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Factors Influencing the Uptake of Community-based Palliative Care

by

Nancy Elizabeth Dudley

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

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By

Nancy Elizabeth Dudley

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Dedication

I dedicate this dissertation to my parents, Patricia and John William Ross. My parents taught me leadership and compassion, and the courage to change things for the betterment of humankind.

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Note

Some of the content of this dissertation has been presented at national conferences. An early draft of Chapter 2 was presented as a poster at the American Academy of Hospice and Palliative Medicine National Conference, Chicago, IL, April 2016.

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Abstract

Factors Influencing the Uptake of Community-Based Palliative Care

Nancy Elizabeth Dudley

Over the past ten years, community-based palliative care (CBPC) has rapidly expanded as older adults are living in the community longer with advanced illness and high symptom burden. Yet there are no models of standardized care for this population. It has been suggested that primary and secondary palliative care be delivered in the primary care setting to address palliative care needs in the community. However, a description of older adults in primary care with advanced illness and symptom burden who would benefit from primary and secondary palliative care, and a description of the process to deliver care are lacking. The aim of this dissertation was to explore the facilitators and barriers to providing palliative care in primary care, and to describe the prevalence of advanced illness and symptoms of older adults in primary care to identify who would benefit from palliative care in primary care.

Using a grounded theory methodology, twenty semi-structured interviews were conducted with primary care and palliative care providers in academic and community settings. Four major themes emerged from the data that are facilitators and barriers in care coordination: (i) role clarity; (ii) feedback and communication; (iii) time constraint and workforce; (iv) education.

A secondary analysis was conducted using the National Ambulatory and Hospital Medical Care Surveys 2009-2011 to examine primary care visits. There were more visits by older adults to primary care for advanced illness and symptoms than to non-primary care.

More visits were due to advanced COPD, CHF, dementia, pain, depression, anxiety, fatigue, and insomnia compared to non-primary care. This research contributes to our knowledge of the delivery of palliative care in the community and the patient population that could benefit from primary and specialty palliative care. I offer a conceptual model of the process of primary care and specialty palliative care in order to coordinate care for older adults with advanced illness and progressive symptomatology.

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Chapter One: Introduction

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Palliative care programs have been shown to reduce pain and other symptoms, improve quality of life, and reduce costs in older adults with advanced serious illness. A new direction in the use of palliative care methodologies includes providing curative treatment concurrently with palliative care upstream from hospice (Institute of Medicine (IOM), 2015; Morrison et al., 2008). However, access to programs remains limited, especially in community settings (Kamal, Currow, Ritchie, Bull & Abernathy, 2013; Agency for Healthcare Research & Quality (AHRQ), 2011). It would be critical to examine community-based palliative care utilization at any stage in a serious illness.

Despite broader availability of hospital-based palliative care programs to manage serious and chronic illness, primary care providers of older adults with serious illness may not have access to refer patients to community-based palliative care programs (Kamal et al., 2013; Quill & Abernethy, 2013; Verret & Rohloff, 2013; Meier, 2011). Delayed referrals result in frequent admissions to emergency departments during the last 30 days of life, and 68 percent of older adults admitted die in the hospital (Smith et al., 2012). Inpatient, hospital based palliative care has been shown to improve care coordination and reduce 30-day hospital readmissions among seriously ill older adults, yet serious gaps exist in the palliative care consultant model used currently to provide care (Enguidanos, Vesper & Lorenz, 2012).

Community-based palliative care is an effective strategy to manage the complex care needs and care coordination for older adults with advanced serious illness (Kamal et al., 2013; National Consensus Project, 2013). Older adults living longer years before end of life often suffer from progressive frequent complications and high symptom burden from multiple, chronic, and progressive illnesses that require complex care (American Geriatrics Society and American Academy of Hospice and Palliative Medicine Leadership

Collaboration, 2012; American Hospital Association, 2012; IOM, 2015). Unaddressed palliative care needs such as uncontrolled pain and dyspnea are associated with frequent re-hospitalizations, high cost, and dissatisfaction with care (Eguindanos et al., 2012; Kamal et al., 2013; Meier, 2011; Morrison et al., 2008; Naylor et al., 2012). It has been suggested primary and secondary palliative care be delivered in the primary care setting to address palliative care needs in the community (von Gunten, 2002). However, a description of older adults in the primary care setting with advanced illness and symptom burden that would benefit from primary and secondary palliative care is lacking. Moreover, literature is limited on the process of the delivery of palliative care in primary care.

Background and Significance

Over the past ten years, community-based palliative care (CBPC) has rapidly expanded as older adults are living in the community longer with advanced illness and high symptom burden, yet no models of standardized care or structure for quality measurement of programs exist (Beresford & Kerr, 2012). There are gaps in care when older adults transition from acute care hospital settings to community-based care. Payers and providers are working together to support the rapid development of CBPC in an effort to meet the needs of this fragile, costliest population who frequently resort to using the emergency department for care (Center to Advance Palliative Care (CAPC), 2014a). Information is needed to understand how CBPC may best serve the elderly population, the services provided, how care is delivered, who will provide services, and how will it be financed (Beresford & Kerr, 2012). All of these elements are key policy issues that need to be addressed as CBPC becomes more systematized.

Widespread adoption of palliative care in the United States (U.S.) health care system has occurred in hospitals with 50 or more beds. From 2000 to 2012, hospitals with palliative care teams increased 163.5% - from 658 (24.5%) to 1,734 (61%) (CAPC, 2014b). Recently, palliative care has expanded into the community setting. A large cross-sectional study of outpatient palliative care in California conducted in 2011 revealed of the 351 acute care California hospitals surveyed, 324 responded (96%), and 27 (8%) reported having outpatient palliative care services (Berger, O’Riordan, Kerr & Pantilat, 2011). Hospitals with outpatient palliative care services were more likely to be large, non-profit, teaching hospitals with inpatient palliative care services, and health system affiliation (Berger et al., 2011). Patients seen had a diagnosis of cancer (55%), cardiac conditions (22%), dementia (14%), pulmonary conditions (10%), and neurological conditions (7%). There is an increased need for CBPC as older adults aging in the community are living longer years before end of life and often experience multiple chronic conditions and associated symptom burden.

The population of older Americans will double over the next 25 years to about 72 million. Two out of three older adults have multiple chronic conditions, and treatment for this population accounts for 66 percent of U.S. health care budget (CDC, 2013). Chronic illnesses that continue to be the leading cause of death and disability include heart disease, cancer, stroke, chronic lower respiratory diseases, Alzheimer’s disease, and diabetes (CDC, 2013). The population considered to benefit from palliative care includes patients with progressive chronic conditions, malignancies, renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, neurodegenerative disorders, and various forms of dementia (National Consensus Project, 2013). Symptoms associated with chronic illnesses commonly include uncontrolled pain and dyspnea, and are the cause of frequent re-

hospitalizations and high-cost care (Eguindanos et al., 2012; Kamal et al., 2013; Meier, 2011; Morrison et al., 2008; Naylor et al., 2012). Primary palliative care could be delivered in the primary care setting to address palliative care needs in the community (von Gunten, 2002).

Primary care is the principle health care service for community-dwelling older adults. Several studies indicate that co-management by primary care and palliative care providers may reduce symptom burden, and reduce potentially avoidable admissions to the emergency department and/or hospital (Bakitas et al., 2009; Brumley et al., 2007; Temel et al., 2010). Yet, co-management of older adults by primary care and palliative care providers to address patient and family needs, coordinate care, and to support aging-in-place is ill defined (Quill & Abernethy, 2013). Few studies have been published about the role of palliative care in primary care, and the process of collaboration with palliative care specialists to provide community-based palliative care (CBPC). Von Gunten (2002) defined three levels of non-hospice palliative care: (1) primary palliative care - care provided in a primary care setting by all clinicians that includes basic pain and symptom management, and discussions about advance care planning; (2) secondary palliative care - referral to specialist-level palliative care for complex symptom management or difficult problems that require advanced communication skills, and (3) tertiary palliative care - research and teaching, the highest level of palliative care expertise.

Prior research has identified a patient population who have benefited from palliative care services that include patients with cancer, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), chronic kidney disease (CKD), dementia including Alzheimer's disease, liver disease and HIV (Berger et al., 2011; Enguidanos et al., 2012; Kamal et al., 2011; Morrison et al., 2008). Patients with two or more chronic conditions,

defined as multiple chronic conditions experience higher rates of disability and death (CDC, 2013). Common symptoms experienced individually or in clusters (Miaskowski, Dodd & Lee, 2004) by this population include pain, dyspnea, fatigue, anxiety, depression, nausea, vomiting, loss of appetite, and insomnia (National Consensus Project, 2013).

There is a gap in knowledge about who may benefit from primary and secondary palliative care in the primary care setting. Few studies have examined the process to deliver palliative care in primary care settings, the prevalence of comorbid conditions and symptoms associated with advanced illness, and the patterns of health service use in different primary care settings. This research will address this gap.

Theoretical Frameworks

Different theoretical perspectives were used to inform this dissertation. First, the Symptom Management Model (Dodd et al., 2001) was used as a framework to evaluate the association of symptoms, morbidity, and components of symptom management strategies. Second, Andersen's Behavioral Model of Health Service Use (2001) was used to explore predisposing, enabling, and need variables at an individual and system level that influence access to care and health care utilization (see Table 1).

I used grounded theory as a methodological approach to conduct a qualitative study to explore the facilitators and barriers to palliative care in primary care. Grounded theory (Charmaz, 2006; Corbin & Strauss, 2008) is based on symbolic interactionism, a theoretical perspective that focuses on the processes of interaction between people exploring human behavior and social roles (Blumer, 1969). According to the theory, humans act toward a situation based on what the person believes to be true. Meaning is derived and modified through an interpretive process. Grounded theory was ideal to study the social process of

communication and collaboration among palliative and primary providers to develop a conceptual model to deliver palliative care in primary care.

Conceptual Framework

The Symptom Management Model informed the quantitative analysis of ambulatory care use of older adults with advanced illness and symptoms. Symptom management (Dodd et al., 2001) is a dynamic process modified by individual outcomes influenced by domains of person, health and illness, and environment. Individual characteristics such as demographics, psychosocial and physiological factors affect the way a person views and responds to the symptom experience. Health and illness variables include risk factors, health status, and different types of disease that may have direct and indirect effects on symptom experience, management strategies, and outcomes. Environmental elements include physical, social, and cultural variables that together refer to the context or setting within which the symptom occurs and influence presentation of symptoms, management, and outcomes (Dodd et al., 2001). The framework was used to evaluate the association of symptoms, morbidity, and the components of symptom management strategy (see Figure 1).

Current literature indicates symptoms are associated with high utilization high cost health care, and are the most common reason people seek care (Humphreys et al., 2008). Uncontrolled symptoms due to comorbid conditions adversely affect functionality, quality of life and mortality (Dodd et al., 2001). Health care providers have difficulty providing symptom management strategies in ambulatory settings because of the paucity of tested models especially for symptoms that occur in clusters, defined as three or more concurrent symptoms related to each other (Miaskowski et al., 2004). In a recent study, correlations among pain, fatigue, and depression in heart failure patients provided further evidence that

symptoms occur in clusters (Conley, Feder & Redeker, 2015) as previously studied in patients with cancer (Miaskowski et al., 2004). Furthermore, patients with COPD experienced dyspnea, pain, fatigue, and anxiety (Blinderman, Homel, Billings, Tennstedt & Portenoy, 2009) comparable to the prevalence and level of distress of ambulatory patients with CHF (Blinderman, Homel, Billings, Portenoy & Tennstedt, 2008) and cancer (Portenoy et al., 1994; Chang, Hwang, Feuerman & Kasimis, 2000). In summary, the studies suggest a need for greater attention to the provision for palliative care in ambulatory patients with advanced cancer, CHF, and COPD, as disease advances and patients experience greater symptom burden years before end of life.

The symptom management model may inform a variety of issues including the complex relationship among comorbid conditions, disease trajectory, related symptoms, and functionality. Moreover, the conceptual model can be applied to evaluate who may benefit from primary and specialist-level palliative care in the primary care setting.

For this research, I aimed to describe the population of older adults with advanced illness and symptoms who visit primary care. The findings have the potential to inform health care systems of patients who could benefit from primary and secondary palliative care. Significant opportunity exists to extend the science of palliative care to the management of older adults with serious illnesses in the primary care setting. This study has implications for health policy. The goal of health care reform is to improve access, quality, and the delivery of care in an effective and efficient way. Palliative care has shown to improve quality, satisfaction, and reduce cost (Bakitas et al., 2009; Brumley et al., 2007; Morrison et al., 2008; Temel et al., 2010). As the delivery of palliative care expands into the community, a description of who could benefit from palliative care in the primary care setting and what are

the perceived barriers and facilitators to palliative care in primary care may help to inform practice, workforce needs, severity-adjusted payment models, and the development of a model of care.

Dissertation Aims

The overall goal of this research was to explore the facilitators and barriers to providing palliative care in primary care, and to describe the prevalence of advanced illness and symptoms of older adults in the primary care setting to identify who would benefit from primary palliative care.

The following aims were addressed in a qualitative study to explore the barriers and facilitators to palliative care in primary care:

- 1) To explore the experience of primary care providers that may refer patients 65 years and older with advanced illness to palliative care.
- 2) To examine the components of communication and collaboration between primary care providers and palliative care providers that influence coordination of care.

The following aims were addressed in a quantitative study to describe the prevalence of advanced illness and symptoms of older adults in the primary care setting to identify who would benefit from primary palliative care.

Primary Aim:

- 3) To describe ambulatory care utilization of older adults age 65 and older by patient characteristics including age, gender, race, ethnicity, insurance, poverty level, and chronic conditions and symptoms.

H₀ There is no significant difference in ambulatory care utilization of older adults age 65 and older with advanced illness by patient characteristics age, gender, race, ethnicity, education, insurance, poverty level, and chronic conditions and symptoms.

Secondary Aims:

In addition to patient characteristics I looked at additional variables to describe organizational characteristics in ambulatory care that includes primary care.

4) To describe ambulatory care utilization of older adults age 65 and older by patient characteristics (age, gender, race, ethnicity, insurance, and poverty level), specialty type (internal medicine, family or general medicine), provider type, setting (office-based primary care, Federally Qualified Health Centers (FQHC), outpatient hospital primary care), hospital type, geographic practice location (urban/rural), and advanced illness and symptoms.

H₀ There is no significant difference in ambulatory care utilization of older adults age 65 and older with advanced illness and symptoms by patient characteristics, specialty type, setting, location, and chronic conditions and symptoms.

Next, I used Latent Class Analysis (LCA) to identify classes (subgroups) of patients 65 and older with advanced illness and symptoms to analyze demographic characteristics and health care utilization.

5) Are there latent class (subgroups) of patients 65 and older who share similar combinations of advanced illness and symptoms, and if so do they differ by demographic characteristics and health care utilization?

H₀ There is no significant difference in latent class (subgroups) of patients 65 and older that share similar combinations of conditions and symptoms by demographic characteristics and health care utilization.

Presentation of Dissertation

This dissertation is presented in five chapters. This introductory chapter has reviewed the problems associated with older adults living longer with advanced illness and symptoms in the community, and highlights the need to provide primary and specialty palliative care. Chapter 2 is a qualitative study that explores the facilitators and barriers to interdisciplinary interactions in primary care to coordinate care with palliative care. Chapter 3 is a secondary analysis of national survey data to examine visits to primary care settings of older adults with advanced illness and symptoms. Total visits to ambulatory care are composed of the subgroups primary care specialty and non-primary care visits. Chapter 4 utilizes latent class analysis to identify latent classes (subgroups) of adults 65 and older who share similar combinations of advanced illness and symptoms, and to describe differences by demographic and provider characteristics. Chapter 5 concludes with a summary of the research findings, implications for clinical practice and policy, and addresses future research needed.

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Figure 1. Symptom Management Model

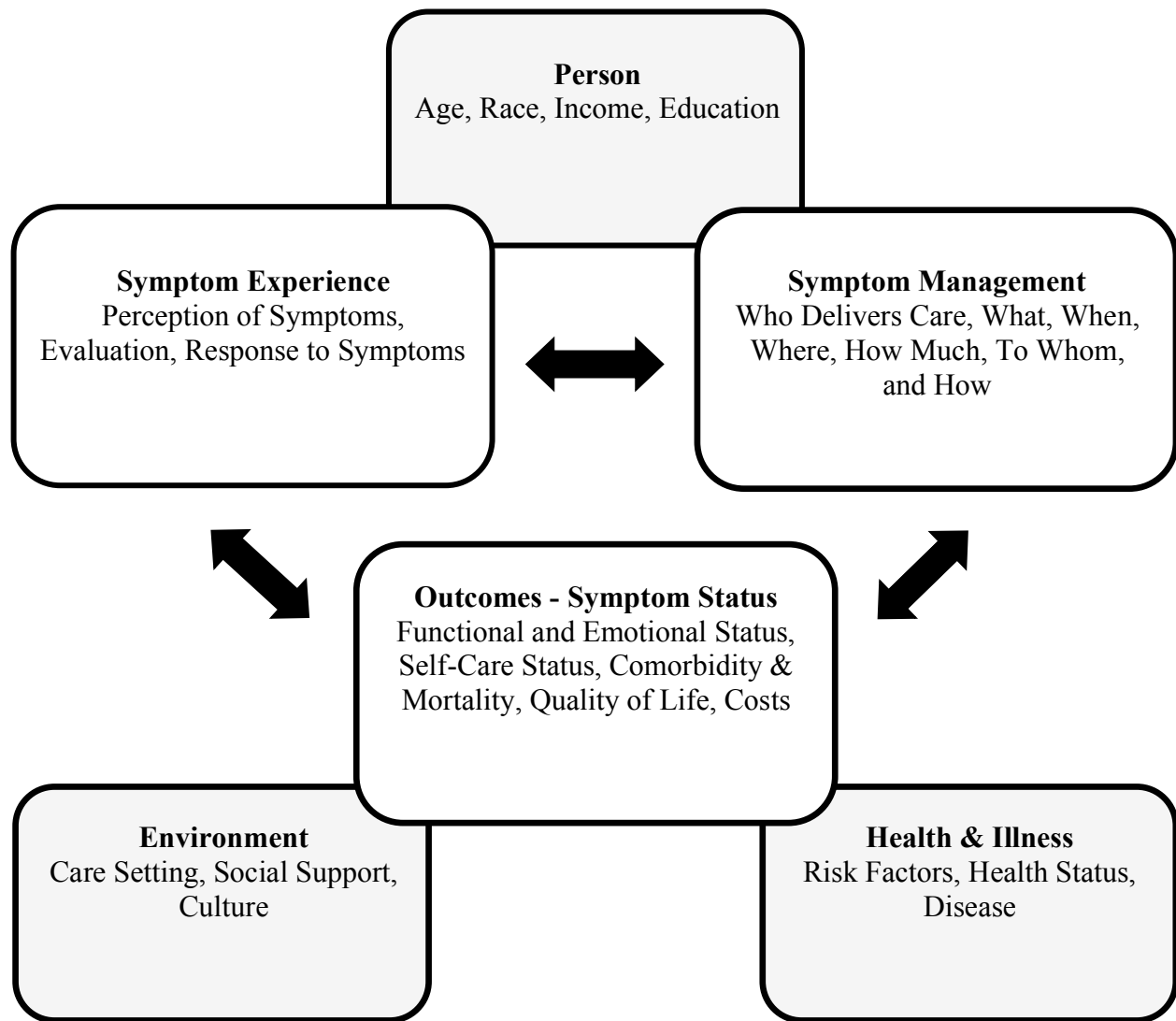


Table 1. Andersen’s Model of Health Services Utilization (2001)

Individual determinants:

1. Predisposing factors, such as age, gender, race and ethnicity, marital status, and education level.
2. Enabling factors, usually measured by insurance, income, and regular source of care.
3. Need characteristics, both perceived and evaluated. Need characteristics account for most of the variance in health service utilization and are dependent on symptom type and comorbidity.

Predisposing Factors

Age, Race/ethnicity,

Gender, Marital status,

Education level

Enabling Factors

Insurance status, Income,

Regular source of care

Need For Services

Symptom type,

Comorbidity

Health system characteristics:

System Level factors associated with barriers of access to and uptake of CBPC include primary determinants, health behavior, and health outcomes.

Primary Determinants

Aging Population

Morbidity, Mortality

Disability Rates

Health Behavior

Supply of Providers

& Facilities

Process of Care

Primary or Secondary care

Health Outcomes

Perceived/Evaluated

Health Status

Satisfaction

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**Chapter 2: Facilitators and Barriers to Interdisciplinary Communication and
Collaboration in Primary Care and Palliative Care**

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Abstract

Purpose of the Study: As a component of advanced illness management, palliative care in the outpatient setting may be able to address the complex care needs of older adults living longer with serious illnesses. Communication and collaboration between primary and palliative care providers are needed to deliver complex care management and to coordinate care, yet optimal strategies for their achievement are ill defined. This exploratory study revealed insights into the study question: What are the facilitators and barriers to interdisciplinary interactions to coordinate care?

Design and Methods: Using a grounded theory methodology, we conducted 20 semi-structured interviews with primary care and palliative care providers, including the disciplines of nursing and medicine in academic and community settings.

Results: Interdisciplinary interactions of engagement emerged as influencing the process of collaboration to coordinate care. Four major themes emerged from the data that influence the process of collaboration: (i) role clarity; (ii) feedback and communication; (iii) time constraint and workforce; (iv) education. Interdisciplinary interactions of engagement to collaborate in order to coordinate care were facilitated by defining roles and responsibilities, frequent in person, email, or electronic medical record (EMR) communication, and education of primary care providers regarding primary and secondary palliative care. Barriers that negatively impacted collaboration and working relationships among primary care and palliative care providers included, not enough time in primary care to provide care, limited workforce in palliative care specialty, and inadequate feedback that prevented a shared understanding of patient's needs and goals of care. Other contributing factors were non-

involvement of primary care providers when specialists referred patients to palliative care, and an unclear concept of primary palliative care and community-based palliative care.

Implications: Data suggest the need for greater attention to processes that promote communication and collaboration as well as strategies to promote a greater awareness of primary and secondary palliative care.

Key Words: Community-based palliative care, interdisciplinary collaboration, coordination of care

Purpose of the Study

Several emerging issues in health policy are attributed to an aging United States population and its impact on the utilization of health services. Older adults are living longer with advanced illness and often have unaddressed palliative care needs. Unaddressed palliative care needs are associated with frequent re-hospitalizations, high cost, and dissatisfaction with care (Kamal, Currow, Ritchie, Bull & Abernethy, 2013; Meier, 2011; Naylor et al., 2012). Access to community-based palliative care (CBPC) allows for the provision of appropriate and comprehensive symptom management. Palliative care programs have been shown to reduce pain and other symptoms, improve quality of life, and reduce costs in older adults with advanced illness. However, access to programs remains limited, especially in community settings (AHRQ, 2011; Institute of Medicine (IOM), 2015; Kamal et al., 2013).

Despite broader availability of palliative care programs, referrals from primary care physicians of older adults with serious illness are often delayed (Kamal et al., 2013; Quill & Abernethy, 2013; Verret & Rohloff, 2013; Meier, 2011). Enguidanos, Vesper & Lorenz, (2012) found that delayed referrals resulted in frequent admissions to emergency departments during the last 30 days of life while Smith and colleagues (2012) found that 68 percent of older adults admitted died in the hospital. Further, an Institute of Medicine report (2015) noted that a lack of knowledge about palliative care among clinicians and not enough palliative care specialists result in a fragmented system and uncoordinated care.

Primary care is the principle health care service for community-dwelling older adults. Several studies indicate that co-management by primary care and palliative care providers may reduce symptom burden and reduce potentially avoidable admissions to the emergency

department and/or hospital (Bakitas et al., 2009, 2015; Rabow, Dibble, Pantilat & McPhee, 2004); Temel et al., 2010). Yet, how to deliver palliative care in primary care to address patient and family needs, coordinate care, and support aging-in-place is ill defined (Quill & Abernethy, 2013).

To address these gaps in our understanding, studies over the past several years have focused on referral to CBPC. Data from this research suggest that barriers and facilitators to CBPC seems to occur in three categories: 1) provider understanding; 2) clarity of prognosis; and 3) inter-professional role clarification. Several studies have shown that referrals to palliative care are dependent on provider understanding and experience with palliative care (DeMiglio & Williams, 2012; Walshe, Chew-Graham, Todd & Caress, 2008). Moreover, some primary care providers and families equated palliative care with "giving up" and "death" especially when communication about prognosis was difficult or absent (Mahtani-Chugani, Gonzalez-Castro, Saenz de Ormijana-Hernandez, Martin-Fernandez & Fernandez de la Vega, 2010). A lack of clarity of prognosis hampered decision-making to establish goals of care, a treatment plan, and to establish an Advance Health Care Directive (Boyd, Murray, Kendall, Worth, Benton & Clausen, 2004; Brazil, Bainbridge, Sussman, Whelan, O'Brien & Pyette, 2009; Mahtani-Chugani et al., 2010; Mc Ilfatrick, 2006; Tallman, Greenwald, Reidenouer & Pantel, 2012; Walshe et al., 2008). Furthermore, definition of roles and relationships were unclear among the primary care physicians, palliative care specialists, and the palliative care team resulting in fewer referrals, fragmented care (Brazil et al., 2009; DeMiglio & Williams, 2012; Kamal, Bull, Kavalieratos, Taylor, Downey & Abernethy, 2011; Mahtani-Chugani et al., 2010; Tallman et al., 2012), and interpersonal tension among professionals (De Miglio & Williams, 2012; Walshe et al., 2008).

The studies accomplished over the past several years have focused on referral to CBPC. However, these have been primarily from an international perspective and within health systems that are structurally different than the U.S. For example, England and Canada utilize a single payer system that provides community-based palliative care primarily with hospice.

In the United States, CBPC is delivered upstream of the Medicare hospice benefit, before a terminal prognosis of six months or less. Moreover, access to CBPC and coordination of care is complicated in the U.S. especially across health care settings (IOM, 2015). CBPC is often not sustainable in a fee-for-service model of care because lower costs from reduced acute care service utilization benefit the payer not the provider. With the growth of Accountable Care Organizations (ACO's) and tying fee-for-service Medicare payments to quality or value, access to CBPC is becoming more widespread.

Care coordination may be hampered by different settings and by the use of different electronic medical record systems. A better understanding of issues involved in coordination of palliative care in primary care is needed to inform practice and to develop models of care. Therefore, to fill this gap in knowledge, our goal was to use a grounded theory approach (Charmaz, 2006; Corbin & Strauss, 2008) to explore a sample of U.S. primary and palliative care providers' (clinical or practitioners in the disciplines of medicine and nursing) understanding of CBPC to gain an understanding of what may influence referrals and collaboration to deliver coordinated care. The research question that guided this exploratory study was: What are the facilitators and barriers to interdisciplinary interactions to coordinate care?

Design and Sample

A qualitative interpretive design was used to conduct twenty semi-structured interviews with primary care and palliative care providers. Data were analyzed using grounded theory methods. Providers included the disciplines of medicine and nursing.

Setting: Data were collected in three diverse care delivery systems: a large academic medical center serving an ethnically diverse patient population; a large community health care system; and a large home health care and hospice organization.

Recruitment: Primary care providers in these three systems were emailed invitations to participate in the study, and after initial enrollment, sampling was by snowball methods. Additionally, participants were given flyers to give to colleagues or hand out at staff meetings. Potential participants contacted the investigators and were invited to select the most convenient time and place for interviews. One to one interviews were conducted in private, away from patient care.

Methods: Prior to data collection, participants were informed of their rights as human subjects and signed an informed consent approved by the University of California, San Francisco Institutional Review Board. Eligibility criteria were (a) nurse practitioner, registered nurse, or physician assistant; and (b) primary care physician and board certified palliative care physician practicing in academic or community setting with CBPC access; (c) patient population included adults age 65 and over; and (d) able to read and understand English. Based upon the literature review and discussions with three experts, an interview guide was developed containing twelve questions in three domains: 1) the role of palliative care in primary care; 2) process of referral to palliative care; and 3) coordination of care after referral. Semi-structured in-depth interviews were conducted to allow flexibility in exploring

topics. Interviews were digitally recorded, transcribed verbatim, reviewed, and verified for accuracy.

Immediately after conducting each interview field notes were written to include: (1) description of overall flow of interview; (2) key insights; (3) salient and interesting points; (4) main issues and themes; (5) description of any problems; (6) new information, concepts, events that emerged in the interview; (7) missing information, and issues that needed follow up and why. At 20 interviews we reached data saturation.

Analysis: Data was collected, transcribed and organized using an inductive conceptual process. A revision of the interview guide was completed after each interview as ongoing analysis identified key issues, emerging themes and concepts revealed during the previous interview (Charmaz, 2006; Corbin & Strauss, 2008). Open-ended questioning was used and, to increase rigor, probes were developed for iterative questioning to further explore topics and clarify concepts (Whittemore, Chase & Mandle, 2001). These research strategies allowed for the examination of the process of communication and collaboration contextually with the aim of identifying and analyzing the multiple factors that influenced the primary care providers' ability to coordinate care when their patients were referred to palliative care. Open-ended coding was used to label and identify concepts, followed by a focused coding process in order to develop the major categories and develop the theoretical code. Field notes were analyzed simultaneously and memos were written during data collection for the building of categories, and to analyze interactions between categories to understand how categories worked together as we developed the theoretical code. Memos containing the results of inductive thinking were used to help identify patterns and emerging themes. Moreover, situational maps to analyze the major human, nonhuman, discursive, and other

aspects of the research assisted to understand relationships among emerging themes and concepts (Clarke, 2005). Emerging codes, concepts, and categories were discussed both with the research team and others outside the team as well as with experts in geriatrics and palliative care. Data were coded and analyzed using ATLAS.ti (Scientific Software Development GmbH, Berlin, 2014).

Results

Process of Engagement to Collaborate and Coordinate Care

Coordination of care is considered the hallmark of a medical home where the primary care provider leads the team and takes responsibility for the ongoing care of their patients to end-of-life (AHRQ, 2011). Primary care providers in the current study supported this perspective, describing their role as the coordinator of care, as someone who is ‘in the loop’ and who knows what’s happening in all realms in order to oversee all aspects of care. Long-term relationships with their patients were very important. The need to be in the information loop with palliative care providers to collaborate in order to coordinate care was emphasized. Thus, it is within this context that interdisciplinary interactions emerged as a key process necessary to promote engagement to be in the information loop to collaborate in order to coordinate care. Four major themes emerged from the data that influence the process of collaboration: (i) role clarity; (ii) feedback and communication; (iii) time constraint and workforce; (iv) education (see Figure 2).

Facilitators to interdisciplinary interactions to coordinate care

Role clarity

Interdisciplinary interactions to collaborate in order to coordinate care were facilitated by defining roles and responsibilities. Some primary care providers (academic setting)

viewed their role as coordinators of care and palliative care providers as consultants with expertise in symptom management.

I consider myself to be someone who is the coordinator of a patient's care and who basically oversees all aspects of the patient's care and *knows* kind of what's happening and can use consultants in a way that makes sense, but that has the big picture of the patient in mind.

Other primary care providers (community setting) preferred to have palliative care embedded within their own practices to work together as a team, especially when providing care to vulnerable populations.

My reaction to the consult part, in terms of palliative care - it's going to come back these are all the things I would recommend - 'Okay, do it, primary care doctor' - and that's what I see with some of my patients we're seeing frequently in the emergency room, which is not where the patients should be going. And so, I guess I would see palliative care as different than like referral to the GI clinic. If it's a patient at that level, it seems to me it needs to be a coordinated team.

Others, including the palliative care providers, physicians, and advanced practice nurses, preferred a palliative care consult model of care because of the high demand for palliative care services, and not enough staff to meet the demand. Palliative care providers also expressed not wanting to take over the care of patients - "We're not here to take over or take control. I mean, that's what we want to make clear to the primary care docs to get their buy-in."

Primary care providers viewed the role of the palliative care practitioner as dealing with the burdensome symptoms experienced while the palliative care providers expanded this definition to include communication and other psychosocial issues that arose as a result of the symptom.

Palliative care - it's a small specialty. They should be managing the most complex patients and those patients that aren't complex *we* should be managing. Although we

may not have expertise ourselves, when we know that we're beyond what *we* know - we tend to use our colleagues (primary care provider).

Pain or nausea symptoms, we can really be more active in that and take the lead, but we're definitely not going to touch their blood pressure pills. The initial referral is almost always around some sort of refractory symptom, some unmet symptom management need. Very often pain, nausea, fatigue... fatigue may be the most common...the initial referral then segue into all these other issues. We spend a little extra time with folks, we're trained in this sort of empathic open ended way (palliative care provider).

Feedback and collaboration – in the loop

Frequent communication and feedback regarding care provided to patients was seen as a facilitator to promote the process of engagement to collaborate in order to coordinate care. Face-to-face communication, being co-located in primary care, and seeing patients together was viewed as facilitators for collaboration. The use of Electronic Medical Records (EMR) was a form of communication that enhanced coordination of care. As one primary care practitioner noted,

Asking me about changes to make would be good, getting updated on who's involved in the care, what they are doing for the patient, and what's their scope of services – the best way is always to talk – if possible. And being sure that both sides know how to contact each other – even if that was only a phone call – 'I'm seeing your patient for palliative care – if you have questions, this is how to get in touch with me. I'll send you a report.

Palliative care providers asked primary care providers their preferred mode of communication - in person, email, or EMR communication.

We ask the PCP how they prefer to be contacted...being sure that both sides know how to contact each other, we can share with the PCP what's going on. We also send a weekly report.

Weekly interdisciplinary palliative care team meetings were utilized to discuss new patients and the plan of care, challenges, and status of goals of care conversations in the home health

agency providing palliative care in the large community health system. Outcomes of these meetings were shared with primary care providers in the community health system.

Education

Continuous education was viewed as a facilitator to further define the roles of primary care and palliative care to promote communication, collaboration, and trigger appropriate referrals to palliative care. Some community primary care providers thought palliative care as only inpatient care - “My understanding of palliative care at *this* point, is that these are inpatient settings.” They also regarded primary palliative care as what they already practice.

Basic primary-palliative care, managing patient's symptoms, their psycho-social needs, their cultural needs, and spiritual... *that's* pretty much the definition of family medicine in primary care.

According to palliative care providers, education about the referral process and providing primary care providers with a basic skill set to practice primary palliative care was thought to facilitate appropriate and early referral to palliative care. Additionally, education regarding advanced communication skills was also viewed as necessary for primary care providers to talk to patients about the uncertainty of prognosis, to ‘unpack’ the emotions of patients and families, and to establish goals of care.

Since outpatient palliative care is a new frontier, it’s taken a lot of education - for primary care we did a lot of education about who would be ideal palliative care patients. So not only is it the prognosis question but also, you know, high-pain symptom burden, psychosocial issues, spiritual distress, and just clarifying and helping with goals of care, advanced care planning, sort of the bread and butter stuff for palliative care (palliative care physician large community system).

More education of the primary care docs around primary-palliative care, that would brighten the line between what's sort of normal for primary care, and what really requires a specialist. So, I *do* think that education of primary palliative care would clarify the need for the specialist (palliative care physician academic setting).

I think a lot of the basic palliative care skills that we do, we just want to help with anything that they're having trouble with but also make sure that they have the basic skill sets to have these conversations and manage symptoms (palliative care physician academic setting).

Barriers to interdisciplinary interactions to coordinate care

Feedback and collaboration – cut out of the loop

Primary care providers expressed frustration with specialists referring to specialists (e.g. oncology to palliative care referrals) without involving the primary care provider, making coordination of care difficult and causing fragmented care.

Someone has to know what's happening in all those realms - I would see that as my job. To be able to say, 'Okay, you know, cardiologists, this is what's happening in the renal realm - we need to adjust the diuretics. What do you think about this?' And, 'Okay, symptom management people. We're having trouble managing the dyspnea. Do you have any other suggestions about how we might do that?' As opposed to, these *specialists* seeing the patient and me being totally in the dark.

Moreover, it is unclear how the primary care providers retain their patients when patients are receiving specialty services such as oncology, and when patients are referred to palliative care (symptom management) for a consult by specialty services causing fragmentation of care.

I have had experiences where my patient is seen in oncology, they're referred directly to symptom management (palliative care), no one loops me in, symptom management is saying one thing, I'm not, you know, kind of part of that conversation - it can actually cut the primary care provider out - there's less kind of cross-communication with me. And it feels like it is dividing the patient's care even further.

Time constraint and workforce

Structural problems in primary care to manage patients with complex needs was acknowledged by palliative care providers, specifically the ‘lack of time’ in primary care to manage complex symptoms and the difficulty with seeing a large panel of patients per day.

We’ve done some surveys of primary care docs and, and specialists and they all feel like they want to do a better job and they tell us they don’t have enough time. It's so hard to find good primary care docs, because it's a ruthless, horribly hard business. I mean thirty or forty patients a day - what the hell are you going to do in fifteen minute visits on these-- come on it's crazy. So, I don't fault the primary care docs at all, in fact I just hug them for even trying to stay in the primary care game. I think those are all structural problems.

Difficulty with access to primary care was also noted.

We'll get them for this initial issue, but invariably they start coming to us with other issues and in one way or another we start assuming a fair amount of their care. Sometimes they don't have a primary care doc, sometimes they just can't get in to see their primary care doc.

At times palliative care providers may assume more of the care for patients. Although, primary care physicians and advanced practice nurses preferred a palliative care consult model of care, as well as palliative care providers, due to the high demand for palliative care services and not enough staff to meet the demand.

In summary, primary care providers stated the need for resources to support education about the role of primary and specialty palliative care in primary care, and how to integrate this model of care into their practices. Further exploration with primary care providers regarding the education they feel is needed, the content, how it is delivered, and the resources to provide the education may shed light on how they use the knowledge learned to facilitate appropriate referrals to palliative care and interdisciplinary interactions to collaborate to coordinate care.

Discussion

Data suggest the need for greater attention to processes that promote communication and collaboration. Both primary care and palliative care providers acknowledge that strategies are needed to promote a greater awareness of primary and secondary palliative care. The literature on whether primary care practitioners have a role and a responsibility to deliver primary palliative care and when they should refer to specialty palliative care is limited. Our findings suggest that there is a need for education to clarify these issues and to assist in defining when primary care providers should refer to specialty palliative care. Education of primary care providers about the role of palliative care in primary care was identified as a key process to facilitate appropriate referrals to palliative care and as a process that would build rapport and trust.

This study further extends the knowledge regarding the facilitators and barriers to the uptake of community-based palliative care, the referral process, and the importance of feedback and communication to collaborate in order to coordinate care. Specialty to specialty referrals, without including primary care providers in the process of referral were found to limit feedback and impede communication and collaboration and coordination of care. Previous studies had shown that referrals to palliative care were dependent on provider understanding and experience with palliative care (DeMiglio & Williams, 2012; Walshe et al., 2008), and recommendations from palliative care to primary care providers were not necessarily followed (DeMiglio & Williams, 2012; Rabow et al., 2004). This study described how face-to-face communication, the use of the EMR, and informal consults with palliative care facilitated collaboration and kept primary care in the information loop to coordinate care. Previous studies described how access to coordinated primary care and palliative care

was inconsistent (Bakitas et al., 2009; Boyd et al., 2004; Brazil et al., 2009; DeMiglio & Williams, 2012; Kamal et al., 2011; Tallman et al., 2012). The primary care providers in this study viewed communication and collaboration between primary care and palliative care as a necessary process for primary care providers to coordinate care. Moreover, specialty to specialty referrals without including primary care providers was viewed as a major impediment to coordinate care.

Unclear definition of roles and responsibilities among primary care and palliative care providers was identified in previous studies as barriers and resulted in fewer referrals and fragmented care (Boyd et al., 2004; Brazil et al., 2009; DeMiglio & Williams, 2012; Kamal et al., 2011; Mahtani-Chugani et al., 2010; Mc Ilfatrick, 2006; Tallman et al., 2012; Walshe et al., 2008). Education about the role of palliative care in primary care in this study was identified as a process to define appropriate referrals to palliative care, roles, relationships, and responsibility to enhance communication, collaboration, and coordinated care.

Lack of resources and time in primary care to coordinate care for patients with advanced illness and complex care needs has been acknowledged in previous studies as well as in this study. Community primary providers in this study welcomed a co-management model of palliative care embedded in primary care while academic primary providers preferred a consult model of palliative care, as well as academic palliative care providers. Inadequate time and resources in primary care to manage advanced illness has been an ongoing problem. The facilitators and barriers described in this study that influence interdisciplinary interactions to communicate and collaborate in order to coordinate care must be further explored from the perspective of patients and families to identify a process that is effective and efficient.

Limitations and Strengths

Our findings are based on the perspectives of the participants interviewed. This study was conducted in an academic and large community health system with established community-based palliative care programs, and may not be representative of other regions in the United States. Although sound methodological techniques were utilized to maximize rigor and trustworthiness (Whitemore, Chase & Mandel, 2001) others may have identified different categories and themes. The providers who participated in this study allow us to extend findings from previous studies by providing insight regarding the facilitators and barriers to interdisciplinary communication and collaboration to deliver palliative care across health care settings in the United States.

Conclusions and Implications

Our study provides an important contribution to the literature to understand facilitators and barriers to the process of interdisciplinary interactions to collaborate in order to coordinate and deliver community-based palliative care in the United States. A description of the components of communication and collaboration that influence coordination of care was provided. By understanding the different perspectives of primary care and palliative care providers, health care systems can better support the process of communication to facilitate collaboration across settings to foster a continuity of care for older adults with advanced illness and symptom burden. Gaining the perspective of patients and families through more data collection will help to inform the development of a model of palliative care in primary care.

From a policy perspective, data suggest the need for greater attention to processes that promote communication and collaboration as well as strategies to promote a greater

awareness of primary and secondary palliative care. Resources including payment and non-clinical time are needed to support education and to develop the workforce to practice primary palliative care in primary care. Through education, primary care providers will gain knowledge of when to refer to specialist palliative care. A process to promote a continuous flow of information to facilitate the delivery of primary and secondary palliative care is needed in primary care to support aging with advanced illness in the community.

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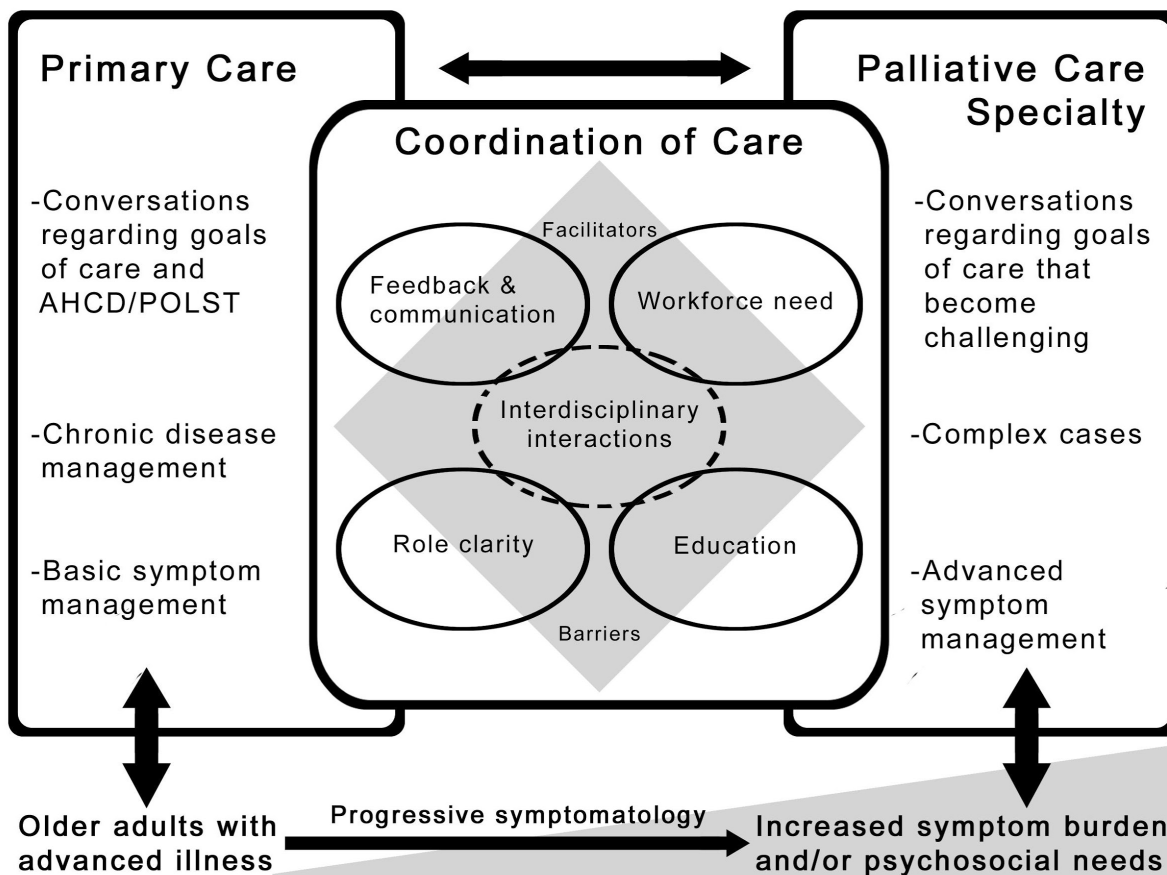
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Figure 2. Process of Engagement to Collaborate in Order to Coordinate Care



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Chapter 3: Characteristics of Older Adults in Primary Care Who May Benefit from Palliative Care

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Abstract

Background: Older adults are living longer in the community with advanced illness and symptoms, but little is known about health care utilization across primary care settings.

Objective: To describe older adults in primary care settings with advanced illness and symptoms that may benefit from primary palliative care.

Methods: A secondary analysis was conducted using the National Ambulatory and Hospital Medical Care Surveys to examine visits by older adults 65 and older to primary care settings in the United States between 2009 and 2011. Total visits to ambulatory care are composed of two subgroups, primary care specialty and non-primary care visits, and compared according to clinical and sociodemographic characteristics including advanced illness and symptoms.

Results: There were more visits by older adults to primary care for advanced illness and symptoms than to non-primary care. More visits were due to advanced COPD, CHF, dementia, pain, depression, anxiety, fatigue and insomnia compared to non-primary care.

Visits to primary care settings were Medicare recipients (79.7%) with chronic problem fare-up (7.1%); females (56.9%); non-Hispanic whites (77.3%) and living in median households with incomes below \$40,077-52,387 (71.6%) and 10-20% poverty in patient zip code. Visits were to physician owned (80.4%) office-based primary care group practices (60.6%) in large metropolitan status area (81.2%) where patients were seen before (80.2%) and providers are patients' PCP (70.1%).

Conclusions: A large proportion of older adults with advanced illness and symptoms are seen in office-based primary care specialty practices. Palliative care provided in primary care may benefit the aging population that is living longer in the community with advanced illness and symptom burden.

Key words: primary care; palliative care; advanced illness and symptoms

Introduction

Older adults are living longer with advanced illness and comorbidities. As these diseases progress and individuals near the end-of-life, many experience a decline in health and functionality. Medicare expenditures for this population are tremendous, with data suggesting that this is partly related to uncoordinated and fragmented care that is insufficient for the needs (Kamal, Currow, Ritchie, Bull & Abernethy, 2013; Meier, 2011; Naylor, Kurtzman, Grabowski, Harrington, McClellan & Reinhard, 2012). Five percent of Medicare beneficiaries with advanced illness and other comorbidities are responsible for fifty percent of Medicare expenditures (Neuman, Cubanski, Huang & Damico, 2015). Because of this, academic and community health systems are integrating palliative care into ambulatory care to manage care for this population (McCormick, Chai & Meier, 2012). However, little is known about health care utilization of this population across primary care settings, and who may benefit from primary palliative care (von Gunten, 2002).

The Institute of Medicine (2015), in the report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, highlights the need for people with advanced serious illness to have access to palliative care specialists. Such access is possible through community-based palliative care (CPBC) programs that are being integrated within primary care settings to deliver care for older adults with advanced illness and a prognosis of less than one year (Salpeter et al. 2012a; 2012b). However, these programs are finding that about half of the older adults in CPBC are living longer than a year. There are many opportunities in primary care to provide basic palliative care upstream from hospice to manage symptoms and integrate care with specialty palliative care to provide care according to patients' goals of care and needs (Quill & Abernethy, 2013; von Gunten, 2002).

Primary care plays a central role in providing and guiding care in the community for older adults with advanced illness accompanied by symptoms, especially since there are not enough palliative care specialists to provide all the care. U.S. policymakers have called for improvement of delivery of care in primary care for seriously ill patients. A medical home model of care is being used in primary care to deliver patient-centered, comprehensive, coordinated, and value-driven care (AHRQ, 2011; IOM, 2015; Reid et al., 2009; Rich, Lipson, Libersky, Peikes & Parchman (2012). Community-based palliative care, a newer delivery model of palliative care, can provide advanced illness care within this model.

Few studies have provided a description of health care utilization of older adults with advanced illness with accompanying symptoms across primary care settings. This information could be useful to health plans, providers, and policy makers in supporting palliative care in primary care settings. Palliative care is associated with improved quality of life as well as patient and family satisfaction (Bakitas et al., 2009; Brumley et al., 2007; Meier, 2011; Temel et al., 2010). However, there is a paucity of studies regarding the integration of palliative care into primary care and care delivery utilizing the medical home model of care. Therefore, the purpose of the current study was to describe visits to ambulatory care of older adults with advanced illness and symptoms across primary care settings based on sociodemographic and provider characteristics (Andersen, 2001; Humphreys et al., 2008).

Methods

A secondary analysis was conducted using the National Ambulatory Medical Care Survey (NAMCS) and National Hospital Ambulatory Medical Care Survey (NHAMCS) from 2009-2011 to look at visits by older adults 65 and older to primary care settings. First,

we examined total visits to ambulatory care and analyzed visits by age 65 and older. Second, we selected visits to office-based practices (OBP), community health clinics (CHC), health maintenance organization (HMO), and hospital outpatient departments (OPD). Finally, we selected primary care specialty to describe visits to primary care. This allowed us to compare primary care and non-primary care visits due to advanced illness and symptoms.

Study design and sample

NAMCS and NHAMCS are nationally representative annual surveys. The surveys are provider-based that allow for analyses of visits to a broad spectrum of ambulatory health care setting in the United States. NAMCS collects data based on a sample of visits to non-federally employed office-based providers, whereas NHAMCS collects data on visits to hospital emergency and outpatient departments of non-institutional general and short-stay hospitals. The surveys are administered by the National Center for Health Statistics (NCHS, 2016).

NAMCS physicians report on a sample of patient visits during a randomly assigned one week reporting period and NHAMCS physicians report on a sample of patient visits within a random 4-week sampling period. NAMCS selects office-based physicians from the American Medical Association and American Osteopathic Association files; physicians in the specialties of anesthesia, pathology, and radiology are excluded. NHAMCS selects non-institutionalized hospitals exclusive of federal, military, and Veterans Administration hospitals. OPDs (all or a sample) are selected from each hospital. From 2009 to 2011 NAMCS and NHAMCS yielded 194,884 encounters, and the overall average physician response rate from NAMCS and NHAMCS-OPD was 71.3%. The sample was limited to visits of older adults 65 and older to office-based practices, community health clinics, health

maintenance organization, and hospital outpatient departments. This study was given an exempt status by the Institutional Review Board at University of California, San Francisco.

Measurement

Total visits to ambulatory care include primary care and non-primary care visits. Visits to primary care and non-primary care are compared according to clinical and sociodemographic characteristics including advanced illness and symptoms. Primary care specialty includes family medicine, internal medicine, and internal medicine subspecialties including geriatrics. Non-primary care includes surgical specialties and medical specialties such as emergency medicine, cardiology, nephrology, neurology pulmonology, oncology, and hospice and palliative medicine. Setting characteristics for primary care specialty included size of office-based practice (solo or group) and ownership, hospital ownership of outpatient departments, geographical region, and metropolitan status. Visits to emergency departments (EDs) were excluded from analyses because EDs are not office-based or clinic providers.

The National Committee for Quality Assurance (NCQA) Palliative and End of Life Care Physician Performance Measurement Set was used to identify older adults with advanced illness (NCQA, 2008). *International Classification of Diseases, Ninth Revision* ICD-9 codes were used for terminal cancer and end stage COPD, CHF, dementia, renal and liver disease, Parkinson's disease, and stroke. Symptom ICD-9 codes that commonly occur with advanced illness were included (pain, dyspnea, depression, anxiety, fatigue, insomnia, nausea, and constipation) (von Gunten, Ferris, Kirschner & Emanuel, 2000). Up to three diagnoses are recorded using ICD-9 codes during each visit.

Visits to primary care were further described by sociodemographic data from the surveys. Data used for these analyses included date of birth for age, race and ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic other), tobacco use, payer (Medicare, Medicaid, private insurance, self-pay, other; categories not mutually exclusive), and metropolitan statistical area (MSA) or non-MSA derived from Zip Code. Median household income in patient's Zip Code is a categorical item defined by four quartiles from the U.S. Census Bureau (2016).

Statistical analysis

Annual estimates of visits were summed over the three study years (2009 to 2011). Survey design elements were provided by NCHS to generate nationally representative estimates of patient visits. Sampling weights were included to adjust for multistage sampling design, clustering within physician practices, nonresponse, and to produce corresponding 95% confidence intervals (CIs).

Descriptive analysis was conducted to determine how demographic and clinical characteristics varied according to primary care specialty for age 65+ among office-based practices and OPDs, and non-primary care specialty. Tests of proportions were used to describe differences in visit rates for sociodemographic and clinical characteristics, with results weighted to allow for national inferences. After determining visits rate for provider and patient demographics, tests of proportions were used to compare visit rates to primary care and non-primary care due to advanced illness and symptoms. Categorical variables were examined by comparing the proportion of visits in each age group (65-75, 75+) that corresponded to a given survey item (e.g. 23% of older adults 75+ visits resulting in depression were women, vs. 10% men). Missing data were assumed to be missing at random.

The criterion for significance was set a priori as $\alpha = .05$. Analyses were conducted in Stata 14 (Stata Corp., 2015) using two-sided analyses with $\alpha = .05$.

Results

Total ambulatory care visits

From 2009-2011 there were 194,884 visits to ambulatory care including office-based practices (physician or group, CHC, HMO) and OPDs (Table 2). This translates to a weighted national estimate of 3,356,223 visits to ambulatory care. When limited to older adults age 65+, there were 42,473 visits, a weighted national estimate of 851,787 visits (25.4% of total visits). Table 2 presents the proportion of total outpatient visits for ambulatory care by age groups, settings, gender, race/ethnicity, payer, and provider characteristics. Visits to ambulatory care include visits to primary care specialties and non-primary care. A larger proportion of total visits to ambulatory care of adults age 65+ were age 65-74 (13.3%), female (56.9%), non-Hispanic white (79.4%), current tobacco users (6.0%; 2.9% female) and non-current tobacco users (59.2%; 34.6% female), payer Medicare (79.2%), median household income \$52,388 or more (27.8%), and living in large metropolitan statistical areas (87.0%). Of these visits compared to males, females have higher rates of hypertension (31.7% vs 23.5%), hyperlipidemia (18.1% vs 15.0%), diabetes (11.8% vs 10.7%), arthritis (15.9% vs 8.6%), and osteoporosis (6.8% vs 1.2%).

Total primary care visits

A greater proportion of visits to primary care were to office-based practices (84.0%) and to PCP's who were the individuals' regular source of care (80.2%). Characteristics of those making these visits included: female (59.8%) non-Hispanic White (77.3%), current tobacco users (7.0%; 3.8% female), non-current tobacco users (60.0%; 36.9% female),

Medicare recipients (79.7%), median household income in patient's zip code \$32,794-\$40,626 (24.6%), and living in large metropolitan statistical areas (81.1%). There were more visits by non-Hispanic Whites to physician or group practices (66.4%) and OPDs (7.8%), and fewer visits to CHCs (1.2%) and HMOs (1.4%). Older Hispanics accounted for a larger share of visits to CHCs than non-Hispanic Blacks (26.3% vs 18.2%), and also a larger proportion of visits to HMOs than non-Hispanic others (22.6% vs 14.2%). Medicaid was the payer for a smaller proportion of total visits (2.0%). Of those, a larger share of visits were to physician or group practices (65.3%), CHCs (11.3%), OPDs (23.3%), and less than 1.0% to HMOs. Of these visits compared to males, females have higher rates of hypertension (38.7% vs 26.3%), hyperlipidemia (25.5% vs 18.1%), diabetes (14.7% vs 12.4%), arthritis (16.3% vs 9.3%) and osteoporosis (9.4% vs 1.5%). Moreover, females had at least 15% of visits due to diabetes, hypertension, and hyperlipidemia.

Advanced Illness

Table 3 compares the proportion of visits to primary care and non-primary care. Of the 348,492 visits to primary care by older adults, 29,499 (8.5%) visits were recorded for advanced illness. Providers in physicians' offices and OPDs provided care for the majority of visits recorded for advanced illness. Of interest, no visits were recorded for end-stage renal or liver disease, or cancer to HMOs; whereas the majority of visits to HMOs for advanced illness were for dementia. Visits to CHCs were mostly for advanced CHF. A higher proportion of visits due to advanced illness took place in primary care settings vs non-primary care (8.5% vs 7.1%), mostly due to COPD and CHF (see Figures 3 and 4).

Symptoms

Table 4 compares the proportion of visits to primary care and non-primary care related to symptoms. Of the 348,492 visits to primary care by older adults 65 and older there were 56,033 visits (16.1%) due to symptoms. More visits to primary care compared to non-primary care were due to pain (7.7% vs 3.8%), depression (1.8% vs 0.5%), anxiety (1.5% vs 0.7%), fatigue (1.6% vs 0.4%), and insomnia (1.3% vs 0.6%). Non-primary care recorded a larger share of visits for dyspnea compared to primary care. A higher proportion of visits due to symptoms took place in primary care settings vs non-primary care (16.1% vs 8.0%) (see Figures 5 and 6).

Discussion

This study offers a description of older adults who may benefit from primary palliative care in primary care. Patterns of visits to primary care specialty (geriatrics, internal medicine, and family medicine) by older adults are described across the settings of office-based practices, community health centers, HMOs, and outpatient departments. Moreover, the proportion of visits to primary care and non-primary care of older adults are described by advanced illness and symptom type.

Several patterns of health care utilization emerge when examining the demographic and clinical characteristics of visits across primary care specialty settings. First, older women accounted for a larger proportion of visits to primary care with higher rates of comorbid conditions compared to males. Older non-Hispanic Blacks accounted for a smaller share of visits compared to non Hispanic Whites. Median household income in primary care was lower than non-primary care. Second, over eighty percent of visits to primary care were to primary providers. Third, most visits to primary care occurred in office-based practices in

large metropolitan areas, and OPDs in not-for profit hospitals. Finally, a larger share of visits was due to pain, depression, anxiety, fatigue, and insomnia and advanced illnesses COPD and CHF in primary care settings compared to non-primary care settings.

Patients with advanced illness and symptoms frequently have unmanaged symptoms and low satisfaction with care and benefit from palliative care (Bakitas et al., 2009; Brumley et al., 2007; Higginson et al., 2014; IOM, 2015; Temel et al., 2010; Teno et al., 2004). Older adults living longer with advanced illness and symptoms in the community receive care from primary providers with whom they have long-standing relationships. This suggests that there is a need to integrate the practice of primary palliative care into primary care so that symptoms can be managed and care tailored to the patients' goals of care (McCormick, Chai & Meier, 2012; von Gunten, 2002).

This study provides data that health providers, health care organizations, and policy makers can use to deliver care to older adults with advanced illness and identify those who may benefit from primary palliative care. Prior work has described older adults with advanced illness and symptoms in outpatient palliative care programs that benefit from palliative care towards end-of-life, and in hospice care (Bakitas et al, 2009; Brumley et al, 2007; Rabow, Dibble, Pantilat & McPhee 2004; Temel et al, 2010). Other work has provided guidelines and studies of older adults in primary care with comorbidity and symptoms (Boyd, Ritchie, Tipton, Studenski & Wieland, 2008; Fried, Tinetti, & Iannone, 2011; Ornstein, Nietert, Jenkins & Litvin, 2013). Previous studies have emphasized older adults with advanced illness experience late referrals to hospice and frequent readmissions to the hospital (Enguidanos, Vesper & Lorenz, 2012; Smith et al., 2012). This study describes older adults in primary care settings upstream from hospice that may benefit from palliative care.

There are several limitations to this study. NAMCS and NHAMCS are nationally representative surveys of outpatient visits; therefore patient level analyses are not available. ICD-9 coding for diagnoses for each patient visit are limited to three. Thus, there may be an underreporting of advanced illness and symptoms. This is more likely to occur in the older adults population who experience more comorbidities and symptoms (Ritchie & Zulman, 2013). Furthermore, this study used NCQA advanced illness ICD-9 codes in a nationally representative study of visits to ambulatory care. So it is likely visit estimates for advanced illness are underestimated because providers may not usually code for advanced illness.

Conclusion

This study examined health care utilization of older adults with advanced illness and symptoms. We described patterns of health service utilization of older adults with advanced illness and symptoms in primary and non-primary care settings. The findings suggest the patterns of health service utilization are distinct between primary care settings and non primary care settings. Primary care has the potential to provide early and integrated primary palliative care. Knowing the characteristics of older adults with advanced illness and symptoms who visit primary care may facilitate timely identification of patients to benefit from primary palliative care.

Implications for Policy or Practice

Comprehensive and coordinated palliative care in the primary care setting is necessary for our aging population living longer in the community with advanced illness and symptom burden. This study provides data to identify older adults with advanced illness who may benefit from primary palliative care. Health care organizations need to develop delivery systems with a continuity of care for older adults with advanced illness and symptom burden.

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Table 2: Total visits to ambulatory care including primary care/non-primary care

2009-2011	Ambulatory Care		Primary Care		Non-Primary Care	
Total Visits	3,258,295		2,674,186		584,109	
Visits Age 65+	851,787	26.1%	348,492	13.0%	503,295	86.2%
65-74	432,112	13.3%	173,131	6.5%	258,981	44.3%
75+	419,675	12.9%	175,361	6.6%	244,314	41.8%
Settings 65+						
Office-based	730,211	85.7%	292,559	84.0%	437,652	87.0%
Health Centers	8,657	1.0%	8,259	2.4%	398	0.1%
HMO	8,632	1.0%	8,433	2.4%	199	0.04%
Hospital Outpatient	57,561	6.8%	39,275	11.3%	18,286	3.6%
Other	46,726	5.5%			55,358	11.0%
Gender						
Female	484,240	56.9%	208,398	59.8%	275,842	54.8%
65-74	239,182	28.1%	98,658	28.3%	140,524	27.9%
75+	245,059	28.8%	109,775	31.5%	135,284	26.9%
Race/Ethnicity						
Non-Hispanic White	676,404	79.4%	269,384	77.3%	407,020	80.9%
Non-Hispanic Black	70,358	8.3%	34,710	10.0%	35,648	7.1%
Hispanic	69,165	8.1%	30,146	8.7%	39,019	7.8%
Non-Hispanic Other	35,860	4.2%	14,253	4.1%	21,607	4.3%
Tobacco Use						
Current	51,000	6.0%	25,000	7.0%	26,000	5.0%
Non-Current	500,000	59.2%	210,000	60.0%	290,000	49.6%
Insurance						
Medicare	674,530	79.2%	277,748	79.7%	396,782	78.8%
Medicaid	14,225	1.7%	7,005	2.0%	7,220	1.4%
Private	129,131	15.2%	5,1925	14.9%	77,206	15.3%
Self-pay	6,985	0.8%	2,474	0.7%	4,511	0.9%
Other	26,916	3.2%	9,340	2.7%	17,576	3.5%
Primary care-regular source of care	332,196	39.0%	286,556	80.2%	45,640	9.1%
MSA	740,714	87.0%	282,697	81.1%	458,017	91.0%
Non-MSA	111,073	13.0%	65,795	18.9%	45,278	9.0%

Table 3: Visits of older adults 65 and older with advanced illness to ambulatory care including primary care/non-primary care

2009-2011	Ambulatory Care		Primary Care		Non-Primary Care		Z-Test * ± 1.96
Visits Age 65+ Advanced Illness (NCQA)	851,787		348,492		503,295		
COPD	25,000	2.9%	15,000	4.3%	10,000	2.0%	62.3*
CHF	13,000	1.5%	7,402	2.1%	5,598	1.1%	37.45*
Cancer	7,907	0.9%	2,489	0.7%	5,418	1.1%	-17.14*
Dementia	5,417	0.6%	2,586	0.7%	2,831	0.6%	10.25*
Parkinson	3,993	0.5%	1,200	0.3%	2,793	0.6%	-13.99*
ESRD	2,863	0.3%	382	0.1%	2,481	0.5%	-30.05*
Liver Failure	1,740	0.2%	373	0.1%	1,367	0.3%	-16.54*
Stroke	364	0.04%	67	0.02%	297	0.1%	-8.73*
Total	60,284	7.1%	29,499	8.5%	30,785	6.1%	
Visits Non-serious Condition	791,503	92.9%	318,993	91.5%			

Table 4: Visits of older adults 65 and older with symptoms to ambulatory care including primary care/non-primary care

2009-2011	Ambulatory Care		Primary Care		Non- Primary Care		Z-Test * ± 1.96
Visits Age 65+ Symptoms	851,787		348,492		503,295		
Pain	46,000	5.4%	27,000	7.8%	19,000	3.8%	79.75*
Dyspnea	10,000	1.2%	3,736	1.1%	6,264	1.2%	-7.27*
Depression	9,160	1.1%	6,382	1.8%	2,778	0.6%	56.29*
Anxiety	8,558	1.0%	5,300	1.5%	3,258	0.7%	39.74*
Fatigue	7,778	0.9%	5,565	1.6%	2,213	0.4%	55.20*
Insomnia	7,308	0.9%	4,363	1.3%	2,945	0.6%	32.81*
Constipation	5,767	0.7%	2,653	0.8%	3,114	0.6%	7.89*
Nausea	1,865	0.2%	1,034	0.3%	831	0.2%	12.78*
Total	96,436	11.3%	56,033	16.1%	40,403	8.0%	
Visits non- symptom related	755,351	88.7%	292,459	83.9%			

Figure 3: Proportion of types of advanced illness reported of older adults visits to primary care

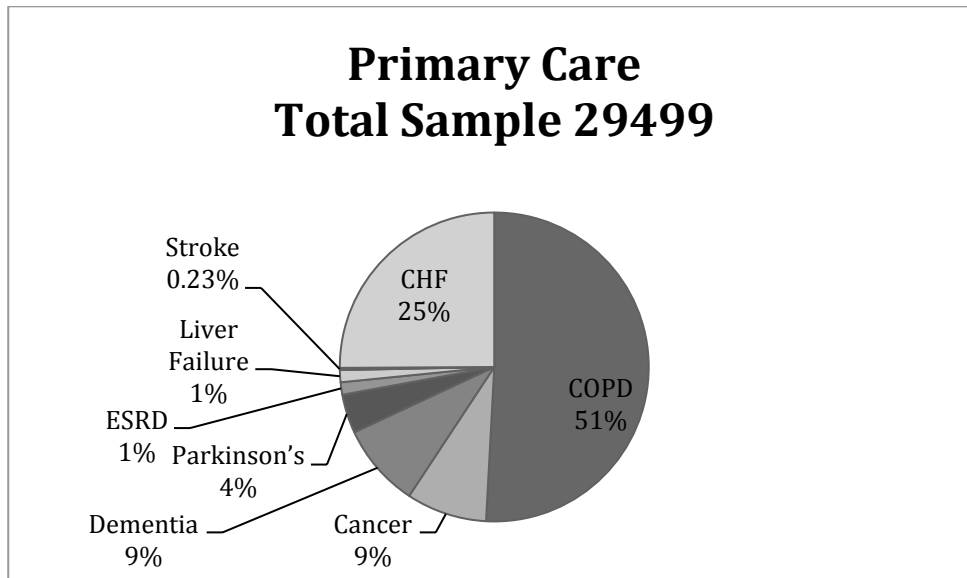


Figure 4: Proportion of types of advanced illness reported of older adults visits to non-primary care

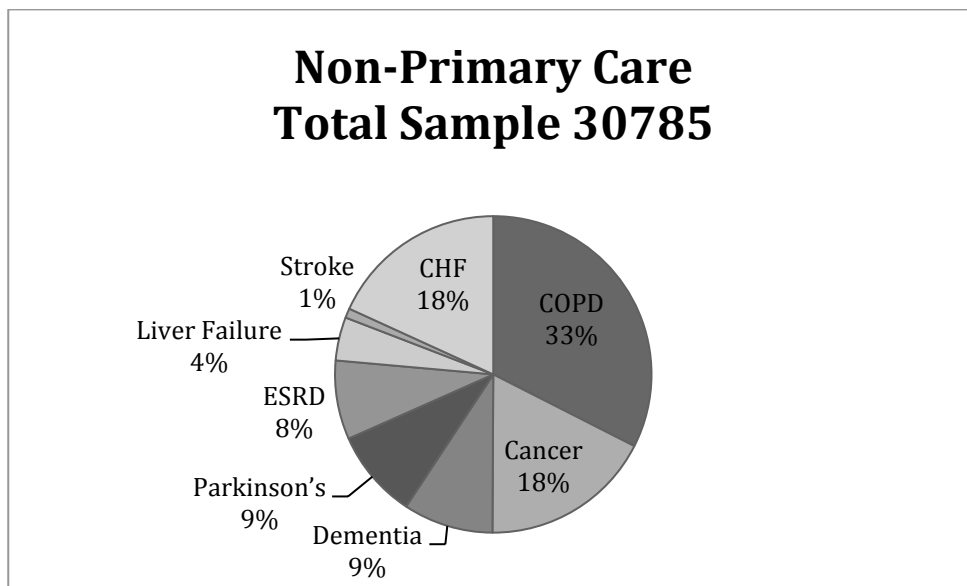


Figure 5: Proportion of types of symptom reported of older adults visits to primary care

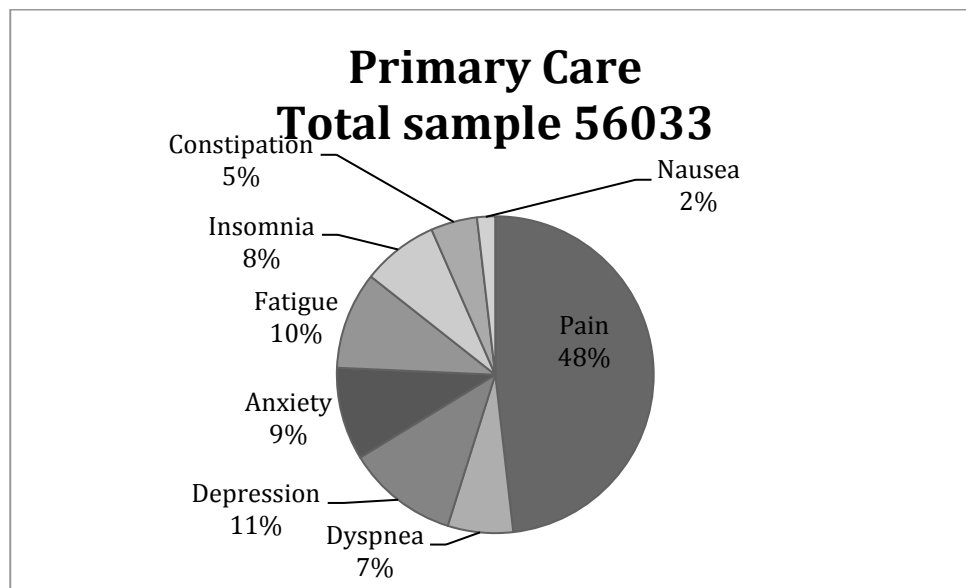
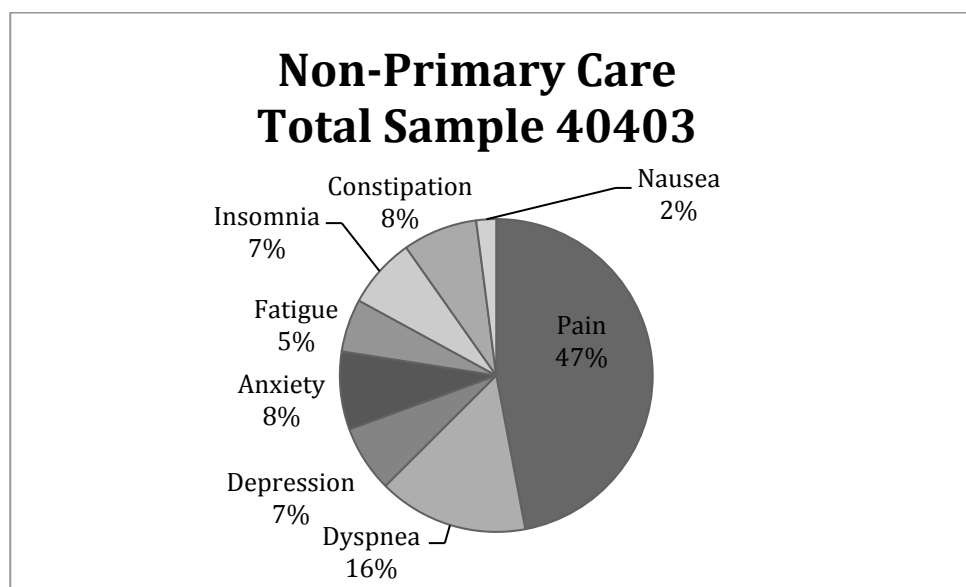


Figure 6: Proportion of types of symptom reported of older adults visits to non-primary care



**Chapter 4: Subgroups of Older Adults in Primary Care Settings Who Would Benefit
from Primary Palliative Care**

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Abstract

Background: It has been suggested that primary palliative care be delivered in the primary care setting. Yet a description of subgroups of older adults with advanced illness and symptoms that might benefit from primary palliative care is lacking.

Objective: Our aim was to identify latent classes (subgroups) of adults 65+ who share similar combinations of advanced illness and symptoms, and to describe differences by demographic and provider characteristics.

Methods: Latent class analysis was conducted to identify subgroups of adults 65+ in primary care settings with advanced illness using NCQA palliative care performance measures. The 2009-2011 National Ambulatory Medical Care (NAMCS) and National Hospital Ambulatory Care (NHAMCS) Surveys were used for analysis.

Results: Models for two classes could not be found that provided a better fit than a single class model (meaning, no latent class variable) for either set of variables for advanced illness and symptoms. For both sets of variables, the BIC (Bayesian Information Criteria) was smaller for the single class models indicating that the one-class model fit better. The VLMR (Vuong-Lo-Mendell-Rubin likelihood ratio) that tested whether a two-class model fit better than a one-class model were not significant.

Conclusions: With many variables displaying proportions $< 1\%$, it is likely that there was not sufficient covariation to identify two or more patterns of occurrence for subsets of variables. Underreporting of advanced illness and symptoms in primary care may make it difficult to identify patients who could benefit from primary palliative care. Future work is needed to explore coding patterns for advanced illness and symptoms in primary care.

Introduction

Older adults with advanced illness experience a variety of physical and psychological symptoms that may benefit from primary and specialty palliative care (Quill & Abernethy, 2013). It has been suggested that primary palliative care be delivered in the primary care setting (von Gunten, 2002). Yet a description of subgroups of older adults in primary care with advanced illness and symptoms who would benefit from primary palliative care is lacking. Few studies have examined the prevalence of comorbid conditions, advanced illness and symptoms associated with patterns of health service use in primary care.

Advanced illness and the terms progressive chronic conditions, complex chronic illness, serious illness, terminal illness, and life-threatening illness are terms used interchangeably in the literature to describe the population that utilizes palliative care services. The type of illness may be acute, serious, or life-threatening, and/or progressive chronic conditions. Cure or reversibility may be a realistic goal, but the treatments, and/or the conditions themselves present significant burdens and result in poor quality of life (National Consensus Project (NCP), 2013).

The terms complexity and multimorbidity are often used interchangeably in the literature to predict health care utilization, cost, and negative patient outcomes (Ritchie & Zulman, 2013; Valderas, Starfield, Sibbald, Salsibury & Roland, 2009). Multimorbidity is commonly defined as the existence of two or more long-term conditions (Boyd, Ritchie, Tipton, Studenski & Wieland, 2008). Classification systems vary in what is considered a condition, and symptoms including physical symptoms (pain, dyspnea), affective symptoms (anxiety or depression), and functional status (physical or cognitive), may not be included (Ritchie & Zulman, 2013; Valderas et al., 2009). The concept, advanced illness, describes the

older adult palliative care population living longer near death with chronic, progressive, and comorbid conditions experiencing frequent complications (American Hospital Association, 2012).

Significant opportunity exists to extend the model of palliative care to the management of older adults with advanced illness in primary care settings. Yet, it is unclear how the interaction of comorbidity and symptoms influence referrals by primary care physicians of their elderly patients to community-based palliative care, and the delivery of palliative care across settings.

Prior research has identified a patient population that benefits from palliative care services to include patients who experience high symptom burden associated with chronic illness. High symptom burden has been associated with cancer (Kamal et al., 2011; Temel et al., 2010; Yennurajalingam et al., 2010), chronic obstructive pulmonary disease (COPD) (Blinderman, Homel, Billings, Tennstedt & Portenoy, 2009), congestive heart failure (CHF) (Blinderman, Homel, Billings, Portenoy & Tennstedt, 2008), chronic kidney disease (CKD), dementia including Alzheimer's disease, liver disease, and HIV (Berger et al., 2011; Enguidanos et al., 2012; Kamal et al., 2011; Morrison et al., 2008). A systematic review (Solano, Gomes & Higginson, 2006) to determine to what extent patients with progressive chronic diseases have similar symptom profiles found the prevalence of eleven symptoms among five diseases to include patients with advanced cancer, acquired immunodeficiency syndrome (AIDS), heart disease, chronic obstructive pulmonary disease, or renal disease. Pain, dyspnea, and fatigue were found in all five diseases in more than fifty percent of patients (Solano et al., 2006).

Correlations among pain, fatigue, and depression in heart failure patients provide evidence that symptoms occur in clusters (Conley, Feder & Redeker, 2015) as found in patients with cancer (Miaskowski et al., 2004). A retrospective study of over 400 cancer patients found outpatient palliative care was associated with significant reductions in pain, fatigue, dyspnea, insomnia, depression and anxiety (Yennurajalingam et al., 2010). Moreover, patients with COPD experienced dyspnea, pain, fatigue, and anxiety (Blinderman et al., 2009) comparable to the prevalence and level of distress of ambulatory patients with CHF (Blinderman et al., 2008), and cancer (Chang, Hwang, Feuerman & Kasimis, 2000; Portenoy et al., 1994). Furthermore, older adults with dementia experience pain, depression, and anxiety (Kales, Gitlin & Lyketsos, 2014).

Given the high prevalence of symptoms occurring in patients with advanced illnesses, findings from previous studies cited suggest identification of subgroups of older adults who share similar combinations of advanced illness and symptoms diagnoses may assist primary care providers in ascertaining those who might benefit from primary palliative care. These patients might also be referred to specialty palliative care for unrelieved physical and psychological symptoms. Therefore, the purpose of this study was to determine if subgroups of older adults in primary care could be identified based on similar combinations of disease and symptoms, and to determine if these subgroups differed on selected demographic and provider characteristics.

Methods

Study sample

Demographic, clinical, symptom, and primary care specialty data of visits of older adults 65+ to primary care settings from the NAMCS and NHAMCS surveys from 2009 to

2011 were used to conduct this secondary analysis of national survey data. This study was given an exempt status by the Institutional Review Board at University of California, San Francisco. NAMCS and NHAMCS are nationally representative annual surveys administered by the National Center for Health Statistics (NCHS, 2016) that allow for analyses of visits to ambulatory care settings.

NAMCS collects data on a sample of visits to non-federally employed office-based practices. Providers report on a sample of patient visits during a randomly assigned one week reporting period. NAMCS selects office-based physicians from the American Medical Association and American Osteopathic Association files; physicians in the specialties of anesthesia, pathology, and radiology are excluded. NHAMCS collects data on a sample of visits to hospital emergency and outpatient departments of non-institutional general and short-stay hospitals. Providers report on a sample of patient visits within a random 4-week sampling period. NHAMCS selects non-institutionalized hospitals exclusive of federal, military, and Veterans Administration hospitals. Outpatient departments (all or a sample) are selected from each hospital.

From 2009 to 2011 NAMCS and NHAMCS data included 194,884 encounters. The average NAMCS physician response rate ranged from 54.1% to 62.1% and NHAMCS outpatient department from 83.6% to 85.3%. The sample was limited to visits of older adults 65 and older to office-based practices (OBP), community health clinics (CHC), health maintenance organization (HMO), and hospital outpatient departments (OPD). Primary care specialty includes family medicine, internal medicine, and internal medicine subspecialty geriatrics.

Advanced illness and symptoms

The National Committee for Quality Assurance (NCQA) Palliative and End of Life Care Physician Performance Measurement Set was used to identify older adults with advanced illness (NCQA, 2008) (see Table 5). *International Classification of Diseases, Ninth Revision* ICD-9 codes were used for terminal cancer and end stage COPD, CHF, dementia, renal and liver disease, Parkinson's disease, and stroke. Symptom ICD-9 codes that commonly occur with advanced illness were included (pain, dyspnea, depression, anxiety, fatigue, insomnia, nausea, and constipation) (see Table 6). Up to three diagnoses are recorded using ICD-9 codes during each visit.

Statistical Analysis

Latent Class Analysis (LCA) is a statistical method used to identify subtypes of related cases (latent classes) from multivariate categorical data. The term "latent" is used because membership in a class cannot be directly observed. In this study, LCA was used to identify distinct diagnostic categories given the presence or absence of various symptoms. In this study, LCA was used to identify subgroups of older adults in primary care settings with similar combinations of advanced illness and symptoms (Muthén & Shedden, 1999; Vermunt & Magidson, 2002). A total of eight advanced illnesses (NCQA, 2008) and eight symptoms were analyzed.

LCA identifies latent classes based on an observed response pattern (Collins & Lanza, 2010; Nylund, Bellmore, Nishina, & Graham, 2007). Cross-sectional data is used to determine the number of latent classes at a single measurement occasion. LCA involves estimating models with incremental numbers of latent classes. Choosing the number of classes is based upon which model provides the best fit to the observed data. The best fit to

the observed data is determined by information-theoretic methods, likelihood ratio statistical test methods, and entropy-based criterion.

The information-theoretical method used in this study was the Bayesian Information Criteria (BIC), which selects models that produce a high log-likelihood value using relatively few parameters. A lower BIC value represents a better model fit. Next, a log-likelihood test was used to further assess the correct number of classes chosen. The Vuong-Lo-Mendell-Rubin test (VLMR) compares the model with k classes to a model with $(k-1)$ classes. A significant p value is used to assess if there is a significant improvement between a specified model and a model with one less class. For instance, a significant p value $< .05$ for a three-class model vs. a four-class model would indicate three latent classes are a better fit to the data. Lastly, entropy indicates how distinct the identified classes are from one another. An entropy value of > 0.80 is desired. In summary, the model that fits the data best has the lowest BIC, a VLMR that shows the estimated model to be better than the model with one fewer class, and entropy > 0.80 (Celeux & Soromenho, 1996; Nylund, Asparouhov, & Muthén, 2007). Finally, well-fitting models should “make sense” conceptually, and the estimated classes should differ as expected on relevant variables that were not part of the generating model (Nylund, Asparouhov, & Muthén, 2007). For example, one might expect classes, subgroups of older adults to differ on types of chronic disease, advanced illness and symptoms. Models were estimated with Mplus Version 7.4 (Muthén & Muthén, 1998-2015).

Results

The estimation of LCA models for both advanced illness and symptoms was not successful in identifying multiple classes (subgroups) for either set of variables. In other words, models for two classes could not be found that provided a better fit than a single class

model (meaning, no latent class variable) for either set of variables. The results are displayed in Table 7 and 8. For both sets of variables, the BIC was smaller for the single class models indicating that the one-class model fit better (31749.88 vs. 31771.42). The VLMR analyses that tested whether a two-class model fit better than a one-class model were not significant.

This means that two-class models for both sets of variables did not fit the data better than one-class models. With such a large sample regarding the actual number of cases, this result is most likely due to the very small proportion of visits reported for each advanced illness and each symptom (see Table 5 and Table 6). For binary variables, the limiting factor for an analysis is not the total number of cases, but the number of cases in the smaller of two categories. With many of the variables displaying proportions less than one percent, it is likely that there was not sufficient covariation to work with that would allow the identification of two or more patterns of occurrence for subsets of variables.

Discussion

Latent class analysis (LCA) was selected as a modeling technique to identify subgroups of older adults who may benefit from primary palliative care. Latent class analysis was selected based on the idea that visits to primary care could be divided into subgroups of older adults with varying types of comorbidity. Comorbidity was measured by the categorical variables including chronic conditions, advanced illness, and symptoms. Previous studies indicate increased symptom burden, a decline in functionality, and increased health care utilization are often associated with patients with comorbidity and advanced illness (Kelley et al., 2016; Ritchie & Zulman, 2013; Valderas et al., 2009). Using LCA, we hoped to identify subgroups of older adults in primary care settings with similar combinations of chronic

conditions, advanced illness and symptoms and high health care utilization to assist primary care providers to identify patients that may benefit from primary palliative care.

The advantage of LCA for the current study was that cases could be part of the analyses even with missing data. Because conditions and symptoms for each patient were limited to only three of each, the analysis of eight advanced illnesses for each patient would have a minimum of five missing values. For the eight symptoms, each patient would also have at least five missing values. Mplus estimates models with missing data using Full Information Maximum Likelihood (FIML) (Enders et al., 2010; Schafer & Graham, 2002) with the Expectation-Maximization (EM) algorithm (Enders et al., 2010; Muthén & Shedden, 1999). This method provides unbiased parameter estimates as long as the missingness is “ignorable.”

The impact of missing data on the results depends on the mechanism that caused the data to be missing. The key distinction with missing data is if the missing data is ignorable or non-ignorable. Missing data can be ignored if data is Missing Completely at Random (MCAR) or Missing at Random (MAR). MCAR means data are missing independently of both observed and unobserved data, therefore, there is no relationship between the missingness of the data and any values in the data set. MAR means the cause of the missing data is unrelated to the missing values, but may be related to the observed values of other variables. Whereas Non-ignorable (NI) missing data is related to the missing values and may bias results.

The assumption that missing data was ignorable was reasonable for the proposed study, since the five missing conditions and symptoms are missing almost by design, which leads to the missing data process called “missing completely at random.” The less restrictive

missingness process is “missing at random,” which is supportable in the current analyses because the missing variables are very likely to be associated with other variables in the model. Both of these forms of missingness are ignorable.

Strengths and Limitations

In this study, LCA was used to identify subgroups of older adults in primary care settings with similar combinations of advanced illness and symptoms (Muthén & Shedden, 1999; Vermunt & Magidson, 2002). The survey data and large sample size allowed for the inclusion of demographic and clinically relevant covariates. Although, limiting the analyses to terminal cancer and end stage advanced illnesses, many variables displayed proportions less than one percent. It is likely that there was not sufficient covariation to identify two or more patterns of occurrence for subsets of variables to identify latent classes.

Despite these limitations, LCA can be used to identify distinct diagnostic categories given the presence or absence of several symptoms to inform delivery of care (DeVon, Ryan, Rankin & Cooper, 2010). Findings from previous studies using LCA identified subgroups of patients experiencing multiple symptoms that negatively impacted functionality and quality of life (Dodd et al., 2011; Illi et al., 2012). Underreporting of advanced illness and symptoms in primary care makes it difficult to identify patients who could benefit from primary palliative care. Research is needed to explore coding patterns for advanced illness and symptoms in primary care. Future research using LCA to identify subgroups of older adults who share similar combinations of comorbid conditions, advanced illness and symptoms may provide insight to assist primary care providers to provide primary palliative care, and refer to specialty palliative care for unrelieved physical and psychological symptoms.

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Table 5: Visits of older adults 65 and older diagnosed with advanced illness to ambulatory care including primary care/non-primary care

2009-2011	Ambulatory Care		Primary Care		Non-primary Care		Z-Test * ± 1.96
Visits Age 65+ Advanced Illness (NCQA)	851,787		348,492		503,295		
COPD	25,000	2.9%	15,000	4.3%	10,000	2.0%	62.3*
CHF	13,000	1.5%	7,402	2.1%	5,598	1.1%	37.45*
Cancer	7,907	0.9%	2,489	0.7%	5,418	1.1%	-17.14*
Dementia	5,417	0.6%	2,586	0.7%	2,831	0.6%	10.25*
Parkinson's	3,993	0.5%	1,200	0.3%	2,793	0.6%	-13.99*
ESRD	2,863	0.3%	382	0.1%	2,481	0.5%	-30.05*
Liver Failure	1,740	0.2%	373	0.1%	1,367	0.3%	-16.54*
Stroke	364	0.04%	67	0.02%	297	0.1%	-8.73*
Total	60,284	7.1%	29,499	8.5%	30,785	6.1%	
Visits Non-serious Conditions	791,503	92.9%	318,993	91.5%			

Table 6: Visits of older adults 65 and older diagnosed with symptoms to ambulatory care including primary care/non-primary care

2009-2011	Ambulatory Care		Primary Care		Non-primary Care		Z-Test * $\pm$ 1.96
Visits Age 65+ Symptoms	851,787		348,492		503,295		
Pain	46,000	5.4%	27,000	7.8%	19,000	3.8%	79.75*
Dyspnea	10,000	1.2%	3,736	1.1%	6,264	1.2%	-7.27*
Depression	9,160	1.1%	6,382	1.8%	2,778	0.6%	56.29*
Anxiety	8,558	1.0%	5,300	1.5%	3,258	0.7%	39.74*
Fatigue	7,778	0.9%	5,565	1.6%	2,213	0.4%	55.20*
Insomnia	7,308	0.9%	4,363	1.3%	2,945	0.6%	32.81*
Constipation	5,767	0.7%	2,653	0.8%	3,114	0.6%	7.89*
Nausea	1,865	0.2%	1,034	0.3%	831	0.2%	12.78*
Total	96,436	11.3%	56,033	16.1%	40,403	8.0%	
Visits non-symptom related	755,351	88.7%	292,459	83.9%			

Table 7: Latent Class Solutions and Fit Indices for One- and Two-Classes for Eight Serious Conditions Reported by NAMCS and NHAMCS Providers for their Patients

Model	LL	AIC	BIC	VLMR	Entropy
1 Class ^a	-15832.31	31680.63	31749.88	n/a	n/a
2 Class	-15795.13	31624.26	31771.42	74.37 ^{ns}	0.97

^a The 1-class solution was selected. The BIC is smaller for the 1-class solution, and the VLMR was not significant for the 2-class solution, indicating that two classes did *not* fit the data better than one class. Although entropy was high, it is based on less than 3% of the sample in the smaller of the two classes, leading to an artificially high value.

^{ns} Not significant

Note. LL = log-likelihood; AIC = Akaike Information Criterion, BIC = Bayesian Information Criterion; VLMR = Vuong-Lo-Mendell-Rubin likelihood ratio test for the K vs. K-1 model.

Table 8: Latent Class Solutions and Fit Indices for One- and Two-Classes for Eight Symptoms Reported by NAMCS and NHAMCS Providers for their Patients

Model	LL	AIC	BIC	VLMR	Entropy
1 Class ^a	-23367.55	46751.09	46820.35	n/a	n/a
2 Class	-23314.7	46663.39	46810.56	105.70 ^{ns}	0.6

^a The 1-class solution was selected. Although the BIC was about 10 points smaller for the 2-class than for the 1-class solution, the VLMR was not significant for the 2-class solution, indicating that two classes did *not* fit the data better than one class. Further, entropy was poor at .60, smaller than the desired .80.

^{ns} Not significant

Note. LL = log-likelihood; AIC = Akaike Information Criterion, BIC = Bayesian Information Criterion; VLMR = Vuong-Lo-Mendell-Rubin likelihood ratio test for the K vs. K-1 model.

Chapter 5: Discussion

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The purpose of this dissertation was to describe the factors associated with the uptake of community-based palliative care for older adults with advanced illness. Data from these studies indicate there is a need in primary care to integrate primary and specialty palliative care to coordinate care for older adults living longer with advanced illness and symptom burden. In this chapter, I first address the current state of knowledge and the study findings. Next, I explore the significance of the findings and discuss the implications for clinical practice and policy. Last, I end with a summary of the study's limitations and future directions for research.

Summary of the Dissertation

The Review of Current Knowledge

I began the dissertation by discussing the current state of knowledge regarding the facilitators and barriers to community-based palliative care (CBPC). I noted there was a gap in knowledge about the process of the delivery of U.S. CBPC including primary care and palliative care providers' understanding of CBPC. An understanding was missing of what may influence referrals and collaboration to deliver coordinated primary and specialty palliative care in the primary care setting. I concluded that current research, primarily international studies, reflected that barriers and facilitators to CBPC seemed to occur in three categories: 1) provider understanding; 2) clarity of prognosis; and 3) inter-professional role clarification. In addition, I highlighted the need for a description of older adults with advanced illness and symptoms in primary care settings who may benefit from palliative care. This research addressed these issues using both qualitative and quantitative methods.

The qualitative study in Chapter 2 explored U.S. primary care and palliative care providers' understanding of CBPC to gain an understanding of what may influence referrals

and collaboration to deliver coordinated care. The quantitative study, Chapters 3 and 4, focused on identifying older adults with advanced illness in primary care settings who could benefit from primary palliative care.

Dissertation Findings

The overarching finding from the data in the qualitative analysis was that the process to deliver coordinated primary and specialty palliative care in the primary care setting was facilitated by interdisciplinary interactions that enhanced collaboration. Interdisciplinary interactions facilitated collaboration in order to coordinate care by: 1) clarifying roles and responsibilities; 2) different modes of communication and feedback to keep the primary care providers “in the loop”; 3) education; and 4) resources that included non-clinical time and funds for primary care to integrate primary and specialty palliative care in primary care settings. Barriers to CBPC that impeded coordination of care stemmed from primary care providers being excluded in the process of providing CBPC, and a misunderstanding of the difference between palliative care and hospice. Moreover, workforce issues in primary care were noted by both primary and palliative care providers that included a lack of time in primary care and not enough providers to provide care. These findings suggest the need for greater attention to processes that promote communication and collaboration as well as strategies to promote a greater awareness of primary and secondary palliative care.

The findings from the quantitative analyses suggest the patterns of health service utilization are distinct between primary care settings and non primary care settings. Data indicate that older adults visiting primary care experience advanced illness and symptoms at different rates compared to non-primary care settings. There were more visits by older adults to primary care for advanced illness and symptoms than to non-primary care. A higher

proportion of visits due to advanced illness took place in primary care settings vs non-primary care (8.5% vs 7.1%), and for symptoms (16.1% vs 8.0%). About half of the visits to primary care and non-primary care for symptoms were due to pain. Providers in physicians' offices and OPDs provided care for the majority of visits recorded for advanced illness.

Latent Class Analysis was used to identify subgroups of older adults with advanced illness and symptoms to benefit from primary palliative care. The survey data and large sample size allowed for the inclusion of demographic and clinically relevant covariates. Although, survey data was limited to three ICD-9 diagnoses for the reason for visit. Therefore, it is likely that there was not sufficient covariation to identify two or more patterns of latent classes to identify subgroups of older adults with advanced illness and symptoms. Better data would allow for identification of subgroups. Underreporting of advanced illness and symptoms in primary care may make it difficult to identify patients who could benefit from primary palliative care.

Implications of the Research Findings

Relevance to Conceptual Frameworks

The research findings are informed through the lens of the Symptom Management Model (Humphreys et al., 2008) and Andersen's Behavioral Model (2001). The research findings support the dynamic process explained by the symptom management model of the interrelation of co-morbidity and symptoms with the delivery of care. Individual characteristics such as demographics, psychosocial, and physiological factors were described according to who provided care and where. Predisposing, enabling, and need factors at an individual and system level helped to illustrate ambulatory health care utilization of older adults with advanced illness and symptoms (Andersen, 2001).

Clinical Practice and Policy

The Institute of Medicine (2015) in the report *Dying in America* recommended access to specialty palliative care for people with advanced illness. However, there are not enough trained palliative care specialists to provide care to a population living longer with advanced illness. Comprehensive and coordinated primary and specialty palliative care in primary care is necessary for our aging population living longer in the community with advanced illness and symptom burden (Kamal et al., 2013; Quill & Abernethy, 2013; von Gunten, 2002). Data from this study highlight the important role of primary care to facilitate primary palliative care and to collaborate with specialty palliative care to deliver CBPC for older adults with advanced illness and symptoms.

Primary care providers need to be in the information loop to provide care for their patients with advanced illness and symptoms. Discussion and documentation of goals of care and basic symptom management should be provided by primary care providers, especially primary care providers who have long-standing relationships with their patients. With increased symptom burden and/or psychosocial distress due to advanced illness, these older adults should be referred to specialty palliative care. Varying levels of co-management of patients by primary care and palliative care during times of increased symptom burden are needed. Clarifying roles and responsibilities to deliver care is necessary. Modes of communication that are efficient for primary care and palliative care providers to give and receive feedback in order to coordinate care are needed.

Policy to support palliative care education of the health care provider workforce is vital. Education about primary and specialty palliative care is needed to define standards of care for primary care, and to define appropriate referrals to specialty palliative care.

Moreover, education of this workforce and the public about palliative care upstream from hospice will promote early referrals to support older adults aging with advanced illness.

Accountable Care Organizations (ACO's) are driving value-based care. Many want to integrate palliative care in medical home model. Palliative care is viewed as value-driven care because it improves quality of life (Temel et al., 2010) and reduces costs (Morrison et al., 2008), but we must be careful not to use palliative care to deny access to health services (Naylor, Kurtman, Grabowski, Harrington, McClellan & Reinhard, 2012).

Limitations of the Study

The secondary analyses of the NAMCS and NHAMCS surveys did provide data regarding health service utilization in primary care of older adults with advanced illness and symptoms. Although, a limitation of the surveys are they don't provide data on functional status, an important measure of the association of trajectory of advanced illness and symptom burden and need for palliative care.

Though I attempted to conduct a LCA to identify subgroups of older adults with advanced illness and symptoms in primary care, I was not able to do so. Although the survey data and large sample size allowed for the inclusion of demographic and clinically relevant covariates, there was not sufficient covariation to identify two or more patterns of occurrence for subsets of variables. By limiting the analyses to advanced illness and not including comorbidities, the sample size was probably insufficient to identify subsets of older adults with advanced illness and symptoms. Underreporting of advanced illness and symptoms in primary care makes it difficult to identify patients who could benefit from primary palliative care. Research is needed to understand coding patterns for advanced illness and the relation to palliative care services.

Future Directions

The uptake of CBPC is not occurring as needed in the U.S. health care system to provide care for older adults with advanced illness and symptom burden living longer in community settings. From a population health perspective, identifying older adults with advanced illness and symptoms to benefit from primary palliative care would enact a system of supportive care along with curative treatment. Integrating primary palliative care in primary care would enable a process of care for early aggressive symptom management and goals of care conversation. Care could be provided according to patient/family priorities and values. Access to CBPC is necessary to support aging in the community. The research findings from this study highlight some research opportunities and gaps that need to be addressed.

Although data from this study indicate older adults have advanced illness and symptoms across primary care settings, research is needed to explore the coding process and patterns for advanced illness in primary care settings to better identify subgroups of patients to benefit from primary palliative care. Furthermore, research should describe the coding process for advanced illness and palliative care services provided in order to better track the utilization of palliative care in community settings.

Next, research should be conducted to include the patient/family caregivers in a triad to better inform the process of coordination of care that is needed to integrate primary and specialty palliative care in primary care settings. Furthermore, based on the trajectory of advanced illness and increasing needs of patient/family caregivers, research could inform the various levels of primary and specialty palliative care needed to support quality of life and management of advanced illness and symptom burden. Different modes of communication

need to be evaluated for effectiveness and efficiency of feedback to keep providers and patient/family caregivers in the loop to coordinate care across settings. This information would be extremely helpful for the medical home model of care and risk adjustment models of care that ACOs are embracing to deliver care in the community.

Lastly, education of the public and workforce about CBPC is needed to promote the uptake of CBPC. Research is needed to understand how to train an interdisciplinary team to provide primary and specialty palliative care in primary care settings to meet the needs of an aging population. Education of the public about primary and specialty palliative care is necessary to promote partnerships, where patients/family and caregivers are members of the team to promote self-management of care.

Summary

My goal in undertaking this study was to provide a description of older adults in the primary care setting with advanced illness and symptom burden that would benefit from primary and secondary palliative care. Moreover, I wanted to understand the process of providing primary and secondary palliative care in the primary care setting. By understanding who could benefit from primary palliative care and the processes of delivering primary and secondary palliative care in primary care, healthcare providers and policy makers can facilitate care to support older adults aging in the community with advanced illness and symptoms. The findings that visits of older adults with advanced illnesses and symptoms differs in primary care compared to non-primary care settings highlights primary care needs for basic pain and symptom management, and discussions about advance care planning. Qualitative data also suggests the need for greater attention to processes that promote communication and collaboration in order to coordinate care for older adults with

advanced illness and symptoms as well as strategies to promote a greater awareness of primary and secondary palliative care. It is vital to ensure effective collaboration and coordination to deliver community-based palliative care. This research contributes to our knowledge of the delivery of palliative care in the community and the patient population to benefit from primary and specialty palliative care. I offer a conceptual model of the process of interdisciplinary interactions of primary care and specialty palliative care to collaborate in order to coordinate care for older adults with advanced illness and progressive symptomatology.

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