark your initials on the data sheet for verified sample and any corrections made

APPENDIX B. TELEPHONE SCRIPT FOR END OF LIFE ANALYSIS

THINGS TO DO BEFORE CALL:

- 1) *Check how long ago veteran died*
- 2) *Check gender!*
- 3) *Check with PCP if they have any knowledge of details of death, and any familiarity with the listed next of kin*

SCRIPT:

Hello My name is _____ calling from VA Palo Alto. If you have a moment I have a few questions to ask, to support our effort to improve care at the VA . I understand your loved one [Mr(Ms)._____] received some of HIS(her) care at the VA Palo Alto, before HIS (her) death. First, let me say I am very sorry for your loss. If you have a moment I have a few questions to ask, to support our effort to improve end of life care at the VA . Is now an OK time to speak for 5 minutes?

I noticed, that at the end of HIS(her) life HE(she) was not in a VA hospital. I have a couple questions about where your loved one received care at the end of HIS (her) life. Then I will ask for your feedback on how the VA could have been of more support..

- 1) Did the Veteran receive hospice
 - a. If so, was it at
 - i. home,
 - ii. a nursing home facility: (name of facility, if known)
 - iii. a Hospital: (name of hospital)

[If respondent does not know what hospice is, and asks can say something like: *"Hospice is a type of care and philosophy that focuses on palliation of pain and symptom control, instead of live-saving treatment, and tends to*

support death occurring in more comfortable setting than hospital intensive care unit, such as at home or a hospice facility.”

- 2) Where did MR/MS. XXXX actually pass away?
 - a. Hospital?
 - b. Home?
 - c. Nursing or Rehab facility?
 - d. Other?: _____

- 3) Is there any way that the VA could have improved the experience of Veteran or Veteran's family at end of life?

Again I am sorry for your loss and thank you for answering these questions. Your experience is valuable to us as we explore and look for ways to improve the veteran's care here at VA Palo Alto.

