Integrating Palliative Care in Medicaid Primary Care in North Carolina: An Educational and Quality Improvement Initiative

By

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INTRODUCTION

Palliative and hospice care services aim to improve the quality of life for patients with serious and/or life-threatening illness by promoting autonomy, eliciting goals of care, optimizing symptom management, and facilitating communication in accordance with individual’s experiences, values, goals, and cultural practices.\(^1\) Inpatient palliative care (PC) programs are rapidly expanding within our nation’s hospitals to provide support with symptom management and complex medical decision-making for patients hospitalized with serious illness.\(^2\) While these inpatient consultation programs have demonstrated reduced symptom distress, lower rates of inpatient death, higher levels of satisfaction with care, and reduced costs, these services often target patients in the acute hospital setting with advanced disease and uncontrolled symptoms.\(^2,3\)

Although they are beneficial, hospital-based PC services are unlikely to meet the growing needs of patients who may be living in the community with serious progressive illnesses and unmet symptoms. This creates disparities in access to high quality care across the continuum. Team-based, inter-professional care models may provide an essential framework to promote patient and population-centered care. Such models can contribute to reliable, timely, cost-effective, and efficient systems of health care delivery while achieving measurable, high quality outcomes as defined by the National Quality Forum (Department of Health and Human Services).

Community Care of North Carolina (CCNC) provides medical homes to 1.1 million individuals in the state of North Carolina and strives to address quality, cost, access, and optimal health care utilization. CCNC is organized as regional non-profit primary care practice networks operated by community physicians, hospitals, health departments, and social services. This well-
resourced network developed and evaluated a systems intervention with educational and quality improvement components to integrate palliative care concepts into care management services to improve access to palliative care and hospice services for Medicaid patients.

This paper aims to evaluate CCNC’s statewide quality improvement and educational intervention and its outcomes in the context of relevant background information to improve the delivery of PC and hospice services to community-based individuals by utilizing skilled care managers (CM). This paper submission is an expansion of a manuscript that has been submitted for publication and is under review. This paper submission systematically reviews programs employing skilled CM in the outpatient setting to promote access to PC and hospice and describes the key educational and quality improvement components of CNCC’s statewide intervention. It includes an expanded review of various program components and additional details about the project intervention. This paper is designed to share the innovative and progressive work being done by Community Care of North Carolina and other programs identified in the literature that will promote future academic, community-based intervention research to facilitate collaborative inter-professional, team-based work and the improvement patient and population-centered health outcomes for patients with life-limiting illness who are living in the community.
Integrating Palliative Care in Medicaid Primary Care

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Running title: Integrating palliative care in Medicaid primary care
Abstract

**Background:** Hospice and palliative care (PC) remain underutilized by Medicaid patients.

**Objective:** To evaluate an intervention to improve communication about advance care planning (ACP) and symptom distress, and facilitate referral to PC and hospice.

**Setting:** Statewide Medicaid primary care network.

**Subjects:** 510 Medicaid care managers (CM)

**Measurements:** PC experts collaborated with leaders in a statewide primary care network on a quality improvement intervention. Training components included education and engagement with local hospice and PC providers. Quality improvement components included feedback of quality measures and a practice toolkit. Evaluation used participant surveys and tracking of key quality measures: 1) percent of at-risk subset of aged, blind, and disabled (ABD) Medicaid patients asked about ACP or symptom distress, 2) cumulative number of ABD Medicaid PC or hospice referrals, and 3) the percent of all non-dual ABD Medicaid decedents enrolled in hospice.

**Results:** After training, CM identified the following areas for expected practice change: ACP (29%); identifying/referring patients for hospice or PC (25%); supporting patients and families (21%); toolkit utilization (10%); and engaging medical providers (10%). Over one year follow-up the percent of moderate and high risk ABD Medicaid patients asked about ACP or symptoms increased from 7% to 31% and 8% to 41%, respectively (p<0.001). The cumulative number of PC or hospice referrals increased from 8 to 155. Hospice enrollment at death was unchanged (29% to 30%, p=NS).

**Conclusions:** A statewide intervention targeting CM in a Medicaid primary care practice network is effective to increase communication and hospice and PC referrals; longer follow-up may be required to determine effect on hospice use.
Introduction

Despite the growing availability of hospice and PC programs, these services remain underutilized by low income patients. In the largest population-based study in the United States, a secondary analysis of the Health and Retirement Study, poverty was associated with greater pain severity, with a trend toward similar patterns for depression and dyspnea. Disparities in access to PC worsen symptom burden and reduce quality of life at end of life. Conversely, better access to PC for Medicaid patients leads to lower likelihood of dying in intensive care, increased care consistent with preferences, increased hospice use, and significant healthcare cost reductions.

Barriers to utilization of hospice and PC among economically vulnerable populations include medical co-morbidities, financial limitations, language, and/or cultural barriers. Weak and fragmented systems of care also make accessing services more difficult. No reliable systems exist to identify and refer seriously ill Medicaid patients; however preliminary evidence supports using care managers (CM) in primary care to extend hospice and PC services.

North Carolina has a well-established statewide network of primary care practices augmented by care management to serve Medicaid patients with chronic illness. The objective of this project was to develop and evaluate a systems intervention in this network, in order to improve communication about advance care planning and symptom distress and facilitate referral to palliative care and hospice services. Specific aims were 1) to deliver statewide training on topics in advance care planning, hospice and palliative care to all Care Managers, 2) to implement a palliative care quality improvement toolkit, and 3) to link Care Managers to regional hospice, palliative and supportive care resources for the patients they serve.
Methods

Educational components of this intervention included didactic and interactive sessions for CM to engage with local hospice and PC experts. Quality improvement components included feedback of practice-specific quality measures and a toolkit for practice change. The intervention was evaluated with CM surveys and assessment of key quality measures around ACP and symptom management, PC/hospice referral, and hospice status at the end of life for aged, blind, and disabled (ABD) patients, who experience most hospitalizations and over 75% of deaths in the Medicaid population. During the study period, ABD patients made up 18% of the CCNC-enrolled population.

Funding was provided by North Carolina Community Care Networks, Inc. in a contractual agreement with the University of North Carolina-School of Medicine. UNC Institutional Review Board determined this study was exempt from further review.

Setting:

Community Care of North Carolina (CCNC) is a clinical partnership between the NC Department of Health and Human Services and health care providers for Medicaid patients. CCNC is organized as regional non-profit primary care practice networks operated by community physicians, hospitals, health departments, and social services. CCNC provides medical homes to 1.1 million individuals and includes 4,500 local primary care physicians.

Participants

The intervention targeted 510 CM serving seriously ill Medicaid patients in North Carolina. CM are largely registered nurses with some master’s level social workers.
Timeframe

The educational component of this intervention was administered from October 2010-February 2011. Performance data collection and feedback occurred through September 2011.

Developing the Intervention

The CCNC PC initiative emerged as a natural outgrowth of the chronic care and transitional care management programs. Existing care management was focused on medication review and teaching for specific chronic illnesses. This service model poorly suited seriously ill patients with functional decline, multiple diagnoses, and frequent hospitalizations, thereby warranting a new paradigm.

The intervention was developed by PC experts, with input from CCNC primary care physicians, CM, nurses, social workers, physical therapists, and community advocates. Stakeholder input was obtained by surveys of clinical leadership in the 14 regional networks. Surveys were delivered to the network directors, clinical directors, and lead CM; these leaders were charged with providing a unified response to survey items for the providers in their network. Respondents indicated a need for improved training of CM in the principles of ACP communication, symptom assessment, and access to regional resources providing palliative care and hospice.

Survey data provided the framework for development of 7 questions on ACP and symptom distress which were then embedded in the electronic clinical record used by Care Managers. The questions were designed to promote opening conversations with ABD Medicaid patients identified as high risk for repeated hospitalization or death.
Education

Educational components of the intervention were delivered in a 1-day conference, repeated in 9 geographic sites. Sessions included intellectual and affective training delivered in large group lectures and small group interactive exercises (Table 1). Content included: 1) ACP; 2) palliative care and hospice services; 3) grief, loss and the role of supportive care; and 4) practice change strategies for quality improvement. All didactic modules were followed by interactive group role play activities facilitated by local experts. Training included use of the 7 PC questions to open dialogue about ACP or symptom distress. During small group exercises CMs practiced facilitating ACP discussions and symptom assessment (Table 2). CMs were encouraged to engage and support patients with serious illness in the process of ACP, and to refer patients for symptom management and supportive care.

Quality Improvement Elements

Regional network leaders identified primary care physician champions. Each network was given resources to hire a coordinating CM, and encouraged to recruit someone with hospice and PC skills; 9 of 14 networks successfully recruited a coordinator with this background to support their cadre of CMs. During the educational conference, all CM received feedback of baseline data on two key quality indicators for PC and hospice: 1) percent of at-risk ABD Medicaid patients asked at least one PC question about ACP or symptom distress, as documented in the care management information system, and 2) the percent of all non-dual ABD Medicaid patients enrolled in hospice care within 90 days of death. They met regional hospice and PC providers who facilitated small group exercises during the conference, and received toolkits to promote patient engagement, communication, and referrals to hospice, palliative and supportive
care resources in their region. The toolkit included a resource guide with region-specific referral information for hospice agencies and inpatient facilities, pain management clinics, PC and supportive care services, community coalitions, services for pediatric and aging populations, as well as national website listings for ACP, and hospice and PC. The toolkit included copies of educational materials for patients and families, the Edmonton Symptom Assessment Scale, and state-approved forms for portable DNR order, Medical Orders for Scope of Treatment (MOST) portable order set, living will, and health care power of attorney (HCPOA).

Following training, network physician champions and coordinators met monthly to share best practices and discuss and practice improvements. They received network-specific quality measure data feedback each quarter sjaromg this data with all CM. They encouraged cultivation of local experts in hospice and PC, and pathways for efficient referrals and access to care.

**Outcome Measures: Evaluation of Training**

To evaluate the educational components of the intervention, CM provided survey feedback to three questions following each training conference: 1) identify any content you feel should have been included or expanded; 2) identify three best educational components; and 3) things you expect to change in your practice as a result of this training. Responses from all participants were grouped, and content coded and categorized to summarize responses. Responses were reported based on the total number of responses for each categorical group.

**Outcome Measures: Practice Quality Improvement**

To evaluate the practice change outcomes of the overall intervention, investigators tracked three key quality measures using quarterly analysis of the electronic care manager
clinical records and North Carolina Medicaid data: 1) percent of a subgroup of ABD Medicaid patients at increased risk for death who were asked at least one PC question about ACP or symptom distress, 2) cumulative number of all ABD Medicaid patients referred to PC or hospice services, and 3) the percent of all non-dual ABD Medicaid patients enrolled in hospice within 90 days of death. All analyses were done with the assistance of the NC Community Care Networks Analytics Team.

Data for the first two quality measures was derived as documented in the electronic care management information system (CMIS), while data for the third quality measure was generated in pre-specified quarterly analyses from the North Carolina Medicaid administrative dataset. Denominator populations for all quality measures were adjusted quarterly for changes in patient enrollment.

To measure the first quality indicator, the at-risk subgroup of the ABD population was defined as those ABD Medicaid patients with moderate risk and high risk for acute complications and death, and who therefore had potential need for PC or hospice. Moderate risk patients were defined as the ABD Medicaid patients who within the past 12 months had a Medicaid claim with at least one ICD-9 Code indicating major chronic illness, and who demonstrated significant acute healthcare utilization (Table 3). High risk ABD Medicaid patients were defined by greater severity of disease and higher acute care utilization. Qualifying ICD-9 diagnoses (available upon request) were derived with minor modifications from the codes listed in the PC and End of Life Physician Performance Measurement Set, approved in 2008 by the Physician Consortium for Performance Improvement, NCQA, and included codes for cancer, cerebrovascular diseases, congestive heart failure, chronic gastrointestinal, liver, pulmonary or
renal disease, and major psychiatric diagnoses (NCQA). Patients in these at-risk subgroups met the first quality indicator if at any time during follow-up they were asked at least one of the key PC questions when assessed by a care manager. The second quality indicator was defined as the cumulative number of all ABD Medicaid patients referred to any hospice or PC service during each quarter of the follow-up period as documented in the CMIS. The third quality indicator was calculated as the percent of all ABD non-dual Medicaid patients who died and who enrolled in hospice care within 90 days of death. Chi-square tests were used to compare the percent of patients meeting the first and third quality indicators at baseline and 1 year later; statistical testing was not used for the second quality indicator, which is a simple cumulative count of referrals.

Results

Evaluation of Training

Of 510 CM in CCNC, 495 CM participated in training and 471 (95%) responded to the evaluation survey. CM offered a total of 1547 written responses evaluating the educational components of the intervention. All responses were categorized and reported based on the total number of responses for each category. Overall responses were largely positive with statements including “the course was very well done – one of the best that CCNC has done” and “outstanding”. Participants described the best educational course components of the training in 638 responses. They praised training on supporting patients and families (23%), the use of role play and small group exercises (21%), information on hospice and PC (14%), facilitator engagement with learners (12%), information on ACP and goals of care (11%), the toolkit (8%), overall content and experience (6%), and help putting learning into action (4%).
Expected practice change (Table 4) based on this training included 471 responses. Participants anticipated taking a more active role in the ACP process (29%), identifying patients for discussion of hospice or PC and making the referral (25%), supporting patients and their families (21%), using the practice toolkit (10%), and educating other providers (10%).

CM responses to the post-training survey also highlighted potential barriers to successful practice. Recurring themes included the need for more guidance about how to educate and collaborate with treating physicians, the need for additional information regarding cost and reimbursement as these relate to Medicaid patients and uninsured, and the need for more information about culture, religion, and specific patient populations including children and persons with mental health needs.

Quality Improvement Outcomes

Evaluation of CM change in baseline practices from September 2010 to September 2011 demonstrated a significant increase in the percent of at-risk subset of ABD Medicaid patients asked at least one PC question (Figure 1). Communication about palliative care increased for the moderate risk subgroup from 7% (718 of 10,457) to 31% (3,435 of 11,137) and for the high risk subgroup from 8% (209 of 2,732) to 41% (1,559 of 3,823). The cumulative number of PC and hospice referrals for all ABD Medicaid patients increased from 8 to 155, representing new referrals for a total of 124 patients (Figure 2). The total number of referrals exceeded the number of patients, since some patients were referred to more than one type of service. The percent of all ABD non-dual Medicaid patients enrolled in hospice care within 90 days of death showed little change over time, from a baseline rate of 29% (545/1,871) to 30% (642/2,108) in the final quarter (p=NS) (Figure 3).
Discussion

This study demonstrates an educational and quality improvement initiative targeting CM in a statewide primary care practice network is effective to enhance CM communication about ACP and symptom distress, and to increase PC and hospice referrals for seriously ill Medicaid patients. CMs were motivated to make practice changes in ACP, hospice and PC referrals, and supportive care for patients and families. Quality indicator data provides evidence of actual practice change, with increases in care manager-patient communication with a subgroup of higher risk patients, and new referrals to hospice and PC services.

Surprisingly, this increase in referral to services had no clear effect on the percent of all non-dual ABD Medicaid patients enrolled in hospice within 90 days of death. The lack of effect on hospice use at death has several potential explanations. First, communication and referrals precede hospice use at the time of death. Many patients represented in the first 2 quality measures are still living at the time of analysis, and longer follow-up may be needed to show change in hospice use at death. Second, the growth in communication and new referrals may yet be too small, relative to the size of the population at risk, to affect the overall percentage of ABD Medicaid patients who enrolled in hospice. Finally, inability to eliminate financial limitations, language, and/or cultural barriers may have also contributed to a lack of observed change in hospice utilization at death. CCNC analysts continue to track all of these quality measures quarterly, to test whether hospice use at death is changing over the longer term.

This intervention aimed to improve care for seriously ill vulnerable patients through the integration of CM expertise with community resources and providers in a statewide primary care practice network serving Medicaid patients. The results of this study build upon the findings of a
small number of prior studies demonstrating successful integration of PC and hospice services through community-based initiatives targeting CM for seriously patients. Specifically, an industry/academic collaborative initiative by Meier et al (2004) led to the development of a CM program serving seriously ill, commercially-insured patients with complex needs, independent of prognosis. This program aimed to identify unmet symptom needs, to support complex decision making and ACP, and to effectively engage medical providers. This initiative was followed by the Caring Connections Project by Pfeifer et al (2006) which demonstrated care manager-targeted educational interventions contribute to improved access to PC for community-based Medicaid patients with advanced cancer but was limited by small sample size, lower than expected referral rate from community providers, and lack of inclusion of other serious or life-limiting illnesses beyond cancer. Head et al (2010) further demonstrated trained care management teams are effective in enhancing access to PC and hospice services for seriously ill Medicaid patients identified on the basis of diagnostic and utilization criteria. However, this project only targeted a subgroup of CM serving seriously ill Medicaid patients with a limited number of CM completing the educational training (N=15).

Attention to study limitations is warranted, to place the results in perspective. First, the analysis of actual hospice use at the time of death was limited to the subset of 57% of North Carolina Medicaid enrollees who have Medicaid as their sole insurer; data for patients dually enrolled in Medicare and Medicaid was not available to investigators. Medicare patients use hospice at a higher rate, and thus the hospice use data may be an underestimate. Second, the study implemented a complex intervention in a unique primary care practice network. CCNC is an innovative model of care that has long been established, and the organization’s PC initiative is continuing to add new elements over time. As a result, precise replication of this intervention
outside this well-resourced and efficient practice network may be challenging. Finally, investigators were unable to use patient or family-centered outcomes such as satisfaction with care or symptoms. Careful consideration and analysis of patient-centered outcomes are essential in future research to ensure changes in healthcare delivery are well-matched to the needs and preferences of patients with serious illness and their families.

Integrating CM in the delivery of clinical services to chronically ill patients is an increasingly common approach and elements of this intervention may be replicated in other primary or specialty care practices that encompass an interdisciplinary approach to care. This model program demonstrated an effective statewide intervention to provide CM in a primary care practice network with the knowledge, skills, and community resources to improve communication about ACP and symptom distress, and increase referrals to hospice and PC for seriously ill Medicaid patients. These results are promising and may guide future community-based interventions to facilitate access to collaborative primary and PC experts for vulnerable populations. Future intervention research should assess the effect of increased conversations and referrals on actual access to services. Also, quality improvement and intervention research components should expand on performance metrics to capture specific PC interventions effect on patient-centered outcomes, healthcare utilization, and cost. Creating more patient-centered systems of care can promote patient autonomy, improve quality of life, and lead to more effective utilization of health care resources for patients living with serious illness.
REFERENCES


Table 1: Curriculum to Engage CM as Palliative Care Communicators

<table>
<thead>
<tr>
<th>1. Introduction to Advance Care Planning and Palliative care</th>
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<tbody>
<tr>
<td>a. Introduction to quality of care in serious illness and the</td>
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<tr>
<td>growing need for patient advocacy, palliative care, and hospice</td>
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<tr>
<td>b. Identifying at-risk patients</td>
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<tr>
<td>c. Feedback of quality measure data on baseline practices</td>
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<table>
<thead>
<tr>
<th>2. Module 1: Advance Care Planning and Goals of Care</th>
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<tr>
<td>a. Key components involved in the process of advance care</td>
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<tr>
<td>planning, how to engage in conversations about medical</td>
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<td>goals of care</td>
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<td>b. Focus on patient autonomy and the right to choose</td>
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<tr>
<td>different approaches to care in serious illness</td>
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<tr>
<td>c. Overview of primary documentation tools – living</td>
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<tr>
<td>wills, Health Care Powers of Attorney, portable DNR</td>
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<tr>
<td>orders, and portable MOST forms</td>
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<tr>
<td>PRACTICE: Role play patient interview</td>
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<tr>
<th>3. Module 2: Hospice and Palliative Care</th>
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<tbody>
<tr>
<td>a. Define hospice and eligibility criteria</td>
</tr>
<tr>
<td>b. Define palliative care and types of patients able to benefit from services</td>
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<tr>
<td>c. Explore approaches to address and overcome barriers</td>
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<tr>
<td>d. Communication strategies</td>
</tr>
<tr>
<td>PRACTICE: Problem-solving exercise on barriers to hospice or palliative care</td>
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<th>4. Module 3: Supporting Patients and Families through Serious Illness</th>
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<tbody>
<tr>
<td>a. Assist in the development of empathy and appreciation for unique</td>
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<tr>
<td>reaction and journey of the individual patient</td>
</tr>
<tr>
<td>b. Role of supportive care from family caregivers, volunteer</td>
</tr>
<tr>
<td>caregivers, community and neighbors, faith communities</td>
</tr>
<tr>
<td>PRACTICE: Grief and loss experiential exercise</td>
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<th>5. Module 4: Putting Palliative Care into Practice</th>
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<tr>
<td>a. Create individualized action plans</td>
</tr>
<tr>
<td>b. Identify opportunities and challenges for</td>
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<tr>
<td>implementing efforts</td>
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<tr>
<td>PRACTICE: Teamwork exercise to assess and respond to a patient’s story</td>
</tr>
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</table>
Table 2: Seven key palliative care questions

1. If you became seriously ill, how confident are you that you would be treated according to your wishes and values?
2. Do you have someone who can make health care decisions for you if you become unable to speak for yourself?
3. Do you have opinions about how you would want to be treated if you become seriously or terminally ill?
4. Are your opinions about how you would want to be treated understood by your primary care physician?
5. Have you put your opinions in writing?
6. Are you experiencing symptoms that affect the quality of daily life?
7. How confident are you that you know how to get help if symptoms worsen?

Table 3: At Risk Medicaid Population Stratified by Diagnostic and Utilization Criteria

<table>
<thead>
<tr>
<th>Moderate Risk</th>
<th>High Risk</th>
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<tbody>
<tr>
<td><strong>Patient has NCQA diagnosis PLUS 2 or more chronic conditions and meets 2 or more of the following criteria:</strong></td>
<td><strong>Patient has NCQA diagnosis PLUS meets 3 of the following 4 criteria:</strong></td>
</tr>
<tr>
<td>1 or more inpatient admissions (included acute, mental health, and long term care admissions), 3 or more ED visits, or 3 or more outpatient providers within the past 6 months</td>
<td>3 or more chronic conditions or top 10% of cost within the past 12 months</td>
</tr>
<tr>
<td>8 or more prescriptions over the past month or 24 over the past 3 months</td>
<td>More than 11 prescriptions in the past 1 month or 33 prescriptions in the past 3 months</td>
</tr>
<tr>
<td>No PCP visit within the past year</td>
<td><strong>OR</strong></td>
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<td></td>
<td>Dual Eligible</td>
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<td></td>
<td><strong>AND</strong></td>
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<tr>
<td></td>
<td>meets all 3 of the following criteria: 1 or more key target conditions (CHF, DM, IVD, Asthma or COPD), 1 or more inpatient admissions, and 2 or more ED visits within the past 6 months</td>
</tr>
</tbody>
</table>

NCQA=National Committee for Quality Assurance, PCP=primary care physician, CHF=congestive heart failure, DM=diabetes mellitus, IVD=ischemic vascular disease, COPD=chronic obstructive pulmonary disease.
Table 4: Care Manager Expected Practice Change after Education

<table>
<thead>
<tr>
<th>Things you expect to change in your practice as a result of this training (471 responses)</th>
</tr>
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<tbody>
<tr>
<td>• Active role in the ACP process, 135 (29%)</td>
</tr>
<tr>
<td>• Hospice/palliative care ID/referral, 120 (25%)</td>
</tr>
<tr>
<td>• Supporting patients and families, 101 (21%)</td>
</tr>
<tr>
<td>• Toolkit utilization, 49 (10%)</td>
</tr>
<tr>
<td>• Engaging providers/medical community, 47 (10%)</td>
</tr>
<tr>
<td>• Asking 7 key palliative care questions, 19 (4%)</td>
</tr>
</tbody>
</table>

Figure 1: Cumulative percent of at-risk Medicaid patients asked at least one palliative care question by a care manager

*Denominator population size ranged from 10,457 to 11,137 for the moderate risk subgroup and 2,732 to 3,823 for the high risk subgroup for the included quarters;

P<0.001 for comparison of rate of use of palliative care questions in 09/2010 vs. 09/2011
Figure 2: Cumulative Number of ABD Medicaid Patients and Number of Referrals to Palliative or Hospice Care*

*Cumulative referrals to hospice and PC increased from 4 to 155 while the number of patients referred increased from 4 to 124 for the included quarters

Figure 3: Percent of all Non-Dual ABD Medicaid patients enrolled in hospice within 90 days of death*

*Denominator population ranged from 1,871 to 2,108 for the included quarters; p=NS for comparison of percent enrolled 09/2010 to 09/2011.
APPENDIX 1: SYSTEMATIC REVIEW

Introduction

The purpose of this literature review is to identify programs utilizing skilled care managers (CM) to improve communication about advance care planning (ACP), symptom assessment and management, and to increase access to hospice and palliative care (PC) services for community-based populations with life-limiting illness. The identified programs share some combination of the following characteristics:


2. Intervention: utilization of skilled CM to improve communication about and access to ACP, symptom assessment and management, support with complex decision-making, and appropriate referrals to PC and hospice.

3. Outcomes: improved communication about ACP and appropriate completion of advance directives, increased symptom assessment, reduced symptom burden, improved quality of life (QOL), increased transitions to hospice, cost analysis, health care utilization.

Methods

Research Question: I conducted this literature review with the intention of answering the following research question: What can be learned from existing programs in which successful implementation of skilled CM in the community improves communication about ACP, symptom distress, and access to hospice and PC services and how can this knowledge be applied to the Community Care of North Carolina (CCNC) PC initiative?
Search Strategy: I conducted a literature review using PubMed to identify articles describing representative programs as outlined above. My search included the terms “Care Management” [MeSH] or “Case Management” [MeSH] AND “Medicaid” [MeSH] AND “Palliative Care/Hospice” [MeSH]. I used these same terms when searching Google Scholar. In addition to performing these searches, I additionally performed hand searches of identified article reference lists as well as associated article lists in PubMed. The PubMed search identified 48 articles. The other methods described above identified 11 additional articles. In consideration of articles describing representative programs, the following criteria were used to narrow the search:

1. The article is English.
2. The article is available in full text format.
3. The article describes a program that aimed at increasing accesscommunity-based palliative care by integrating palliative care principles into care management practices. This includes previous (limit 20 years) or current programs, pilot projects, demonstration projects, clinical trials, or randomized controlled trials.
4. The program shares one or more central elements with a specific focus on care management practices in the community setting to improve communication about ACP, symptom assessment, quality of life, appropriate transitions to hospice, explore impact on health care utilization and costs.

After reviewing 59 article titles, abstracts, and texts based on the above characteristics a criteria, I narrowed the search to 17 articles. First, 42 articles were excluded because they did not include a specific program to integrate PC principles into CM practices. Following full-text review of the remaining 17 articles, I further narrowed the search to eight articles by excluding case studies.
(n=2), earlier pilot programs of subsequent studies with published results (n=3), non-community-based settings such as the hospital or emergency department (n=2), and programs specifically targeting pediatric populations (n=2). The eight articles selected and representative programs utilized CM with PC expertise to promote the delivery of PC in some capacity such as improved communication about ACP, symptom distress, and psychosocial issues, and facilitated appropriate transitions to hospice for community-based individuals. Some of these articles focused primarily on program components to varying degrees while others included program components and actual outcomes (i.e., symptom burden, QOL, transition to hospice, utilization of health care resources, and cost). These programs are summarized and evaluated below. Additionally, the important elements of these programs are highlighted in Table 1.

Summary of Programs


The PhoenixCare program was one of 22 projects funded by the Robert Wood Johnson Foundation to one of the largest community-based hospice providers in the country to promote exceptional care at the end-of-life (EOL) by utilizing CM to extend PC to chronically ill individuals; many of whom were Medicare or Medicaid eligible.¹ This program considered the rare integration of CM into community models to enhance the delivery of PC services. Participants (n=192) were enrolled between July 1, 1999 through March 31, 2001, had a diagnosis of class IIIIB or IV congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), were receiving active disease treatment from one of seven managed care
organizations and had a life expectancy of up to two years. All participants experienced limited activity due to disease severity, illness exacerbation requiring emergency department (ED), urgent care (UC), and hospital treatment within three months of enrollment, and had access to a home telephone and translator if non-English speaking.

This program aimed to understand the influence of intensive outpatient care management on the following key areas via telephone interviews at baseline and every three months: 1) self-management of illness and knowledge of resources; 2) preparation for EOL; 3) physical and mental functioning; and 4) utilization of medical services based on claims data. Participants were randomized in blocks of 30 to PhoenixCare (53%) and control (47%). The intervention included home-based services provided by registered nurse CM focused on disease and symptom management, patient and caregiver education, social and psychological support, and coordination of services with primary care physicians. CM received support from a medical director, social worker (SW), and pastoral counselor. Protocols addressed three phases of service delivery including initial admission and management of unstable patients followed by continued management of stable disease and support during periods of exacerbation.

The results of this intervention demonstrated significant improvement in participants’ disease self-management and awareness of community services at time zero (three month follow-up), and subsequent three month follow-up time periods. Specifically, PhoenixCare participants’ mean scores adjusted for initial status on a 4-point Likert Scale (where 1=mostly false and 4=mostly true) were higher for having received education about community resources at three months (1.80 to 2.57 vs. 1.76 to 2.02, p<0.05), knowledge of who to contact regarding medical
concerns at six months (1.57 to 2.63 vs. 1.76 to 2.19, p<0.05), and knowledge of how to handle medical emergencies at six months (3.51 to 3.90 vs. 3.52 to 3.51, p<0.05).

Outcomes at six months showed higher completion of living wills or advance directives among the PhoenixCare group participants compared with controls, increasing from 52% to 71% (p<0.05) in the intervention group. Additional outcomes at three and six months demonstrated that the PhoenixCare group participants reported initiating or resuming an activity they enjoyed in the preceding four weeks (34% to 49%, p<0.05 at three months and 45% at 6 months). Furthermore, COPD participants reported less distress on a five-point scale (where 1=not at all and 5=very much) compared to control subjects. This finding remained significant at three months (4.38 to 3.41, p<0.05) with a similar trend at six months (2.85).

Functional status outcomes showed physical functioning in the PhoenixCare group remained the same (CHF) or improved (COPD) comparing the trend in their slopes relative to controls (p<0.05). Similar patterns were observed for scores of general health (COPD and CHF) and vitality (COPD). There was no significant change in medical utilization outcomes compared to six months prior to study onset.

A significant strength of this study design was the randomized, controlled approach which the researchers employed in order to register and enroll participants in this study and to compare the outcomes and efficacy of the intervention against the standard of care. Significant strengths of the intervention included the evaluation of patient-centered outcomes (i.e., measures of symptom assessment, activity level, awareness of community resources, preparedness to address illness exacerbations and emergencies, and actual completion of living wills and advance
directives). These are important components in evaluating whether a program intervention not only transforms practices, but leads to measurable patient-centered outcomes.

An additional strength of this intervention included the utilization of CM to directly provide services extending beyond care coordination in the community and positively impacted clinical care and QOL within CM scope of practice. This represents an important shift in service delivery and care management for PC and Hospice patients which have far-reaching implications given the limited workforce in PC and hospice. Furthermore, the evaluation of this program included common measures of medical utilization, which are critical components in assessing the efficacy and potential impact of CM interventions on health systems.

Limitations of this study were the inclusion of patients who only had two chronic illnesses who may not have been too healthy to benefit from palliative care services or require hospice care. This was evidenced in that only one-third of the patients died or were referred to hospice in the first three months. Additionally, this study was limited by the lack of evidence-based data to prognosticate two-year life expectancy, which may have diluted the overall impact of the intervention due to non-equivalence in the life expectancy of the sample population. Further, the evaluation of this program was limited by the reliance on claims data which may not have fully reflected the complexity of each patient’s situation or their medical utilization as only ED visits were evaluated throughout this intervention. While the researchers had intended to assess hospital length of stay, hospital claims data was fraught with inconsistency and inaccuracy and it was difficult for the researchers to clearly differentiate between admit/discharge dates and provide any usable data. These limited measures may fail to adequately account for actual
medical utilization and for shifts in the costs of care (i.e., less ED visits, but more office visits) among this population.

**Allen, et al. (2012). The Promoting Effective Advance Care for Elders (PEACE)**

**Randomized Pilot Study: Theoretical Framework and Study Design.**

This pilot study was designed to determine the feasibility and effectiveness of a home-based interdisciplinary (IDT) care management intervention incorporating PC and geriatric medicine principles. This program’s focus on home-based care originated from the belief that the majority of individuals with chronic life-limiting illness reside in the home setting. The framework of this program is based on the investigators’ application of Wagner’s Chronic Care model suggesting health care delivery systems must improve organizational structure and information systems, the establishment of community networks and resources, and the implementation of efficacious systems to promote better self-management and evidence-based decision support in order to optimize care for patients with life-limiting illness.

This program’s referral source is new enrollees of PASSPORT, Ohio’s community-based, long-term care (LTC) Medicaid waiver program. The development and implementation of this comprehensive program was only made possible by the successful collaboration of PASSPORT with the Agency on Aging. Eligible individuals are low income, aged 60 or older, have Medicaid and possibly Medicare, are nursing home eligible, and have limitations in activities of daily living in two or more domains. Participants are randomized to usual care or an Interdisciplinary Team (IDT) model aiming to incorporate strategies encompassing the six key principles from Wagner’s model.
The initial CM assessment following randomization included contact with the participant’s primary care physician (PCP) to ascertain information regarding patient goals followed by a home visit with the participant. This evaluation considers participant “connections, comfort, ethics, client and family well-being, and grief”. The PASSPORT CM then meets with the IDT which included a hospice and PC physician and nurse specialist, a geriatrician, a SW, a spiritual advisor, and a pharmacist. Care plans are generated based on patient and family goals and consider evidence-based recommendations from the Assessing Care for Vulnerable Elders (ACOVE) project, the National Consensus Project (NCP) for Quality Palliative Care, and the International Association of Hospice and Palliative Care (IAHPC). Following development of a care plan, the CM shares this plan with the patient, family, and the PCP; academic detailing is employed to promote communication and increase the PC and geriatric medicine skills of PCPs. IDT care plans are communicated electronically to PCP offices by fax or telephone with the intent to ultimately develop a more efficient electronic system to transfer essential documents.

Once all parties agree with the care plan, subsequent CM home visits focus on symptom management, functional needs, medication review, caregiver education, and referrals for psychosocial and spiritual support. Additionally, CM provided assistance to facilitate optimal communication and completion of any legal documents; standardized protocols exist to guide these plans of care. CM then follow-up with participants at least monthly and as needed.

The study outcomes at three, six, nine, and twelve months included the following: 1) symptom management (Memorial Symptom Assessment Scale); 2) Quality of life/death (QUAL-E); 3) Relationships (Meaning in Life Scale); Decision making, care planning, continuity,
communication (Patient Activation Measure); and 4) Depression and Anxiety (Hospital Anxiety and Depression Scale). The data are still being collected and, therefore, preliminary results are not yet available.

The strengths of this study included the randomized controlled trial study design implemented to compare the experiences of patients who receive usual care with those of patients who receive the aforementioned comprehensive intervention. Additionally, this study is evaluating patient-centered outcomes via validated instruments.

A complementary strength of this program is its focus on improving care coordination by eliminating disease-focused, encounter-based, fragmented care and facilitating optimal communication among patients, families, and health care providers. Additionally, this program’s development and implementation of evidence-based care plans and standardized protocols to guide CM care in home settings is a significant achievement. The latter in combination with complex chronic disease management programs to promote self-management are essential in creating successful community-based service delivery models which integrate and optimize care across disciplines, promote inter-professional practice, and maximize all IDT roles within their scope of practice.

This program’s incorporation of computerized care plans shared electronically with PCP offices is an essential task in improving communication systems and information transfer moving forward. This program aims to provide access to advance directives electronically and to promote information transfer during transitions of care. Furthermore, this program’s novel implementation of Wagner’s Chronic Care model creates a comprehensive framework from
which other programs can adapt/replicate key components based on the needs of their organizations and service delivery systems.

A limitation of this study included a potential population bias. This study has been implemented in a well-resourced system of care includes a strong network of interdisciplinary health providers to meet the specific needs and challenges of the target population. As a result, this may limit the implications, application, and reproducibility of this study’s findings in many poorly resourced areas in which low income, older adults with life-limiting illness are served.

In terms of program limitations, physician providers may perceive participation requires more time and effort than they are willing to commit, given the need to complete multiple questionnaires regarding patient goals. There is no mention of the cost associated with hiring and training CM, providing the comprehensive IDT services, and maintaining the program, which makes it challenging to evaluate the true cost-benefit relationship of this program. However, the investigators acknowledge the importance of understanding costs associated with program implementation and potential cost savings, and suggest future trials will address costs by tracking Medicaid and Medicare databases including a cost-effectiveness analysis of providing the intervention. Further, the outcomes related to patient physical and psychological symptoms provide no insights on the transitions to hospice, referrals to community resources, and the intervention’s impact on health care utilization.

This study aimed to determine the effect of a PC intervention on QOL, symptom intensity, and resource utilization. The PC intervention employed principles of the chronic care model and incorporated case management and education to support patients with advanced cancer to get activated to participate in the self-management of their illness. This randomized controlled trial enrolled participants from November 2003 to May 2007. Participants were randomized to the intervention (n=145) or usual care (n=134) which included standard access to oncology and PC services.

Participants randomized to the intervention group received an initial telephone assessment by skilled PC advanced practice nurses. This assessment included administration of the Distress Thermometer, an 11-point visual scale (where 0=no distress and 10=extreme distress) to screen for any potential distress secondary to physical or emotional problems or difficulties with family, practical issues such as work, and spiritual or religious concerns. A score of greater than three precipitated further inquiry about perceived problems or concerns and the opportunity to engage in problem-solving techniques based on the following four modules developed during a prior study, ENABLE I: 1) problem solving; 2) communication and social support; 3) symptom management; and 4) ACP and unfinished business.

Study participants were offered four formal support sessions and at least monthly follow-up calls thereafter based upon needs assessment as well as appropriate referrals to community resources. In addition to encouraging participants to contact clinical services when they experienced difficult-to-manage symptoms or needs, advanced practice nurses actively facilitated
this process. Furthermore, participants were invited to engage in shared medical appointments with a PC physician and nurse on a monthly basis. Advanced PC practice nurses, physicians, and nurses participating in the intervention received training via didactics, written treatment manuals, role play activities, and problem solving.

Primary outcomes of this study included measures of QOL, symptom burden, and resource utilization (hospital and intensive care unit or ICU days, ED visits); a secondary measure was mood. QOL was higher for the intervention group (mean [SE], 4.6 [2]; p=0.02) based on the Functional Assessment of Chronic Illness Therapy for Palliative Care measure. There was a trend toward lower symptom intensity (mean [SE], -27.8 [15] as measured by the modified Edmonton Symptom Assessment Scale or ESAS). Scores for mood were significantly lower in the intervention group (mean [SE], -1.8 [0.81]; p=0.02) based on the Center for Epidemiological Studies Depression (CES-D) Scale. Interestingly, there were no significant differences between intervention and usual care patients for hospital days (6.6 vs. 6.5), ICU days (0.06 vs. 0.06), or ED visits (0.86 vs. 0.63). Additionally, post hoc analysis demonstrated no significant differences between groups of patients in survival with a median survival of 14 months for patients in the intervention group and 8.5 months for patients in the usual care group.

A significant strength of this study was the randomized controlled design in which this program was implemented which allows for more accurate comparisons between the patients who received the CM intervention and those who received customary care for their condition. This study included patient-centered outcome measures and structured, validated instruments for collecting this data.
Significant program achievements included the use of structured training for interventionists and the inclusion of previously developed and validated modules to guide care plans. Additionally, this program implemented innovative information technology advances to reach community-based cancer patients at risk for being underserved. There is a significant need for advancement in and application of information technology systems optimizing interprofessional practice in the face of workforce shortages. This study included patient-centered outcomes and measures of resource utilization. Furthermore, this study was resource-sparing given the small number of interventionists who were required to conduct assessments and guide care plans over the phone.

A potential limitation of this study was the exclusive focus on one group of patients, those with advanced cancer. These patients often have a steeper trajectory of clinical decline and more confined resource utilization compared with patients who have complex chronic illnesses like COPD and CHF. These factors could contribute to overestimating the impact of this program when considering the broader context of life-limiting illness. Additionally, although the trend was promising with respect to the symptom reduction in patients who were randomized to the intervention, this finding was not statistically significant. This is likely due to low symptom intensity at baseline and the small sample size; a larger sample size would have been possible with more interventionists.

When considering program limitations, this program only included two trained advanced practice nurses to provide community-based services. The lack of more personnel to provide these essential services may compromise this program’s ability to provide equivalent and/or adequate services to each patient or to reach a wider patient population. Furthermore, this
intervention failed to demonstrate a significant reduction in health care resource utilization. This is an important consideration in developing and implementing cost effective solutions to support improved patient-centered and utilization outcomes.

**Head, et al. (2010). Palliative Care Case Management. Increasing Access to Community-Based Palliative Care for Medicaid Recipients.**

This single group, prospective, pilot intervention project aimed to develop and implement a program which integrated PC principles and practices into the daily workflow of CM who were serving Medicaid recipients. This was accomplished by the successful collaboration of Passport Health Plan and the University of Louisville’s Interdisciplinary Program for Palliative Care and Chronic Illness. This twelve-month project enlisted nursing and SW leaders with PC expertise to comprise a Palliative Care Case Management (PCCM) team which supported CM serving Medicaid recipients and facilitated key relationships with community services like clergy. This program included the development of a training curriculum for CM and other staff providing care. In addition to learning about specific domains in PC, goals of care, management strategies, and common life-limiting illnesses, CM received 13 specialized training sessions on the appropriate identification of patients requiring PC or hospice services. Furthermore, a resource manual to guide care plans and to facilitate referrals to appropriate community services was developed for CM reference.

Patients were selected to participate in the PCCM intervention if they had advanced disease, were not considered to be in the final months of life, or refused hospice and were possibly receiving life-prolonging medical treatments. This pilot project’s outcomes included: 1) evaluation of training sessions with pre- and posttest knowledge assessments; 2) impact of the
program on patients; 3) CM acceptance; 4) managed care provider benefits; and 5) hospice referral patterns. Selected program patients were provided with the opportunity to participate in a research component which assessed the program’s impact on symptoms and associated distress using Memorial Symptom Assessment Scale scores while evaluating participants’ satisfaction with CM services.

The overall program evaluations by CM and other staff (n=15) were largely positive with educational experience being identified as the greatest strength and caseloads and limited pediatric patient information as the most significant weaknesses. CM and other staff identified program opportunities including ongoing education and program threats including the lack of perceived physician support. In terms of knowledge assessments, CM posttest mean scores were significantly higher than their pretest scores (20.6 vs. 15.6, p<0.0001) suggesting that CM felt they had more knowledge regarding PC principles following the training sessions. Interestingly, CM were more likely to refer participants to the PCCM team than to provide independent management with the use of skills gained and manuals; this was attributed to a perceived lack of experience and time.

Of the 68 participants involved in the program, only 35 consented to the research component. Significant differences were found for symptom assessment between first and second physical sub-score measures using the Global Distress Index (GDI) and Memorial Symptom Assessment Scale (MSAS), and between first and third sub-scores for psychological domains. Patient satisfaction scores were significantly higher after two months of being in the program. In terms of hospice referrals, four participants were referred to hospice care during the project.
In addition to evaluating patient-centered outcomes, the project team conducted a cost analysis on seven patients who participated in the program long enough to provide comparisons. In one case, a patient had a 13.2% decrease in costs during the intervention followed by a 61% (cost reduction of $12,049 per month) decrease in costs after admission to hospice. The second case, a CHF patient with significant inpatient costs, had a cost reduction of 52.6% which translated into a cost savings of $4,077. A third case involving a patient with end-stage lung cancer demonstrated reduced costs, but there was only a cost savings of 1% for this patient during the intervention. However, this patient’s costs decreased by 70.8% following admission to hospice. Additional cases of patients with HIV, COPD, and end-stage renal disease involved cost reductions of 19.5%, 54.5% (primarily inpatient costs), and 27.6%, respectively. One final case, a patient with COPD had cost savings of 70.8% following hospice admission.

The strengths of this program included the successful collaboration of a university-based PC program and managed care organization to improve delivery of PC services to Medicaid recipients via CM. The development of a curriculum to train CM to deliver community services, overall CM acceptance of the experience, and improved CM knowledge scores are positive outcomes of this program. Additionally, the project aimed to collect data on patient-centered variables such as symptom intensity and satisfaction which are important program assessment characteristics. Furthermore, after realizing that multiple variables confounded (i.e., diagnosis, stage of illness, age, timing, and the length of palliative care management) the use of claims data to compare cost among patients who received the palliative care management intervention and those patients who did not, the project team decided to evaluate the total costs of individual patients who participated in the program long enough to provide comparative data.
The limitations of this program included the small number of CM targeted in this intervention and CM propensity to refer patients to the PCCM team instead of applying the knowledge and skills they developed during this project to guide their individual care of patients. The patient sample size was small, which potentially underestimated any positive benefits. Additionally, cost analysis was limited to individual cases, which makes it difficult to determine the true cost savings benefit of this program.


This program was made possible by the successful collaboration of an academic/care management health plan partnership between Mount Sinai School of Medicine, Franklin Health, a care management organization, and South Carolina Blue Cross and Blue Shield. Franklin Health provides complex case management to community-based patients and families with the goal of improving access to high quality and cost-effective care relative to individual values and informed wishes. The purpose of this project was to screen and identify appropriate participants likely to benefit from CM services based on specific life-limiting illnesses such as cancer, heart disease, chronic lung, kidney, liver disease, and to evaluate resource utilization among a group of these patients who were randomized to a CM intervention.

The four specific objectives of this project included: 1) development of training modules highlighting PC key principles for CM and strategies for physician engagement; 2) formal assessment with physician feedback; 3) outcome evaluation for participants receiving PC CM services compared to standard CM; and 4) feasibility assessment of this model for patients, families, providers, and industry. The initial phase of the project involved a comprehensive training experience with the development of treatment and follow-up protocols, and instruments
to determine perceived utility and acceptability. This was followed by the selection of appropriate participants through a multistep process, initial patient assessment, and the development of care plans in accordance with patient/family wishes, goals, next steps, medications, and services. Participants were randomly assigned to the control group (n=169) or to the intervention group (n=152). Nurses were randomly assigned to provide standard care (n=4) to the control group or PC focused services (n=5).

Intervention assessments included a communication toolkit with an ACP questionnaire to assess patients’ readiness to engage in ACP discussions with family and providers, and several validated instruments to assess symptom burden and well-being: the ESAS, Missoula-VITAS QOL Index, and the Morpace Satisfaction Instrument; the assessment occurred every two weeks for stable participants and weekly if patients were unstable. Symptoms and associated treatment protocols based on computerized treatment recommendations were forwarded to PCP offices by telephone.

The program outcomes included the percent of eligible participants who agreed to participate and from whom assessments were obtained, assessment results, overall acceptability for all participants, and the overall impact on patient care. Additionally, this study assessed measures of utilization including hospital and ICU days, ED use, inpatient/outpatient physician visits and relative value units, CM length of involvement, referrals to hospice, home care use, analgesic/anxiolytic/antidepressant prescribing, and place of death.

In terms of results, the investigators reported this program has demonstrated improvement in patient and family satisfaction and general feasibility, but final data are currently unavailable to evaluate the success of this program. Overall, this was an innovative program.
design because it targeted seriously ill home-based individuals based on diagnosis and utilization criteria (hospitalization, home-care service use), aimed to compare outcomes of usual CM services compared with services provided by skilled CM in key domains of PC, included computerized treatment protocols to facilitate access to high quality care, and incorporated health information technology to promote provider education and communication; the CM role was to support the patient, family unit, and community provider. Key elements of this program such as computerized treatment recommendations, communication protocols, and toolkits could potentially be incorporated into service delivery models in other health care systems.

The major limitation of this study is the lack of published data of patient-centered and health utilization outcomes. CM reported significant challenges in communicating with physicians throughout the course of this study. This finding emphasizes the importance of identifying community physician champions to obtain their input and buy-in, to facilitate viable mechanisms of communication with them, and to create sustainable processes for delivering high quality care in accordance with patient and family unit needs.

**Pfeifer, et al. (2006). The Caring Connections Project: Providing Palliative Care to Medicaid Patients with Advanced Cancer.**

This pilot program, the Caring Connections Program (CCP), was a collaborative effort between the University of Louisville Schools of Medicine and Nursing, the Kentucky Hospital Research and Education Foundation, and Passport Health Plan to promote PC services for Medicaid recipients with advanced cancer via CM. The purpose of this program was to identify advanced cancer patients who would potentially require additional support before significant health issues arose. A skilled care manager (n=1) provided specific services to patients and
families including ACP, disease education, care plans to guide optimal symptom assessment and management, mechanisms to promote appropriate transitions of care, and strategies to facilitate communication with community providers.

Program participants were initially recruited from local practices and depended largely on provider awareness of the services and willingness to refer. Program recruitment began in May 2002 and ended in May 2005. Over the three year enrollment period, only 56 participants were enrolled in the program. After limited referrals from community providers, additional strategies were implemented to recruit patients via other sources. Of the patients recruited, 64% (n=21) received hospice services with an average length of stay (LOS) of 68 days prior to expiring. Overall, this program was well received by participants and there were several case descriptions detailing how this program supported the delivery of PC on an individual basis. Highlighted successes of this program included patient and family advocacy, self-management, coordination of care, facilitation of communication, decision-making support, promotion and documentation of advanced care directives, encouragement of provider order completion, and support of appropriate hospice transitions.

The strengths of this program included the initiative to train a care manager with PC expertise who facilitated care delivery in accordance with patient and family values and preferences and supported community providers. Program perceptions were largely positive and suggested the need for future initiatives addressing common stereotypes about Medicaid recipients, pain management, patient advocacy, staff education strategies, patient goals, and promotion and support of providers.
This program had significant limitations including a small sample size, the inclusion of only advanced cancer patients, and the lack of outcome measures above and beyond hospice referrals. However, the program team recognized the need to expand services for individuals with other life-limiting illnesses and sought additional funding in 2005 to develop a more expansive program.  


This program evaluated the role of an interdisciplinary comprehensive Care team (CCT) composed of SW-CM, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator, and three physicians in providing outpatient PC to adult patients with cancer, advanced COPD and CHF with a life expectancy of one to five years.  

Outcomes for the intervention group were compared to those receiving standard primary care. The CCT intervention included seven components: 1) CM providing initial patient assessments used to make recommendations based on physical and psychological symptoms, social support, spiritual well-being, and ACP (provided to PCP in writing/email); 2) CM supporting ACP in person and by phone; 3) a nurse offering caregiver training; 4) a pharmacist reviewing charts for potential medication interactions; 5) a chaplain providing spiritual and psychological support; 6) participants being invited to and attending monthly support groups; and 7) medicine and pharmacy students calling patients weekly and providing support and advocacy.

Study outcomes included functional status, symptom burden, QOL, patient satisfaction, and ACP which were obtained via surveys at enrollment, six months, and 12 months. Specific assessments included the Rapid Disability Rating Scale, the San Diego Shortness of Breath
Questionnaire, the Brief Pain Inventory, six sleep outcomes from the Medical Outcomes Study, the Profile of Mood States, the CES-D scale, the Spiritual Well-Being Scale, and the Multidimensional QOL Scale. Computerized billing records were reviewed to determine charges for office visits, ED visits, and hospital days.

The study enrolled 90 participants who were randomly assigned to the CCT intervention group or the standard care group based on “a coin flip”. Fifty patients were assigned to the CCT intervention group while forty patients were assigned to the standard care group and both groups had similar baseline characteristics. CCT patients (69%) stated a preference for earlier services and 74% received needed durable medical equipment. Symptom assessment at three months revealed that the CCT group experienced significantly less dyspnea (p=0.01) and a trend toward improved sleep quality while there was no difference in their pain level and no significant improvement in their anxiety scores. Additionally, the CCT group reported higher spiritual well-being (p<0.007), but there were no differences in their QOL or health care satisfaction. Interestingly, although CCT recommended antidepressants for 46% of participants, only 17% (n=3) had newly prescribed medications. In terms of ACP, 55% of CCT participants (n=12) and 28% (n=5) of controls designated a health care power of attorney.

In terms of health care utilization, CCT participants made fewer PCP visits (mean, 7.5 vs. 10.6; p=0.03) and urgent care visits (mean, 0.3 vs. 0.6; p=0.03). However, there were no statistically significant differences for subspecialty visits, ED visits, hospital days, and number of hospitalizations. There were no statistically significant differences with respect to place of death or overall health care charges.
An important strength of this study included the randomized controlled study design in which this intervention was examined. This design allowed for the comparison of outcomes between patients who received an integrated CM intervention and those who received standard care for their health condition. The inclusion of patient-centered outcome measures, standardized instruments to collect patient-centered data at multiple time points, resource utilization, and cost analysis are important considerations in evaluating the success of this program.

A positive aspect this program was the intent to promote the timely transfer of health information across settings. The seamless flow of information across the continuum is an important benchmark which any successful integrated CM intervention will need to achieve in order to effectively manage the care of community-based PC patients going forward. The utilization of SW-CM to conduct the initial and follow-up assessments and to discuss them with the CCT is progressive and aligns with the need to promote further collaborative interprofessional practice in order to meet the often complicated health needs of patients with life-limiting illness.

The limitations of this study included the setting and population in which this program was implemented. Given this program served “a minority” of Medicaid or self-pay patients who may have been at an increased risk for unmet symptom needs, there is a possibility that a population bias have positively influenced the outcomes and impact of the CCT intervention among those who were randomized to this group.

Although systems were implemented to facilitate the efficient flow of information across settings, this program was limited by the lack of feedback mechanisms to ensure physician
follow-through with orders and recommendations. The lack of physician follow-through may have negatively affected the potential impact of this program as the results suggest that although the CCT made clear and actionable recommendations regarding patients’ health care needs, the patients’ physicians did not always follow through on these recommendations. Additionally, there were no direct measures of CM performance as it relates to engaging in ACP discussion and communication and supporting patient/family decision-making.

Rosenfeld and Rasmussen (2003). Palliative Care Management: A Veterans Administration Demonstration Project.

This demonstration project was made possible by the commitment of the VA Greater Los Angeles Healthcare System (GLAHS) to improve EOL care and overcome deficiencies in the continuity and coordination of care for patients with life-limiting illness. This program targeted stage IV non-small-cell lung cancer (NSCLC), advanced CHF, end-stage COPD, and advanced cirrhosis. The goals of this program included: 1) identifying poor prognosis patients early in the process; 2) initiating goals in accordance with patients’ values and preferences; 3) addressing PC domains throughout the illness; 4) facilitating continuity and coordination of care; 5) providing family and caregiver support. The project’s primary aim was to integrate key PC principles into the organization’s delivery system.

Following informed consent, patients received disease-specific information, information regarding common symptoms and management strategies, supportive material to assist them with potential emotional and spiritual issues, ACP resources, and a contact list in the case symptoms or urgent issues arose. Each patient received an initial assessment exploring PC domains with the Pathways team, which was composed of a nurse case manager, SW, dietitian, chaplain,
psychologist, and physician director. The nurse case manager’s role was “critical” and included phone or in-person symptom assessment and management, medication review, patient/family education, care coordination with home care staff, specialists, and PCPs, and facilitation of appropriate care transitions. Participants with active issues were reviewed at a biweekly team meeting and information technology was employed to alert the nurse case manager if a participant was hospitalized.

Program outcomes included patient satisfaction with care, symptom assessment, QOL, and well-being. Due to study limitations, the authors did not provide any study results or outcomes data. The authors reported that only 65 of 132 participants (49%) consented to survey completion and among consenters, only 49% completed baseline surveys and 32% completed the first three month follow-up survey. Investigators suggested that the project might have been better served if there had been less focus on patient-centered outcomes and greater emphasis on measures of program feasibility and acceptability since their aim was to integrate this program into the organization’s infrastructure. A major strength of this program included the investigators’ concerted attempt to develop an effective model to facilitate patient-centered, coordinated care across the continuum as this is a key element in integrating and organizing care for PC/hospice patients. Utilizing nurse CM to provide PC further supports the importance of harnessing the skills and abilities of each member of an interdisciplinary team to meet the increasing demands of this patient population and to more effectively delegate the PC CM responsibilities with a more limited and heavily burdened workforce. Additionally, the use of information technology to alert CM provided a reliable and efficient means of communication to transfer information across the care continuum, which could be incorporated into other potential programs.
The limitations of this study included the lack of outcomes data. There was no description of the instruments used to collect outcome measures. Additionally, there was no reference to the specific management protocols or education materials which were employed.

Analysis

The overall effectiveness of programs utilizing skilled CM to deliver high quality PC care to community-based individuals with life-limiting is promising, but remains unclear. In part, this is due to the majority of programs being limited by small sample size, inclusion of a single diagnosis, lack of outcome measures data, or no comparison groups. Although programs demonstrated feasibility and acceptability among patients and physicians, statistically significant findings for a program's effect on patient-centered outcome measures such as symptom burden, QOL, functional status, and hospice referral patterns, and resource utilization such as ED visits or hospitalizations were not consistent. Additionally, cost analysis outcomes were often not included or reported.

Four studies included outcomes of symptom distress and demonstrated reduced symptoms with the intervention. One study evaluated functional status but did not find consistent results, with improved function among COPD participants, but not those with CHF. Two studies included data about QOL with one showing improved QOL among intervention participants and the other demonstrating no significant difference. One study assessed activity level and did find improved activity in the intervention group. One study evaluated mood scores and did find lower scores for depression among those exposed to the intervention group. Two studies reported a positive effect of the intervention on completion of advance directives. Two studies showed improvements in disease self-management. One study examined
mortality and found no difference.\textsuperscript{3} One study commented on hospice referrals, but had no comparison group.\textsuperscript{5} Three studies included health care utilization outcomes with one demonstrating reduced PCP and urgent care visits, but no change in ED visits, hospital length of stay, or number of hospitalizations;\textsuperscript{9} the other two\textsuperscript{1,3} studies demonstrated no change in utilization. Two studies examined cost with one showing reduced costs following the intervention based on individual analysis\textsuperscript{5} while the other study demonstrated no change in cost with the intervention.\textsuperscript{9} Three of the studies described had no published data available to determine effect of care management interventions on patient-centered outcomes, health care utilization, or cost.\textsuperscript{2,7,10}

In terms of program evaluation, a problematic aspect of these programs is that although they all employed CM to improve the delivery of PC services to community-based participants, they did not fully describe the training experience of CM or the specific program components such as management protocols. This is makes it challenging for other programs to apply specific elements of these programs to accommodate their organizational needs and infrastructure. There was limited information pertaining to how these programs provided feedback to CM regarding performance and potential opportunities for improvement; one study did assess CM pre/post knowledge scores with training.\textsuperscript{5} This makes it difficult to distinguish the overall effect of the interdisciplinary care team versus individual CM roles.

Interestingly, with the exception of a few studies\textsuperscript{1,3,5,9} demonstrating some benefit on patient-centered outcomes, other studies revealed no statistically significant differences in symptoms or QOL between CM intervention group and usual care group patients. However, this is in the setting of three comprehensive interventions lacking published data to-date. The
effect of the CM interventions appeared to have no statistically significant effect on cost or health care utilization\textsuperscript{3} or showed inclusive utilization patterns with a decrease in PCP and UC visits, but no change in subspecialty visits, hospitalizations, or hospital days.\textsuperscript{9} In part, this is likely a component of the short time frame over which data was collected; more significant effects are likely to be observed over longer follow-up time periods. Regardless, this is an important consideration with rising health care costs and limited resources and poses a significant question regarding the efficacy of and investment in these programs moving forward.

Although a number of programs discuss the utilization of health information technology to facilitate the transfer of information/recommendations to PCP offices,\textsuperscript{2,3,9,10} there was only one program describing a process to extend education about disease specific prognosis, management strategies, and the role of CM in coordinating care for individuals with life-limiting illness; physicians were invited to participate in training.\textsuperscript{8} Few programs described the process of identifying key community stakeholders and physician champions,\textsuperscript{10} which is important given physician follow-through is a recurrent barrier to delivering high quality care.

**Conclusion**

This literature review focused on eight programs employing CM to provide PC services to community-based individuals with life-limiting illness. Overall, the programs and study designs suggest innovative mechanisms to implement care management services to improve communication about ACP, to assess and manage symptoms, and to facilitate coordinated care across the continuum through the provision of education, resource toolkits, decision-making support, disease/symptom management protocols, and the utilization of health information.
technology. These programs share similar features with the Community Care of North Carolina (CCNC) PC initiative.

The limited influence of programs utilizing CM to consistently improve symptoms, QOL, functional status and to reduce costs and utilization of medical resources makes it challenging to draw meaningful conclusions from these programs thus far. This literature review suggests the need for future programs and studies to include more rigorous study designs with comparison groups, larger sample sizes, and longer follow-up periods to evaluate the true impact of CM programs on patient-centered outcome measures, transitions to hospice, resource utilization, and cost.

Conducting studies among community-based patients eligible for PC and hospice services will continue to present many challenges. Careful attention must be placed on recruiting an adequate sample size to control for numerous extraneous variables. Ideally, research projects would be multi-site in nature to help control for regional differences and the effects of local practice patterns. The research design must ensure procedures will be conducted in a consistent manner regardless of the practice setting or patient situation and include the collection of both qualitative and quantitative data. Furthermore, research methods and outcome measures must be clearly defined and measured in a valid and reliable manner to better understand which PC interventions affect outcomes to target future initiatives, delivery models, and practices. Until such studies are conducted with robust methodologies and consistent outcome measures, questions about the effectiveness of employing CM in these types of efforts will remain largely unanswered.
REFERENCES


Table 1: Summary of studies employing CM to improve PC and hospice services for community-based adults with life-limiting illness

<table>
<thead>
<tr>
<th>Study</th>
<th>Description of Intervention</th>
<th>Study Population</th>
<th>Study Design</th>
<th>Study Results</th>
<th>Strengths/ Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aiken, et al. (2006). Outcome Evaluation of a Randomized Trial of the PhoenixCare Intervention: Program of Case Management and Coordinated Care for the Seriously Chronically Ill.</td>
<td>Home-based care management by RN CM addressing disease/symptom management, patient self-management, knowledge of resources, preparation for EOL, physical and mental functioning, and utilization of medical services</td>
<td>COPD and CHF patients with an estimated 2-year life expectancy</td>
<td>Randomized, controlled trial</td>
<td>PhoenixCare participants' mean knowledge scores higher at three months for community resources (1.80 to 2.57 vs. 1.76 to 2.02, p&lt;0.05), at six months for medical concern contacts (1.57 to 2.63 vs. 1.76 to 2.19, p&lt;0.05) and handling emergencies (3.51 to 3.90 vs. 3.52 to 3.51, p&lt;0.05), preparation for end-of-life at 6 months for completion of wills/directives (p&lt;0.05, OR=4.47 [CI: 1.10, 18.18]), initiating/resuming activity at three and six months (34% to 49% and 45%, respectively), lower symptom scores at three months (4.38 to 3.41, p&lt;0.05) and six months (2.85, p=0.07), physical functioning remained same (CHF) or improved (COPD) (p&lt;2.50, p&lt;0.05), no significant differences in vitality or general health, no difference in medical system utilization</td>
<td>Strengths: study design, inclusion of patient-centered outcomes, CM involvement in managing clinical care and supporting QOL, and inclusion of medical utilization outcomes. Limitations: relatively small sample size, lack of information on hiring/training CM, inclusion of patients with only two diagnoses, limited two-year life expectancy data, observed number of deaths, over-reliance on claims data, and limited set of medical utilization outcomes.</td>
</tr>
<tr>
<td>Allen, et al. (2012). The Promoting Effective Advance Care for Elders (PEACE) Randomized Pilot Study: Theoretical Framework and Study Design.</td>
<td>Home-based interdisciplinary CM intervention addressing symptom management, psychosocial/emotional support, ACP, functional improvement, and polypharmacy</td>
<td>New enrollees in PASSPORT, Ohio's community-based Medicaid waiver program, who have geriatric/PC health care needs</td>
<td>Randomized, controlled trial</td>
<td>Study is in progress and data are being analyzed; preliminary results are currently unavailable</td>
<td>Strengths: study design, focus on and strategy to improve care coordination and communication, inclusion of patient-centered outcomes, development and implementation of care plans and management protocols, incorporation of electronic information transfer/communication, use of Wagner's Chronic Care Model to guide service delivery. Limitations: provider perception of time/effort constraints.</td>
</tr>
<tr>
<td>Study</td>
<td>Description of Intervention</td>
<td>Study Population</td>
<td>Study Design</td>
<td>Study Results</td>
<td>Strengths/ Limitations</td>
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<tr>
<td>Bakitas, et al. (2009). Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer.</td>
<td>Psycho-educational advanced practice nurse CM intervention combining training on problem solving, communication, symptom management, ACP, unfinished business, and supportive care resources with regular follow-up and group shared medical appointments with PC physician/nurse</td>
<td>Patients with advanced cancer in rural comprehensive cancer care center and outreach clinics</td>
<td>Randomized, controlled trial</td>
<td>QOL higher for the intervention group (mean [SE], 4.6 [2]; p=0.02), lower symptom intensity (mean [SE], -27.8 [15]; p=0.06), lower depression score (mean [SE], -1.8 [0.81]; p=0.02), no significant differences in resource use and vital status</td>
<td>Strengths: study design, inclusion of structured training for CM, use of developed/validated protocols for care plans, innovative implementation of health IT, inclusion of patient-centered and medical utilization outcomes, and efficient use of health resources in administering intervention. Limitations: inclusion of patients with only one diagnosis, use of only two trained RN CM, and lack of significant differences in symptom reduction and medical utilization.</td>
</tr>
<tr>
<td>Head, et al. (2010). Palliative Care Case Management. Increasing Access to Community-Based Palliative Care for Medicaid Recipients.</td>
<td>PC nurse/SW CM intervention to integrate PC principles and practices into day-to-day operations of Medicaid MCO through development of CM PC training curriculum, identification of patients, PCCM delivery, PCCM outcome assessment, and development of CM resource manual</td>
<td>Patients with advanced heart, lung, liver, or neurological disease, HIV/AIDS, renal failure, or advanced cancer with evidence of disease progression and declining self-care or daily functioning</td>
<td>Pilot, single group intervention project</td>
<td>CM knowledge posttest mean scores significantly higher than pretest scores (mean difference 5.4, p&lt;0.0001), CM more likely to refer participants to the PCCM team versus providing independent management, significant differences in symptom assessment between first and second physical subscore measures and between first and third subscores for psychological domains, patient satisfaction scores significantly higher after two months. hospice referrals seemed to</td>
<td>Strengths: successful collaboration with university-based PC program and MCO, development of CM training curriculum, CM acceptance of training experience, and improved CM knowledge scores, inclusion of patient-centered outcomes, and inclusion of cost evaluation. Limitations: small number of CM, CM referral patterns, small participant sample size, and limited cost.</td>
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<tr>
<td>Study</td>
<td>Description of Intervention</td>
<td>Study Population</td>
<td>Study Design</td>
<td>Study Results</td>
<td>Strengths/ Limitations</td>
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<tr>
<td>Meier, et al. (2004). Integrating Case Management and Palliative Care.¹</td>
<td>Nurse CM intervention addressing symptom burden, prescribing practices, ACP, doctor-patient continuity, communication, decision-making, home care support, and health utilization</td>
<td>Seriously ill, commercially insured HMO members through BC/BS of SC and Companion Health Care</td>
<td>Randomized, controlled trial</td>
<td>Study is in progress and data are being analyzed; no preliminary results are currently available, though intervention seems to have increased patient and family satisfaction and seems to be generally acceptable and feasible</td>
<td>Strengths: study design, inclusion of patient-centered and medical utilization outcomes, use of computerized treatment protocols, incorporation of health IT to promote provider education and communication, and use of patient toolkits. Limitations: lack of published data on patient-centered and medical utilization outcomes, and CM-reported communication difficulties with physicians</td>
</tr>
<tr>
<td>Pfeifer, et al. (2006). The Caring Connections Project: Providing Palliative Care to Medicaid Patients with Advanced Cancer.²</td>
<td>PC cancer CM intervention addressing care planning, patient/family education about condition, prognosis and treatment options, anticipation of needs, aggressive pain and symptom management, access to appropriate community resources, and facilitation of care transitions</td>
<td>Passport Health Plan (a Medicaid MCO) patients with advanced cancer who had high health utilization and were in need of support</td>
<td>Pilot, single group intervention project</td>
<td>Program able to support the delivery of PC on an individual basis and was well-received by patients, successes included patient and family advocacy, self-management, coordination of care, facilitation of communication, promotion of ACP with appropriate documentation, support of decision-making, encouragement of provider order completion, and support of appropriate hospice transitions</td>
<td>Strengths: initiative to train CM with PC expertise, program perception, positive program perception, patient/family advocacy, encouragement of self-management, coordination of care, facilitation of communication, promotion of ACP, support of decision-making and transitions to hospice, and encouragement of provider order completion. Limitations: small sample size, inclusion of patients with only one diagnosis, and lack of medical utilization outcomes beyond hospice referrals</td>
</tr>
<tr>
<td>Nahow, et al. (2004). The Comprehensive Care Team. A Controlled Trial of Outpatient</td>
<td>IDT and SW CM intervention addressing advanced PC</td>
<td>Patients with advanced CHF, COPD, and cancer with a life</td>
<td>Randomized, controlled trial</td>
<td>Improved symptom assessment at three months for CCT group with less</td>
<td>Strengths: study design, inclusion of patient-centered</td>
</tr>
<tr>
<td>Study</td>
<td>Description of Intervention</td>
<td>Study Population</td>
<td>Study Design</td>
<td>Study Results</td>
<td>Strengths/ Limitations</td>
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<tr>
<td>Palliative Medicine Consultation.³</td>
<td>consultation, symptom management, polypharmacy, ACP, spiritual and psychosocial support, and family caregiver training</td>
<td>expectancy of 1 to 5 years</td>
<td></td>
<td>dispense (OR, 6.07; 95% CI, 1.04-35.56) and improved sleep (P²=4.05; p=0.07), improved spiritual well-being (I²=8.21; p=0.007), no difference in pain, insignificant trend toward less anxiety, no significant QOL or health care satisfaction differences, more CCT patients (n=12) than controls (n=5) had HCPQA at end of study, CCT patients had significantly fewer PCP visits (mean, 7.5 vs. 10.6; p=0.03) and urgent care visits (mean, 0.3 vs. 0.6; p=0.03); no significant differences in other measures of medical system utilization</td>
<td>outcomes, medical utilization, and cost analysis, efficient use and transfer of health information, and use of SW CM to conduct patient assessments and follow-up and coordinate care with an interdisciplinary team. Limitations: potential study population bias, lack of feedback mechanisms to ensure physician follow-through, and lack of direct measures to assess CM performance on engaging in ACP discussions and supporting patient/family decision-making</td>
</tr>
<tr>
<td>Rosenfeld and Rasmussen. (2003). Palliative Care Management: A Veterans Administration Demonstration Project.¹⁵</td>
<td>RN CM intervention addressing patient identification, interdisciplinary assessment, care goals, symptom management, patient education about condition and prognosis, coordination and continuity of care, transitions of care, and family caretaking/ emotional support</td>
<td>VA patients with inoperable lung cancer, advanced CHF, end-stage COPD, and advanced cirrhosis</td>
<td>Pilot, single group intervention study</td>
<td>mean length of stay in program 4.6 months for enrollees who died and 16.7 months for patients who were still alive, program well-received and highly acceptable to patients/providers, ACP completion in patient who died of 56% for HCPQA and 31% for living wills, 43% of patients able to die at home (vs. only 28% in hospital), 56% of patients received volunteer support services, in final 30 days of life, patients averaged 3.5 days in hospital 0.4 days in ICU; due to study limitations, no other outcomes data provided</td>
<td>Strengths: attempt to develop a model to facilitate patient-centered, coordinated care, utilization of RN CM to provide PC, and utilization of health IT to support communication and information transfer. Limitations: lack of outcomes data, lack of description regarding instruments used to collect outcomes data, and lack of information on management protocols and education materials</td>
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APPENDIX 2

A more detailed description of the intervention’s educational component

The educational component of this intervention was designed through a successful collaboration of key leaders in CCNC’s practice network and faculty from UNC-CH’s Palliative Care Program, Center for Aging and Health, Public Health Leadership Program, Sheps Center for Health Services Research, Project Compassion, Duke Center for Palliative Care and various regional experts.

A multidisciplinary team of physicians, nurses, social workers, physical therapists, community advocates, project managers, and research assistants developed and participated in the delivery of a comprehensive curriculum and resource toolkit designed specifically for care managers (CM) who were assisting a subset of community-based Medicaid patients defined as aged, blind, and disabled (ABD) at moderate and high risk for morbidity and mortality. The curriculum was offered at eight regional sites across the state of NC to reach the greatest number of CM serving this population. One-day training sessions included the combination of didactic presentations and interactive small group role play activities to facilitate application of the presented materials.

Didactic sessions included an introduction to quality of care in serious illness and the growing need for patient advocacy, palliative care (PC) and hospice services state-wide. Although the research intervention aimed to target patients based on diagnostic and utilization criteria, the target population was introduced to CM by diagnostic criteria (i.e., incurable cancer,
advanced chronic organ system failure, progressive neurodegenerative conditions). The introduction was followed by didactic sessions offered in a series of four modules.

The curriculum included seven key questions (Table 1) developed by experts to facilitate CM ability to engage patients and families in the process of advance care planning (ACP), to assess pain and symptom distress, and to introduce tools from the resource toolkit. Specifically, during the first module, CM received education and training with an emphasis on key components involved in the process of ACP (Table 2): 1) initiating the conversation, 2) assessing readiness, 3) effectively identifying and addressing barriers, 4) selecting surrogate decision-makers, and 5) engaging in and documenting conversations about medical goals of care (Table 3). Also, relevant order forms such as Do Not Resuscitate (DNR) and Medical Order Scope of Treatment (MOST) forms were reviewed. Additionally, CM received instruction about how to communicate patient preferences and needs with community-based providers to facilitate timely and effective symptom management and to promote completion of order forms reflecting patients’ preferences for medical treatment. This didactic session was followed by interactive role play sessions facilitated by local experts (Figure 1).

The second module included key information about PC and hospice (Table 3). Topics covered included operational definitions and services provided, how to identify patients likely to benefit, a review of hospice eligibility, demonstration of effective communication approaches, and strategies to overcome barriers to delivering PC and hospice to patients and families. This didactic session was followed by opportunity for skill development through facilitator lead interactive group sessions with role play.
The third module provided CM with the opportunity to explore the patient’s experience of serious illness and to reflect on the emotional, spiritual, and practical needs that are part of this experience (Table 3). Community-based supportive care services and strategies were reviewed. CM participated in an emotional support exercise to help them understand the impact serious illness has on many domains of one’s life while also reviewing ways in which to provide support (Table 3).

The fourth and final module involved interactive large and small group activities that encouraged CM to apply content covered throughout the day to patient case scenarios. CM were encouraged to create an action plan to address a patient’s needs, while identifying perceived opportunities as well as challenges encountered as an integral member of an interdisciplinary community-based health care network. CM were empowered to consider their role in supporting the delivery of timely, efficient, and high quality care to seriously ill patients in the community.

In addition to receiving didactic and interactive role play sessions, CM were provided with binders consisting of the presentation slides used for the training sessions and a resource guide that included information for CM about local and regional hospice agencies and inpatient facilities, pain management clinics, palliative care and supportive care services, community coalitions, and services for pediatric and aging populations. This toolkit, available in print and electronically, also included copies of educational materials for patients and families, the Edmonton Symptom Assessment Scale, and state-approved forms for portable DNR order, (MOST) portable order set, living will, and health care power of attorney (HCPOA). This resource also included national website listings for advance care planning, hospice and palliative care, and specific diseases such as the National Cancer Institute, American Foundation for AIDS
research, ALS Association, Alzheimer’s Association, American Cancer Society, National Brain Tumor Foundation, American Diabetes Association, Cerebral Palsy, Cystic Fibrosis, American Heart Association, Parkinson Disease Foundation, Multiple Sclerosis Society of America.

**Figure 1: Training session agenda**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Content</th>
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<tbody>
<tr>
<td>8:30-9:00</td>
<td>Introduction</td>
</tr>
<tr>
<td>9:00-10:15</td>
<td>Module 1: Advance Care Planning and Goals of Care*</td>
</tr>
<tr>
<td>10:15-10:30</td>
<td>Break</td>
</tr>
<tr>
<td>10:30-11:45</td>
<td>Module 2: Hospice and Palliative Care Services*</td>
</tr>
<tr>
<td>11:45-12:30</td>
<td>Lunch and Question/Answer session</td>
</tr>
<tr>
<td>12:30-1:45</td>
<td>Module 3: Supporting Patients and Families through Serious Illness*</td>
</tr>
<tr>
<td>1:45-2:00</td>
<td>Break</td>
</tr>
<tr>
<td>2:00-3:15</td>
<td>Module 4: Putting Palliative Care into Practice*</td>
</tr>
<tr>
<td>3:15-4:00</td>
<td>Action Plan and Evaluation</td>
</tr>
</tbody>
</table>

*All modules were followed by interactive role play sessions facilitated by local experts*

**Table 1: Seven key palliative care questions**

8. If you became seriously ill, how confident are you that you would be treated according to your wishes and values?
9. Do you have someone who can make health care decisions for you if you become unable to speak for yourself?
10. Do you have opinions about how you would want to be treated if you become seriously or terminally ill?
11. Are your opinions about how you would want to be treated understood by your primary care physician?
12. Have you put your opinions in writing?
13. Are you experiencing symptoms that affect the quality of daily life?
14. How confident are you that you know how to get help if symptoms worsen?
Table 2: Initiating the Process of ACP

<table>
<thead>
<tr>
<th>What is your role in the process?</th>
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<tr>
<td>• “Open the door” and start the ACP conversation</td>
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<tr>
<td>• Identify barriers and encourage continued conversations</td>
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<tr>
<td>• Help patients identify their surrogate and to define goals and preferences</td>
</tr>
<tr>
<td>• Assist in the completion of HCPOA and/or advance directives</td>
</tr>
<tr>
<td>• Facilitate appointments with physicians to complete portable DNR and MOST forms</td>
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<tr>
<td>• Provide emotional and practical support</td>
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</table>

Table 3: Curriculum to Engage CM as Palliative Care Communicators

6. **Introduction to Advance Care Planning and Palliative care**
   a. Introduction to quality of care in serious illness and the growing need for patient advocacy, palliative care, and hospice
   b. Identifying at-risk patients
   c. Feedback of quality measure data on baseline practices

7. **Module 1: Advance Care Planning and Goals of Care**
   a. Key components involved in the process of advance care planning, how to engage in conversations about medical goals of care
   b. Focus on patient autonomy and the right to choose different approaches to care in serious illness
   c. Overview of primary documentation tools – living wills, Health Care Powers of Attorney, portable DNR orders, and portable MOST forms
   PRACTICE: Role play patient interview

8. **Module 2: Hospice and Palliative Care**
   a. Define hospice and eligibility criteria
   b. Define palliative care and types of patients able to benefit from services
   c. Explore approaches to address and overcome barriers
   d. Communication strategies
   PRACTICE: Problem-solving exercise on barriers to hospice or palliative care

9. **Module 3: Supporting Patients and Families through Serious Illness**
   a. Assist in the development of empathy and appreciation for unique reaction and journey of the individual patient
   b. Role of supportive care from family caregivers, volunteer caregivers, community and neighbors, faith communities
   PRACTICE: Grief and loss experiential exercise

10. **Module 4: Putting Palliative Care into Practice**
    a. Create individualized action plans
    b. Identify opportunities and challenges for implementing efforts
    PRACTICE: Teamwork exercise to assess and respond to a patient’s story
APPENDIX 3

An expanded discussion with program limitations and strengths

This study demonstrates how an educational and quality improvement (QI) initiative targeting CM in a statewide primary care practice network is effective to enhance CM communication about ACP and symptom distress, and to increase PC and hospice referrals for seriously ill Medicaid patients. CMs were motivated to make practice changes in ACP, hospice and PC referrals, and supportive care for patients and families. Quality indicator data provides evidence of actual practice change, with increases in care manager-patient communication with a subgroup of higher risk patients and new referrals to hospice and PC services.

Interestingly, this increase in referral to services had no clear effect on the percent of all non-dual ABD Medicaid patients enrolled in hospice within 90 days of death. The lack of effect on hospice use at death has several potential explanations. First, communication and referrals precede hospice use at the time of death. Many patients who were represented in the first two quality measures were still living at the time of analysis, and longer follow-up may be needed to show change in hospice use at death. Second, the increase in communication and new referrals may yet be too small, relative to the size of the population at risk, to affect the overall percentage of ABD Medicaid patients who enrolled in hospice. Finally, the inability to eliminate financial limitations and language and/or cultural barriers may have contributed to the lack of observed change in hospice utilization at death. Medicaid recipients are more likely to have lower socioeconomic status. This can result in the inability of friends and family to take time away from employment to provide the caregiver support that is necessary to remain home with hospice services. Also, they may lack funds to hire caregiver support outside the home. Additionally,
language and/or cultural barriers may limit access to and understanding of literature, media, and direct communication about the benefits of hospice services thereby negatively influencing utilization. CCNC analysts continue to track all of these quality measures quarterly in order to assess whether hospice use at death is changing over the longer term.

This intervention aimed to improve care for seriously ill, vulnerable patients through the integration of CM expertise with community resources and providers in a statewide primary care practice network serving Medicaid patients. The strengths of this program include the strong community-based, academic collaborations and the well-resourced practice network within which this initiative was implemented. The majority of PC programs have been developed in the hospital setting and there is emerging evidence how PC services following hospital discharge are associated with reduced 30-day readmission rates.\(^1\) CCNC’s PC initiative aimed to reach a defined population of individuals most likely to benefit from services based on utilization and diagnostic criteria beyond the hospital setting.

Additional strengths of this program included the format of training sessions as the time commitment was only one day and sessions were delivered across the state to target the greatest number of CM while limiting CM travel time. This one-day session provided intensive learning included didactics and role play activities with experts and develop partnerships to promote the future delivery of care. CM were invited to provide feedback following sessions on content for future educational programs. Additionally, toolkits were developed with resources specific to each region. Furthermore, this program included a QI component which entailed monthly meetings between network physician champions and coordinators in order to share best practices.
and to discuss progress in practice improvement based on network-specific quality measure data feedback.

The results of this educational and QI intervention study add to growing body of literature about programs to integrate PC principles into CM practices to serve community-based individuals living with serious illness\(^2\). Specifically, Aiken et al (2006) demonstrated patients with advanced congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) receiving intensive outpatient PC care management had higher adjusted mean scores on a four point likert scale (where 1=mostly false and 4=mostly true) for having received education about community resources at three months (1.80 to 2.57 vs. 1.76 to 2.02, p<0.05), knowledge of who to contact regarding medical concerns at six months (1.57 to 2.63 vs. 1.76 to 2.19, p<0.05), and knowledge of how to handle medical emergencies at six months (3.51 to 3.90 vs. 3.52 to 3.51, p<0.05).\(^2\) Outcomes at six months showed higher completion of living wills or advance directives by participants receiving PC care management services compared with controls, increasing from 52\% to 71\% (p<0.05) in the intervention group. Additional outcomes demonstrated resumption of activities participants enjoyed in the preceding four weeks (34\% to 49\%, p<0.05 at three months and 45\% at six months). COPD participants reported lower scores for symptom distress on a five-point scale (where 1=not at all and 5=very much) compared to controls which persisted at three months (4.38 to 3.41, p<0.05) and trended toward persisting at 6 months (2.85). The results of this study are promising and should guide future CCNC initiatives to evaluate how CM practices affect patient-centered outcomes.

Another ongoing two-group randomized pilot study by Allen et al (2012) is evaluating the feasibility and effectiveness of a home-based interdisciplinary (IDT) care management
intervention incorporating PC and geriatric medicine principles and targeting frail, elderly individuals with life-limiting illnesses through Ohio’s community-based, long-term care Medicaid waiver program. The elements of this program have been described in detail and include a comprehensive care management intervention sharing elements with CCNC’s PC initiative such as coordination of care, establishment of community partnerships, ACP discussions, symptom distress assessment, and expecting CM to play an integral role in goal-setting, creating care plans, and assisting patients with problem-solving. However, this program includes an interdisciplinary team (IDT), academic detailing for community providers, careful review of medications by geriatric pharmacists, improved communication systems (fax, phone, office visit), and the use of evidence-based protocols which synthesize recommendations from the Assessing Care for Vulnerable Elders (ACOVE) Project, the National Consensus Project (NCP) for quality PC, and the International Association of Hospice and PC (IAHPC). The outcomes to be assessed at three, six, nine, and twelve months include the following: 1) symptom management (Memorial Symptom Assessment Scale); 2) QOL/death (QUAL-E); 3) relationships (Meaning in Life Scale); decision making, care planning, continuity, communication (Patient Activation Measure); and 4) depression and anxiety levels (Hospital Anxiety and Depression Scale). The data are still being collected and, therefore, preliminary results are not yet available. However, certain program elements overlap with the CCNC PC initiative and future results may inform CCNC’s program.

Bakitas et al (2009) instituted a program to evaluate the effect of case management and education provided by advanced practice nurses (APN) with PC expertise to support patients with advanced cancer in the community. This program was evaluated during a randomized controlled trial in which participants received usual oncologic care or usual plus supportive care...
and education delivered by skilled PC APN. The latter included assessments for any distress secondary to physical or emotional problems, difficulties with family, challenges with practical issues such as work, and spiritual or religious concerns. Additionally, they included the opportunity to engage in problem-solving techniques based on the following four modules developed during a prior study, ENABLE I: 1) problem solving; 2) communication and social support; 3) symptom management; and 4) ACP and unfinished business. Study participants were offered four formal sessions and at least monthly follow-up thereafter pending needs assessment in association with appropriate referrals. In addition to encouraging patients to contact clinical services based on symptoms or needs, APN CM facilitated the process.

Furthermore, participants were invited to engage in shared medical appointments with a PC physician and a nurse on a monthly basis. Advanced PC practice nurses, physicians, and nurses participating in the intervention received training via didactics, written treatment manuals, role play activities, and problem solving.

Primary outcomes of this study included measures of QOL, symptom burden, and resource utilization (hospital and intensive care unit or ICU days, ED visits); a secondary measure was mood. QOL was higher for the intervention group (mean [SE], 4.6 [2]; p=0.02) based on the Functional Assessment of Chronic Illness Therapy for Palliative Care measure. There was a trend toward lower symptom intensity (mean [SE], -27.8 [15] as measured by the modified Edmonton Symptom Assessment Scale (ESAS). Scores for mood were significantly lower in the intervention group (mean [SE], -1.8 [0.81]; p=0.02) based on the Center for Epidemiological Studies Depression (CES-D) Scale. Interestingly, there were no significant differences for hospital days (6.6 vs. 6.5), ICU days (0.06 vs. 0.06), or ED visits (0.86 vs. 0.63). Additionally, post hoc analysis demonstrated no significant differences in survival with a median
survival of 14 months in the intervention group and 8.5 months in the usual care group. Although this study did not show significant differences in health care utilization, results did demonstrate outpatient PC care management programs are effective in improving QOL and reducing symptom distress for participants with advanced cancer. These results are promising and emphasize the importance of including patient-centered outcomes as part of future CCNC PC initiatives.

Another program, the Caring Connections Program (CCP), was a pilot collaborative effort between the University of Louisville Schools of Medicine and Nursing, the Kentucky Hospital Research and Education Foundation, and Passport Health Plan to promote the delivery of PC services for Medicaid recipients with advanced cancer via CM. A skilled care manager (n=1) provided assistance with ACP, disease education, plans of care to guide optimal symptom assessment and management, mechanisms to promote appropriate transitions of care, and strategies to facilitate communication with community providers. Over the three-year enrollment period, the program experienced a lower than expected referral rate from community providers (n=56) and failed to include patients with other serious or life-limiting illnesses beyond cancer. However, the program was well received by participants and several case descriptions detail how this program supported the delivery of PC on an individual basis. Highlighted successes included patient and family advocacy, self-management, coordination of care, facilitation of communication, promotion of ACP with appropriate documentation, decision-making support, encouragement of provider order completion, and support of appropriate transitions to hospice.

An additional pilot intervention project by Head et al (2010) aimed to develop and implement a program which integrated PC principles into the daily workflow of CM who were
serving Medicaid recipients. The target population in this study aligns with the CCNC PC initiative to integrate PC into Medicaid primary care in North Carolina. This twelve-month project enlisted leaders in nursing and social work (SW) with PC expertise to comprise the Palliative Care Case Management (PCCM) team which supported CM serving Medicaid recipients and facilitated key relationships with community services like clergy. This program included the development of a training curriculum for CM and other staff providing care similar to the CCNC PC initiative. In addition to learning about specific domains in PC, goals, management strategies, and common life-limiting illnesses likely to be encountered, CM received a total of 13 specialized training sessions on the appropriate identification of patients requiring PC or hospice services; in contrast to the CCNC PC initiative which involved a one day training session. Furthermore, a resource manual to guide care plans and facilitate referrals to appropriate community services was developed for CM reference, similar to the resource guide developed in the CCNC PC initiative.

This pilot project’s outcomes included: 1) evaluation of training sessions with pre- and post-test knowledge assessments; 2) impact of the program on patients; 3) CM acceptance; 4) managed care provider benefits; and 5) hospice referral patterns. Patients identified for the program were provided with the opportunity to participate in a research component to assess the program’s impact on symptoms and associated distress via the Memorial Symptom Assessment Scale, and to evaluate participants’ level of satisfaction with CM services. Of the 68 participants involved in the program, only 35 consented to the research component. Significant differences were found for symptom assessment between first and second physical sub-score measures, and between first and third sub-scores for psychological domains. Patient satisfaction scores were significantly higher after two months. In terms of hospice referrals, four participants were
referred to hospice care during the project. Additionally, individual cost analysis did show
significant cost reductions for patients receiving PC care management especially following
hospice transitions.

Evaluations by CM and other staff (n=15) were positive with the educational experience
being identified as the greatest strength. Weaknesses identified included heavy caseloads and
limited information about pediatric patients. The latter was similar to feedback provider by
CCNC CM following educational training sessions. CM in this program identified ongoing
education programs as opportunities to learn and deliver services while perceived threats to the
program included lack of physician support. This is similar to the feedback received following
the training sessions during the CCNC initiative. In terms of knowledge assessments, the post-
test mean scores were significantly higher than the pre-test scores (mean difference 5.4,
p<0.0001) suggesting CM felt they had more knowledge regarding PC principles following the
training sessions. The CCNC initiative did not include pre/post-test knowledge scores, but
should be considered for future intervention studies.

Another industry/academic collaborative PC initiative by Meier et al (2004) led to the
development of a CM program serving seriously ill, commercially-insured patients with complex
needs, independent of prognosis. The four specific objectives of this project included: 1)
development of training modules highlighting PC key principles for CM and strategies for
physician engagement; 2) formal assessment with physician feedback; 3) outcome evaluation for
participants receiving PC CM services compared to standard CM; and 4) feasibility assessment
of this model for patients, families, providers, and industry. Overall, this program aimed to
identify unmet symptom needs, to support complex decision making and ACP, and to effectively engage medical providers.

Intervention assessments included a communication toolkit with an ACP questionnaire to assess patient’s readiness to engage in discussions about ACP with family and providers, and several validated instruments to assess symptom burden and well-being: the ESAS, Missoula-VITAS QOL Index, and the Morpace Satisfaction Instrument; the assessment occurred every two weeks for stable participants and weekly if patients were unstable. Symptoms and associated treatment protocols based on computerized treatment recommendations were forwarded to PCP offices by telephone.

The program outcomes included the percent of eligible participants who agreed to participate and from whom assessments were obtained, assessment results, overall acceptability for all participants, and the overall impact on patient care. Additionally, this study assessed measures of utilization including hospital and ICU days, ED use, inpatient/outpatient physician visits and relative value units, CM length of involvement, referrals to hospice, home care use, analgesic/anxiolytic/antidepressant prescribing, and place of death. While investigators reported this program demonstrated improvement in patient and family satisfaction and general feasibility, the data for this study have not been published.

Rabow et al. (2004) designed a randomized controlled trial to evaluate the role of an interdisciplinary comprehensive care team (CCT) including social work CM, and a nurse, a chaplain, a pharmacist, a psychologist, an art therapist, a volunteer coordinator, and three physicians to deliver outpatient PC to adult patients with cancer, advanced COPD and CHF with a life expectancy of one to five years. This program randomized participants based on a “coin
flip” to the intervention group (n=50) which received care from the CCT or to a control group (n=40) which received standard primary care. The CCT intervention included seven components: 1) CM providing initial patient assessments to make recommendations based on physical and psychological symptoms, social support, spiritual well-being, and ACP (provided to PCP in writing/email); 2) CM supporting ACP in person and by phone; 3) a nurse offering caregiver training; 4) a pharmacist reviewing charts for potential medication interactions; 5) a chaplain providing spiritual and psychological support; 6) participants being invited to and attending monthly support groups; and 7) medicine and pharmacy students calling patients weekly and providing support and advocacy.

Outcomes assessed in this program included functional status, symptom burden, QOL, level of satisfaction, and ACP which were obtained via surveys at enrollment, six months, and 12 months. Computerized billing records were extracted to determine charges for office visits, ED visits, and hospital days. Symptom assessment at three months revealed the CCT group experienced significantly less dyspnea (p=0.01) with a trend toward an improved sleep quality while there was no difference in pain level. Additionally, the CCT group reported higher spiritual well-being (p=0.007). There were no differences in QOL or health care satisfaction. Interestingly, although the CCT recommended antidepressants for 46% of participants, only 17% (n=3) had newly prescribed medications. In terms of ACP, 55% of CCT participants (n=12) and 28% (n=5) of controls designated a health care power of attorney.

Measures of health care utilization showed CCT participants made fewer PCP visits during the 12 month study period (mean, 7.5 vs. 10.6; p=0.03) and urgent care visits (mean, 0.3 vs. 0.6; p=0.03). However, there were no statistically significant differences for subspecialty
visits, ED visits, hospital days, and number of hospitalizations. There were no statistically significant differences with respect to place of death or overall health care charges.

Overall, previously described studies draw attention to CCNC’s PC initiative strengths as discussed above as well as limitations. One limitation is the training session evaluation method only included CM feedback, but there were no measures of pre and post knowledge scores. Although CM received education about symptom assessment and management, the program did not include disease-specific symptom management protocols to guide CM practices or recommendations to providers. Additionally, the program did not include comparison groups to determine differences in practices based on those CM exposed to the educational and QI components versus those just exposed to the QI component. Furthermore, although the program elements included tracking of CM communication of seven key PC questions and PC and hospice referrals, data collection did not include how these practices affected 1) actual access to hospice and PC; 2) patient-centered outcomes such as reduction in symptoms, improved QOL, improved level of satisfaction for patients and families; 3) completion of medical order forms and congruence of actual treatment received with preferences for care; or 4) health care utilization and costs. Careful consideration and analysis of patient-centered outcomes are essential in future research to ensure changes in healthcare delivery are well-matched to the needs and preferences of patients with serious illness and their families. Given rising costs associated with health care expenditures in the last year of life, it will be important to examine the impact of PC interventions on health care utilization and costs.

Additional limitations to the study include the analysis of actual hospice use at the time of death. This was limited to the subset of 57% of North Carolina Medicaid enrollees who have
Medicaid as their sole insurer; data for patients dually enrolled in Medicare and Medicaid was not available to investigators. Medicare patients use hospice at a higher rate, and thus this data may underestimate actual hospice use. The study implemented a complex intervention in a unique primary care practice network. CCNC is a well-established innovative model of care, and the organization’s PC initiative is continuing to add new elements over time. As a result, precise replication of this intervention outside this well-resourced and efficient practice network may be challenging.

Integrating CM in the delivery of clinical services to chronically ill patients is an increasingly common approach and elements of this intervention may be replicated in other primary or specialty care practices encompassing an interdisciplinary approach to care. This model program demonstrated an effective statewide intervention to provide CM in a primary care practice network with the knowledge, skills, and community resources to improve communication about ACP and symptom distress, and increase referrals to hospice and PC for seriously ill Medicaid patients. These results are promising and may guide future community-based interventions to facilitate access to collaborative primary and PC experts for vulnerable populations. Future intervention research should assess the effect of increased conversations and referrals on actual access to services. Quality improvement and intervention research should consider expanded performance metrics to capture specific PC intervention effects on patient-centered outcomes, healthcare utilization, and cost. Creating more patient-centered systems of care can promote patient autonomy, improve quality of life, and lead to more effective utilization of health care resources for patients living with serious illness.
REFERENCES


### APPENDIX 4: Logic Model

<table>
<thead>
<tr>
<th>RESOURCES</th>
<th>ACTIVITIES</th>
<th>OUTPUTS</th>
<th>SHORT-TERM OUTCOMES</th>
<th>LONG-TERM OUTCOMES</th>
<th>IMPACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>In order to accomplish our set of activities, we will need the following:</td>
<td>In order to address our problem, we will conduct the following activities:</td>
<td>We expect that once completed or underway, these activities will produce the following evidence of service delivery:</td>
<td>We expect that if completed or ongoing, these activities will lead to the following changes in 1-3 years:</td>
<td>We expect that if completed or ongoing, these activities will lead to the following changes in 4-6 years:</td>
<td>We expect that if completed, these activities will lead to the following changes in 7-10 years:</td>
</tr>
<tr>
<td>Funding source</td>
<td>Identify project director</td>
<td>Collaborative program with educational and QI components</td>
<td>Improve CM understanding of hospice and PC programs including key differences and eligible patients</td>
<td>Further define effective “PC interventions”</td>
<td>Improve patient-centered outcomes to include family/patient satisfaction, symptom distress, QOL</td>
</tr>
<tr>
<td>Identification and endorsement by key stakeholders</td>
<td>Identify regional champions within CCNC practice network</td>
<td>High quality educational curriculum</td>
<td>Improve CM awareness of community resources and toolkit utilization</td>
<td>Improve patient/family awareness/comfort level with hospice and PC services</td>
<td>Improve provider satisfaction</td>
</tr>
<tr>
<td>Strong organizational support to establish well aligned with organizational strategic plan and goals</td>
<td>Develop partnership with academic-based institution</td>
<td>Well-resourced toolkit</td>
<td>Improve CM coordination of care with physician practices</td>
<td>Increase access to hospice and PC</td>
<td>Demonstrate congruence in receipt of care consistent with preferences</td>
</tr>
<tr>
<td>CCNC Practice network and UNC institutional resources</td>
<td>Partner with community-based experts to determine community resources and to facilitate training</td>
<td>Number of CM participating in educational training</td>
<td>Improve patient/family autonomy</td>
<td>Reduce symptom distress and improve QOL</td>
<td>Reduce rates of hospitalization and death in the ICU for patients with neurodegenerative disorders, COPD, CHF, advanced cancer</td>
</tr>
<tr>
<td>Strong community and academic-based collaborative relations</td>
<td>Convene advisory group to design the program, develop educational curriculum, identify community resources, and develop toolkits</td>
<td>Knowledge about level of satisfaction with educational training</td>
<td>Improve referrals to hospice and PC for eligible patients and actual number of patients who die with hospice</td>
<td>Improve identification of HCPOA and completion/utilization of medical order scope of treatment forms across settings</td>
<td>Reduce inappropriate utilization of healthcare</td>
</tr>
<tr>
<td>Educational curriculum</td>
<td></td>
<td>Data about number of</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## APPENDIX 4: Logic Model

| Regional toolkits | Computer-based tracking system and database | A location in each region to deliver training | Survey for CM to evaluate training sessions | Provide educational training across the state to target the greatest number of CM with consideration of regional variations in resources | Develop surveys to evaluate CM level of satisfaction with training and identify opportunities for improvement | Develop database | Increase number of at-risk patients asked at least one PC question by a CM; hospice referrals; hospice enrollment within 90 days of death | Increase number of patients asked at least one PC question by CM, and improve discussions about ACP, symptom distress | Increase level of interprofessional collaborative practice across the state to improve access to services | services and costs |

| | | | | | | | | | | |