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Enhancing Palliative Care for Low-Income Elders with Chronic Disease: Feasibility of a Hospice Consultation Model

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Abstract

Challenges exist in assimilating palliative care within community based services for nursing home eligible low-income elders with complex chronic illness as they approach the end of life. This study assessed the feasibility of a consultation model, with hospice clinicians working with three Care Wisconsin Partnership Program teams. Consults occurred primarily during team meetings and also informally and on joint patient visits and were primarily with the palliative care nurse addressing physical issues. 57% of consultant recommendations were implemented. Benefits of consultation were identified with focus groups of clinical staff as were opportunities and barriers to the implementation. Models of integration are proposed.

Introduction

The population of the United States (U.S.) is aging rapidly. The number of adults in the U.S. age 65 or older will more than double to approximately 71 million by 2030 (Center for Disease Control, 2011). Approximately 80% of older adults have at least one chronic disease and the numbers of elders living in the community with serious, eventually fatal chronic conditions has increased dramatically over the last decade placing tremendous strain on family members (Wilkinson & Lynn, 2005). Chronic diseases, such as cancer, dementia, heart and lung disease and diabetes are among the leading causes of death (Gorina, Hoyert, Lentzner, & Goulding, 2006). The Medicare Hospice benefit, initially established in 1982, is “well suited to the care of patients with cancer and people who need support at home for a

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short time at the end of life” (Shugarman, Lorenz & Lynn, 2005, p. 255). Further, for many elders with chronic conditions, years may lapse between diagnosis and end of life, and it is often difficult to recognize when the chronic condition becomes terminal. Although efforts have been made to widen the net of patients served to include diseases other than cancer, regulatory and other barriers limit service utilization of hospice and specialty palliative care services among elders who die with chronic, progressive, and ambiguous co-morbid conditions (Ahmed, Bestall, Ahmedzal, Payne, Clark, & Noble, 2004; Fox, Landrum-McNiff, Zhong, Dawson, Wu, & Lynn, 1999). Given the variability in how and where elders die, the challenge of our fragmented health care system, the scope of need, and regulatory barriers, a variety of approaches are called for to achieve meaningful reform (Shugarman et al., 2006).

Innovations in Care for Frail Elders

Recommendations to meet the complex chronic care needs of frail elders and their family call for health care systems that provide comprehensive interdisciplinary, medical and community care with services tailored to emerging needs, integration of care across settings, and anticipation of death as eventual outcome (Field & Cassel, 1997; Lynn & Adamson, 2003). These recommendations are especially important for the 5.5 million elders who are dually eligible for Medicare and Medicaid (Social Security Administration, 2011), who constitute the most vulnerable sub group of Medicare beneficiaries (Kaiser Commission on Medicaid and the Uninsured, 2011). In recent decades several innovative programs have been developed to more effectively meet the needs of elders with chronic conditions as an alternative to traditional long-term care programs (e.g., nursing home). For example, the “Wisconsin Partnership Program (WPP) and the related Program for All-inclusive Care for the Elderly (PACE) have emerged as systems of care that are ideally suited to provide comprehensive community based care for nursing home eligible low-income elders with complex chronic illness” (Kramer & Auer, 2005, p. 651). Emphasizing interdisciplinary consumer-directed care, provider consistency within health professional teams, and integrated financing (Sachs, 1995), these programs integrate long term care (i.e., primary and acute) under Medicare and Medicaid capitation arrangement, and share comparable consumer satisfaction (Kane, Homyak & Bershadsky, 2002). Another innovative program is the partially integrated Medicaid managed long term care model, the Wisconsin Family Care program. This program makes use of interdisciplinary teams, that include a care manager (often a social worker), and a registered nurse, that assess and manage the comprehensive care needs of elders served (Alexih, Olearczyk, Neill, & Zeruld, 2003).

End-of-Life Care Challenges Faced by Innovative Elder Care Models

Although these programs are viewed as innovations in elder care that are influencing the development of programming in other states that seek to replicate and expand on these models (APS Healthcare, 2005; Leutz, 1999; Polivka & Zayac, 2008), they were not originally designed to “care for the dying.” Yet approximately 75% of elders in the Wisconsin Family Care program and 72% of the Wisconsin Partnership program remain enrolled until death. Recent evidence suggests that these innovative care models are beset with challenges in providing care at the end of life. For example, in a recent study of the Milwaukee County Family Care program, lead supervisors and care managers reported substantial end-of-life

care challenges due to complexity of care and high level of support needs, reluctance of elders and families to engage in advance care planning, family conflicts in end-of-life decision making, insufficient communication and collaboration between elders, families, teams and service providers, and limited bereavement and grief support for families and teams after elders die (Kwak, Kramer, Lang, & Ledger, 2012). Similarly, through ongoing research and a continuous quality improvement collaboration between the Primary Investigator (first author) and the Care Wisconsin Partnership Program (CWPP) of Dane County (previously called Elder Care Partnership), it was revealed that the CWPP staff face many challenges in providing end-of-life care and that there are several areas in which they feel they could improve end-of-life palliative care provision to low-income elders with multiple co-morbid chronic conditions (Kramer & Auer, 2005).

Efforts to address these challenges and enhance palliative care in these and other community-based long-term care models must acknowledge the reality that team members providing chronic care may have difficulty recognizing when a medical condition becomes terminal. Indeed, there may not be a clear cut division between care to treat the condition and palliative care. Second, team members may be insufficiently prepared to identify and address end-of-life care needs. Indeed “Fulfilling specialist requirements is difficult for a professional when palliative care is not the main focus of daily activity” (Vernooij-Dassen, Groot, van den Berg, Kuin, van der Linden, van Zuylen, Crul & Grol, 2007, p. 316). Although one solution might be to simply encourage more referrals to hospice, this is an overly simplistic and insufficient solution given that for most elders, “a mix of curative and comfort care...is most effective” (Hume, 1998, p. 2), and the existence of financial and practical disincentives. Consistent with other research documenting prognostication challenges as a barrier to hospice utilization, the complex and unpredictable nature of advanced chronic disease and co-morbidities of the population served in the CWPP, were reported as persistent challenges, exemplified in fifty-four percent of deaths reviewed (Kramer & Auer, 2005). Other widely documented barriers to hospice enrollment include patient, family or clinician inability or reluctance to identify or accept that one is dying; lack of knowledge regarding eligibility criteria, cultural or religious barriers; hospice benefit regulatory barriers, and patient preferences for continuity in care (Tilden & Thompson, 2009; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). Integrated community-based models such as PACE and WPP are predicated on long-term continuity of care from an interdisciplinary team including physician, nurse practitioner, registered nurse, and social worker. Due to regulatory constraints, referral to hospice may lead to change in the long-term provider relationships and fragmentation of care.

Need for Enhanced Collaboration between Hospice and Community-Based Long Term Care

Acknowledging the challenges of a rapidly growing population of elders with multiple, chronic progressive conditions who often have complex needs and fragile social support systems, training service providers across the continuum of care and developing strategies to enhance collaboration between hospice and community-based long-term care programs is essential. National standards call for “professionals at all levels to have the necessary knowledge, skills and attitudes to deliver care for those at the end of life (Procter, 2012, p.

339), and clinical practice guidelines for quality palliative care advocate for continuity in care, collaborative relationships between service providers and hospice, and commitment to quality improvement initiative (National Consensus Project, 2009). In addition, as “increasing emphasis is placed on the medical home, chronic and advanced illness care, and systems changes to decrease care fragmentation, geriatrics and hospice and palliative medicine stand to benefit by blending efforts and common interests to improve care for patients and their loved ones.” (McCormick, 2012, p. 583). Palliative care consultation models have been used successfully to enhance care provided by other health care professionals with less experience (Vernooij-Dassen et. al. 2007) and may offer one method for enhancing collaboration and palliative care provision among team members in the fully integrated managed care model.

The purpose of this study was to assess the feasibility of a “consultation model,” whereby a hospice nurse (RN) and social worker (SW) were available to provide palliative care consultation to three CWPP teams for a 10-month period. This pilot study sought to address four primary study aims: (1) determine the extent to and ways in which consultants will be used by the teams; (2) identify the potential benefits of consultation from the perspective of the CWPP staff, (3) examine the extent to which consultation will assist CWPP team members to enhance their perceived success in the provision of palliative care; and (4) identify implementation challenges or barriers associated with the consultation model.

Methods

Setting and Sample

CWPP was chosen over the three other WPP sites in the state of Wisconsin because it is the largest, and has been operating for the longest period of time. CWPP employed 10 Interdisciplinary Teams each consisting of Master’s level Social Worker, a Nurse Practitioner (NP), and two Registered Nurses (RNs) at the time of this study, with each team providing care to 40 to 50 low income older adults with chronic diseases who were at or near nursing home level of care. Teams contract with the elder’s physician, who, jointly with the NP, manages the participant’s medical care. CWPP had enrolled approximately 470 elders, with 289 current enrollees, at the time of the study, with annual incomes below \$10,000, an average of 29 medical diagnoses, 7 – 8 major chronic medical conditions, and 3 or more Activities of Daily Living dependencies; nursing home eligible. The average length of enrollment in CWPP was 2.4 years, and the primary reason for disenrollment was death.

Design

This project was a descriptive longitudinal (10-month) case study that documented how three CWPP interdisciplinary teams made use of and potentially benefit from having a hospice RN and a hospice SW available at 25% FTE each, to consult regarding issues relevant to clinical care of dying elders with advanced chronic disease. The study was guided by a pragmatic perspective, a view that is increasingly employed in applied and social science research in which emphasis is on the “practical implications of the research” of real world problems (Creswell, 2013, p. 28), and the selection of study questions, and research design and methods that consider the practical consequences of the research

(Cherryholmes, 1992). The format of the consultation intervention was determined by the study authors (BK and JC) in collaboration with the hospice RN and SW, the CWPP Medical Director (JM) and the CWPP Quality Improvement Manager, and was approved by the Institutional Review Board of the researchers' academic institution. Although we considered including a hospice Chaplain on the consultant team, we decided against it for two reasons. First, CWPP teams work with the elder's personal spiritual care provider as needed and there is not a Chaplain designated to the team. Second, funds were not available to cover more than two consultants. The consultants, paid through a grant from the National Cancer Institute as part of the *Integrating Aging and Cancer Research Grant*, participated in weekly, 2 hour CWPP interdisciplinary team meetings. In these meetings, CWPP team members discuss interdisciplinary care of those elders who have active, acute, subacute, chronic, or palliative needs of a medical, psychosocial, or functional nature. The hospice RN and SW engaged in problem solving and planning with the teams as relevant cases were reviewed. CWPP teams maintained full responsibility for care provided to elders, but had the hospice RN and SW available to them for consultation in the care planning process. The consultation model was flexible to meet the needs of the teams. For example, although consultants were required to attend weekly meetings, teams could additionally call upon them at their discretion for phone consultation or request their presence on home visits as necessary.

Data Collection

Three primary sources of data were collected.

Consultation Documentation Sheet and final report completed by Research Staff—As part of their research duties, hospice consultants recorded in detail the nature of their consultation activities. They documented who requested the consultation, the nature of the inquiry (i.e., the issue or concern to be addressed), the setting in which the consultation took place (e.g., team meeting, phone, home visit), the nature of their recommendation (i.e., what they advised), the extent to which the recommendation was implemented, and their perception of outcomes that might have been affected by the consultation. At the end of the study, the consultants prepared written responses to the following questions. What was it like to serve as a consultant to the CWPP teams? What were the advantages or disadvantages to different forms of consultation? How do you think the team members influenced you? How do you think you influenced them? In what situations is consultation most beneficial or useful? What do you think was most/least helpful about the consultation service? What problems or barriers developed in the consultation service? Is there anything that could have been done differently to improve the consultation model? This data is used to address study aim 1 and 4.

Deceased Participant Survey Completed by CWPP Team Social Worker—CWPP social workers completed brief surveys to describe the team member's experiences with the consultation model in relation to caring for elders who died during the 10 months of the intervention and for whom consultation was utilized. This survey is a streamlined version of a more detailed survey that was previously completed by all of the CWPP social workers during a two year period prior to the onset of this study, following the deaths of 120

elders (Kramer & Yonker, 2011). This *brief survey* elicited the primary causes of death from broad categories of diagnoses, primary residence and place of death, and questions relevant to the end-of-life care needs of the patient. (i.e., pain, medication management, caregiver support, psychological and emotional response of the elder, psychological and emotional response of the family, spiritual issues, grief and/or bereavement and coordination with facility). As noted elsewhere (cite other paper under review with the journal; blinded for review), for each end of life care need that was addressed by the teams, social workers were asked to “Rate the extent to which you believe that you and/or the team was successful in achieving goals relevant to each condition, issue, or need during the last six months of life” (1 = *a little* to 4 = *extremely successful*). In addition, an open ended question elicited the social workers’ description of the ways in which the palliative care consultants assisted the team in providing end-of-life care. Comparing ratings on “extent to which the team was successful in achieving goals” relevant to palliative end of life care pre and post the consultation model will provide a modest way to determine if hospice consultation might increase perceived success. This survey data is used to address study aim 2 and 3.

Focus groups with CWPP Team Members—Focus groups were conducted separately for each team involved in consultation at the end of the 10 month period to explore experiences with the consultation model. The focus groups were audio taped and transcribed. Questions inquired about what it was like to receive consultation, perceived advantages and disadvantages to different forms of consultation, what was gained, what was learned, problems or barriers in the model, and outcomes affected by the service. Sample questions from the focus groups include: “What was it like to have the palliative care consultants available to the team? What were the advantages or disadvantages to different forms of consultation? How do you think the hospice consultants influenced you? In what ways did the consultation service influence care provided? What was most/least helpful about the consultation? In hindsight, is there anything that could have been done differently to improve the consultation model? Focus group data is used to inform study aim 2, 3 and 4.

Data Analysis

Descriptive statistics were used to summarize quantitative data from the deceased participant survey and the consultant documentation sheets will be reported. All qualitative data, including the social workers’ hand written comments on the surveys and the audio tapes from the focus groups were transcribed verbatim, reviewed by the primary investigator and compared with the original documents and audio files for accuracy. Directed content analysis, a structured deductive approach, was conducted to identify major themes related to the study objectives (Hsieh & Shannon, 2005). Consistent with this method, content categories (i.e., potential consultation benefits, consultation influence in enhancing perceived success in provision of palliative care and implementation challenges or barriers) were predetermined (Hsieh & Shannon, 2005). Directed content analysis involves coding, data reduction, and theme identification in relation to the predetermined content categories (Graneheim & Lundman, 2004). A three-step approach was followed. Initial line by line open coding of the transcripts yielded key phrases or meaning units that formed initial codes relevant to each of the content categories. Definitions for each of the initial codes were developed. Next, codes were clustered into families of categories or concepts and refined

into sub-themes that were further defined (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

Several approaches were employed to enhance rigor (Padgett, 1998) including prolonged engagement (i.e., this was a 10 month study involving ongoing data collection rather than a one shot survey effort), triangulation (i.e., data were obtained from a variety of sources and representing views of team members and consultants), member checking (i.e., findings were presented to consultants and at staff meetings to validate the codes generated), and auditing (i.e., careful documentation of the process was followed in the development of codes, memos, and analytic decisions).

Results

Ways Consultants were used by Teams

The first study aim sought to identify the extent and ways in which the consultants would be used by teams. The consultants provided a total of 184 incidents of consultation over the ten month period. Approximately 25% (n = 47) were general educational recommendations arising in conversations not salient to particular patients. A total of 30 patient's needs were addressed during the ten month period; 19 of these (approximately two-thirds) died during the course of the study. Consults occurred primarily during regularly scheduled 2 hour CWPP interdisciplinary team meetings as patient care plans were discussed (84% and 77% for nurse and social worker respectively). A total of 12 home or site visits were scheduled in the later phase of the study. A larger number of consults were sought from the nurse than the social worker; 140 versus 44 respectively. The majority of nurse consults (n = 64) involved helping team members recognize and address physical declines in functioning, and physical issues centered on pain and medication management (n = 33). Nurses and NPs tended to have specific request regarding palliative treatment for symptoms. Interestingly, 50% (n = 22) of the consultations documented by the hospice social worker, were those she offered to educate team members as opposed to being directly asked for consultation. Only 10% (n = 13) of the total nursing consults were those offered versus those requested. It is possible that social workers feel more comfortable in their knowledge of psychosocial issues across the continuum of care, although most social work consults centered on helping team members to understand and address psychological, emotional and spiritual issues (n = 23) and family support (n = 17). Of the recommendations made by the consultants, 104 (57%) were implemented.

Benefits of the consultation from the perspective of the staff

The second study aim sound to identify the benefits of the consultation model as perceived by CWPP team members. Seven major themes were identified from the focus group data to represent the benefits of the consultation model from the perspective of the team members. These themes represent aspects of the consultation model that were viewed as particularly useful. These themes, along with four identified sub-themes and illustrative quotes are presented in Table 1 and described below.

Enhanced Comfort and Conversational Skills to talk about Death and Dying—

Palliative care consultants modeled a high degree of comfort and ease in talking about death and dying, and discussing end-of-life issues. Their ongoing involvement with the consultants over this 10-month period and repeated invitations to consider and talk about end-of-life issues, and to normalize the dying process, substantially reduced death anxiety for some of the team members that inhibited conversations with elders and their family members. Tremendous benefit was gained from learning a different vocabulary and method for approaching conversations related to death and dying. Consultants shared case examples from past experience to illustrate concepts, offered words and metaphors to use in communicating with elders and their family members (e.g., “journey” instead of “death”), and offered more skillful ways to introduce sensitive topics. During home or site visits, consultants modeled communication skills, and then also provided critique, affirmation and feedback of observed team member’s conversations with elders and family members.

Increased Recognition of the Dying Trajectory—Participating in weekly team meetings gave consultants substantial insights into the elder’s level of functioning and care needs. One of the nurses commented that the consultants “had this objective ear to hear things we don’t hear.” Their enquiries from the “outsider’s perspective” pushed teams to see and think in different ways about the health status of elder’s served and helped them to recognize when a participant was approaching end of life.

Increased Understanding of Interventions for Treating Pain and Other

Symptoms—Palliative care consultants were able to help team members learn the “tricks of the trade” for treating pain and other symptoms that were viewed as highly novel by team members. They also helped to confront some of the misperceptions about pain treatment to encourage more aggressive pain management.

Increased Understanding of how to Help Family Members Understand the Dying Process—

In addition to increasing comfort and skills to talk about death and dying, another benefit of the consultation model was helping team members understand how to help family members understand what to expect during the dying process. They modeled ways to communicate the stages of dying and what family members might expect to see, and also how to normalize loss of appetite so that family members could feel less anxious about mom or dad not eating.

Increased insights about End-of-Life Care Needs—There were two subthemes that were relevant to ways in which the consultants helped team members gain insights about the end-of-life care needs of elder’s served. First, teams were *empowered to address wishes* that they previously would have felt impossible. The illustration provided in Table 1 describes a scenario in which a chronically ill woman’s desire to take a trip seemed highly impractical, until the consultants helped the team to understand that this might be “her last trip to see her family in Florida.” Second, teams were pushed to understand the importance of *spiritual needs*, and as a result began to ask simple questions about religion and spirituality.

Introduction to Ritual to Memorialize Elders—As they learned about some of the hospice customs from the consultants, team members were introduced to the value of norm

of having a ritual in place to memorialize the deceased and assist staff in their grief. The quote provided in Table 1 illustrates the impact this idea had on one of the team members who is hopeful that their team will implement such rituals in the future.

Crossed Boundaries to Enhance Collaboration—A very important benefit that resulted from this consultant model was enhanced appreciation for both team members and palliative care consultants regarding the similarities and differences and strengths in the services provided by CWPP and hospice that helped to reduce some of the barriers to inter-agency collaboration. A fee for service arrangement with hospice evolved between the two agencies during this study and one of the teams involved in the consultation model was the first to make use of it.

Extent that Consultation Enhanced Team Members' Perceived Success

The third study aim sought to examine the extent to which consultation would assist CWPP team members to enhance perceived success in the provision of end-of-life care. Pre and post consultation mean ratings regarding the extent to which teams believed they were successful in achieving goals relevant to common issues in EOL care are presented in Table 2. Although the small sample sizes preclude the estimation of the significance of the difference in pre and post scores, all post consultation mean scores were higher for all three teams on all of these items. These means support the qualitative data suggesting enhanced sense of skills, knowledge and comfort. One nurse practitioner noted that after “doing it for 10 months and talking about it with a lot of our older participants and our hospice team members, I think everybody’s gotten better at it. Maybe we don’t even notice how much better at it we are.”

Implementation challenges or barriers associated with the consultation model

The fourth study aim sought to identify the challenges or barriers to implementation of the consultation model. The feasibility of this consultation model is influenced by several barriers to be addressed in future study. First, early misperceptions that palliative care consultants from hospice could only be utilized in care situations involving “active dying,” constrained consultant involvement. For example, a nurse practitioner shared “I was in the mode of using them for actively dying process, I think that was kind of a misperception I had and I don’t know why.” She went on to say that if she could do it over she “would identify people... who have a hard time even talking about loss of function and how they cope with that, let alone thinking about death and dying, and I probably would want to do a joint visit right away to introduce them.” Second, some team members felt defensive receiving suggestions from “outsiders.” A social worker shared “I think a barrier for me was defensiveness. Sometimes the way they would express things about you know well “why didn’t you ask this?””

Third, although home visits appeared to be a very important method for feedback and modeling, team member’s apprehension about introducing consultants to participants as “hospice” employees. It took time for team members to find the right language to use to invite elders to have a home visit from a hospice consultant. Dying elders who were in denial about their end of life status and elders who were not comfortable having

conversations about death or dying or planning for end-of-life care, tended to react negatively to a hospice consultant. Team members learned how to engage elders by emphasizing the palliative benefit of a consultant's visit while honoring the elder's preferences and perspectives. In addition, scheduling difficulties from both agencies limited planned and impromptu visits. In the end, several team members expressed sincere regret that they did not involve consultants more consistently and on home visits earlier as illustrated in the following two quotes

I think the meeting part was alright. I know we did use them on the phone a few times. For me I got the most out of pulling her (the social worker) in on the situations and going out with her to see someone. And that is why I regret not pulling her in earlier...that's where I learned the most and then she saw me working with them too and could voice how I could have done it differently, so I was getting feedback that way too.

I think we realized near the end that we missed out and it would have been better if we had just taken them out on visits where they could meet them initially, whether they were in the dying process or not, and then they could get a sense too of where we are at and work from there. It seemed that we came to some conclusions at the end that maybe if we would have started with those conclusions it would have been easier, like maybe we should have introduced the consultants to all of our participants right off the bat. So that when we brought them in in EOL situations when it kind of arose in a crisis way, it wasn't a huge surprise that they had met them before.

Fourth, the consultants' time was not fully utilized during the weekly team meetings. The majority of patients who were discussed at team meetings were not at or near end of life. Team members felt concerned about wasting the consultant's time when they were not directly involved as illustrated here: "Felt bad that they had to listen for everything, such as resource allocation, and I felt so bad for them that they had to sit through, you know talking about meals on wheels and just you know, those real mundane things that I hate to sit through and then they had to sit through it." A great deal of discussion ensued regarding how the consultation model might be adapted in order to address this particular challenge. There were two primary themes that represented alternative approaches that could be considered in model redesign. These included 1) doing formal combined team-consultant case review, and 2) considering the use of an "on call" consultation model to use consultant time more efficiently as illustrated in the following example quotes:

I'm wondering if there could be set times where we would go through our whole case load, well this person is completely independent, they drive, and this one has been hospitalized 5 times and this or that. Because sometimes we'd just be talking at the team meeting about someone and they'd say, well that person is EOL, and I'd look at them like "they're EOL, what do you mean?" um and so I think maybe some kind of a shortened meeting where we would just go through our participants and kind of give them a flavor for what the ppt. was doing and things and just have them give their opinion about it.

I would change it to an as needed, kind of an on call basis, to use them as needed. And again there are different levels of comfort with different employees, so it just seemed like, because not all of our participants are actively dying, in fact most of them are doing ok. It seems like a waste of consultant's time. For weeks sometimes nothing would happen. Yeah, like if we have an active process happening, like we need you at this meeting.

Finally, team members described some barriers they faced in implementing recommendations for pain medications that primary care physicians viewed as not customary for treating chronic disease, as illustrated in the following quote: "I think some of it might have been when they have recommendation for medications, some of the barriers were from physicians, um, because some of it was pretty new or novel and (Ritalin), shot down by the doctor."

Discussion

Well-coordinated continuity of care and careful monitoring and management of services are foundational service delivery elements for meeting the complex care needs of frail low-income elders with complex chronic diseases (Lynn & Adamson, 2003). Integrated managed care organizations have an advantage of offering coordinated, comprehensive, and continuous care across settings that are not customary in other fragmented health and social service delivery systems (Hume, 1998). Professionals in these organizations bring substantial expertise and skill to the work that they do, but as is reported by professionals from a variety of disciplines across care settings (Block & Sullivan, A.M., 1998; Csikai & Rayamer, 2002; Ryan, Guerin, Dodd, & McEvoy, 2010; Sullivan, Lakoma, Matsuyama, Rosenblatt, Arnold & Block, 2007), without specialist training in palliative and end-of-life care, team members may not be adequately prepared to meet the physical, social, psychological and spiritual needs of patients and their families that typically intensify as chronic diseases progress through the dying process.

Findings provide preliminary evidence that offering regularly scheduled nursing and social work palliative care consultation to professionals in this community based managed care program may enhance knowledge and practice to improve care of elders dying from advanced chronic disease and enhance inter agency collaboration. From the perspective of team members who had the consultants available to them, they gained confidence and communication skills for talking about death and dying, were better able to recognize the dying trajectory, increased their knowledge and skills for treating symptoms and addressing family member concerns related to the dying process, increased insights about end-of-life care needs and greater recognition of spiritual needs, and learned the value of ritual to memorialize elders. Pre- and post-consultation mean ratings increased on measures of the extent to which teams believed they were successful in achieving palliative care goals. Importantly, consultants and team members developed greater appreciation of the differences between the hospice and CWPP service settings and barriers to collaboration were reduced. For example, as a result of gaining a better understanding of eligibility criteria for hospice, two of the teams identified patients appropriate for hospice referral and a fee for service contact was formalized during the course of the study. In the end, team members

wished the palliative care consultation service could continue. One nurse said “I wish they were still available to come. We do miss them.”

As palliative care is promoted as ideally suited to meet the needs of older adults (Lo & Woo, 2006), and as specialty palliative care services are diversifying to reach patient populations in a variety of settings (Froggatt, 2001) innovations for infusing palliative care philosophy and practice will need to be developed to train and or partner with professional service providers in divergent settings. Ideally all professionals who work with patients with chronic and/or life threatening illness should be trained in the fundamentals of palliative care, which was an important goal underlying the national training programs for physicians (i.e., Education Physicians in End-of-Life Care), nurses (End-of-Life Nursing Education Consortium Project) and social workers, psychologists and chaplains (The Advocating for Clinical Excellence Project) (Griffin, Koch, Nelson, & Cooley, 2007). Consultation services may offer an additional or alternative method for educating professionals and enhancing collaboration between agencies.

In terms of considering elements of the consultation model that may influence team members’ comfort, knowledge and skills, it is important to acknowledge that nearly half of the recommendations made by the social work consultant were offered, rather than requested. During the weekly interdisciplinary care planning meetings with the teams, the social worker felt the need to educate team members about the spiritual, emotional, and psychological needs of patients, strategies and language to use when having conversations, and to encourage discussions about end-of-life issues with elders and their family members. A study by Vernooij-Dassen and colleagues (2007) reported that physical and pharmacological problems are most common precipitators of palliative care consultation service, and that psychosocial and spiritual problems are primarily identified by the expert consultants as they seek to explore and clarify the primary concerns. This is an important finding that has implications for consultation model design. Palliative care consultation models tend to be based on care provider requests. In other words, there is an identified problem or need and a care provider contacts the palliative care service for consultation. This works best when needs are obvious to care providers, as is often the case with physical pain or suffering. However, it may not work well to increase skills for addressing content and skill areas that are not well understood by care providers. For example, one of the team members commented that it is helpful to have the consultant participate in weekly team meetings “because until you have someone sitting in on the meeting and going “what about this and that?” you aren’t going to think about it. Cause you don’t know what you don’t know.”

We identified several challenges or barriers to the consultation model that have important implications for replication including misperceptions about what consultants might help with, difficulty recognizing when elders enter the dying trajectory, defensiveness in receiving suggestions, apprehension about introducing consultants to patients as “hospice employees,” gaps in consultant utilization, and barriers in recommendation implementation. Because one of the aims was to determine the extent to and ways in which consultants will be used by the teams, we did not provide clear guidelines regarding how and when to use the consultants and how to introduce them to patients. While this likely contributed to the

barriers identified, it also provided valuable insight regarding measures needed to overcome these barriers, laying the framework for future intervention. To address these barriers, we would recommend emphasizing a collaborative approach and providing opportunity for relationship building to minimize defensiveness, providing ample time for orientation for both the team members and consultants to understand the respective agency purpose, mission and goals, and clear guidelines regarding the wide range of ways that consultants may be called upon.

The lessons learned from this feasibility study have implications for model adaptations for future consideration. There were two primary adaptations for consultant utilization suggested by the CWPP team members. One approach ensures that consultants' input is provided across the array of cases on a team. The other emphasizes an on-call, as needed approach that increases efficiency but decreases opportunities for consultants to identify and address gaps in team members' knowledge, and may be problematic when teams "don't know what they don't know". Two alternative models could be considered to integrate these approaches. The first is a two phase model involving an integration phase (i.e., orientation, team meetings to build relationships and case review), followed by an on call or targeted consultation phase utilizing clear guidelines regarding when consultants should be requested. Patients and families to be targeted for consultations may include elders with chronic loss of function or pain, complex medical problems, who have difficulty talking about their conditions and care preferences, whose family members have differences of opinion, or whose family caregiver is overwhelmed with health care changes or needs. Once these elders are identified, consultants would be introduced to them as "advisory" team members that the elders may expect to see in the future (to normalize their presence on the team). The second is an "internal" palliative care expert consult model to minimize staff defensiveness, scheduling difficulties, and orientation time. This would involve hiring a staff person who has substantial prior training in palliative care. This model would not serve the benefit of strengthening the potential for inter-agency collaboration.

Study Limitations

A few limitation of this study are important to acknowledge. First, although we identified a number of perceived benefits of the consultation model, we were unable to document these with quantitative data. Although we originally had intended to keep the consultants in place for a full year, and monitor team records in the following months to determine how practices may have changed over time as a result of the consultation service, it became necessary to end the study after 10 months due to staff turnover and team restructuring. Since the composition of the teams were in flux, it was no longer feasible to assess how the teams receiving the intervention might have changed their practices. One team member explained that what she learned through observing the consultants would inform her work in the future, but that she had not yet had the opportunity to put it into practice. "They met with me and the participant and I sat with them and listened to the way they presented it and it was so smooth. So it helped to have that, and I processed it and thought well I'll use it sometime in the future." Second, given that we only identified the "perceived benefits" of the consultation model, we can make no claims regarding the quality of care actually provided to elders, how that has been enhanced, or how that care might compare with hospice

utilization itself. Third, there may be other potential benefits or challenges that team members did not express, and that we were unable to detect. For example, the NIH, State of the Science Conference on EOL Care (2004) called for research to develop and evaluate strategies to improve continuity and enhance end-of-life care in a variety of settings, with attention to costs. An important question is the extent to which a palliative care expert consultation model might facilitate earlier recognition of the dying trajectory, increase palliation as disease burden increases, reduce costs (e.g., reduce hospitalization rates and use of unnecessary treatments), increase hospice referral rates, and improve palliative care in other settings (e.g., nursing homes), while simultaneously enhancing collaboration and continuity of care across care settings (e.g., reducing barriers to hospice utilization). Finally, we did not have funds to include a chaplain consultant and this may have curtailed the potential benefits of the model.

In sum, findings from this study offer insight into a potentially viable method for enhancing the palliative care knowledge and skills of community based service providers serving elders with complex care needs. Further research is needed to confirm benefits reported here and replicate findings in different settings to define essential components of successful palliative care consultation.

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Table 1

Benefits of Consultation.

Themes and Subthemes	Examples from Quotes
<p>Enhanced comfort and conversational skills to talk about death and dying</p> <p>Decreasing death anxiety</p> <p>Finding the right language and method</p>	<p>I grew up where nobody talks about EOL and it's a scary terrible thing and that kind of sticks in my mind that it is, that it's something private the family has to deal with. It helped me with growing up in that family, that you can look at it as a good thing, not a good thing, but it's a beautiful thing, it's a process of life. It's something that family should gather and talk about, and that's how it enlightened me... it's always scared me to talk about death with my patients or even my family... having been able to talk more about it makes it more comfortable</p> <p>"I think...feeling more comfortable in talking about end of life issue. Partially because you saw that their comfort level in discussing and talking about things ...helped me to be more comfortable too."</p> <p>"...the word "journey" I've found that's a nice word to use, and it's subtle but it also puts the emphasis on, if the person has a belief in the after life, that this isn't the stopping place, so knowing what the person's belief system is, to know that is respectful of that.</p> <p>"...when —(hospice RN) would say "when we die" you know trying to make this so normal. When explaining things like "when we die," so making it not seem so abnormal and unreal.</p> <p>"I'm using language that is gentler and I'm not tackling a bunch of questions per se, but I'm incorporating it more in a discussion...I am doing that a little more gracefully"</p> <p>"I'm phrasing things differently and coming at things in kind of a back door approach. I think we are peeling back more layers in talking about it more openly than we might have before. There are different opportunities to talk about it. Whereas before, I might not have made the different opportunities, so they might not have shared that with me. "</p>
<p>Increased recognition of dying trajectory</p>	<p>"We'd be discussing a participant and it was the farthest thing from my mind that they were end of life, and they would present it like this person is end of life, and I was like "what do you mean, they are not actively dying?" You know, but they were experiencing a decline, and every time they had a decline, it was a little less recovery than where they were at... and it helped me to see it earlier. Ok this is a decline, they are end of life and you need to start talking about this.</p>
<p>Increased understanding of interventions for treating pain and other symptoms</p>	<p>"I think they were very helpful with dealing with chronic pain. They had a lot of good ideas. The symptomatology of it. They threw out a lot of really cool, like wow, never heard of that, but sounds like really neat kind of interventions, you know. Like the um, Ritalin. I mean just some interesting interventions. Because we are not in that biz, 24/7 like they are. They just have so many more tricks up their sleeve."</p> <p>"Last fall we just started a whole bunch of people on oxycontin, because we were like why are we holding out on all these people, because they are suffering. These people have had really awful chronic pain problems. Because of their personality problems or their addiction history we have been kind of hesitant to give them something that might actually treat their pain.... and they have done better, the ones who have been put on the oxycontin."</p>
<p>Increased understanding of how to help family members understand the dying process</p>	<p>"..they did such an excellent way of saying this is part of the process, its ok if she doesn't want to eat, it is part of the process. And just how smooth that went and how well the family was able to accept that piece of the dying process.... they met with me and I sat with them and listened to the way they presented it and it was so smooth."</p>
<p>Increased insights about end-of-life care needs.</p> <p>Empowered to address wishes</p> <p>Spiritual needs</p>	<p>I think they made us think about some of the things that might be important to participants that we may not think are important that kind of made you stop and think. We had one participant that wanted to go on this trip, and very complex health issues... what if this happens when she gets there, and it was, they just sort of made us think about, well we can make arrangements for this and this, and if something happens when she gets there, they'll deal with it. So I think that made us think a little differently about, well if somebody really chooses to do something and we might not think it is important, or that it is even something they should try, because it is too risky, you know you have to kind of stick your neck out and say, hey we can do this and this...you know we were thinking, well what if she dies on the plane, but the bigger picture was that this might be this woman's last trip. Her last trip to see her family in Florida.</p> <p>"For me it was bringing in the whole spiritual end of things definitely cause I don't think I, I mean I didn't focus on religion as much, and all that, if they weren't bringing it up I was feeling it must not be</p>

Themes and Subthemes	Examples from Quotes
	as big of an issue to them, so ask a simple question of “what is your religion” those sorts of things, and then if they’re not going to expand on that then well maybe it’s not as big of a focus for them.”
Introduction to ritual to memorialize elders	“one thing that I liked... is to just take a moment to recognize the people after they die. You know, like I hope we do try to do that, because they did just a simple thing with a candle... and we saw ... that once a month or however often they do it, they remember, so I hope that we will remember to take time to do that when we lose people.”
Crossed boundaries to enhance collaboration	<p>“well I think they have an appreciation for ...what we can provide. I think we mutually shared or crossed our boundaries and we know more about what the other is like now.”</p> <p>“I think it has influenced the collaborative efforts, because now we have the fee for service, and now we have had the nurse and social worker, we can call them, and just knowing someone over there helps. We do have two people on the fee for service for hospice, which is new. Our team is the first to use it.”</p>

Table 2

Pre- and Post-Consultation Death Totals and Perceived success in achieving end-of-Life Care Goals

	Pre Consultation Death total in prior 15 months		Post Consultation Death totals during study duration	
	Team 2	4	Team 2	4
	Team 6	12	Team 6	4
	Team 8	10	Team 8	11
Extent to which team was successful in achieving goals relevant to:	Pre Consultation Mean		Post Consultation Mean	
Pain	Team 2	2.5	Team 2	3.0
	Team 6	2.4	Team 6	3.0
	Team 8	2.6	Team 8	3.2
Medication management	Team 2	2.7	Team 2	3.4
	Team 6	2.9	Team 6	3.5
	Team 8	3.2	Team 8	3.8
Caregiver support system involvement	Team 2	2.3	Team 2	3.5
	Team 6	2.8	Team 6	3.5
	Team 8	3.6	Team 8	3.8
Psychological and emotional response of elder	Team 2	3.0	Team 2	4.0
	Team 6	1.9	Team 6	3.0
	Team 8	3.1	Team 8	3.5
Psychological and emotional response of family	Team 2	2.2	Team 2	3.3
	Team 6	2.5	Team 6	3.5
	Team 8	3.2	Team 8	3.6
Spiritual Issues	Team 2	3.0	Team 2	3.3
	Team 6	1.7	Team 6	2.0
	Team 8	3.2	Team 8	3.7
Grief and/or bereavement	Team 2	2.5	Team 2	3.0
	Team 6	2.0	Team 6	2.8
	Team 8	3.1	Team 8	3.3
Coordination with facility	Team 2	2.5	Team 2	3.3
	Team 6	3.4	Team 6	3.3
	Team 8	3.7	Team 8	3.8

Note: Scores ranged from 1 – 4 (1 = a little successful; 4 = extremely successful)