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doi: <https://doi.org/10.57709/7030577>

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**A SYNTHESIS OF HOME-BASED PALLIATIVE CARE ON CLINICAL
EFFECTIVENESS, COST-EFFECTIVENESS AND QUALITY OF LIFE: POLICY
IMPLICATIONS EXPLORED**

BY

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A CAPSTONE SUBMITTED TO THE GRADUATE FACULY OF THE SCHOOL OF
PUBLIC HEALTH AT GEORGIA STATE UNIVERSITY IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE

MASTER OF PUBLIC HEALTH

SPRING 2015

ABSTRACT

Background: By 2050, 27 million people will need some type of long-term care service, most of whom will have multiple chronic diseases. Longer life spans and aging baby boomers will double the population of Americans aged 65 years or older during the next 25 years to about 72 million. Since two out of every three older Americans have multiple chronic conditions, long-term care and end-of-life (EOL) care is going to continue growing as a significant healthcare burden. Palliative care, particularly home-based palliative care, can help to reduce healthcare costs at the end of life.

Purpose/Approach: This review seeks to examine literature surrounding home-based palliative care in terms of 1) clinical effectiveness, 2) cost, 3) cost-effectiveness, 4) quality of life and patient satisfaction, and 5) recommendations for healthcare policy and practices. Research articles were found through a comprehensive search of PubMed and GlobalHealth (EBSCO) databases. A policy brief will be included which will describe the aging population and the burden on the U.S. healthcare system, opportunities for home-based palliative care, and policy recommendations.

Review of Literature: Evidence shows that home-based palliative care compared to palliative care in other environments may result in fewer hospitalizations, fewer hospital days, fewer ED visits, and fewer physician office visits. Home-based palliative care reduces the likelihood of readmission to a hospital within 30 days and increases the likelihood of completing an advanced directive. It has shown to be cost-effective and result in lowered spending at a healthcare system and an individual level. Home-based care patients and their families report high levels of quality of life and satisfaction with their care.

Recommendations: A primary obstacle is the financial burden for patients since many insurers, public and private, do not cover home-based palliative care. A barrier related to getting timely access to palliative care is physicians and other healthcare staff not initiating conversations around palliative care or EOL issues. Recommendations that will help remove barriers to care include revising the Medicare hospice benefit to have less restrictive eligibility for home-based care, providing incentives to healthcare providers for discussing and integrating palliative care, and systematically training and educating health professionals on palliative care issues.

Conclusion: As the U.S. population continues to get older and suffer from multiple chronic conditions, millions of people are going to require long-term care. Healthcare spending is also going to continue to increase among the elderly and sick. Ensuring affordable and timely home-based palliative care to this population is a critical step in reducing healthcare costs and improving quality of life.

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CHAPTER 1: INTRODUCTION

It is estimated that by 2050, 27 million people will need some type of long-term care service, most of whom will have multiple chronic diseases (Giovanni, 2012). Longer life spans and aging baby boomers will double the population of Americans aged 65 years or older during the next 25 years to about 72 million (CDC, 2013). Since two out of every three older Americans have multiple chronic conditions, long-term care and end-of-life (EOL) care is going to continue growing as a significant healthcare burden (CDC, 2013). Treating patients with advanced illness at the end of life is costly and complex. Palliative care, particularly home-based palliative care, can help to reduce healthcare costs at the end of life. Currently, Medicare beneficiaries must choose between receiving treatment and receiving palliative care. Therefore many people who could benefit from quality palliative care are not receiving it due to choosing treatment. Palliative care is an essential service that should be accessible and affordable to anyone who needs pain management and supportive care while living with chronic conditions or other debilitating diseases.

By the year 2030, adults over 65 will account for about 20 percent of the population. Americans are living longer into their 70s, 80s, and beyond. The percentage of Americans who are ages 85 to 94 grew by 30 percent between 2000 and 2010 (Werner, 2011). The aging population has wide-range implications for many facets of society, including the burden to the healthcare system as more people are living with chronic diseases. During the past century, a major shift has occurred in the leading causes of death for all age groups, including older adults, from infectious diseases and acute illnesses to chronic diseases and degenerative illnesses (CDC, 2013). Heart disease has been the leading cause of death since 1920 and cancer has been the second leading cause of death since 1938 (CDC, 2013). These chronic conditions and others such

as stroke, chronic lower respiratory disease, Alzheimer's and diabetes pose the greatest risks to older adults.

According to a 2012 CDC report, there were 133 million Americans who had at least one chronic disease, and nearly 25 percent of those with a chronic disease had limitations in their activities of daily living. People with chronic diseases often have other health problems like substance abuse or addiction disorders, mental illness, dementia, or developmental disabilities. Those with multiple chronic conditions face an increased risk of unnecessary tests, adverse drug effects and avoidable hospitalizations (CDC, 2013). Long-term care is needed for many older adults who suffer from multiple chronic conditions. Treating chronic illnesses accounts for 66 percent of the country's healthcare budget and these expenditures are expected to continue to rise. Medicare spending alone is expected to rise from \$555 billion in 2011 to \$903 billion in 2020 (CDC, 2013). Chronic conditions account for 95 percent of healthcare costs for older Americans (CDC, 2013). Furthermore, the cost of providing healthcare for someone older than 65 is three to five times higher than the cost for someone younger than 65.

With the aging, sicker population, there is an increasing importance to consider EOL care as an integral part of the healthcare system. Palliative care as a supportive service has expanded and transformed in the U.S. and will continue to grow. Healthcare systems and payers must increasingly respond to the increased demand of older adults with multiple chronic conditions who need care both in a healthcare setting as well as in their home. Due to the growing demand of supportive care for people who need pain management and enhanced quality of life, there should be an option to receive affordable home-based palliative care. However, there are too often barriers to receiving this care.

There is evidence that home-based palliative care can reduce the cost of care, as well as provide higher quality of care. This article reviews the literature on home-based palliative care based on its results in terms of clinical effectiveness, cost, cost-effectiveness and quality of life, and recommends policies and practices to ensure affordable and timely care.

DEFINING PALLIATIVE CARE AND THE GROWING NEED

The World Health Organization (WHO) provides a definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Longer life expectancies, changing illness trajectories and advances in medical technology have changed the historical view of palliative care (Meghani, 2004). Palliative care is distinct from hospice care or EOL care in that it is not solely for those who are dying, but for those whom alleviation of suffering and improvement of quality of life are relevant goals (Meghani, 2004). Instead of a focus solely on treating the illness or condition, palliative care responds to the whole patient and family, accepting individual preferences, values and goals (National Consensus Project, 2009). In other words, EOL care can be considered palliative care, but palliative care is not necessarily EOL care.

Palliative care provides an “extra layer of support that can be provided alongside disease-oriented treatments” (Hughes & Smith, 2014). Patients who need palliative care include those with chronic conditions, serious acute illnesses, longer-than-anticipated length of stay, or those

experiencing major complications (Verret & Rohloff, 2013). An effective palliative care program fosters clear communication among clinicians, patients, and families, as well as establishes and focuses on clear patient care goals (Verret & Rohloff, 2013). As this paper will showcase, effective palliative care programs have demonstrable measures of public benefit, including cost savings, increased patient satisfaction and reduced hospital length of stay.

Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life, optimizing function, helping with decision making, and providing opportunities for personal growth (Snapp, 2010). It affirms life by supporting patient and family goals, including hope for cure or life-prolongation, as well as hope for peace and dignity through the course of illness, the dying process and death. Comprehensive and patient-centered care manages pain and other symptoms, as well as incorporates psychosocial and spiritual care (Snapp, 2010).

The need for palliative care is going to grow substantially in the next decades. From 2000 to 2010, more than 1,000 new hospital-based palliative care programs have been created (Hughes & Smith, 2014). In 2000, 25 percent of large U.S. hospitals had a palliative care team, compared with 66 percent in 2010. However, palliative care continues to be too often unknown, underutilized or misunderstood (Verret & Rohloff, 2013).

There is a major opportunity for palliative services in the U.S. to be offered in the patient's home. Most people prefer to receive care in one's home as opposed to a nursing home or hospital due to the familiar surroundings of home and community (Panasci, 2009). In this environment, the patient would have less opportunity for exposure to infectious agents and the sole attention of the caregiver.

BARRIERS TO PALLIATIVE CARE ACCESS

There are problems with insurance coverage for some who seek home-based palliative care. For instance, Medicare is an acute-level insurer and will only cover home care if the patient's condition requires short-term or intermittent care (Panasci, 2009). Palliative care, on the other hand, may continue for an unknown amount of time until the patient improves or passes away.

Anecdotal evidence has described the struggle of some who have wanted to have care at home instead of the hospital, but barriers would not allow it. One New York Times article (2014) describes the story of Joseph Andrey who had been discharged to a nursing home over and over again, but would not be allowed to go home because neither Medicaid nor Medicare would cover home care. For-profit hospice companies only agreed to provide home visits if the doctor certified that Mr. Andrey only had six months to live.

In the New York Times article (2014), Dr. Joan Teno, a gerontologist and author of "Dying in America" says: "We have these frail older people moving about in the medical-industrial complex that we've constructed. It's all about profit margins. It's not about caring for people." Teno (2013) found that most Medicare beneficiaries over the age of 65 received treatment in a hospital in their last days and this percentage has increased since 2000. Transfers of older patients among facilities and home have steadily increased since 2000. Also, only about one third of Medicare beneficiaries die at home (Teno, 2013).

According to the Centers for Medicare and Medicaid's (CMS) (2013) definition of Medicare benefit, hospice is restricted to patients with a terminal illness with a prognosis of six months or less to live who agree to forego "curative" care. Bonebrake et. al. (2010) describes barriers around physicians initiating palliative care discussions and patients who may seek

palliative care but fear doctors and loved ones will think they are “giving up” or seeking to forego treatment. There is a need for people at high risk of death and disease, but are not eligible or not interested in hospice. For instance, Bonebrake et. al. (2010) describes a case study in which a man with prostate carcinoma was provided palliative care consultation for pain management and supportive care. He did not have a prognosis of six months or less to live but he did need his symptoms and pain managed. Home-based palliative care can be an important option in these situations.

PURPOSE

This review seeks to examine literature surrounding home-based palliative care in terms of 1) clinical effectiveness, 2) cost, 3) cost-effectiveness, 4) quality of life and patient satisfaction, and 5) recommendations for healthcare policy and practices. The research will determine whether home-based palliative care is a viable option worth pursuing and making policy changes. This will influence whether patients should have equal opportunities for home-based palliative care and other types of palliative care. A policy brief will be included which will describe the aging population and the burden on the U.S. healthcare system, opportunities for home-based palliative care, and policy recommendations.

APPROACH

This capstone reviews the literature on home-based palliative care in terms of clinical effectiveness, cost-effectiveness and quality of life of the patient and family. The body of research will inform policy and practice recommendations that will help ensure affordable and timely home-based palliative care to those who need it. Research articles were found through a comprehensive search of PubMed and GlobalHealth (EBSCO) databases. The databases included Medline, CINAHL, PAIS International, Web of Science, Cochrane Library, and Academic Search Complete. Articles found through the databases were peer-reviewed and written in the English language. The EBSCO disciplines searched were “Complementary and Alternative Medicine,” “Consumer health,” “Health & Medicine,” “Psychology,” “Public Health,” and “Social Sciences and Humanity.”

Search terms included “home-based,” “palliative or hospice,” “effectiveness” or “cost” or “cost-effectiveness” or “quality of life” or “satisfaction.” Articles searched were published between January 2003 and January 2015. All articles that referred to home-based palliative care were reviewed. Articles that compared home-based palliative care to other types of palliative care were included but not a requirement for inclusion. Due to the limited number of U.S. based studies, articles from other developed countries similar to the U.S. were included. Commentaries on home-based palliative care were reviewed for background information. Gray literature produced by government agencies was also included.

CHAPTER 2: REVIEW OF LITERATURE

CLINICAL EFFECTIVENESS

In general, palliative care has been shown to produce many clinical benefits including quality of life improvement, better quality of care with less aggressive EOL care, and less emotional distress (Hughes & Smith, 2014). This section of the literature review will describe studies related to the effectiveness of palliative care in general, as well as outpatient palliative care. Additionally, it will describe the clinical effectiveness of home-based palliative care based on the following indicators: 1) hospital and emergency department (ED) visits, 2) place of death, 3) completion of advance directives, 4) symptom management, and 5) readmission rates.

There have been several studies demonstrating the possible prolongation of life with the use of palliative care or hospice. For example, Verret & Rohloff (2013) describe a Massachusetts study that followed patients with lung cancer who received palliative care along with standard treatment, and patients who had standard treatment only. They found that although the palliative care patients received less aggressive EOL care than the standard care patients, the palliative care patients lived an average of 2.7 months longer (Verret & Rohloff, 2013).

There has also been some evidence of effectiveness in outpatient palliative care. For instance, Scheffey et. al. (2013) showed patients in clinic-based outpatient palliative care had, on average, longer length of stays at hospice than patients who did not receive palliative care. This indicates that the patients were living longer while in hospice. There is less evidence of the effectiveness of home-based palliative care in comparison to inpatient palliative care, but the evidence is nonetheless important in showing that home-based care can actually offer improved benefit over standard care.

Hospital and ED visits

Research shows that hospital visits, hospital utilization and ED visits are reduced when home-based palliative care is used. Lukas et. al. (2013) sought to evaluate a single, home-based, non-hospice, palliative medicine consultation practice that was fee-for-service. The particular practice called Optimizing Advanced Complex Illness Support (OACIS) serves patients with a variety of diseases regardless of their specific prognosis or utilization of curative treatments. Patients are seen in homes or assisted-living facilities, but not skilled nursing facilities. The purpose of each visit was to improve symptoms and coordinate care, while also reconciling patient and family expectations and plans with the actual illness severity (Lukas et. al., 2013). Researchers evaluated hospital and ED visits and costs with a pre-post, single-patient group design. The longitudinal analyses indicated that there were significant reductions in hospital utilization after the 18-month study period, including number of hospitalizations and total hospital days. There was no change in the probability of an ED visit. While causality cannot be claimed, the results are encouraging given the emerging interest in home-based palliative medicine.

The primary limitation of Lukas et. al. (2013) was the absence of a randomized control design. The referral to a palliative medicine service may reflect selection bias and factors that determine referral were not measured. Authors also only had access to hospital utilization data from one healthcare network. Regardless, the article suggests that this delivery model can bring palliative services to patients much earlier in the illness trajectory than currently possible with hospice.

The next study shows less hospital use and fewer ED visits for the palliative care group compared to a usual care group. Brumley et. al. (2003) was conducted at the Home Health

Department at Kaiser Permanente in southern California between March 1999 and August 2000 to compare patients enrolled in a palliative care intervention to those receiving usual care. The Palliative Care Program at Kaiser Permanente is an interdisciplinary home-based system of healthcare designed to provide treatment to enhance comfort and improve the quality of a patient's life. The patients could decide to continue restorative treatment while also receiving symptom control, patient education, and psychosocial services. The comparison group receiving "usual care" was treated for conditions and only received home care when they met the Medicare-certified criteria of an acute condition.

Data were collected from patient interviews and from the Kaiser Permanente service utilization database. During the two year study, 300 patients were included in the sample. Hospital and ED visits were significantly lower for the palliative care group than comparison group patients. Comparison group patients had twice as many ED visits and four times as many hospital days than the palliative care group. The palliative care group also had lower physician office visits and less skilled nursing use (Brumley et. al., 2003).

Brumley et. al. (2007) completed a randomized, control trial in order to compare standard care with an in-home palliative care program, specifically in the programs' ability to improve patient outcomes. The trial was conducted at two managed care sites in Hawaii and Colorado. The patients were those who had 12 months or less to live and had visited the ED or hospital at least once within the previous year. When referred to the program, they were randomly assigned to standard care or in-home palliative care. The proportion of patients who died during the study period was not significantly different between the study groups (Brumley et. al., 2007).

There were, however, significant differences between the groups in terms of service use, with 20 percent of palliative care members going to the ED compared to 33 percent of usual care

members. Furthermore, 36 percent of those receiving palliative care were hospitalized, compared with 59 percent of those enrolled in usual care. After adjusting for survival, age, and severity of illness, authors found that enrollment in the palliative care program reduced hospital days by 4.36 and ED visits by 0.35 (Brumley et. al., 2007).

Other developed countries have also analyzed the effects of home-based palliative care. A population-based study from Spain compared ED admissions and inpatient days among cancer patients in a geographic area with a palliative home care team and in an area without a palliative home care team (Alonso-Babarro et. al., 2013). Authors found that the palliative care patients used emergency services and inpatient services less frequently. The authors found that the use of hospital resources during the last two months of life was significantly lower in the palliative home care area (Alonso-Babarro et. al., 2013). However, a limitation is that the variations may have been due to other regional differences not measured rather than whether the palliative home care was located in that area.

Place of death

The place of death is an important indication of whether a patient's wishes are met or not. One narrative appraisal by Higginson et. al. (2013) looked at the science of dying at home. This debate is increasingly relevant for all palliative care stakeholders and constitutes a public health issue due to the rising numbers of deaths and increasing health expenditures. Preferences for place of care and death show that home is the main preference, followed by hospice, but there is a need for a greater understanding of factors underlying change of preferences and how often or why these change over time. Kerr et. al. (2014) indicated that enrollment in home-based palliative care may increase the likelihood of dying at home rather than in another setting.

Brumley et. al. (2003) found that 90 percent of palliative care patients died in their home compared to 57 percent of the comparison group patients. These findings remain significant even after controlling for days of service and severity of illness. Limitations of Brumley et. al. (2003) was the lack of a randomized controlled trial and the limited generalizability.

Brumley et. al. (2007) found that 71 percent of palliative care patients died at home, compared with 51 percent of those receiving usual care. One limitation of the study was the inadequate sample of individual minority groups, as well as limited generalizability since it was conducted within a managed care setting (Brumley et. al., 2007). This study provides strong clinical evidence supporting the provision of palliative care in the home of terminally ill patients.

Alonso-Babarro et. al. (2013) found in their Spain-based study that the frequency of deaths in the hospital was significantly lower among patients in the geographic area with palliative home care compared to the area without palliative care. The probability of a hospital death increased in direct relationship with the number of visits to the emergency center or inpatient hospital and with the number of inpatient days. The article is another piece of evidence that improvements can be made in EOL care through public health policy and home deaths should be an important part of the conversation.

There have been two systematic reviews on the effectiveness of home palliative care services. A 2011 systematic review by Shepperd et. al. looked at four randomized controlled trials to compare EOL care at home with inpatient or hospice care. Two trials were conducted in the United States, one in Norway and one in the United Kingdom. In terms of place of death, authors found that those receiving EOL home care were significantly more likely to die at home compared with those receiving usual care, including hospice care, inpatient care and routinely available primary healthcare (Shepperd et. al., 2011). A more recent 2013 systematic review by

Gomes et. al. looked at studies of patients largely with advanced cancer but also congestive heart failure and other chronic illnesses. Meta-analysis showed that home palliative care increased odds of dying at home.

A better understanding of the factors influencing preferences for place of care and death, including age, culture, social conditions or previous care experiences, could inform the model of factors affecting place of death and contribute to the development of responsive palliative care services and clinical practice (Higginson et. al., 2013).

Advance directives

Advance directives are important for ensuring that a patient's EOL wishes are adhered to in a time when the patient may not be able to communicate for him or herself. Kerr et. al. (2014) looked at the clinical impact of a home-based program through a hospice-private payer partnership. Home Connections (HC) is a home-based palliative care program established in Cheektowaga, New York in 2008. The HC team includes a palliative care-trained registered nurse coordinator, social worker, trained volunteers, and a palliative care physician. Two local private insurance payers support the program through a per member/per month fee. Referrals come from physicians, palliative care agencies, local insurers, or the community. For this study, administrative and clinical data were gathered retrospectively (Kerr et. al., 2014). Approximately 88 percent of HC patients had one or more completed advance directives, with 71 percent of those without advance directives before enrollment subsequently completing them. This indicates that home-based palliative care programs can increase the rate of actionable advance directive completion.

Symptom management

Another indicator of care effectiveness is the successful management of pain and other symptoms. Kerr et. al. (2014) examined symptoms of patients in the palliative care group and the usual care group. The average score for all symptoms (i.e. anxiety, appetite, depression, dyspnea, nausea, pain, weakness, and well-being) improved during the first 10 weeks of enrollment in HC. All of the symptom improvements were statistically significant, except those for depression and pain. After the 10th week of enrollment, scores of all symptoms remained stable on average (Kerr et. al., 2014). Results of this study showed that enrollment in home-based palliative care appeared to result in multiple symptom improvement. A primary limitation of the study was the retrospective design and absence of a comparison group (Kerr et. al., 2014).

In a 2011 systematic review by Shepperd et. al. did not find a difference between home-based and inpatient or hospice care in terms of patients' functional status and psychological well-being or cognitive status. However, there was a difference in caregivers' report of pain control between the two groups and assessment of depression and anxiety. Caregivers in the home-based care group reported less pain and less depression and anxiety (Shepperd et. al., 2011). A 2013 systematic review by Gomes et. al. found small but significant beneficial effects of home palliative care services compared to usual care on reducing symptom burden for patients.

Readmission rates

An important component of clinical effectiveness is readmission rates. If home-based palliative care services can reduce the 30-day readmission rate, they may have an important role to play in post-acute care, particularly in Accountable Care Organizations (ACOs). Hughes & Smith (2014) found that palliative care programs in general helped to reduce readmissions by 50

percent. There is evidence that suggests home-based palliative care can reduce hospital readmission rates as well. For instance, Lukas et. al. (2013) found that the probability of a 30-day readmission was reduced after an 18-month study period of a home-based palliative care practice.

One study was conducted in the University of Pennsylvania Health System post-acute care program (Penn Homecare and Hospice Services) among patients who were admitted to a home care program or a palliative home care program (Ranganathan et. al., 2013). The palliative home program was staffed by hospice nurses rather than home care nurses, and had access to a phone line that provides 24-hour access to a hospice nurse. An interdisciplinary team discusses the palliative care patients biweekly, which is different than the standard home care group. Researchers calculated the average treatment effect on treated patients, which is a measure of the impact of palliative care on 30-day readmission, compared to what their readmission rates would have been in the regular home care group (Ranganathan et. al., 2013). Results showed that palliative care patients had a 30-day readmission probability of 9.1 percent compared to 17.2 percent in the home care group. Therefore, palliative home care programs may have the potential to improve patient-centered outcomes by reducing readmission rates. More research may be needed on how palliative care may reduce the 30-day readmission rate (Ranganathan et. al., 2013).

COSTS

Not only do home-based palliative care programs need to be effective, but they should not be more costly than other alternatives. Changes in Medicare reimbursement (i.e. 30-day readmission policies) as well as the mandate through the 2010 Affordable Care Act that requires

all people to have health insurance make it imperative for health systems to develop models that reduce healthcare costs. One way to reduce healthcare costs is by delivering care in non-hospital settings. Lukas et. al. (2013) found that reducing unnecessary hospital visits and treatments may benefit hospital finances, even in a fee-for-service environment. This section provides evidence that home-based palliative care programs are less costly than care in other settings in terms of inpatient/ hospital costs, patient costs, and societal costs.

Inpatient/ hospital costs

There have been several articles that reviewed the costs of home-based palliative care. Hughes & Smith (2014) found that palliative care programs helped to lower overall healthcare costs by reducing the cost of inpatient stays and allowing each hospital to calculate the financial savings from adding or expanding their palliative care team. The savings estimate is partly based on reductions in inpatient length of stay, but it also includes savings from moving a patient from a high-cost venue such as the intensive care unit (ICU) to a lower-cost setting such as usual or palliative care—so called “cost avoidance.”

Morrison et. al. (2008) compared direct costs of patients who were cared for by a palliative care team with direct costs of matched patients who were not covered by palliative care. The study analyzed data from eight hospitals and found that the use of palliative care saved an average of more than \$7.5 million a year. This does not include indirect cost savings nor savings from unwanted or unnecessary procedures which would make the cost savings even greater. Savings included significant reductions in pharmacy, laboratory and intensive care costs (Morrison et. al., 2008). The authors concluded that an average 400-bed hospital seeing 5,000

patients a year could achieve annual net savings of \$1.3 million by implementing a palliative care program.

Patient costs

Brumley et. al. (2003) found that patients enrolled in the palliative care group had an average \$6,580 reduction in cost from the average cost for those in the comparison group receiving usual medical care. Average cost of care for the comparison group was \$14,570 and for those in palliative care, the average cost was \$7,990. Therefore, receiving palliative care reduced medical costs of care by 45 percent.

Brumley et. al. (2007) completed a randomized, control trial to compare standard care with an in-home palliative care program, specifically in the programs' ability to reduce the costs of medical care at the end of life. Authors found significant differences in the cost of care between home-palliative care and standard care. The analysis revealed that overall costs of care for those enrolled in the palliative care program were 33 percent less than those receiving standard care. The average cost per day incurred by palliative care recipients (\$95.30) was significantly lower than that of usual care group members (\$212.80). Authors concluded that providing a palliative care team to homebound patients can have a positive effect in reducing costs of care at the end of life.

Societal costs

A study out of Canada sought to examine the societal costs of home-based palliative care and the socio-demographic and clinical factors that account for variations in costs over the course of the palliative trajectory (Guerriere et. al., 2010). Patients were recruited from Mount Sinai Hospital in Toronto and costs were assessed between time of admission and death.

Caregivers were interviewed every two weeks. The Ambulatory and Home Care Record (AHCR) was used to comprehensively measure costs of services from a societal perspective by quantifying publicly financed care and private family costs. The majority of the sample reported receiving both publicly funded medications and out-of-pocket medication costs. The average monthly cost of care per patient was \$24,549. Costs were higher closer to death compared with time points more distant from death (Guerriere, et. al., 2010). One limitation of the report is that the study relied on self-reports obtained through phone interviews. Also, the results may not necessarily be generalized to people receiving services from other types of palliative care programs. Lastly, approximate prices had to be used to derive the costs (Guerriere, et. al., 2010).

Another Canadian study analyzed the resource utilization and costs of a home-based palliative care service over 15 months (Klinger et. al., 2013). The Niagara West End-of-Life Care Project was designed to provide enhanced interdisciplinary home-based shared-care in a rural community setting. The project collaborated with primary care teams and a palliative care consultant or team. Most of the patients enrolled in the project had a cancer diagnosis, while a few had advanced heart disease, chronic obstructive pulmonary disease, amyotrophic lateral sclerosis, and Alzheimer's. Frequently used services included specialized nursing, homemaking, equipment rentals, and occupational and physical therapy. Most patients and families accessed bereavement services, psycho-spiritual care and pain management.

The average length of stay in the program was 145 days. The total costs for all patient-related services during the study were about \$1,625,658 or \$17,112 per patient (Klinger et. al., 2013). A majority of the billing was for specialized nursing services, homemaking and equipment charges. These costs were well within the parameters of the U.S. Medicare Hospice Benefits and on par with the per diem funding assigned for long-term care homes. This is

important because it indicates that home-based palliative care is not more expensive than hospice or other long-term care facilities, and gives credence to the argument that Medicare benefits should include home-based palliative care.

Limitations of this article include the relatively small number of study participants and short timeframe that hamper generalizability. It was also a retrospective review using datasets from one community hospital. Authors conclude that this analysis indicates that home-based service provision is less costly than hospital-based alternatives (Klinger et. al., 2013). Future projects should use economic analysis from the societal perspective in the study design from the beginning to allow for comparisons across settings.

COST-EFFECTIVENESS

The literature in this section first examines the cost-effectiveness of palliative care in general and reviews the cost-effectiveness of home-based palliative care. Most settings for palliative care are shown to be cost-effective. Guerriere et. al. (2010) describes how opportunities to improve the cost-effective allocation of palliative care services may be calculated by comparing the incremental gains in satisfaction to the incremental cost of care over the palliative trajectory, between care providers, and across alternative levels of service intensity.

Community-based palliative care

Higginson et. al. (2009) showed through a cost-effectiveness analysis based on the Palliative Care Outcome scale and the Zarit Carer Burden Inventory, a caregiver self-report measure, that the intervention group with palliative care had lower costs and better outcomes

47.3 percent of the time, and higher costs and better outcomes 48 percent of the time. Therefore, it was cost-effective about half of the time but always clinically effective.

Although not a home-based care program, one report describes the cost-effectiveness of a palliative care program in a rural Alabama community hospital (McGrath et. al., 2013). The average cost per day for the palliative care recipients was \$754 and \$1,027 for non-palliative care recipients. Palliative care patients had a net savings of \$273 per day. The palliative care cost savings were calculated to be \$148,471, which yielded a net cost savings of \$46,971 (McGrath et. al., 2013).

Home-based palliative care

The most rigorous cost-effectiveness analysis of home-based palliative care was a prospective cost-effective analysis of the Palliative Care Extended Packages at Home (PEACH) pilot randomized control trial in Sydney, Australia (McCaffrey et. al., 2013). Community care in New South Wales is provided by a specialist palliative care team, general practitioners, and community nurses. Patients enrolled in the PEACH trial had complex or unstable symptom management and high care needs. Participants were randomized to receive PEACH or usual care. Specialist palliative care services and PEACH costs were estimated using hourly rates of local salaries, agency staff costs and equipment hire. Incremental net monetary benefit and cost-effectiveness acceptability curves were estimated at potential threshold values for one extra day at home.

PEACH participants had 13.1 average days at home, which was one more day than usual care (McCaffrey et. al., 2013). PEACH costs varied widely with one high cost outlier attributable to a large number of additional nursing hours. Of participants who died, 56 percent were in the

PEACH pilot, and 80 percent were in usual care. The average direct cost associated with PEACH was \$3,489 per participants and was offset by \$2,450 inpatient cost savings.

Authors found that the incremental net monetary benefit over 28 days for PEACH versus usual care became positive when the threshold value for one extra day at home exceeded \$1,068. When the high cost outlier was removed, it reduced the threshold value to \$846. The cost-effectiveness acceptability curve indicates the probability of PEACH being cost-effective versus usual care for potential threshold values for one extra day at home. Findings suggest home-based palliative care can reduce hospitalizations and associated costs (McCaffrey et. al., 2013). More research may be needed to determine if one extra day at home is meaningful to decision makers.

Limitations of the study include differences in baseline characteristics that may have been associated with home deaths between intervention groups. Also, informal care costs were not included and generalizability will be limited to care provided by similar costing and funding models. Authors found that most of the costs of intensive, home-based care packages are offset by reduced inpatient stays, while days at home are increased (McCaffrey et. al., 2013). These findings provide great support for the financial feasibility of home-based palliative care programs.

QUALITY OF LIFE & PATIENT SATISFACTION

The literature demonstrates that palliative care has implications for both patients and families. It is important to see improved quality of life, relief of suffering, and the enhancement of human dignity as a result of home-based palliative care. Families should also have improved coping, less distress, and more support through the care process. The patient-family care experience is of utmost importance for all palliative care services.

Hospitals are in the business of healing, and there is a point where curative care is no longer realistic (Verret & Rohloff, 2013). Healing is not just the curing of disease, but also holistically addressing the physical, psychosocial, emotional, and spiritual wellness of a patient. Palliative care provides a service to address the holistic care of patients and their families, especially when chronic or severe conditions are not curable or resolvable (Verret & Rohloff, 2013). While palliative care can be administered in addition to curative treatment, many times it is in lieu of curative treatment. This section will review literature showing that home-based palliative care provides increased quality of life for patients and caregivers by looking at the following indicators: 1) patient satisfaction, 2) patient symptoms, and 3) caregiver satisfaction.

Patient satisfaction

Studies of home-based palliative care consistently indicate higher quality of life and patient satisfaction. Brumley et. al. (2003) compared the satisfaction of patients in the palliative care group and comparison group when they enrolled and 60 days following enrollment. Satisfaction with services was significantly higher in the palliative care group 60 days following enrollment than at baseline ($t = -2.57, p = 0.01$) while satisfaction remained the same for comparison group members ($t = -0.5, p = 0.6$) (Brumley et. al., 2003). Kerr et. al. (2014) found that the patients, caregivers and physicians were consistently satisfied with the program throughout the study.

Brumley et. al. (2007) conducted a randomized control trial among patients in two health maintenance organizations in Hawaii and Colorado and there was no significant difference in the portion of participants reporting to be very satisfied at baseline or at 60 days after enrollment. Rates of satisfaction did increase in the intervention group at 30 days and 90 days after

enrollment, with 93 percent of those enrolled in the palliative care group very satisfied with care at 90 days after enrollment, compared with 81 percent of usual care patients. This indicates that an in-home palliative care program plus usual care can increase patient satisfaction compared with usual care alone (Brumley et. al., 2007).

Similarly, a Japanese day hospice was evaluated to determine advanced cancer patients' quality of life and satisfaction with day hospice (Miyashita et. al., 2008). A cross-sectional questionnaire was administered to patients cared for at day hospices or home palliative care services. Compared to national standard values, the average physical component summary and mental component summary was significantly lower in both the day hospice and home palliative care service patients and caregivers. For eight of the 11 questions, 70 percent or more patients were satisfied. Eighty percent of caregivers were satisfied about patient-related items and caregiver-related items (Miyashita et. al., 2008). Although advanced cancer patients and caregivers have a lower quality of life compared to the general population, patients and caregivers were mostly satisfied with the home palliative care based on this article.

Patient symptoms

Peters and Sellick (2006) describe the quality of life of cancer patients receiving inpatient and home-based palliative care. Authors compared the symptom experience, physical and psychological health status, level of personal control over the illness, and quality of life of patients in both groups. Symptoms were assessed using the Memorial Symptom Assessment Scale (MSAS), a self-report instrument. Physical health was assessed using the Palliative Performance Scale (PPS) and the Hospital Anxiety and Depression Scale (HADS) was used to indicate anxiety and depression.

The most prevalent symptoms (more than 70 percent) reported by the inpatient group were weakness, fatigue, dry mouth, sleeping during the day, and pain. The least prevalent symptoms (less than 20) were mouth sores and weight gain. For home-based patients, fatigue, pain, weakness and flatulence were the most prevalent and diarrhea, headache, mouth sores and weight loss were the least prevalent symptoms (Table 1). Higher average scores were recorded for the inpatient group on all four symptom measures (Peters & Sellick, 2006).

Table 1- Peters & Sellik, 2006

Symptom prevalence for inpatient and home-based groups (ranked for inpatient patients)				
Symptom	Inpatient		Home-based	
	n	%	n	%
Weakness	28	87.5	18	69.2
Fatigue	27	84.4	21	80.8
Dry mouth	24	75	17	65.4
Sleeping during the day	24	75	15	57.7
Pain	23	71.9	20	76.9
Lack of appetite*	21	65.6	10	38.5
Flatulence	19	59.4	18	69.2
Thirst	18	56.3	11	42.3
Belching*	17	53.1	7	26.9
Nausea	16	50	12	46.2
Diarrhoea**	15	46.9	3	11.5
Constipation	15	46.9	12	46.2
Shortness of breath	14	43.8	14	53.9
Taste alteration	13	40.6	10	38.5
Vomiting	12	37.5	7	26.9
Sweating	12	37.5	8	30.8
Dizziness	11	34.4	6	23.1
Weight loss	11	34.4	5	19.2
Cough	9	28.1	11	42.3
Swelling of arms/legs	9	28.1	11	42.3
Bad taste	9	28.1	11	42.3
Headache	8	25	4	15.4
Itchy skin	7	21.9	9	34.6
Weight gain	5	15.6	6	23.1
Mouth sores	4	12.5	4	15.4

*P < 0.05; **P < 0.01

Results showed that home-based patients had statistically significantly higher physical health scores for physical status and lower depression scores. Although not statistically significant, the home group also scored higher on the PPS and lower on the anxiety scale. The

home-based group scored significantly higher on all personal control measures (control over daily symptoms, control over the course of the illness, and control over medical care and treatment). Both groups scored higher on “personal control over symptoms and medical care” and “treatment” than on “the course of the disease” (Peters & Sellick, 2006).

The impact of disease on quality of life was less for patients at home than those receiving inpatient care on all measures. Although the two groups were similar on a number of measures, patients receiving home-based palliative care tended to have better physical and psychological health and quality of life. Home-based patients also experienced fewer adverse effects from their symptoms and reported having more control over their illness and treatment (Peters & Sellick 2006). However, caution is needed when interpreting these findings given that a higher proportion of patients in the home-based group were married, of Australian descent, had private health insurance and were less likely to be living alone.

An Australian study compared the prevalence of anxiety and depression in palliative care patients being treated at home with those being treated as inpatients (Austin et. al., 2011). HADS was used to measure anxiety and depression symptoms in the patients. The Karnofsky Performance Status Scale (KPS) was used as an indicator of functional status. The home-treated patients and inpatients did not differ significantly in terms of average age or gender, but did differ in functional status and socioeconomic status.

The groups did not differ significantly on HADS depression, anxiety or total scores (Austin et. al., 2011). Younger age and lower KPS scores were associated with higher HADS scores. About 20 percent of all the palliative care patients showed meaningful anxiety and depression which underscores the importance of addressing psychological distress in palliative

care services. Appropriate and equal staff resources should be used on palliative care inpatients and those being treated at home.

Caregiver satisfaction

Within a larger article about cost variations in home-based palliative care, Guerriere et. al. (2010) measured satisfaction of caregivers using the Quality of End-of-Life Care and Satisfaction with Treatment (QUEST) scale. The majority of caregivers reported being either very satisfied with the quality of care provided by physicians and nurses (71 percent and 60 percent, respectively) or satisfied (26 percent and 33 percent, respectively).

Guerriere et. al. (2013) used QUEST to interview family caregivers about their satisfaction with home-based physician and nursing palliative care services. Satisfaction is defined as the degree to which expectations of several aspects of care are met. The authors designed a prospective, longitudinal cohort study that measured satisfaction with care from admission until death. This particular palliative care program provides community multidisciplinary care, including symptom management and practical/emotional support to individuals at home 24 hours per day, 7 days per week. Study participants were interviewed every two weeks and reported their perceptions of satisfaction over the previous two days.

A majority of the caregivers were female and were generally either spouses or children of the patient (Guerriere et. al., 2013). Data from 748 interviews was analyzed and the majority of interviews resulted in high satisfaction with both nursing and physician care. On five different categories, caregivers reported being very satisfied with physician care (an average 87 percent) at a higher rate than they did for nursing care (an average 71.2 percent). The categories included bedside manner, common courtesy, way of talking to patient, clinical and technical skills in

treating patient, and concern for patient as an individual (Table 2). Quality-of-care parameters included questions about the provider spending enough time with the patient, arriving on time, accessibility, attentiveness and personal concern. Authors found that quality-of-care parameters are strong predictors of satisfaction (Guerriere et. al., 2013).

Table 2- Guerriere et. al. 2013

Caregivers' perceived satisfaction by scale items and professional category					
		Nurses (N= 274)		Doctors (N= 154)	
		n	%	n	%
Bedside manner					
	very satisfied	199	72.6	137	89.5
	dissatisfied	75	27.4	16	10.5
Common courtesy					
	very satisfied	196	71.5	138	90.2
	dissatisfied	78	28.5	15	9.8
Way of talking to patient					
	very satisfied	191	69.7	136	88.9
	dissatisfied	83	30.3	17	11.1
Clinical and technical skills in treating patient					
	very satisfied	189	69	134	87.6
	dissatisfied	85	31	19	12.4
Concern for patient as an individual					
	very satisfied	201	73.4	128	83.7
	dissatisfied	73	26.6	25	16.3
Overall satisfaction					
	very satisfied	185	67.5	116	75.8
	dissatisfied	89	32.5	37	24.2
Months to death					
	0	40	26	47	17.1
	1	38	24.7	59	21.5
	2 to 3	37	24	64	23.4
	4+	39	25.3	104	38

Sociodemographic variables were not shown to be significant predictors of satisfaction. The article demonstrates that healthcare providers should be meeting quality parameters, in part to increase family caregivers' satisfaction with home-based palliative care services. One limitation of the study was not measuring the patients' perceptions, only the caregivers' perceptions. The results may not be generalizable to individuals receiving services at other types of palliative care programs (Guerriere et. al., 2013).

Another article based in Australia sought to assess how family caregivers were supported in three home-based palliative care services (Thomas et. al., 2010). Focus groups with health professionals were conducted to determine what services were currently available for the caregivers, how well the services met caregivers' needs, and perceived barriers to supporting caregivers. A file audit was also conducted to determine the frequency of actual support services received by caregivers. Authors found that there were not formalized procedures for assessing and responding to family caregiver needs in a comprehensive way (Thomas et. al., 2010).

SUMMARY

The existing literature suggests that home-based palliative care compared to palliative care in other environments may result in fewer hospitalizations, fewer hospital days, fewer ED visits, and fewer physician office visits. There is evidence that the probability of readmission to a hospital within 30 days is less for home-based patients. The research also shows that those receiving home-based care are more likely to die in their home, which is the preference for a majority of people. Other positive benefits include a higher likelihood of completed advanced directives by those receiving palliative care at home. Completing advanced directives improves the chance that patients will receive life-saving care, or not receive care if desired, in times when they are unable to speak for themselves.

An ideal healthcare situation for a person with a chronic disease or debilitating condition would be to have his or her treatment and palliative care options described by a team of healthcare professionals, including an option for home-based palliative care. This option would be presented once the healthcare team, patient and family agree that care can be adequately managed at the home and a plan for curative care, or lack thereof, is understood by all parties. Many articles suggest that home-based care may be the preferred option for patients who are in better health, wish to remain independent, believe that they have control over the effects of their illness and treatment, and who have supportive networks at home. Alternatively, inpatient care, particularly in hospice, is the more likely choice for patients who are very ill or require intensive symptom management, or where the family is unable to cope with the burden of care. If home-based care is chosen, it may be delivered integrally by a specialized palliative care team or individual physicians and nurses, depending on the patient's medical condition. Appointments in the hospital or other healthcare settings can still be arranged at designated intervals or as needed when testing or other follow-up services cannot be adequately performed in the home setting.

Several articles found that there was a cost reduction by bringing care to the home. Most of the costs were derived from specialized nursing, homemaking, and equipment. Furthermore, these home-based costs were found to be well within the parameters of the U.S. Medicare Hospice Benefits. Therefore Medicare should cover beneficiaries' home-based care costs at the same level as hospice and inpatient settings. An incentive for covering home-based care through government insurance is cost reduction, which may help to reduce overall U.S. healthcare costs. Other cost-effectiveness articles found a net savings when people received care at home as opposed to an inpatient setting. Home-based palliative care is an effective and encouraging option for reducing healthcare spending.

Quality of life and satisfaction was found to be favorable in home-based patients and often times higher than inpatient patients and families. Various studies showed patient satisfaction to be higher after 30 days of care, 60 days of care, and 90 days of care. Other evidence showed high percentages of home-based patients who are very satisfied or satisfied with physicians and nurses. Some results showed higher physical health and lower depression for home-based patients. Home-based groups were also found to score higher on personal control measures. Just as important as patient well-being is family and caregiver well-being. Research presented evidence that families of home-based palliative care patients had high satisfaction with physicians and nursing staff. The evidence indicates that wider availability and accessibility of home-based palliative care would be highly valued by patients and families who want to spend, in many cases, the end of the patient's life together in the comfort of their own home.

CHAPTER 3: RECOMMENDATIONS

This article presents important findings that suggest home-based palliative care can be clinically effective, cost-effective and improve quality of life among patients and their families. However, there are many barriers that prevent affordable and timely access to care. A primary obstacle is the financial burden for patients since many insurers, public and private, do not cover home-based palliative care. For instance, Medicare, one of the nation's largest health insurers, only provides the hospice benefit as an EOL option for patients. The current Medicare hospice benefit only covers palliative and support services for patients designated to have a terminal illness and a life expectancy of six months or less (CMS, 2013). The hospice benefit will not cover treatment costs, room and board, care in an emergency room or inpatient facility, nor care from any hospice provider not set up by the hospice medical team (CMS, 2013). By electing to receive the benefit, patients forfeit any conventional treatment for the condition. This may feel to the patient that they are "giving up" or resigning themselves to death. Due to the large number of older adults suffering from multiple chronic conditions who could benefit physically and psychosocially from supportive care, there should be insurance coverage for palliative care without the requirement to have a terminal illness. When care is not covered by insurance, the financial burden of paying for care out-of-pocket is so large that it is often unmanageable and unrealistic.

A barrier related to getting timely access to palliative care is physicians and other healthcare staff not initiating conversations around palliative care or EOL issues. This may be due to the lack of incentives offered to healthcare professionals to initiate EOL conversations and a lack of education around palliative care and when to discuss the topic. Doctors may feel that they do not have enough time, resources, or knowledge to have these types of discussions with

their patients and therefore do not initiate the conversation until it is too late to have any valuable impact.

These following recommendations serve to limit barriers to affordable and timely home-based palliative care:

- 1. Medicare benefit should include home-based palliative care without the requirement to forego treatment**

Medicare should cover home-based palliative care similarly to the way Medicare covers hospice benefits but without the requirement to be terminally ill, have six months or less to live, and to forego treatment. The benefit would cover doctor services, nursing care, medical equipment and supplies, prescription drugs, counseling and other care as described in the 2013 Medicare Hospice Benefits. Palliative care should be available for those patients who wish to receive care at home, but may also want to continue getting life-saving treatment. Patients should not feel forced to be in an inpatient setting to receive care that can be provided in the home. The current Medicare hospice model does not address patients with multiple chronic conditions and ambiguous prognoses. Research has shown that providing palliative care earlier in the course of disease leads to better health outcomes, higher satisfaction with care and reductions in healthcare costs (California HealthCare Foundation, 2013). It has also been shown that there is considerable value in the concurrent delivery of palliative and curative care.

Calls have certainly been made to increase the availability of and access to palliative care services in the U.S. healthcare system (Meier, 2011). Medicare beneficiaries are receiving care that is fragmented and uncoordinated and does not take into account their overall care needs. Evidence supports the need for fundamental changes in the design of the U.S. healthcare system by adjusting our current hospice benefit to better meet the needs of patients or developing a new,

“pre-hospice” palliative care benefit that provides a bridge between standard medical care and hospice care (Brumley et. al., 2007). For the past several years, policymakers have debated reform of the Medicare hospice benefit, in terms of eligibility, financing, and structure (MEDPAC, 2012). In 2009, Congress gave CMS the authority to revise the hospice payment system. Since the CMS Secretary had not exercised that authority, the recommendation was printed again in the 2014 Medicare Payment Advisory Commission (MEDPAC) report.

The 2010 Affordable Care Act (ACA) is requiring that data be collected by CMS regarding hospice quality (MEDPAC, 2014). ACA mandates a three-year demonstration to test the effect on quality and cost of allowing simultaneous hospice and conventional care. Through the pilot Medicare Care Choices Model, CMS is providing an option for Medicare beneficiaries to receive palliative care services from certain hospice providers while concurrently receiving services provided by their curative care providers. CMS will evaluate whether providing hospice services will improve the quality of life, increase patient satisfaction, and reduce Medicare expenditures. The results of this study will be important for implications on how Medicare hospice benefits are structured in the future.

Medicare is already spending about \$15 billion on hospice a year and 34.5 percent of the hospice patients receive a week or less of care (NHPCO, 2015). If home-based palliative care was offered to those same patients earlier in their illness trajectory, costs could potentially be avoided by reducing unnecessary care and managing high-need, “at risk” patients.

Medicare needs to replace the eligibility requirement for hospice benefits to include those who have Medicare Part A and are certified by a physician as having an advanced or late-stage, progressive or degenerative chronic illness in which the disease or physical ailment significantly worsens, grows, or spreads over time. While a prognosis of six months or less to live is difficult

to certify and should not be required, the illness should be considered “advanced”, cause a significant amount of impairment to the patient’s daily activities, and require continuous medical care, as determined by a primary healthcare provider. Examples of progressive disease would include Alzheimer’s disease, cancer, chronic obstructive pulmonary disorder, Huntington’s disease, multiple sclerosis, Parkinson’s disease and others as classified by the National Institutes of Health.

2. Compensation to healthcare providers for discussing and integrating palliative care

The 2014 Institute of Medicine report, “Dying in America,” was released by a committee of 21 experts that calls the U.S. EOL care system “broken” and recommends several ways to improve care. One of the recommendations is reimbursing providers to discuss EOL care and advance planning with their patients. Authors found that incentives under fee-for-service Medicare result in increased use of medical services and late enrollment in hospice, which can jeopardize the quality of EOL care and add to costs. Incentivizing provisions of comprehensive palliative care and discouraging the use of costly and unnecessary medical procedures can improve patient outcomes and reduce healthcare costs (IOM, 2014). The report recommends that the federal government require public reporting on quality measures, outcomes and costs regarding care near the end of life for programs like Medicare and encourage other healthcare delivery systems to do the same. There should be financial incentives for medical services that decrease the need for emergency room and acute care services, coordination of care across settings and providers, and improved shared decision making and advance care planning (IOM, 2014).

The 2013 MEDPAC report also recommends a Medicare payment to compensate physicians or interdisciplinary teams for voluntary advanced care planning. This would help incentivize quality care and working with the patient and family to carry out their wishes. Advanced care planning may include discussions of where the patient would like to receive care and for how long he or she would want to be treated. According to the Dartmouth Atlas Brief (2013), Medicare spending in the last two years of life increased 15 percent between 2007 and 2010 from \$60,694 to \$69,947 per patient. Furthermore, Riley (2010) found that about 25 percent of the Medicare budget is spent on care during the last year of life. Nicholas et. al. (2011) found that advance directives specifying limitations in EOL care were associated with lower costs in regions where EOL spending was highest. The savings to Medicare due to reduced EOL spending would help offset the cost of Medicare-financed incentives to healthcare providers. Federal or state governments could subsidize incentives for private practice physicians contingent on meeting quality standards.

Landers (2009) describes the Medical Home initiative using MEDPAC recommendations as a concept that creates a way for primary care clinicians to receive payment for added care coordination, care integration, quality improvement, and education activities for patients with chronic diseases. The extra payments would be accompanied by added requirements and accountability for outcomes. Providing compensation to physicians and other healthcare providers for discussing palliative care options and coordinating care would increase the number of patients who understand their care and treatment options.

3. Better training for health professionals on palliative care topics

There needs to be improved training of health professionals on issues like patient-centered care and palliative care as a longer term approach in improving care for patients with advanced illness. This training can be included in medical school curriculum, nursing school curriculum, and other healthcare training curriculum. According to the 2014 MEDPAC report, very short hospice stays are still common which indicates that patients enter hospice in the last week or so of their life, unable to receive the full benefit of palliative care. This may be due to physicians' reluctance to have conversations about hospice or death, difficulty in some patients and families to accept death, and financial incentives in the fee-for-service system which value volume over quality (MEDPAC, 2014). Zhang et. al. (2009) found that patients who had an EOL conversation with their doctor had 36 percent lower expenses compared to those who did not have those discussions.

The IOM report (2014) recommends improving palliative care training among all physicians. Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies and healthcare delivery organizations should establish appropriate training, certification and licensure requirements to strengthen palliative care knowledge and skills of all physicians who care for patients with advanced illness (IOM, 2014). Basic palliative care competencies include communication skills, interprofessional collaboration and symptom management. Certifying bodies should require competency in palliative care, and educational institutions and professional societies should provide training throughout the professional's career (IOM, 2014). Other entities like healthcare delivery organizations, academic medical centers, and teaching hospitals should increase the number of available training positions for specialty-level palliative care.

It is still engrained in the psyche of the American hospital system that healthcare professionals should continue treating the patient until the last possible moment. Additional training would help health professionals resist the idea that palliative care is the same thing as hospice and should be reserved for those who have a short time to live. Training of healthcare professionals needs to emphasize high-quality care and comfort of the patient, including home-based palliative care options and advanced care planning. Acknowledging advanced illness and mortality provides an opportunity to deliver high standards of care, grounded in choice and responsiveness to needs for both the patient and their family.

When palliative care is taught, results can be impressive. A systematic review by Bickel-Swenson (2007) found that EOL educational curricula and clinical training found in a wide range of formats improved the competency of medical students. Authors found a 23 percent improvement in knowledge, a 56 percent improvement in feelings of competence, and a 29 percent decrease in concerns. Improvements are already being made by several universities and associations. For example, George Washington University includes a standardized patient case on palliative care and a course on medical interviewing and decision making. The University of Rochester includes content on advance care planning, chronic pain management, and discussion of treatment goals. The Association of American Medical Colleges is in collaboration with the Coalition to Transform Advanced Care to identify relevant core competencies.

CRITICISM

There was debate in 2009 related to Medicare paying physicians to discuss EOL care with their patients, with critics calling them “death panels” out of fear that the physicians would ration healthcare to elderly patients. Some believe that government payment for counseling on EOL decisions would lead to more government regulation and oversight, and create a conflict of

interest between the government's fiscal needs and patients' medical needs. As a result of the controversy, the ACA did not include that piece of legislation. However, the 2014 IOM report emphasizes that the important question related to EOL discussions is whether patients near the end of their lives are getting the care they actually want. By reimbursing physicians to discuss EOL care, patients can be more informed and empowered to make decisions on how to spend their final days. Reimbursements should be tied to standards and quality measures so that the quality of patient care would be improved, not diminished.

There are also politically conservative critics who oppose any additional funding to Medicare, either to pay for additional benefits or for physician incentives. However, the research indicates that offering home-based palliative care not only can improve the quality of life of a vulnerable population, but can result in cost-savings at the individual and provider level. Healthcare costs are high and rising in the United States, and improving accessibility and affordability of home-based palliative care through Medicare is an opportunity to reduce EOL costs throughout the country.

CHAPTER 4: DISCUSSION

The aging of the American population is quickly expanding the healthcare burden, in large part by the 66 percent of older adults who have multiple chronic conditions. Treating advanced illness and chronic conditions in the older population is complex and expensive. Medicare spending is expected to increase from \$555 billion in 2011 to \$903 billion in 2020. As the U.S. healthcare system struggles to keep up with the demand for care, there will be an increasing need for high-quality palliative care in all settings, but particularly home-based settings. Home-based palliative care has been shown to be at least equally effective as inpatient palliative care, less costly than inpatient care, and results in improved quality of life and patient satisfaction. Therefore, patients and their families should have the choice to use home-based palliative care when it is available, without the burden of financial or accessibility barriers.

Providing this home-based option will greatly alleviate the strain on inpatient settings and will reduce hospital and patient costs. An approach toward high-quality care and coordination and away from over-treating or inappropriately treating patients will improve quality of life as well as reduce unnecessary medical costs. This is an opportunity that the U.S. healthcare system and Medicare cannot afford to ignore. It is critical that federal, state, and local regulatory and payment policies evolve to support the delivery of high-quality palliative care to a growing elderly population who often live for many years with the burden of serious, chronic illnesses (Unroe & Meier, 2013). Legislation needs to be passed to implement these policy changes.

SUCCESSFUL PROGRAMS & MODELS

There are opportunities for health systems to model home-based palliative care programs after successful HMO programs like Kaiser Permanente and other ACOs. The Kaiser

Permanente in-home program, offered as a standard benefit to most members, includes an interdisciplinary team of providers who manage patient's symptoms and pain, provide emotional and spiritual support, and offer ongoing education about changes in the patient's condition (AHRQ, 2009). The patients do not have to forgo curative care in this program. Brumley et. al. describes the evidence of a randomized controlled trial (2003) and a comparison-group study (2007) which shows that Kaiser Permanente's program increased patient satisfaction, increased the portion of patients dying at home rather than in the hospital, and reduced ED visits, inpatient admissions, and costs.

The Pioneer ACO Model is designed for healthcare organizations and providers that are already experienced in coordinating care for patients across settings and allows them to move from a shared savings payment model to a population-based payment model, similar to the Medicare Shared Services Program (CMS, 2015). The model is designed to work in coordination with private payers by aligning provider incentives, which will improve quality and health outcomes among patients and achieve cost savings for Medicare, employers and patients (CMS, 2015). There are currently 19 ACOs participating in this model and being evaluated for performance. This is an innovative example of changing payment models and providing incentives for high-quality, coordinated care.

There are other ACO programs that can be adopted such as the Medicare Shared Savings Program which helps Medicare fee-for-service providers become an ACO, and the Advance Payment ACO model, which is a supplementary incentive program for selected participants in the Shared Savings Program. As home-based palliative care is implemented in various healthcare systems, there will be even more robust evidence to justify new practices offering this type of

care. Furthermore, as more healthcare organizations use home-based palliative care, it would be expected that insurance and payers will begin to cover these important services.

ADVANCING POLICY RECOMMENDATIONS

While policy recommendations are important, it is critical to understand the actions that must be taken to ensure the guidance provided is utilized and implemented through policy changes. An important first step is the engagement of all relevant stakeholders and participants impacted by the recommended changes to the hospice payment system. Kingdon (1995) provides a useful policy framework to inform efforts aimed at achieving policy change, suggesting a focus on “three streams” of policymaking – problems, policies (i.e., solutions), and politics. Kingdon suggests that if advocates can 1) help policymakers recognize their issue as an important problem, 2) develop attractive and feasible policy solutions, and 3) catalyze broad support among stakeholders that catalyzes political will, a policy window will open that allows for the adoption of the desired policy.

Framing the problem

Efforts to frame the problem of lack of access to palliative care may benefit from guidance from Stone (1989) who suggests that causal arguments can lead to agenda-setting in politics. Stories framed in this manner can lead to emotional responses and increased support for proposed policy solutions. Casual arguments place blame or responsibility of a problem on a person or system and seeks to fix the problem through political means (Stone, 1989). An example of a narrative that is emotional and defines the problem is from a response submitted through the online public testimony questionnaire for the 2014 IOM report:

“We got hospice when my mother-in-law died, but only for 2 weeks. She declined steadily for 2 years before her death, as we bounced back and forth between hospital, nursing home, and home (with private-paid caregivers). It was a bad way to go, with much pain, suffering, and expense for her and our family. There were too many barriers to getting the care she needed. Medicare pays for all types of care that is unbeneficial (911 trips to the hospital, certain tests, treatments, medications, surgeries, and skilled nursing home stays for rehab, etc.). But it will not pay for the care people actually need during chronic, progressive illness—custodial care, comfort care, nursing care. We need to fix this.”

This testimony is an example of a real problem that families of people at the end of their life face every day. When palliative care for those with advanced chronic illness is not affordable because insurance does not cover it and/or is not accessible because physicians do not discuss the patient’s options, there is a major financial and emotional strain on families and caregivers. Certifying six months or less to live is difficult for physicians since every illness progresses in different ways and over various lengths of time. Furthermore, Riley (2010) found that 25 percent of the Medicare budget is spent on care during the last year of life, which indicates large amounts of money is being spent on life-saving treatments which may or may not be desired by the patient or family. Often times in hospitals, the default is to treat and perform intensive procedures in attempts to prevent the death of a patient. With advanced care planning and integration of a palliative care team, patients can decide how much treatment they want and at what point they prefer to opt out of treatment. Promoting policy solutions to address this problem is essential to reducing EOL spending and improving quality of care for the aging population.

Promoting the policy solution

As mentioned above, Medicare beneficiaries who have Medicare Part A should be eligible for hospice benefits if they are certified by a physician as having an advanced or late-stage, progressive or degenerative chronic illness. Medicare should also compensate physicians or interdisciplinary teams for conducting advanced care planning with patients. In order to advance the policy recommendation for CMS to revise the hospice benefit and payment system, the MEDPAC commissioners must first vote on the MEDPAC recommendations. The Commission chairman, Glenn Hackbarth, and the vice chairman, Michael Chernew, may have influence over the opinions of the Commission's 17 members.

Once MEDPAC publishes a recommendation, a representative should introduce a bill to Congress that addresses modifications to the Medicare hospice benefits. The bill should be introduced during a lame duck period between November and the inauguration of officials early the next year, and with little fanfare in order to achieve bipartisan support. According to Mitchell & Washington (2014), members of Congress are three to four percent less likely to vote along party lines during lame duck sessions and more likely to vote for general interest. The MEDPAC recommendations will serve as strong evidence for support of the bill. Building political support among stakeholders and advocates is monumental for pushing the policy solution forward.

Building political will

Key health advocates can play an important role in promoting the bill and building political support. Organizations such as the Robert Wood Johnson Foundation, American Medical Association, AARP, the Center to Advance Palliative Care (CAPC) and the National Hospice and Palliative Care Organization (NHPCO) should provide leadership in making the

case to update the hospice payment system to Rep. Kevin Brady, the chairman of the House Committee on Ways and Means Subcommittee on Health. Part of the rationale for proposed changes was recently stated by Alice Rivlin, an economist and former U.S. Federal Reserve official in her May 2013 testimony before the House Committee on Ways and Means Subcommittee on Health. Ms. Rivlin stated:

“Why reform Medicare? The main reason for reforming Medicare is not that the program is the principal driver of future federal spending increases, although it is. The main reason is not that Medicare beneficiaries could be receiving much better coordinated and more effective care, although they could. The most important reason is that Medicare is big enough to move the whole American health delivery system away from fee-for-service reimbursement, which rewards volume of services, toward new delivery structures, which reward quality and value. Medicare can lead a revolution in health care delivery that will give all Americans better health care at sustainable cost (Rivlin, 2013)”

Rivlin’s testimony adds support to the effort to modify the Medicare hospice benefit to provide better care options to those with chronic disease. Other federal partners that may support the bill include the Administration of Aging, the Agency for Health Resources and Quality, and the Senate Commission on Long-Term Care, which issued detailed recommendations on the ways to strengthen supports for family caregivers. Advocates of passing legislation should lobby representatives in the House Committee on Ways and Means Subcommittee on Health months prior to the introduction of the bill so that once a policy window opens, swift action can be taken to introduce and pass the bill.

PROMOTING TRAINING & CREDENTIALING

Advocating for enhanced training and credentialing of physicians on palliative care, EOL care, and advanced care planning involves many stakeholders. The Accreditation Council on Graduate Medical Education needs to require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness (including primary care clinicians). For this to happen, there needs to be support from the following member organizations: the American Board of Medical Specialist, American Hospital Association, American Medical Association, Association of American Medical Colleges, and the Council of Medical Specialty Societies. The Liaison Committee on Medical Education requires accredited U.S. medical schools to teach EOL care but the requirement is vague and does not specifically mention palliative care and is not rigorously enforced through specific standards (IOM, 2014). Directors of the major medical associations need to urge the committee to clarify and specify this accreditation requirement.

Other stakeholders include the American Board of Hospice and Palliative Medicine which certifies physicians seeking to demonstrate competence in the palliative care field. Questions on EOL and palliative care need to be included on the U.S. Medical Licensing Examination which is a professional exam sponsored by the Federation of State Medical Boards (FSMB) and the National Board of Medical Examiners (NBME). Top leaders from CAPC and the NHPCO need to meet with the heads of FSMB and NBME to emphasize the importance of testing students on these healthcare issues.

Furthermore, Schools of Public Health should include EOL care in public health courses which can help lead future health care administrators and policy makers to incorporate principles of palliative care into health care systems. It is important to promote cross-collaboration and

coordination among the various educational institutions, credentialing bodies and accrediting boards to ensure a cohesive and integrated approach to improving palliative care knowledge among health professionals.

CONCLUSION

As the U.S. population continues to get older and suffer from multiple chronic conditions, millions of people are going to require long-term care. Palliative care provides important physical, psychosocial, and spiritual services, as well as pain management, to provide comfort and quality of life to those at the end of their life or continuing curative treatment. Most people, when given an option, would choose to receive palliative or EOL care in the familial surroundings of their own home. In the next decades, palliative care is going to grow substantially in the United States. Healthcare spending is also going to continue to increase among the elderly and sick. Ensuring affordable and timely home-based palliative care to this population is a critical step in reducing healthcare costs and improving quality of life.

Research shows that home-based palliative care is clinically effective, cost-effective and increases patient and family satisfaction. Recommendations that will help remove barriers to care include revising the Medicare hospice benefit to have less restrictive eligibility for home-based care, providing incentives to healthcare providers for discussing and integrating palliative care, and systematically training and educating health professionals on palliative care issues. There are successful programs and models that public and private healthcare systems can model their own programs after, document the results, and build the evidence base for home-based palliative care.

The adoption of recommended policies will require a well-planned advocacy strategy that engages key stakeholders and target key constituencies and policymakers. As noted above, this strategy should include an established policy framework that is focused on communicating the problem effectively, promoting thoughtful and impactful policy solutions, and implementing approaches to build political will. It is imperative that improvements in quality of palliative care

and access to care are made so that all Americans, regardless of their financial status or medical prognosis, receive the highest quality care possible.

LIMITATIONS

While this article describes important information related to the clinical effectiveness, cost-effectiveness and quality of life through home-based palliative care, there are a few limitations that are important to address. Many of the articles lacked the strength of a randomized control design and also lacked generalizability due to the specific settings where each study took place. Additional research should be done with a strong study design to further compare home-based palliative care and non-home based palliative care in the United States. More research should also be done to compare different models of home-palliative care and determine which ones work most effectively and efficiently.

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APPENDIX: Policy Brief

Addressing End-of-Life Care in America: The Opportunity for Home-Based Palliative Care

The problem of America's aging population and end-of-life care

By 2050, 27 million people will need some type of long-term care service, most of whom will have multiple chronic diseases (Giovanni, 2012). Longer life spans and aging baby boomers will double the population of Americans aged 65 years or older during the next 25 years to about 72 million (CDC, 2013). Since two out of every three older Americans have multiple chronic conditions, long-term care and end-of-life (EOL) care is going to continue growing as a significant healthcare burden (CDC, 2013).

Treating patients with advanced illness at the end of life is costly and complex. Palliative care, particularly home-based palliative care, can help to reduce healthcare costs at the end of life. Palliative care is not solely for those who are dying, but for anyone whose goals are to alleviate suffering and improve their quality of life, including those at the end of their life. Currently, Medicare beneficiaries must choose between receiving treatment and receiving palliative care. Therefore many people who could benefit from quality palliative care are not receiving it due to choosing treatment. The need for palliative care is going to grow substantially in the next decades and there is a major opportunity for palliative services in the United States to be offered in the patient's home. Palliative care is an essential service that should be accessible and affordable to anyone who needs pain management and supportive care while living with chronic conditions or other debilitating diseases.

Benefits of home-based palliative care

Evidence shows that home-based palliative care compared to palliative care in other environments may result in fewer hospitalizations, fewer hospital days, fewer ED visits, and fewer physician office visits (Lukas et. al. 2013, Brumley et. al. 2003 & 2007, Alonso-Babarro et. al. 2013). Home-based palliative care also reduces the likelihood of readmission to a hospital within 30 days (Ranganathan et. al. 2013) and increases the likelihood of completing an advanced directive (Kerr et. al. 2014). Completing advanced directives improves the chance that patients will receive life-saving care, or not receive care if desired, in times when they are unable to speak for themselves.

Home-based palliative care has shown to be cost-effective and result in lowered spending at a healthcare system and an individual level (Lukas et. al 2013, Hughes & Smith 2014, Morrison et. al. 2008, Brumley et. al. 2003 & 2007, Guerriere et. al. 2010, Klinger et. al. 2013). Patients in home-based palliative care are more likely to die in their own home, which is the preference for a majority of people (Brumley et. al. 2003 & 2007, Alonso-Babarro et. al. 2013, Shepperd et. al. 2011, Gomes et. al., 2013). Furthermore, home-based care patients and their families report high levels of quality of life and satisfaction with their care (Brumley et. al. 2003 & 2007, Miyashita et. al. 2008, Guerriere et. al. 2013, Thomas et. al. 2010).

Barriers to home-based palliative care

Many barriers prevent affordable and timely access to palliative care. A primary obstacle is the financial burden for patients since many insurers, public and private, do not cover home-based palliative care. For instance, Medicare, one of the nation's largest health insurers, only provides the hospice benefit as an EOL option for patients. The current Medicare hospice benefit only covers palliative and support services for patients designated to have a terminal illness and a life expectancy of six months or less (CMS, 2013). By electing to receive the benefit, patients forfeit any conventional treatment for the condition. This may feel to the patient that they are "giving up" or resigning themselves to death.

A barrier related to getting timely access to palliative care is physicians and other healthcare staff not initiating conversations around palliative care or EOL issues. This may be due to the lack of incentives offered to healthcare professionals to initiate EOL conversations and a lack of education around palliative care and when to discuss the topic. Doctors may feel that they do not have enough time, resources, or knowledge to have these types of discussions with their patients and therefore do not initiate the conversation until it is too late to have any valuable impact.

Recommendations to limit barriers

1. Medicare benefit should include home-based palliative care without the requirement to forego treatment

Medicare should cover home-based palliative care similarly to the way Medicare covers hospice benefits but without the requirement to be terminally ill, have six months or less to live, and to forego treatment. Palliative care should be available for those patients who wish to receive care at home, but may also want to continue getting life-saving treatment. The current Medicare hospice model does not address patients with multiple chronic conditions and ambiguous prognoses. Providing palliative care earlier in the course of disease leads to better health outcomes, higher satisfaction with care and reductions in healthcare costs (California HealthCare Foundation, 2013). There is also considerable value in the simultaneous delivery of palliative and curative care.

If Medicare included a benefit for home-based palliative care that did not require terminal illness and the choice to forego treatment, many more people would benefit from improved quality of life through palliative care and healthcare costs may be reduced. Medicare is already spending about \$15 billion on hospice a year and 34.5 percent of the hospice patients receive a week or less of care (NHPCO, 2015). If home-based palliative care was offered to those same patients earlier in their illness trajectory, costs could potentially be avoided by reducing unnecessary care and managing high-need, "at risk" patients.

2. Compensation to healthcare providers for discussing and integrating palliative care

The 2014 Institute of Medicine report, “Dying in America,” was released by a committee of 21 experts that calls the U.S. EOL care system, a large part of which is palliative care, “broken” and recommends several ways to improve care. One of the recommendations is reimbursing providers to discuss palliative care and advance planning with their patients. Incentives under fee-for-service Medicare result in increased use of medical services and late enrollment in hospice, which can jeopardize the quality of EOL care and add to costs. Incentivizing provisions of comprehensive palliative care and discouraging the use of costly and unnecessary medical procedures can improve patient outcomes and reduce healthcare costs (IOM, 2014).

The 2013 MEDPAC report also recommends a Medicare payment to compensate physicians or interdisciplinary teams for voluntary advanced care planning. Providing compensation to physicians and other healthcare providers for discussing palliative care options and coordinating care would increase the number of patients who understand their care and treatment options. Over time, the savings to Medicare due to reduced unnecessary spending would help offset the cost of Medicare-financed incentives to healthcare providers. Federal or state governments could subsidize incentives for private practice physicians contingent on meeting quality standards.

3. Better training for health professionals on palliative care topics

There needs to be improved training of health professionals on issues like patient-centered care and palliative care as a longer term approach in improving care for patients with advanced illness. According to the 2014 MEDPAC report, very short hospice stays are still common which indicates that patients enter hospice in the last week or so of their life, unable to receive the full benefit of palliative care. This may be due to physicians’ reluctance to have conversations about hospice or death, difficulty in some patients and families to accept death, and financial incentives in the fee-for-service system which value volume over quality (MEDPAC, 2014). The IOM report (2014) recommends improving palliative care training among all physicians. Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies and healthcare delivery organizations should establish appropriate training, certification and licensure requirements to strengthen palliative care knowledge and skills of all physicians who care for patients with advanced illness (IOM, 2014). Training of healthcare professionals needs to emphasize high-quality care and comfort of the patient, including home-based palliative care options and advanced care planning. Acknowledging advanced illness and mortality provides an opportunity to deliver high standards of care, grounded in choice and responsiveness to needs for both the patient and their family.

When palliative care is taught, results can be impressive. A systematic review by Bickel-Swenson (2007) found that EOL educational curricula and clinical training found in a wide range of formats improved the competency of medical students. Authors found a 23 percent improvement in knowledge, a 56 percent improvement in feelings of competence, and a 29 percent decrease in concerns. George Washington University includes a standardized patient case

on palliative care and a course on medical interviewing and decision making. The University of Rochester includes content on advance care planning, chronic pain management, and discussion of treatment goals. The Association of American Medical Colleges is in collaboration with the Coalition to Transform Advanced Care to identify relevant core competencies.

The time to act is now

The aging of the American population is quickly expanding the healthcare burden, in large part by the 66 percent of older adults who have multiple chronic conditions. Treating advanced illness and chronic conditions in the older population is complex and expensive. Medicare spending is expected to increase from \$555 billion in 2011 to \$903 billion in 2020. As the U.S. healthcare system struggles to keep up with the demand for care, there will be an increasing need for high-quality palliative care in all settings, but particularly home-based settings. Patients and their families should have the choice to use home-based palliative care when it is available, without the burden of financial or accessibility barriers. Providing this home-based option will greatly alleviate the strain on inpatient settings and will reduce hospital and patient costs. An approach toward high-quality care and coordination and away from over-treating or inappropriately treating patients will improve quality of life as well as reduce unnecessary medical costs. It is imperative that improvements in quality of palliative care and access to care are made so that all Americans, regardless of their financial status or medical prognosis, receive the highest quality care possible.