

**Innovations in End of Life Care for Elders with Advanced Chronic Disease**

**A Proposal Submitted to the John A. Hartford Foundation**

by

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“The true test of a health care system is how well it serves the people who need it most. We must move beyond a system organized around acute illness and reactive management of disease to one that deals effectively and proactively with chronic illness and the needs of an aging population.”  
(Donald M. Berwick, MD, President and CEO Institute for Healthcare Improvement)

## **A. SPECIFIC AIMS**

The proposed research will seek to understand how end of life (EOL) care is provided to frail elders with advanced chronic disease, in an innovative, fully “integrated” managed care program in which social workers play a key role on an interdisciplinary team. My over arching desire is to figure out the best way to provide care to this vulnerable population and to illuminate the role and contribution of gerontological social workers in EOL care. The primary objectives of this study are to: (1) determine how EOL care is defined and implemented in this setting according multiple stakeholders (i.e., administrators, team members, participants, and family members); (2) identify the implicit and explicit outcomes of quality EOL care according to participants, family members, team members, and administrators; (3) identify the structures and processes of care that influence these quality EOL outcomes, with attention to the contributions of social work; and (4) identify the care dilemmas, barriers, and helps to providing quality EOL care to elders with advanced chronic disease and their family members.

## **B. BACKGROUND AND SIGNIFICANCE**

**Shortcomings of End of Life Care in America.** Inadequate care of the dying is emerging as a major concern in the United States among health care providers, educators, and policy makers. Although “care for those approaching death is an integral and important part of health care,” far too many elders suffer from pain and other distress that practitioners could prevent or relieve, and significant gaps remain in scientific knowledge about EOL care (Field & Cassel, 1997, p. 4). Several studies document deficiencies in care of the dying (Meier, Morrison, & Cassel, 1997). Perhaps the most rigorous study conducted to date, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), was a \$28 million project that enrolled over 9,000 patients with life-threatening illness in five U.S. teaching hospitals over a four-year period. SUPPORT demonstrated deficiencies in provider/patient communication of treatment preferences, over reliance in aggressive

treatment, poor control of pain, and limited response of physicians to interventions designed to increase discussions of patient preferences (SUPPORT Principal Investigators, 1995). In a representative sample of bereaved family members of elders who died in multiple settings, respondents reported deficiencies in health care provider availability, and communication skills, and stressed the need for improved and expanded care at home (Hanson, Danis, & Garrett, 1997).

**Improving the Care of the Dying.** The shortcomings in EOL care in America, have led to the development of the “End of Life movement” (Sherman, 1999, p. 113), whereby foundations, Academic Centers, Institutes, and professional Associations are seeking to improve training, research and services in this domain. Several National Initiatives are urgently seeking to improve practices and policies relevant to care at the end of life care, reduce barriers presented by the health care industry, and enhance professional knowledge and skills in medicine, nursing, and social work (Meier et al., 1997). “Hospice programs represent one substantial innovation of the past quarter century that successfully addresses the care needs of some people coming to the end of life” (Lynn, 2000, p. 2509), by providing comprehensive interdisciplinary team care. Despite its advantages, however, hospice is utilized for only a short time, by a small portion of the dying population (Fox, Landrum-McNiff, Zhong, Dawson, Wu, & Lynn, 1999). Hospice serves narrowly defined populations. First, they tend to cover a single disease category with 80% of enrollees being persons with advanced metastatic cancer (National Hospice Organization, 1995). Second, these enrollees have a comparatively predictable final course of disease consisting of a one to two month phase of progressive decline (Fox et al., 1999). Third, hospices serve primarily middle class Caucasian populations and several deterrents to access and service utilization have been noted among persons of color (Haber, 1999). In sum, “because of the restrictive regulatory climate and the interpretation of what is an appropriate disease trajectory for a hospice person, hospice seems ill-equipped to respond” to the growing numbers of elders who die from chronic diseases other than cancer (Brenner, 1999, p. 391). Unfortunately, as will be discussed below, most dying patients don’t fit this profile, and those outside of hospice programs face substantial pain and isolation and much preventable adversity as they die (Field & Cassel, 1997). Given these restraints and the notable gaps in

quality of care for dying persons, the Institute of Medicine has recommended that models for the care of the dying must be developed that integrate the principals of quality EOL care in all settings.

**Expanding Our Conceptualization of End of Life Care.** The Institute of Medicine (Field & Cassel, 1997) identified three prototypical trajectories at the end of life. The first trajectory is sudden death from an unexpected cause, such as an accident or homicide. The second trajectory is the steady decline in health status from a progressive and predictable disease with a “terminal” phase, such as cancer. The third trajectory is advanced chronic illness marked by slow decline with periodic crises that may result in sudden death. Technological and medical advances have ensured that approximately three-fourths of adults who die in the U.S are elders with advanced chronic diseases such as heart disease, stroke, chronic obstructive pulmonary disease, renal failure, and Alzheimer's disease, who fit this third trajectory (Donaldson & Field, 1998). “With less certain disease paths-ways and more complex and ambiguous choices, the growth of this geriatric population challenges us to develop a broader conceptualization of end of life care” (Zuckerman, & Wollner, 1999), and to develop EOL care models that address the unique needs of this client population and their support networks.

**A Response: Innovations and Integration in Health Care.** Major new initiatives are being developed to support and provide community based care for frail elders with complex chronic illness. During the 1990s there has been a movement to integrate primary and acute care services (largely funded by Medicare) with long term care services (largely funded by Medicaid) to manage both social and health needs of chronically ill elders, in attempts to reduce costs, address the fragmentation in delivery systems, ensure access to primary and preventative care, and improve accountability for health outcomes (Leutz, 1999, New England States Consortium, 2000). Programs vary in terms of their degree of “integration.” For example, many partially integrated programs utilize Medicare for health services and Medicaid for community based care, but the financing remains separate, and multiple providers delivering various services, operate from different sites. Although many states are experimenting with service integration, only two community-based programs that provide services to elders with nursing home level of care needs, are fully “integrated” and operational (Leutz, 1999, B. Bowers and P. Saucier, personal communication, 1/21/01). The first, the Program for All-inclusive Care for the Elderly

(PACE), is a Nationally replicated healthcare-delivery model designed to optimize health and well-being of frail elders who are eligible for nursing home admission (Miller, Miller, Mauser, & O'Malley, 1998). Key features of this model include the use of interdisciplinary teams and the integration of primary care with adult day health center and in-home services.

The second, the Wisconsin Partnership Program (WPP), is an innovative, capitated system of health care designed to integrate health and long-term care for elders and persons with disabilities (Hamilton, 1994). As with the PACE program, a key feature of the WPP is the use of interdisciplinary teams (although these teams are smaller than teams used in the PACE model and thus less costly), which work to manage the comprehensive care needs of frail, vulnerable older adults who meet state nursing home eligibility requirements, but maintain community living arrangements (Miller et al., 1998, p. 20). The hallmark of WPP is the emphasis on consumer choice, involvement, and provider consistency. As demonstration sites, these innovative programs have the potential to dramatically influence the development of programming as other states seek to replicate and expand on these models. Indeed, thirteen other states are participating in an initiative to integrate Medicare and Medicaid to restructure the way in which they finance, and deliver acute and long term care, that builds upon the experience of these programs (University of Maryland Center on Aging, 2000). However, there is virtually no information about EOL care in these settings. The timing is right to examine and document how these agencies are responding to elders dying from advanced chronic disease in these integrated service systems, in order to inform the development of other programs, improve services currently in place, and to determine if these models promote good EOL care.

As a first step in addressing these issues, I will engage in an in-depth case study of one of the four WPP sites. Case study is an approach to research and evaluation that has a distinguished history in the social sciences, and the disciplines of anthropology, education, psychology, and sociology (Creswell, 1998), which stresses the uniqueness and situationality of a case (Mabry, 1998), and is the preferred design when interest is on a contemporary phenomenon within a real-life context. Case study allows for an in-depth analysis of a single case (i.e., program).

The Elder Care Partnership (ECP) program, was selected as an ideal site for defining and contextualizing EOL care for elders with advanced chronic disease in an integrated service system for several reasons. First, as noted above, as one of only two fully integrated programs for nursing home eligible elders, it is unique and innovative. It was chosen over one of the many PACE sites or programs, because it was designed to build on the best qualities of PACE while eliminating features that have slowed census growth (e.g., limited consumer choice), and indeed appears to be increasing in popularity. For example, although the census of the Elder Care PACE program has slowed sufficiently to warrant its recent closure, the ECP program is thriving with an ever increasing enrollment. It was chosen over the three other WPP sites in the state of Wisconsin because it is the largest in terms of the number of participants, it has been operating for a longer period of time so that the team members have the most experience with the model (i.e., since December, 1995), it is one of only two of the sites that provides services solely to elders, and the director of operations, and director of clinical operations who originated and helped to develop WPP are the current CEO and Quality Coordinator of ECP respectively. Rather than risk diluting the analyses and sacrificing depth by conducting a multi-site study, I additionally selected the Madison program because I have developed a solid working relationship with this agency, and its location will allow greater ease of access for observation and data collection. Second, since funding for ECP partially overlaps with the Hospice Medicare benefit, the teams retain most patients until their death, with participants dying on average of within three years of enrollment into the program. The agency has established an End of Life committee to facilitate enhanced programming and planning. They are also committed to engaging in planning and research efforts to improve services, and I view this project as an initial step that will facilitate and stimulate future research. Third, ECP serves clients who follow the most common, but least understood trajectory toward death described previously. Consistent with the characteristics of other elders who are dual eligible (i.e. for Medicare and Medicaid), the majority of ECP participants have a serious chronic disease, averaging 7 – 8 chronic conditions, and 3 or more serious functional limitations (Report to the Special Committee on Aging, U.S. Senate. 2000). They are by definition poor with annual incomes

below \$10,000, and 21% of enrollees are persons of color, which is disproportionate to the small percentage of older persons of color living in Dane County (i.e., approximately 2%).

Finally, ECP has been shown to successfully infuse several program characteristics that are touted as essential standards for quality EOL care, including delivering care through an interdisciplinary team, offering members information to make informed decisions, maximizing the ability of members to live in the setting of their choice, and facilitating members' ability to exercise their rights, responsibilities, participation, and choice (Wisconsin Department of Health and Family Services, 1998, B. Bowers, Personal Communication, 1/29/01).

**Social Work, Interdisciplinary Teams and EOL Care.** The aforementioned trends in the health care arena, have revolutionized health care provision and the roles and functions of health care social workers. Social workers are challenged to “become part of a primary care network of community-oriented delivery systems focused on chronic disease management” (Berkman, 1996, p. 541), and to be key players in the growing interdisciplinary health care environment. The fundamental assertion of service integration advocates is that the often complex needs of older adults are better served through interdisciplinary and coordinated service provision (Schofield & Amodeo, 1999; Waldfogel, 1997, p. 467), and the interdisciplinary team approach is widely regarded by social work educators as the preferred method for working with vulnerable geriatric populations (Mellor, & Lindeman, 1998; Saltz & Damron-Rodriguez, 1999; Zeiss & Steffen, 1996). Hartford Foundation innovation in interdisciplinary clinical team training has made a major contribution in preparing professionals to provide quality geriatric care (Hyer, 1998). Now it is incumbent upon the social work profession to illuminate the contributions of social workers to the interdisciplinary team in community based managed care settings. The Institute of Medicine has made it very clear that although quality EOL care should entail interdisciplinary practice, we must seek to understand and evaluate “the benefits and costs of particular configurations of interdisciplinary expertise” (Field & Cassel, 1997, p. 245). An in-depth multi-method case study of interdisciplinary teams providing EOL care is an opportunity to better understand the roles and contributions of social work to the team approach to EOL care, and will provide the foundation for future evaluation of this cutting edge practice.

### **C. CONCEPTUAL MODEL**

Stewart, Teno, Patrick, and Lynn (1999) proposed a conceptual model, that is useful starting point for considering contextual and programmatic factors that may affect the quality and outcomes of EOL care. As shown in Figure 1, this framework includes three primary domains: (1) patient and family factors affecting health care and its outcomes, (2) the structure and process of care; and (3) patient and family outcomes of care including satisfaction with care and quality and length of life. Stewart et al., (1999) drew upon the EOL literature and current domains proposed as essential by the American Geriatrics Society (AGS, 1996). This study will build upon and modify this model by investigating the latter two domains of structure and process of care, and outcomes of care as they are experienced by stakeholders in this innovative agency. It will also elaborate upon the contributions of the social worker to the team and seek to better understand interventions utilized with this client population. It is likely that there will be additional factors that this conceptual model has not taken into consideration.

### **D. PRELIMINARY STUDIES**

A primary aim of Dr. Kramer's research has been to understand the experience and variation found among family members caring for older adults with chronic and terminal illnesses in order to enhance services provided to this population. Her self initiated studies have involved in-depth interviews and analysis of secondary data, and have greatly enhanced Dr. Kramer's expertise in conducting research involving later life families. She has published works relevant to grief and social work education and practice (Kramer, 1998, 2000), and has conducted three agency based research projects. Two of these employed qualitative ethnographic methods to investigate the communication

strategies used by staff and their utility for working with older adults with chronic impairments (Kramer & Gibson, 1991; Beach & Kramer, 1999). The other study utilized agency records to understand the perceptions of interpersonal family stress among patients and their caregivers (Kramer, Gibson, & Teri, 1992). In the context of the proposed project, Dr. Kramer has initiated a solid working relationship with the agency in which the proposed study will take place. She has facilitated two one hour meetings involving representatives of four stakeholder groups (i.e., agency administrator, director of managed care programs, program manager, and team members) in the identification of evaluation needs in the agency, and in-depth discussions with all members of the EOL committee. The proposed study will build upon the preliminary studies conducted with the agency by Dr. Bowers (who will serve as one of the mentors for this project), that focused upon consumers and providers perceptions of “quality care” (Bowers, Esmond, Holloway, & Norton, 1996). Finally, Dr. Kramer was recently awarded the Project on Death in America Social Work Leadership Development Award, by the Open Society Institute, that will greatly complement the proposed research. She will be working with a group of State and National experts to develop EOL content guidelines for the social work profession, use these standards to conduct a critical review of 50 of the most frequently used textbooks in social work education, and work collaboratively with Dr. Nancy Hooyman to write a text that will address some of the gaps identified in her review in order to enhance educational resources available to educators, students and practitioners. This project will allow Dr. Kramer to attain a greater grasp of the issues relevant to EOL care. In developing the standards for the profession, she will more keenly assess the quality of the care provided at ECP, and to programmatic needs.

#### **D. DESIGN AND METHODS**

##### **Research Design**

An Embedded Case Study design will be utilized. “Case study is an approach to research and evaluation which emphasizes the uniqueness and situationality of a case” (Mabry, 1998). The targeted “case” is the phenomenon of EOL care within the Elder Care Partnership (ECP) Program. This approach is a comprehensive research strategy that is appropriate to empirical inquiries that investigate a contemporary phenomenon (EOL care) within its real-life context (Yin, 1994). “A case study is an

exploration of a “bounded system” or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information (observations, interviews, audio-visual material, documents, reports) rich in context (Creswell, 1998, p. 61). An “embedded” case study is chosen because there is more than one unit of analysis (Yin, 1994). For example, there are multiple units of data that may serve as valuable areas of inquiry such as the total system (programmatic level in which I will look at documents, the mission of the program, the structure of care), intermediate units of interest such as the Team and the EOL committee (goals and activities of the committee, processes of care), and the individual units including individual team members, clients, family members (interviews, surveys, following cases). Since innovation occurs at each of these levels, replication of such programs requires understanding of each.

### **Agency Setting**

Elder Care of Dane County, is a not-for-profit organization which has provided community based long term support services for older adults and their family caregivers since 1976. ECP is the largest program operated at this site. ECP currently employs 10 Interdisciplinary Teams that each consist of a Nurse Practitioner, a Master’s level Social Worker, and a Registered Nurse. Each team contracts to work with the client’s community based physician who jointly manages the medical care of ECP members with the nurse practitioner. Since its inception in 1995, ECP has enrolled approximately 470 older adults, with 289 current enrollees. As noted previously, participants average 7 – 8 chronic medical conditions and 3 or more dependencies in Activities of Daily Living. Seventy-two percent of the disenrollments are due to death, with an average of three deaths per month.

### **Methods**

Although a multi-method approach will be utilized, this study will rely heavily on qualitative methods for the following reasons. First, as noted previously there is virtually no information about how service providers in integrated service systems are thinking about and responding to EOL needs among the elders dying from advanced chronic disease. It would be premature to make assumptions about what and how this care is provided and experienced or about how it should be. Qualitative methods are ideally suited to research that is “exploratory or descriptive, that assumes the value of context and

setting, and that searchers for a deeper understanding of the participants' lived experiences of the phenomenon" (Marshall & Rossman, 1994, p. 38). Second, a qualitative approach will likely provide a rich understanding of these issues that could better inform future program evaluation. Indeed, evaluators of the multi-million dollar SUPPORT project that failed to document any care improvements in following the EOL intervention, have recently suggested that perhaps their fundamental assumptions about what would work were flawed (Lynn et al., 2000). I believe resources will be better utilized if we use interpretive methods to more fully understand the issues we are concerned about. Third, taxonomies of quality end-of-life care have been developed from the medical "expert" perspective rather than those of patients and families (see Bowman et al., 2000). Qualitative methods and a stakeholder based approach will bring multiple voices to understanding these issues.

I intend to establish an Advisory Committee for ongoing consultation on the implementation and progress of this research. This Advisory group will consist of members of the EOL committee at ECP, local and state experts on EOL care, and experts in both interpretive methods and collaborative agency based research.

Data will be obtained using a variety of methods to increase the validity of the study. The primary methods utilized in case study research are participant observation, in-depth interviewing, and document analysis (Yin, 1994). As will be described in more detail below, I intend use these methods, and complement them with brief surveys of 1) team members, 2) clients, and 3) post-bereaved family members. I will organize the data collection methods in two phases (see Research Timetable below for an outline of activities). Phase I will focus on collecting data within the agency and from professionals (i.e., the EOL committee, administrators, team members and agency documentation). Phase II will focus on collection of data from clients and family members. I will describe the data collection methods as they relate to the two Phases of the proposed research.

**Phase I.** First, approximately one to two months will be spent in the field becoming familiar with the agency protocols, documentation, procedures, and staff. I will seek to understand the current constellations of teams, and program administrator and managers perceptions about EOL care in the agency. I will observe weekly meetings of teams targeted for in-depth interviews (see below), and will

attend monthly EOL care committee meetings, during this initial period and for the duration of the study. I will become familiar with the client population served through agency documentation and will retrieve and synthesize data available in the agency data base to describe the contextual and demographic characteristics of deaths that have occurred in ECP. For example, I will request summary statistics for all deceased participants on age, race, diagnoses, place of death, duration and intensity of service, and symptoms with one month of death. Summary statistics and brief chart reviews may reveal information on which to base improvement of care for dying (Goodlin, Winzelberg, Teno, Whedon, Lynn, 1998).

Second, face to face, in-depth interviews will facilitate understanding of how team members define and implement EOL care (i.e. Aim 1), the outcomes relevant to EOL (i.e., Aim 2), the structures and processes of care that influence these outcomes (i.e., Aim 3), and the care dilemmas, barriers, and helps in providing quality EOL care to elders and their family members (i.e., Aim 4). I will conduct a minimum of 15 in-depth interviews with respondents representing five interdisciplinary teams. In case study research, it is customary for the researcher “to arrive with a short list of issues-oriented questions, possible handing the respondent a copy, indicating there is concern about completing an agenda” (Stake, 1995, p. 55). The purpose is to obtain descriptions, understandings, and explanations relevant to the inquiry. A sampling of questions that may be explored in the interviews are detailed in Appendix A.

Third, structures and processes in place will additionally be revealed through review of relevant client records, examination of the policies and procedures followed by team members, and conversations with team members. Team members will be able to provide information on their tasks, roles, functions, and their perceptions concerning how client outcomes are influenced by and through social workers.

Fourth, Instruments used in End of Life Care, developed by the City of Hope Pain/Palliative Care Resource Center will be utilized (City of Hope Pain/Palliative Care Resource Center, 1999) to survey all team members regarding EOL attitudes, knowledge, and barriers to care in this setting, during phase 1. These instruments will allow me to describe and compare the team members attitudes and knowledge regarding EOL care, and will provide a quick assessment of potential barriers to care (i.e., Aim 4). Given that these are newly developed measures, there is little reliability and validity data

available. They were chosen because to my knowledge, there are no other “standardized measures” of these domains currently available, and these are intended to be used for needs assessment purposes. These forms are clearly designed and easy to administer and complete, and have been used successfully to document the state of EOL care in other agency settings (Ferrell, Virani, & Grant, M., 1998; 1999). In addition, I will modify the Organizational Assessment instrument, developed by members of Supportive Care of the Dying (Supportive Care of the Dying, 2001), to assess the supportive structures which make it possible to deliver EOL care. The assessment is a useful tool for reviewing current policies and procedures, standards of care, practice guidelines, strategies to identify populations, organizational priorities, and services (i.e., Aim 2).

**Phase II.** As with Phase I, a multi-method approach will be utilized including in-depth and semi-structured interviews with 15 participants and family caregivers (see a sampling of issues questions in Appendix A), and a post bereavement survey to family members about their experiences and satisfaction with ECP, and the circumstances around the death of their family member. I will work with the Advisory Committee mentors, and ECP staff to carefully craft this phase of the research given the many conceptual, ethical, and methodological challenges of conducting research with families receiving EOL care (McClement & Woodgate, 1998). Indeed “the decision to use dying patients as research subjects is one of the most controversial an investigator can make (Katz, 1972, p. 1053). I fully recognize that it will be essential to pay careful attention to informed consent, freedom to withdraw, and voluntary participation with these vulnerable subjects (Kristjanson, Hanson, & Balneaves, 1994). Never the less, quality EOL care is most appropriately viewed from the perspective of care recipients and family members, even though their voices are largely unheard (Bowman, Martin, & Singer, 2000).

Over the two-year period, I intend to additionally observe the course of events surrounding the death of at least 5 individuals in more depth. Specific data collection procedures will consist of the following: attendance at team meetings; conversations with team members after team meetings or at other times about those patients who are near death or who might die; discussion with family members, personal care workers, or friends who are involved in the care of these elders; conversations with clients, and review of client charts. For these embedded cases, I will narrate the study through the techniques

such as a chronology of major events followed by an up-close or a detailed perspective about essential incidents. Through this data collection process, a detailed description of the case will emerge, along with an analysis of themes or issues, and my interpretation or assertions about the case (Stake, 1995).

**Sampling for In-depth Interviews.** As mentioned previously, I intend to interview a minimum of 15 members from five teams, and a minimum of 15 participants and family members. I will select the first team based on input from the EOL committee, and program manager. The first informants for in-depth interviews will include all members of one team, who have been functioning as a team for a minimum of 3 years, and who have experienced the death of numerous clients. As is common to qualitative inquiry, the criteria for the selection of informants is likely to change over the course of the study. I may want to then compare the responses of this team with that of a more recently formed team. Additional team members will be interviewed until saturation is obtained. I will seek input from the Advisory Committee and the team members to determine the most appropriate clients and family members to interview. I would like to obtain a divergent sample of persons that represents potentially diverse perspectives.

### **Analysis**

Given the many sources and complexity of data, analytic strategies and standards for case study research are not clearly explicated. Two common strategies for reaching new meanings in case study research is through direct interpretation of individual events and through aggregation of experiences (Stake, 1995), and both of these strategies will be employed. Yin (1994) recommended selecting an overall strategy to follow in order to successfully complete the analytic phase of the research that can otherwise become unwieldy. One strategy proposed that is most consistent with my study aims is the general analytic strategy of developing a descriptive framework for organizing the case study. This approach is useful in developing an overall pattern of complexity that may be used to explain phenomenon (Yin, 1994). In so doing I will rely on a variety of analytic techniques that are recommended for case study research (Yin, 1994), such as content analysis, matrix displays, creating data displays for examining the data, putting information in chronological order (Miles & Huberman, 1994), and grouping sources of data. Clearly it will be necessary to develop a system for carefully

organizing the various sources of data. Through my intensive guided study with Dr. Bowers, I will initially review several methods of qualitative data to determine the most promising analytic and organizational strategies. All face-to-face interviews will be audiotaped and transcribed verbatim into a word processor format, and summaries of transcripts will be made so that incomplete portions or ambiguous data can be clarified. Each transcript will be verified for accuracy by listening to the audiotapes while reading the printed transcript. Conversations will be collected by descriptive notetaking including verbatim notation during conversations. Pertinent information will be extracted from multiple documents in the form of thematic excerpts and sorted into program categories and domains of interest to this study (e.g., program operations, structures, processes, outcomes, care dilemmas, barriers, and helps to providing care). This information will be used to depict program theory in some form of graphic representation. Analyses will be shared with stakeholders to confirm its accuracy.

### **Trustworthiness**

Since this research relies heavily upon qualitative methods to investigate EOL issues, I will address the canons and standards for the quality of the conclusions against which the trustworthiness of the research must be evaluated (Lincoln & Guba, 1985; Marshall & Rossman, 1994). Credibility will be enhanced by the use of the constant comparative method, by maintaining and recording events in a field journal and using members of the advisory committee to improve conceptual clarity and completeness. Dependability will be enhanced by carefully document an audit trail that peers and colleagues can follow. I intend to develop an organized record keeping system to carefully keep track of the research processes and data in retrievable form. Information that may affect data analysis, that is not documented during the interview tapings such as thoughts, impressions, situations, rationale for decisions and design changes will be kept in a journal. Confirmability and objectivity are defined as neutrality and freedom from researcher bias. Confirmability or member validation will be established by conducting member checks with stakeholders to check interpretations of the data collected to verify agreement.

## **E. EXPECTED CONTRIBUTION AND NEXT STEPS**

There are several contributions of the proposed study. First, this study will contribute to the development of a model for expanding our conceptualization of EOL care, that is grounded in the experiences of frail elders, their caregivers, and health care providers. My hope is that dissemination of study findings will inspire greater research attention to EOL care for elders with advanced chronic disease. Second, this study will illuminate the contributions of gerontological social workers to EOL care, and will inform the development of recommendations for interdisciplinary team models to collectively manage the needs of chronically ill and dying patients and their family members. It is likely that this study will identify educational and training needs of team members. Third, this study has implications for improving care of dying elders receiving integrated services, as it seeks to characterize current care and identify opportunities for improvement. This study will reveal the structures and processes in place (and those not in place), and will identify care dilemmas, and barriers in this service setting. This will have clear implications for developing strategies for addressing and overcoming these barriers and improving services. Fourth, this study will contribute to policy recommendations for integrated programs. One anticipated product from this study would be guidelines on EOL care for integrated service systems. The New England States Consortium (2000) develops guidelines for policy makers and program designers, that are presented as a series of questions to be considered “when designing, overseeing, evaluating or improving integrated care programs” (p. 5). Currently, there are no guidelines on EOL care in this document. I intend to develop guidelines to specifically address this important domain. Fifth, the conceptualizations behind quality of care from the perspective of multiple stakeholders will lead to instrument development, as outcomes not heretofore addressed in our current models of EOL care will be identified. Finally, this project will lay the ground work for getting funds for future research. For example, depending upon the results of this case study, logical next steps might entail one of the following: (1) program development or enhancement efforts; (2) readying the program for evaluation; or (3) conducting an impact assessment. I additionally envision several other projects that may generate from this study. For example, this project would lay the ground work for research with the Wisconsin Family Care initiative, which is currently being pilot tested in nine counties, with

plans to expand to the entire state. Family Care is a partially integrated system, with an interdisciplinary team model, that faces the similar challenge of providing care for older clients until their death.

Findings from this study will inform service provision within Family Care, and serve as pilot data for a proposal to compare service systems (e.g., the differential challenges experienced by a fully integrated program, compared to a partially integrated program). Future investigations may also attend to evaluation of specific EOL social work interventions in these innovative settings.

## **F. RESEARCH TIMETABLE (Sept. 1, 2001 – Aug. 31, 2003)**

**Work in Progress and/or to Precede Start Date.** In the summer of 2000, I will establish and convene the Advisory Committee for this project, and develop the case study and training protocols for the Project Assistant.

### **YEAR 1: Phase 1 – Professional Perspectives**

#### First Quarter (Fall 2001)

- Develop and submit IRB proposal for Phase 1
- Initiate review of program documents and interviews with administrator and funding stakeholder
- Collect and analyze data concerning characteristics relevant to deceased participants

#### Second Quarter (Winter, 2002)

- Conduct Organizational Assessment
- Distribute EOL Knowledge, Attitude, and Organizational Assessment Survey to Staff
- Commence in-depth interviews with Team members
- Observe Interdisciplinary Team Meetings and review pertinent client records
- Initiate Data Analysis

#### Third Quarter (Spring, 2002)

- Continue in-depth interviews with Team members
- Continue with data analysis
- Observe Interdisciplinary Team Meetings and review pertinent client records
- Verify analysis with respondents

#### Fourth Quarter (Summer, 2002)

- Finish interviews with team members
- Complete data analysis
- Verify analysis with respondents

### **YEAR 2: Phase 2 - Client and Family Perspectives**

#### First Quarter (Fall, 2002)

- Modify and develop post bereavement survey instruments
- Develop and submit IRB proposal for Phase 2

#### Second Quarter (Winter 2003)

- Team to send letters to bereaved family members inviting participation in follow up survey
- Mail out post bereavement survey
- Initiate recruitment protocols for participants and family members
- Commence interviews with participants and family members
- Analyze data and verify analysis with respondents

#### Third Quarter (Spring, 2003)

- Initiate data analysis and entry of post bereavement surveys
- Continue interviews with participants and family members
- Verify analysis with respondents

#### Fourth Quarter (Summer, 2003)

- Synthesize findings, initiate manuscript preparation
- Finalize report and determine next steps

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## APPENDIX A

### POTENTIAL ISSUE QUESTIONS TO CONSIDER FOR EACH AIM OF THE STUDY

Questions related to AIM #1: (How EOL care is defined and implemented in this setting?)

#### Professionals:

How do team members describe their experiences of shifting from “routine” care to EOL care?

Do they even make that distinction and what contributes to that?

What characteristics of consumers trigger this shift?

How does it affect the kind of care they provide?

How do they define “quality” EOL care?

What do social workers consider “good” EOL care?

What distinguishes excellent from good (from fair, from poor) care provided to dying elders?

What does it consist of?

What is important for other professionals to know in order to do this work well?

#### Clients and Family Members:

Have they given thought to the future and what it holds for them?

Do they conceptualize their experience as being one of approaching death?

How do they define “quality” EOL care?

How do they experience this?

Who provides it?

**Questions related to AIM #2: (Identify the implicit and explicit outcomes of quality EOL care)**

#### Professionals:

What are the outcomes that team members strive to achieve?

What influence does social work have? Does this vary across teams?

What do team members view as the most important outcome of their work?

#### Clients and Family Members:

What are their concerns and what is most important to them?

What outcomes are most important to clients and family caregivers and does the program address these?

How has their life changed since enrolling in the ECP program?

How satisfied are they with care?

Have clients given thought to their preferences about their EOL care?

Have they had discussions with team members about their preferences?

**Questions relevant to AIM #3: (Identify the structures & processes in place that influence quality EOL outcomes, and the contributions of social workers)**

Professionals:

- How do team members define and strive for “quality” EOL care?
- How do team members strive to achieve outcomes?
- What specific roles and contributions to social workers have relevant to EOL care?
- What do other team members value about the social workers’ contribution?
- Are there protocols to follow when clients are approaching death?
- Who do team members turn to for EOL issues?
- How do team members construct their notions about what quality EOL care is?
- How do they make decision about symptom management?
- How do they operate in terms of pain management and communication with patients and family members?
- How do they involve the caregiver and patient?
- What do they view as the most important thing that they can do for their clients?

Clients and Family Members:

- What factors contribute to satisfaction and to quality of life?
- How do participants and family caregivers experience the program?
- What is important to them at this time in their life and how do social workers (or other team members) provide or enhance that?

**Questions related to AIM #4: (Identify the care dilemmas, barriers, and helps to providing quality EOL care in this innovative program)**

Professionals:

- What are team members’ perceptions of care dilemmas and barriers to providing quality EOL care?
- What are team members’ perceptions of things that facilitate quality EOL care?
- What don’t team members have time for that they feel is important?
- What do team members think clients at EOL need most from them and from the agency?
- Have they and the agency been able to provide that? Why or why not?
- What is viewed as most difficult about this work?

Clients and family members:

- If clients and family members could change anything about this program, what would it be?
- Do clients and family members wish things could be done differently? If so, what?
- What do clients and family members like or appreciate about the program, and what do they not like?