Challenges to Providing End-of-Life Care to Low-Income Elders With Advanced Chronic Disease: Lessons Learned From a Model Program

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Purpose: This study explored the challenges in providing end-of-life care to low-income elders with multiple comorbid chronic conditions in a fully “integrated” managed care program, and it highlighted essential recommendations. Design and Methods: A case-study design was used that involved an extensive analysis of qualitative data from five focus groups with interdisciplinary team members, two in-depth interviews with administrators, and open-ended survey responses from social workers detailing death experiences of 120 elders. Results: Seven major themes characterized primary end-of-life care challenges: (a) the nature of advanced chronic disease; (b) the incapacity of support systems; (c) barriers to honoring care preferences; (d) challenges with characteristics and needs of participants; (e) needs of complex family systems; (f) barriers with transitions; and (g) barriers with culture and language. Implications: The lessons learned suggest recommendations with implications for program development, practice, policy, and future research.

Key Words: End of life, Palliative care, Managed care, Case-study design, Qualitative methods

As highlighted in the October 2002 special issue of The Gerontologist on end-of-life research, inadequate care of the dying is a major concern; there is an urgent need for research that will facilitate improvements in care-delivery systems for elders. Studies document aggressive treatment, deficiencies in provider communication and pain management (SUPPORT Principal Investigators, 1995), fragmented care, and limited availability of in-home caregivers (Hanson, Danis, & Garrett, 1997). Although hospice programs represent a substantial innovation in palliative and end-of-life care (Lynn, 2000), regulatory and other barriers limit service utilization to elders who die with chronic, progressive, and ambiguous comorbid conditions (Fox et al., 1999). Recommendations to meet the complex end-of-life-care needs of these elders and their families call for health care systems that provide comprehensive interdisciplinary 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).

The Wisconsin Partnership Program (WPP) and its parent, the Program for All-Inclusive Care for the Elderly (PACE), provide comprehensive community-based care for nursing-home-eligible low-income elders with complex chronic illness. They integrate long-term care (i.e., primary and acute) under Medicare and Medicaid capitation arrangement, and they share comparable consumer satisfaction (Kane, Homiyak, & Bershady, 2002). The WPP eliminated features of the model that constrained enrollment (i.e., limited choice of physician and mandatory day center). Program characteristics include interdisciplinary consumer-directed care, integrated financing, and provider consistency (Sachs, 1995).

Although these programs were not originally designed to care for the dying, the majority of persons enrolled in them remain until death. Prior research addressing challenges in end-of-life care...
have focused on barriers to providing quality end-of-life care in institutional settings such as nursing homes (Evans, 2002), hospices (Farnon & Hofmann, 1997), and hospitals (Campbell, 2002; Kirchhoff & Beckstrand, 2000); on challenges in treating particular conditions or symptoms (Blasi, Hurley, & Volcier, 2002; Payne, 2000); and on barriers to accessing care (Krakauer, Crenner, & Fox, 2002). Little attention has been given to identifying the specific challenges confronted by service providers in community-based integrated managed care programs serving frail elders. As the movement to develop integrated community-based managed care programs for poor and frail elders grows (Leutz, 1999), it becomes important to understand the challenges model programs have faced in providing end-of-life care. These innovative programs could dramatically influence the development of programming and policy development as other states seek to replicate and expand on these models. The purpose of this qualitative investigation is to explore the challenges encountered in providing end-of-life care to low-income elders with multiple comorbid chronic conditions in the Elder Care Partnership (ECP) program, the first WPP site, and to highlight essential recommendations.

Methods

Design

This project was part of a larger longitudinal case study. The case study is an approach to research and evaluation that has a distinguished history in the social sciences (Creswell, 1998). Case study stresses the uniqueness of a case (or cases; see Mabry, 1998), and it is the preferred design when interest is on a program or a contemporary phenomenon within its real-life context (Yin, 1994). Although our broader aim was to understand the phenomenon of end-of-life care within the ECP program, the results reported here address the challenges experienced by the teams in providing end-of-life care. Strategies used for enhancing rigor relevant to the case-study design included (a) prolonged engagement (this 2-year study involved ongoing data collection and frequent contact with staff at team and end-of-life committee meetings), and (b) triangulation (the data were obtained from a variety of sources representing views of multiple stakeholders; see Padgett, 1998).

Setting and Sample

Elder Care of Dane County, a not-for-profit organization, has provided community-based services for elders since 1976. ECP, the largest program operated at this site, employed 10 interdisciplinary teams consisting of a nurse practitioner (NP), a master’s-level social worker, and two registered nurses (RNs) at the time of this study. Teams contract with the elder’s physician, who, jointly with the nurse practitioner, manages the participant’s medical care. Since its 1995 inception, the ECP program has enrolled approximately 470 elders, with 289 current enrollees. Participants have annual incomes below $10,000, and they average 29 medical diagnoses, seven or eight major chronic medical conditions, and three or more activities of daily living dependencies. Seventy-two percent of disenrollments are due to death, averaging three deaths per month.

All team members were invited to participate in discipline-specific focus groups, and the social workers additionally completed questionnaires to describe the care experiences related to 120 deaths. As the primary administrative staff that could provide information addressing aims of the study, the program manager and end-of-life committee chairperson agreed to be interviewed.

Data Collection

We relied on qualitative methods because, consistent with our study objective, they are ideally suited to research that is “exploratory or descriptive, that assumes the value of context and setting, and that searches for a deeper understanding of the participants’ lived experiences of the phenomenon” (Marshall & Rossman, 1994, p. 38).

Interviews and Focus Groups.—We initially collected qualitative data through the use of in-depth interviews with two administrators, followed by five discipline-specific focus groups with staff (two with RNs, one with NPs, and two with social workers). The sole interviewer was the primary investigator (PI), who is a University professor and a Project on Death in America Social Work Leader, whose research seeks to improve end-of-life-care practices. She has 7 years prior experience as a gerontological social worker in varied settings. We used the administrator interviews to gain an understanding of the program more broadly, but they included questions about the perceived challenges to providing end-of-life care to elders in the ECP program. We chose a focus-group methodology to provide insight into the complex phenomenon of end-of-life care and the range of challenges experienced by staff (Krueger & Casey, 2000). Following recommended guidelines for focus-group protocols, our inquiry included opening, introductory, transition, key, and ending questions (Krueger, 1994). The key question explored in the focus groups was as follows: “What are the primary challenges you face in providing end-of-life care in the partnership program?”

Questionnaire.—Surveys were completed by social workers to describe the care experiences particular to 120 deaths. These surveys were both retrospective (i.e., based on recall and case-record
review of most recent elder deaths; \(n = 75; 62\%\), and concurrent (i.e., completed as deaths occurred; \(n = 45; 38\%\)). Two open-ended items on the survey analyzed for the current study included (a) “What, if any, were the primary care dilemmas, barriers, or challenges that you experienced in providing care to this participant during his or her last 6 months of life?” and (b) “Given what you and the team have learned from working with this participant or his or her family members, are there changes you would recommend for improving services and addressing the care dilemmas, barriers, or challenges you were faced with?”

**Data Analysis**

We ensured that the interviews, focus groups, and qualitative survey data were all transcribed verbatim. We followed methods of qualitative thematic analysis and code development frequently employed in case-study research (Boyatzis, 1998; Stake, 1995). We read the transcripts several times and then followed a three-step approach. The PI and project assistant independently performed initial line-by-line open coding of the transcripts and then discussed it. This process yielded key words and themes that formed initial codes. Next, we clustered the codes into families of categories or concepts that reflected challenges and corresponding recommendations. Finally, we developed and refined themes to represent broader conceptual categories and the clusters of codes (Coffey & Atkinson, 1996). We reached a point of data saturation whereby no additional codes emerged (Drisko, 1997; Patton, 2002). The themes were substantially exhaustive. We used NUD*IST Vivo software to store, organize, and retrieve coding structures.

We did not conduct any intercoder reliability tests. Strategies for enhancing analytic rigor and trustworthiness of the findings included (Lincoln & Guba, 1985; Padgett, 1998) the following: (a) peer debriefing and a cocoding process involving ongoing comparative analysis and discussion and intersubjective agreement between the PI and the project assistant at each step, as well as periodic transcript and coding frame review with members of an interdisciplinary qualitative analysis team; (b) auditing that involved careful documentation of the process followed in the development of codes, memos, and analytic decisions; and (c) member checking whereby the agency staff reviewed and validated the analysis, interpretation, and conclusions.

**Results**

**Focus Group Participants**

A total of 38 out of 40 interdisciplinary team members employed at the time participated in the focus groups. Nine social workers (who additionally completed the surveys) ranged in age from 24 to 62 years (\(M = 33\)), 10 NPs ranged in age from 34 to 55 (\(M = 43\)), and 21 RNs ranged in age from 31 to 55 (\(M = 42\)), and 21 RNs ranged in age from 31 to 55 (\(M = 42\)), and 21 RNs ranged in age from 31 to 55 (\(M = 42\)), and 21 RNs ranged in age from 31 to 55 (\(M = 42\)), and 21 RNs ranged in age from 31 to 55 (\(M = 42\)). All respondents were Caucasian and all but one was female. According to a confidentiality agreement, the characteristics of the two administrators are not reported.

**Demographic and Background Characteristics of Elders Served**

Table 1 describes demographic characteristics of the deceased elders representing 62% of the total and...
most recent deaths in the program. Elders ranged in age from 57 to 103 years, with a mean age of 80 (SD = 9.6). The majority were female (68%), nearly half were widowed (46.7%), and fewer than 35% had completed high school. Twenty percent were persons of color, which is disproportionate to the percentage of elders of color living in Dane County (2%). In terms of location of death, 29% of the elders died in hospitals, 30% died in nursing homes, and about 18% died at home. The top four causes of death were categorized as cardiovascular disease (37%), pulmonary disease or infection (19%), multisystem failure (12%), and dementia (10%), reflecting common causes of late-life death (Bern-Klug & Chapin, 1999).

**Challenges and Lessons Learned**

Seven major themes emerged from the data. For practical relevance (regarding the pervasiveness of the various challenges associated with the reported deaths), we provide the frequencies of each theme for the survey data only, noting that frequency computation is not advisable or customary in focus group and interview data (Krueger & Casey, 2000). The challenges were described in 108 of the total surveys (N = 120; representing 90% of the deaths reviewed), and they were typically co-occurring (with an average of two reported for each death). The major themes that emerged in various sources of data and the corresponding recommendations enumerated by the social workers in the surveys specifically are highlighted in Table 2 and described in the paragraphs that follow.

**The Nature of Advanced Chronic Disease.** —The complex and unpredictable nature of advanced chronic disease and comorbidities of the population were reported as persistent challenges, exemplified in 54% of the surveys (n = 65). This theme included descriptions of complex care needs that confounded health care providers such as when an elder had multiple chronic conditions coupled with unpredictable medical crises, and the uncertainty of predicting approaching death. One social worker made this observation: “The primary barrier was that the team was not expecting ppt [participant] death. There was actually a sense of optimism that she was . . . establishing a ‘new start’ . . . ppt was showing signs of stability.” Team members expressed how frequently deaths caught them off guard while they were distracted by acute-care needs or complications: “The focus of his care seemed to be his amputations/wound care and this . . . shifted our focus from how ill ppt was. It is . . . easier in hindsight to look back and say ‘of course, he was critically ill, why didn’t we deal more with these issues,’ but at the time there . . . seemed to be hope that he would improve.” Thirty-one percent of the deaths were similarly unexpected.

**Recommendations.** —Two fundamental recommendations relevant to the nature of advanced chronic disease were described by social workers. First is the need to routinize and normalize end-of-life-care planning and palliative care principles. Rather than waiting to initiate end-of-life-care planning until a time that the elder is perceived to be “actively dying” or is experiencing an acute medical crisis, team members should routinely engage elders and family members in discussions about the future. Initiating at least one family-care-planning meeting to include health care agents regardless of participant’s health status, ensuring that conversations are comprehensive to include health maintenance and treatment options, end-of-life scenarios and preferred outcomes, burial wishes, and do-not-resuscitate (DNR) order status may be helpful. The goal is to demystify end-of-life planning, normalize end-of-life conversations, and infuse palliative care principles. Second is the need to maintain a panoramic view. This encourages staff to be mindful of the bigger picture during acute medical events and to consider multiple interventions for end-of-life-care planning. Social workers noted that acute medical crises are opportunities to educate elders and families about a variety of future scenarios, to help them see the bigger picture, and to deepen awareness of end-of-life-care needs.

**Incapacity of Support Systems**

Fifty-two percent of the survey responses (n = 62) described challenges reflecting incapacities of support systems. This theme included examples of deficiencies in end-of-life care in varied health care systems, and how formal or informal resources or supports were not available or were not willing to partner with the team. Team members described insufficiencies in formal settings (i.e., hospitals, community-based residential facilities, or nursing homes) in which they had to “push” staff to respond to elders’ comfort needs, or “fight” to prevent invasive diagnostic tests or treatments, as follows: “ER was not oriented toward EOL [end of life]. They did not consider pain meds until writer [social work respondent] requested and basically dismissed ppt once clarifying DNR status. . . . Writer advocated strongly for pain meds . . . based upon moaning noises, hand gestures, and the family’s concern for his comfort. . . . The family and ppt. were moved to three different rooms during his stay in the ER.” Incapacities of informal systems (i.e., family or friends) reflected the variability in caregivers’ abilities to provide care or in their willingness to work cooperatively with the team, as subsequently illustrated: “Ppt’s primary caregiver was her husband
who was extremely frail ... and at times their needs went unmet. Other family members at home were quite ... unreliable ... and could be ... hostile towards personal care workers.”

**Recommendations.**—Social workers described four primary recommendations to address the incapacities of support systems. The first affirms the mandate to **infuse palliative care throughout health care settings.** Elders often require care across a continuum of care settings as their functional status declines. There is need to enhance palliative and end-of-life-care knowledge and skills among providers across settings and to develop or modify policies to ensure quality and continuity. For example, reimbursement and other incentives for palliative care training and service provision are needed across sites. The second is the need to **aggressively address site-specific care-quality concerns.** This includes conducting preplacement training with facility staff

### Table 2. Recommendations to Address Challenges to Providing Quality End-of-Life Care to Low-Income Elders With Advanced Chronic Disease

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Specific Examples</th>
<th>Recommendations</th>
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<tr>
<td>The nature of advanced chronic disease</td>
<td>• Advanced, multiple and complex care needs&lt;br&gt; • Elusive EOL status&lt;br&gt; • Acute unpredictable medical crises</td>
<td>• Routinize &amp; normalize EOL care planning&lt;br&gt; • Maintain a panoramic view</td>
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<td>Incapacity of support systems</td>
<td>• Incapacity of other health care systems to provide quality EOL care&lt;br&gt; • Unavailability of needed formal services or informal supports&lt;br&gt; • Unwillingness or inability of support systems to partner with team</td>
<td>• Infuse palliative care throughout health care settings&lt;br&gt; • Aggressively address site-specific care-quality concerns&lt;br&gt; • Enhance availability of resources and supports&lt;br&gt; • Embed support systems into the team model</td>
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<td>Barriers to honoring care preferences</td>
<td>• Elder’s care preferences unclear or unknown&lt;br&gt; • Elder’s limited comprehension of care options and consequences&lt;br&gt; • Incongruent care preferences: the “Tug of War”&lt;br&gt; • Limited acceptance of health decline&lt;br&gt; • Balancing safety, risk, and cost; professional liability</td>
<td>• Initiate conversations early&lt;br&gt; • Enhance communication with collateral service providers&lt;br&gt; • Articulate clear and specific wishes&lt;br&gt; • Anticipate ethical dilemmas</td>
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<td>Challenges associated with characteristics and needs of the elder</td>
<td>• Recently developed conditions&lt;br&gt; • Enduring characteristics&lt;br&gt; • Personal response to death or dying</td>
<td>• Employ unique assessments and interventions for elders with dementia&lt;br&gt; • Utilize the therapeutic relationship in the face of emotional distress&lt;br&gt; • Recognize what can and cannot be changed: “The wisdom to know the difference”</td>
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<td>Competing needs of complex family systems</td>
<td>• Limited family resources&lt;br&gt; • Family conflict&lt;br&gt; • Precarious mental health and well-being of family members</td>
<td>• Facilitate family meetings to diffuse conflict and provide support&lt;br&gt; • Provide ongoing education to maximize family absorption of the EOL process&lt;br&gt; • Recognize what can and cannot be changed: “The wisdom to know the difference”</td>
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<td>Challenges associated with transitions to other health care systems</td>
<td>• Care settings refuse admission&lt;br&gt; • Fear or misperceptions about sites of care&lt;br&gt; • Unnecessary transitions spurred by approaching death&lt;br&gt; • Breakdowns in communication&lt;br&gt; • Disequilibrium of elder and/or family following transition&lt;br&gt; • Loss of palliative care</td>
<td>• Prevent unnecessary transitions: encourage continuity and dying in place&lt;br&gt; • Ease into transitions&lt;br&gt; • Engage in aggressive advocacy: “Don’t be shy”</td>
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<tr>
<td>Barriers associated with culture and language</td>
<td>• Perceived distrust&lt;br&gt; • Communication barriers&lt;br&gt; • Cultural beliefs and decision-making norms&lt;br&gt; • Lack of culturally appropriate assessment tools</td>
<td>• Enhance cultural competence of team&lt;br&gt; • Pursue cultural liaisons&lt;br&gt; • Develop collective models of decision making&lt;br&gt; • Develop culturally appropriate assessment tools for the EOL</td>
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*Note: EOL = end of life.*
Barriers to Honoring Care Preferences

Barriers to honoring care preferences were described in 47% of the survey responses (n = 56). Team members noted that it was challenging to honor care preferences when they were unclear or unknown, vacillated, or the elder with diminished capacity could not comprehend care options or consequences. Incongruence or outright disagreements about care preferences between the elder or family members was a major barrier that was often complicated by “family convergence” near the time of death, as noted here: “the family does come out of the woodwork,” “they haven’t been there for 50 years and now . . . somebody’s dying and they’re . . . in your face saying, you’re not going to do this, you’re not going to do that.” One social worker described the complexities of caring for a woman with 14 adult children who all had “differing opinions . . . on how and where she should be cared for.” Challenges previously described including complex care needs and the incapacity of support systems often contributed to the challenge of honoring wishes while balancing safety and risk assessment and costs (e.g., this largely contributed to the high percentage of elders, 43%, who were unable to die in their preferred location).

Recommendations.—Four primary recommendations were made to address barriers to honoring care preferences. First is the need to initiate conversations early. Early on, talking about and increasing the frequency of care-preference conversations with as many family members as the elder will allow may prevent conflicts. If teams can establish rapport and engage family members earlier, then when family members do converge in times of crisis, they may be more informed and prepared. Second, professionals should enhance communication with collateral service providers. The inclusion of collateral service providers in discussions (e.g., physician, hospice consultants) to offer unbiased support and education may be helpful. Team members should take an active role as liaisons between providers and families (e.g., by facilitating discussions between family and hospital physicians and relaying wishes to medical staff). Third, varied approaches may be implemented to help elders articulate clear and specific wishes. Social workers suggested that creative techniques involving reminiscence or life review that explores values and prior experiences could be used as a springboard toward discussions envisioning future scenarios and preferences. Fourth, several strategies to anticipate ethical dilemmas were suggested, such as developing and integrating risk-assessment protocols, identifying ethical dilemmas and referring to ethics committee earlier, and educating staff regarding the legal pathways for protecting participants from family who disregard their preferences.

Challenges Associated With Characteristics and Needs of Participants

Challenges associated with characteristics and needs of participants were described in 44% of the deceased elder surveys (n = 53). Characteristics and needs included those that developed more recently (e.g., cognitive or sensory declines that developed in later life), or those that were more enduring (e.g., long-term mental illness). For example, “because of schizophrenia diagnosis . . . issues of pain were difficult to monitor . . . no matter what, she would always say her pain was extreme.” Other challenges described by team members included the elder’s personal response to the end of life (e.g., limited acceptance of health decline, emotional distress, resurgence of unresolved grief).

Recommendations.—Three fundamental recommendations were made to address challenges associated with the elder’s characteristics and needs. The first is to employ unique interventions for persons with dementia at end of life. Social workers suggested conducting early and ongoing assessments for capacity and to individualize therapeutic approaches to address changing stages and symptoms. Complementary and creative interventions to facilitate healing and grief expression despite cognitive loss (e.g., art, music, massage, and validation therapy) should be tested. The second is the need to utilize the therapeutic relationship in the face of emotional distress. Identifying and using strengths of team members, being flexible in roles, developing an alliance with those who “carry the most weight” with the elder, and using one team member as the primary contact if necessary may enhance relationships to better address emotional distress. The final recommendation is to recognize what can and cannot be changed. Practitioners set themselves up for a feeling of failure when they held high expectations for things
that may not be amenable to change. One social worker noted the following: “Many times these things you hope will be resolved at the end aren’t…. [There are] alienated family members that they don’t get in contact with…. spiritual needs that somehow can’t be fulfilled [and]…. we tend to take that on, to like, that’s kind of our responsibility to make sure these issues are resolved.”

Competing Needs of Complex Family Systems

Competing needs of complex family systems were described as challenges in 33% of the deceased participant surveys (n = 40). Apart from caregiving, family resources were often already stressed as a result of financial hardships and external demands, as in the following: “Her daughter was the most dependable but had children of her own and would try to hold down two jobs, many times leaving the children with ppt.” Distinctions emerged in the forms of family conflict that were enduring (e.g., long-standing disagreements) and situation-specific conflict (e.g., recently developed conflicts related to elder’s needs or condition) that often emerged from the inequity in caregiving expectations. Competing needs of family members emerging at the end of life often played out in the context of decision making and care outcomes, as illustrated here: “Ppt had dementia and it was difficult for her to stand up to her daughter. Daughter who was activated POA [power of attorney] was making decisions contrary to what participant wanted. Other daughters went to court to have neutral guardian appointed. … Conflict between siblings was never resolved.” Additional challenges included the precarious psychological well-being of family members including depression, schizophrenia, drug or alcohol use, anxiety, caregiver stress, and, as noted by one social worker, the difficulty of engaging “family members with a history of drug addiction, incarceration, homicide, violence …”.

Recommendations.—Three recommendations were made relevant to the competing needs of complex family systems. The first is the need to facilitate family meetings to diffuse conflict and provide support. This suggestion stressed the value of facilitating family meetings early to ensure mutual understanding of care needs, diagnosis, and prognosis and maximize shared responsibility. When situations intensify, repeated family meetings are necessary to diffuse conflict. Social workers emphasized the value of providing a nonjudgmental and supportive assessment that explores family members’ contributions to caregiving, historical and current family conflict and dynamics, and psychological well-being. The second is the need to provide ongoing education to maximize family absorption of the end-of-life process. Specific recommendations included breaking end-of-life discussions into several meetings to allow family members to contemplate what they have heard, generate questions, and follow up with renewed understanding. Concrete information in the form of packets, videos, or books was recommended to help prepare family for death. The third recommendation is to recognize what can and cannot be changed. As with the prior suggestions for addressing the needs of elders, social workers learned that some family conflicts need to “play out” and may not always be eliminated. One social worker noted that “A lot of families have not dealt with conflict their whole lives. They’ve avoided it…. Sometimes you can resolve some of it [conflict] and sometimes you can’t.” Social workers suggested the value of inquiring about the history and patterns of family relationships and power dynamics, and delineating between situational specific conflict and lifelong patterns of conflict to better understand what may be amenable to intervention.

Barriers Associated With Transitions to Other Health Care Systems

Barriers associated with transitions in care settings were reported in 17% of the deceased participant surveys (n = 20). This theme included situations in which transitions were blocked (e.g., denied nursing home admission), the elder or family were anxious about transitions (e.g., fearful of nursing home), or approaching death initiated “unnecessary” transitions (e.g., family or residential facility staff’s personal preferences or panic near the time of death precipitated hospital admission). Problems arose during transitions, including communication breakdowns, that had serious ramifications for the elder’s care such as when the “CBRF [community-based residential facility] failed to send info on DNR with EMTs.” An unfortunate and unanticipated problem associated with transitions was the loss of palliative care, reflecting the previously identified barrier of the incapacity of other health care systems to provide quality end-of-life care: “The biggest barrier to ppt’s care was… when he went to the nursing home for EOL care. The nursing home… made comments like ‘He is not allowed to eat in his room because he might choke to death.’ He was dying and could not go to the dining area—it would have been cruel and inappropriate. … The nursing home had no concept of comfort care—they did not follow through on family or team requests (i.e., more pillows, simple things that would have made his life better at the end).”

Recommendations.—Three recommendations were made to address the challenges associated with transitions. First, attention is needed to prevent unnecessary transitions and encourage continuity and dying in place. Quality improvement initiatives to track transitions and outcomes and to provide
facilities with end-of-life-care plans and emergency protocols are needed to minimize discomfort or panic as death approaches. Second, strategies are needed to help elders and their family members ease into transitions, by “planting seeds” in advance of the need, reframing terminology (e.g., “life transition center” vs “adult day care”; “skilled nursing” or “convalescent center” vs “nursing home”), and suggesting “trial runs.” Other recommendations included communication protocols to ensure team participation in transition decisions; education of staff about the distinctive elder and family needs in settings where transitions occur (e.g., nursing home, hospital, community-based residential facility); and posttransition follow-up. Aggressive advocacy is necessary in situations in which posttransition care is inadequate. Social workers need to aggressively advocate for comfort and clearly communicate concerns when care providers inappropriately focus on active treatment or fail to provide compassionate patient-centered care.

Barriers Associated With Culture and Language

Four types of barriers associated with culture and language were reported in 10% of the deceased participant surveys (n = 12). First was a sense of perceived distrust, as reflected in one social worker’s experience with an African American family: “the mom was dying and pretty much wanted to be left alone but . . . daughters . . . saw comfort care as racially motivated to end her life.” Second, communication barriers were multiple, especially related to the use of interpreters (e.g., few interpreters available, inadequacies in conveying and understanding information, and concerns about confidentiality). Cultural norms that constrained communication were noted as follows: “One of the biggest challenges . . . was trying to discuss health care . . . and EOL wishes. . . . [Their] culture does not allow them to discuss these issues for fear they would become true.” Third, a wide variety of challenges were described that reflected cultural beliefs and decision-making norms, as in this example: “Family in U.S. deferred to family in Asia to make decisions . . . believed placement was culturally inappropriate even though daughter could not cope with demands of caregiving. . . . Oldest son should have made decisions but was not available.” One social worker described the dilemma she faced in confronting cultural incongruence between the consumer-directed approach focused on the individual versus the collective approach preferred by some families.

“...[Our society is . . . so individualized . . . that it’s like ‘this should be the spokesperson.’ . . . What do you do when it’s like an entire family . . . they want to be interchangeable and to have that . . . meld with our culture and . . . our legal system demands, can be challenging.” The absence of culturally appropriate concepts and assessment tools posed additional challenges (e.g., caregiver stress concepts or measures culturally incongruent; mental status tools normed on U.S. populations).

Recommendations.—Four recommendations were made regarding barriers associated with culture and language. The first is to continuously strive to enhance cultural competence by learning from elders and their families and by promoting agency-based training. The ECP program has initiated discussions to facilitate understanding of how to work with ethnically diverse populations so teams can learn from one another (e.g., sharing what was learned, what worked, and what didn’t work in selected cases), and it is considering other educational initiatives. The second is the need to pursue cultural liaisons. Hispanic community leaders served as mediators and helped to facilitate discussions with families. Native American tribal leaders facilitated teams’ understanding of the Native American cultural community, and an intermediary from the Hmong community helped to identify interpreters outside the home and community. The third is the need to develop collective models of decision making. Social workers explained that, like other consumer-directed programs, ECP places emphasis on the elder’s needs and preferences, and that there is a dissonance between patient-centered care and the communal approach often preferred by families. Staff learned the necessity of working within the communication and decision-making norms of the family but called for the development of collective decision-making models to provide guidance for practitioners. Finally, there is need to develop culturally appropriate assessment tools that will assist teams to assess elders and their family caregivers at the end of life.

Discussion

We chose the ECP program as a useful site to examine the challenges encountered in a fully integrated managed care program, in providing quality end-of-life care to poor elders with complex chronic conditions. A few limitations of this study should be noted. First, there was partial reliance on recall data regarding challenges associated with recent deaths. Tempering this concern is that the underlying themes of these deaths were not dissimilar to those reported in the concurrent surveys and the focus-group data, and our results were validated through member checking. Second, although this study describes the challenges reported by staff caring for low-income frail elders, the study design does not allow us to draw conclusions about which challenges may be attributed to socioeconomic status. Cross-site comparative studies or predictive studies in managed care organizations with socioeconomically diverse
care recipients are needed. Third, because we were interested in the challenges facing professionals in providing end-of-life care, we did not elicit perspectives from elders and their family members. Further inquiry into the care-recipient experience may reveal insights into the complex phenomenon of end-of-life care and suggest additional recommendations. Finally, although focus groups have several advantages and readily facilitate exploration of complex phenomenon, they also have limitations (Hughes & DuMont, 1993, Krueger, 1994). The focus-group methodology may have limited the depth with which we could fully understand the many causes and conditions underlying the challenges, and the resulting consequences for care. Grounded-theory studies are needed to elaborate this area of inquiry.

As a case study, results are not presumed to be generalizable but are generated for their potential value in what they might teach us about particular issues (Creswell, 1998). Although the themes put forth are not in and of themselves surprising, taken together and within context they provide a picture of the constellation of challenges confronting service providers that may be considered in the development of other integrated managed care programs for elders. As Mabry (1998, p. 168) explained, “understanding one case promotes understanding of similar cases of general issues encountered in programs.” Many states are experimenting with service integration as a means to meet the complex needs of elders with multiple and advanced chronic disease (Leutz, 1999). For example, 13 other states are participating in an initiative to integrate Medicare and Medicaid to restructure the way in which they finance and deliver consumer-directed acute and long-term care that builds on the experience of the WPP and PACE programs (University of Maryland Center on Aging, 2000). It is notable that, even in this relatively resource-rich program environment, the challenges are complex, pervasive, and interrelated, cutting across micro (i.e., individual, family), mezzo (i.e., organizational and health care environments) and macro (i.e., cultural, societal, and policy) levels, suggesting implications for program development, practice, research, and policy.

The most pervasive challenges reported in this organization were those stemming from the nature of advanced chronic disease and comorbidities of the elders served. Trends in aging in the 21st century indicate that the majority of elders will encounter severe chronic illness in the last phase of life (Lynn & Adamson, 2003). With the growth of an aging population confronting less certain disease pathways and more complex care needs, our conceptualization of end-of-life care should be expanded (Zuckerman, & Wellner, 1999). In contrast to the more traditional palliative care model of hospice in which patients enroll with an anticipation of approaching death, results from this study suggest that approximately one third of the deaths were unexpected by the team members. There was a sense from our many discussions with professionals in this organization that “shifting gears” to address end-of-life care needs was not seamless. After years of addressing programmatic goals seeking to treat chronic disease, foster independence, and maintain elders in the community, infusing palliative care concepts was difficult for some staff, as noted by this nurse: “… it’s hard to shift gears. You’ve known people for five or six years—helping them be independent and all of a sudden, they start to die and … Elder Care’s fostering independence or whatever our motto is and all of a sudden, we’re going to be helping them die. Sometimes it’s hard.” Efforts to infuse and normalize end-of-life-care planning within and across community care settings that acknowledge the unpredictable nature of death in this population are warranted, but they should address potentially divergent programmatic goals.

The findings suggest several important considerations for consumer-directed programs that place emphasis on individual autonomy and decision making. Several recommendations call for earlier involvement of family in care planning and support, and are consistent with other calls for collective models of decision making that accommodate sociocultural values and communication practices (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998). Although the family is considered the unit of care in the hospice care model, consumer-directed integrated programs are not funded to assist families or provide bereavement care. In addition, elders’ preferences may limit the extent to which teams may address competing needs of family members, and they may contribute to the end-of-life crisis when family appears after periods of uninvolvement. Consumer-directed integrated care policies and programs may have to be modified to adequately address the needs and preferences of family systems of elders served.

Consistent with the recently released Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project, 2004), the lessons learned from this case study support the need to infuse palliative care across settings to address the incapacities of health care systems to provide quality end-of-life care. This will require continued and ongoing initiatives to enhance training across the continuum of gerontological service settings. Emerging interventions to integrate palliative care and address quality-of-care concerns in nursing homes, hospitals, community-based residential facilities, and other settings should be further developed and tested (Tuch, Parrish, & Romer, 2003). Policy modifications also are needed to reduce barriers to service coordination, particularly with attention to financial disincentives to collaboration. For example, recent reinterpretation of policy by the Center for Medicare Management has made it possible for the WPP and other PACE sites to develop contractual relationships with hospice to purchase complementary...
services without relinquishing the full Medicare benefit. As a result, and as an outgrowth of this study, we are currently conducting a feasibility study to examine collaborative care models between the ECP program and hospice to address targeted needs.

In sum, this study offers a glimpse into the complex and interrelated challenges of providing end-of-life care in an integrated managed care program. Several recommendations for improving end-of-life care are put forth, and future research is needed to further develop and test these recommendations. Research is needed to develop assessment and intervention protocols to address family conflict, incongruence in care preferences, grief, and the distinctive needs of individuals with dementia. Developing and testing the efficacy of models that infuse end-of-life-care planning, address site-specific quality-of-care concerns, enhance team and support-system collaboration, enhance communication, address ethical dilemmas, and identify and address individual or family needs that are amenable to change are all needed. Attention is also needed to modify and evaluate policies that will enhance service coordination and continuity and to allow staff to address the needs of family members at the end of life. Finally, several national research agendas have called for studies to further examine transitions across care settings at the end of life (e.g., see Kramer, Christ, Francoeur, & Bern-Klug, 2005; Lunney, Foley, Smith, & Gelband, 2003; Stahl, 2000). Recommendations from this study call for research to identify and prevent unnecessary transitions, smooth necessary transitions, and promote dying in place.

References
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