Improving End-of-Life Experience and Care in the Community: A Conceptual Framework

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ABSTRACT

End-of-life research and interventions have mostly focused on patients and family. There are compelling reasons for studying end-of-life experience and care from a community perspective. "Whole community" approaches to end-of-life care have been endorsed by the Institute of Medicine Committee on Care at End of Life. (1) Building on the model developed by Stuart and colleagues, (10) which integrates quality of life and quality of health indicators, a conceptual framework is presented that describes pertinent whole-community characteristics, structures, processes, and outcomes. The framework offers a map for whole-community research, intervention, and evaluation with the goal of changing the community culture related to life's end and thereby improving the quality of life for dying people and their families.

INTRODUCTION

In a 1997 report, *Approaching Death*, the Institute of Medicine Committee on Care at End of Life," endorsed the value of "whole community" approaches to end-of-life care. (1) Although the Committee emphasized professional aspects, it noted that "public and private policies, practices, and attitudes that help organizations and individuals" were required, including "support systems provided through workplaces, religious congregations, and other institutions to ease the emotional, financial, and practical burdens experienced by dying patients and their families." Additionally, the Institute called for "public education programs that aim to improve general awareness, to encourage advanced care planning, and to provide specific information at the time of need about resources for physical, emotional, spiritual, and practical caring at the end of life." (1)

There are compelling reasons for studying end-of-life experience1[1] and care2[2] from a community3[3] perspective. The experiences of serious illness, dying, caregiving4[4], grieving and death cannot be completely understood within a medical framework alone. These events are personal, but also fundamentally communal. Every community responds to its members who are living through these difficult experiences in ways that at once reflect and shape community life. Medical care and health services constitute essential components of a community's response, but not its entirety. It therefore is important to consider how end-of-life quality improvement programs can include both non-medical and medical aspects of care in a community-wide context.

Community-based research and social change efforts are not new. For example, public health interventions and campaigns cover an array of social problems, such as unmet needs of the chronically ill (2), primary prevention of cardiovascular diseases (3) (4) (5) (6), reduction of tobacco use (7), preventing low birth weight, child abuse, and school attrition (8) to name a few. However, applying community-wide social change efforts to improve end-of-life experience has only recently become a focus of attention. Efforts to improve the quality of end-of-life care have focused almost exclusively on health care settings and health care practices. (9) Increasingly, people receive care in private homes and other community settings such as assisted-living and long-term care facilities. Additionally, a variety of contemporary health programs and clinical services are based outside medical institutions, for example, home nursing care, IV infusion services, home respiratory and physical therapy, nursing aides and personal care attendants and supportive services such as Meals on Wheels.

Whole-community efforts to improve the quality of end-of-life experience would benefit from a conceptual framework that supports research and program evaluation and contributes to community dialogue and action. The conceptual framework must partition relevant community components of community life in a manner that (a) enables development of an evidence base regarding current practices, (b) identifies areas in need of quality improvement, (c) provides a basis for reaching agreement on effective interventions, and (d) supports ongoing evaluation. Clear definitions of the pertinent characteristics, structure, and processes of community that contribute to the quality of end-of-life experience will facilitate comprehensive and effective quality improvement. We must also identify outcomes relevant to individuals, families, and whole communities. Such a framework should support quantitative and qualitative research and collection of meaningful objective and subjective data.

Stewart et al. (10) developed a conceptual model that identified key concepts and domains of clinical end-of-life care and related patient and family health care experience. Using the Donabedian (11) (12) structure-process-outcome framework, the goal of the model was to integrate quality of life and quality of health care indicators. Building on this model, we have constructed a conceptual framework to support the research, quality improvement interventions, and program evaluation of a whole-community approach to improve the quality of life's end. This framework was developed for the Missoula Demonstration Project, a long-term, community-

based effort to improve the quality of end-of-life experience in Missoula, Montana, as a model for the nation.

We have constructed a research and quality improvement model that encompasses non-clinical as well as clinical aspects of end-of-life experience and discerns relevant community characteristics, structures, processes and outcomes. Cultural mores, assumptions and behaviors critically shape communities. This conceptual framework enables cultural community traits pertinent to illness, caregiving, dying, and grief to be studied and analyzed. With this conceptual framework we adapt the continuous quality improvement (CQI) model developed in manufacturing and widely used in clinical institutions, expanding the scope and response cycle of the CQI model to fit whole-community applications. (13) (14) While the framework is presented as abstract categories and interactions, the theory has practical implications for whole-community interventions. The framework is intended to enable communities to become effectively engaged in improving the quality of life's end. It allows research methods to be applied in a focused, efficient manner within a community for the purposes of identifying areas needing improvement, informing the design of targeted interventions, and conducting evaluations to track progress. The unit of analysis and target of interventions within this whole-community conceptual framework are determined by the specific characteristic, structure, or process that is being measured or impacted. For example, geographically bounded areas such as counties, health care institutions, social service agencies, or faith communities each may serve as the unit of analysis. (15)

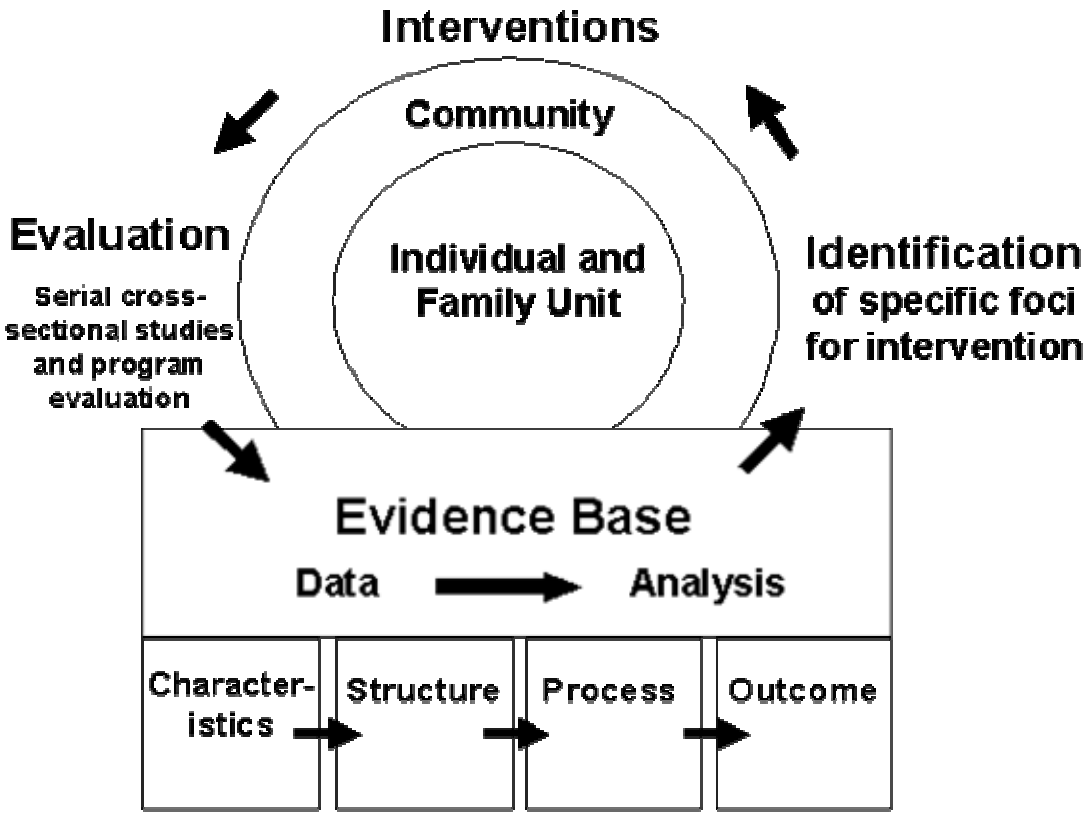
In this paper we provide an overview of a proposed conceptual framework and detail examples of pertinent community characteristics, structures, processes, and outcomes. We describe an adaptation and expansion of the continuous quality improvement model applied to study and improve end-of-life care community-wide. Finally, we offer specific examples from the Missoula Demonstration Project's experience to illustrate real-world application of this theoretical model.

A CONCEPTUAL FRAMEWORK FOR WHOLE-COMMUNITY QUALITY IMPROVEMENT

Quality improvement models use an evidence base developed from data relevant to the experience and service under study. These models enable information to be used in design and evaluation of interventions. (13) (14) (Figure 1) As can be seen in Figure 1, community-based quality improvement efforts incorporate two dimensions of evidence that correspond to two types of interventions: individual-focused and community focused.

Figure 1

An evidence base and operational model for community-based quality improvement interventions



The first type of evidence and intervention involves the individual community member, the family5[5], and their immediate social network. This dimension includes the provision of, as well as receiving, professional care, informal care, and social support6[6]. Key individual and family characteristics, structure and processes of care, and outcomes of care have been well delineated by Stewart et al, (10) and are built upon here. The individual and family characteristics include patient factors affecting health care, as well as the personal and immediate social environment of care. Structures of care include access to services within the health care system, organization of care, formal support services, and physical environments of care. Processes of care include technical clinical interventions, provision of information, patterns and procedures used in making therapeutic decisions, and counseling and communication with patient and family. Outcomes of care include satisfaction with health care, comprised of both

patient and family satisfaction, as well as quality of patient and family life, the length of the affected individual's life, and the quality of the dying experience. (10)

To act comprehensively and effectively to improve the quality of the dying experience, we believe a broader type of evidence and intervention is required involving the whole community. This dimension of the framework addresses collective experiences and expectations (as might be shown in a community survey of generally held attitudes and typical behaviors attitudes and practices related to advance care planning), pertinent community-wide environmental features (including transportation, housing, medical facilities, senior centers), and the milieu of geographic and component sub-communities (, neighborhoods, faith communities, insititutions, social organizations, etc.). Whole-community interventions can affect experience at the individual/family level and at a community level, which is broader and more pervasive than the direct impact that clinical care and assistance of networks of friends and social supports have on dying individuals and their families.

This quality improvement framework emphasizes community values and expectations (including hopes and fears) and assesses the degree of concordance or variance between generally held values or hopes and experienced or observed outcomes in the community. As described by this conceptual framework, community characteristics, structures, and normative processes interact to influence outcomes of end-of-life experience, care and support. These aspects of community life can change over time by interventions that address, not only health and social services, but also prevailing beliefs, attitudes and behaviors.

To apply this framework, analysts need instruments that can reliably assess aspects of end-of-life experience of most importance to dying people and their families. This assessment provides the evidence-base from which the development of interventions can proceed. Over the last decade researchers have developed a variety of methodologies to assess quality of life and patient and family satisfaction. A number of tools now exist to assess these domains and quality of care7[7] prospectively and retrospectively. Examples include structured and semi-structured interviews, surrogate after-death interviews, and medical chart review instruments. (16)(17)(18)(19)(20) Ethnographic or cultural anthropological techniques can also be applied. (21) (22) Structured interviews, surveys and standardized tests can assess the knowledge, attitudes, and skills of professionals with regard to end-of-life care. Although these tools were often designed to assess and improve clinical care of individuals, they may also aid researchers in whole-community analysis. Community assessment at a given point in time can be enhanced by using such tools to describe patterns of care across institutions or provider groups within a community, and to discern aggregate quality among available services and attributes of aggregate personal experience among community members.

Using information obtained from these various data-gathering methods, interventions can focus on three specific targets for quality improvement: 1) Professional services and care that are documented to be at variance from recognized standards for professional service and practice; 2) prevalent misconceptions by the lay public and professionals that potentially contribute to outcomes that are inconsistent with widely-held values and hopes; and 3) normative

behaviors8[8], including common patterns of professional practice and informal social interaction, that are incongruent with prevailing values and hopes and consequently contribute to undesirable outcomes. In addition, this information may also be used to identify areas in which recognized standards or prevalent values and hopes might be elevated in a way that improves the quality of end-of-life experiences in the community. Following is a description of various aspects of community characteristics, structure, processes, and outcomes relevant these defined targets for quality improvement.

COMPONENTS OF THE WHOLE COMMUNITY

Community Characteristics

Whole-community characteristics include geography, demographics, social and cultural environment, and history. Within any county, city or town, **geographic** component sub-communities may be defined by neighborhoods or specific areas or landmarks. A **community's demographics** include the size of its population, socio-economic distribution, and ethnic diversity.

The **social and cultural environment** includes predominant attitudes and beliefs as played out in local issues, industries, and prevalent sources of income as well as popular recreational activities, civic and social organizations, and public events. Community members' willingness (or resistance) toward addressing end-of-life issues within formal and informal interactions, groups, and social settings is a whole-community characteristic that can influence end-of-life outcomes. Related specific characteristics include prevailing values, attitudes and tendencies toward extending social support and informal care for one another during times of advance illness, caregiving, and grief. Culture9[9] is a critical characteristic of any community and encompasses a constellation of attributes that apply to the community as a whole or to component sub-communities.

For purposes of research and quality improvement, there is value in distinguishing between the culture of the whole community and that of the professional care sub-community, particularly the professions of medicine, nursing, social work, respiratory and physical therapies, and pastoral care. The culture of the professional health care sub-community is comprised of values and attitudes regarding serious illness, caregiving, dying, death, and bereavement, as well as assumptions about the ways that communication and medical decision making occur. Professional expectations, including hopes and fears related to end-of-life experience and care are pertinent.

Community culture is dynamic. While it is significantly defined by attitudes, assumptions and previous experience that collectively give rise to beliefs and expectations about end-of-life experience, culture is also influenced by individual and collective outcomes and, therefore, is changeable. Cultural values, attitudes, expectations, and modes of behavior tend to be deeply rooted. They are instilled individually early in childhood and reinforced in the home, in schools and in community life. The mutually reinforcing influences of values, attitudes and expectations create a synergy that gives a local culture its power.

Significant shifts in community culture tend to occur slowly, and sometimes change spans several generations. However, at times, significant spurts of cultural change can be observed within short time frames. For example the dying experiences of well-known public figures may advance a shift in cultural expectations. Public accounts of the illness and death of Richard Nixon, who chose to avoid further life prolonging care, of Jackie Onassis who decided to be cared for at home as she died, and of author James Michener who decided to discontinue renal dialysis and allow death to occur gave rise to heightened awareness and expectations within American culture and, at least transiently, generated increased requests for living wills and interest in home care services.

People are at once a product of their culture and a participant in its ongoing evolution. Patterns of individual care and informal interaction shape the culture of the community by reflecting these attitudes and assumptions, which in turn influence an individual's future expectations and assumptions about the way things should be done.

The **history** of community includes sweeping influences ranging from the region's chronology of ethnic immigration to natural disasters and the local impact of the World Wars. Institutional histories affect prevailing professional culture. Institutions' founding principles, the impact of founders and previous strong leaders, specific clinical cases – good and bad – that garner significant attention can influence current attitudes and approaches of the health care community.

Community Structures

Whole-community structures relevant to end-of-life experience include clinical institutions such as hospitals, nursing homes, home health and hospice programs and local public service agencies such as home nutrition support programs, aging services, and child welfare programs. Churches, private social and service groups, neighborhood councils, funeral homes, and memorial societies are aspects of structure. Additionally, the paid professionals who provide formal services related to the end of life are elements of structure. When research studies triangulate data across these various structures, and interventions are designed to improve the quality of some component of end-of-life care (i.e. spiritual care) across structures or platforms of care, whole-community change becomes possible.

Although formal, professional or paid health care has most often been the focus of research, the majority of hands-on care for people with chronic illness is provided by less formal means, principally by families. (23) (24) Spiritual care and caregiving may be provided by members of an individual's or family's faith community, or by volunteers. Examples of structures that may organize or support services that help with transportation, meals, chores, or limited financial assistance, include religious congregations, workplaces, and civic associations or service organizations. Other groups provide peer support for patients and families and are often organized around specific illnesses, such as cancer or Alzheimers disease. Bereavement groups can help alleviate the common sense of isolation and fear of losing one's mind that grieving people often report, providing assurance that the distressing symptoms of grief are normal. One example is Candlelighters, a national organization whose chapters support parents who have suffered the death of children. Programs such as Parish Nursing and Stephen's Ministry programs extend spiritual care and guidance to people confronting challenges of illness, caregiving and grief. In a handful of

communities, several private organizations such as Compassion in Action© and Care Team Networks© assist in the provision of direct, informal care.

Other community structures that can indirectly affect end-of-life experience are schools, local media, and the arts. Any specialized programs in the schools for supporting students dealing with serious illness or grief and any specific courses that focus on end-of-life issues are part of a community's "structure." Local newspapers, radio and television news shows, and public information programming are structural avenues for reaching large numbers of people with information and social messages about end-of-life issues. A community's symphony, art museum(s) and any art expression programs may incorporate subjects of illness, death, and grief. Some "structures" are ad hoc or temporary. Events such as town meetings, or theater presentation and time-limited projects of committees and task forces may also contribute to whole-community or individual end-of-life outcomes.

Community Processes

Many community processes correspond to the formal care, informal care, related services, and social support provided through the structures discussed above. Formal services are usually delivered from a larger structure such as a hospital, county health department, state agency or large voluntary health association. Those providing formal services are usually paid for their work. Licensure, accreditation and oversight are all formal processes.

Formal individual/family processes encompass the manner in which people interact with local systems and service providers. The most obvious set of formal processes affecting end-of-life experience are those comprising clinical care. Screening, diagnostic work-ups, treatments, and symptom management are key clinical activities. Although these processes involve and impact individuals and families, in the aggregate, levels of access, patterns of usage and types and standards of services may vary significantly from one geographic community to another, and also from one institution or office to another. For instance, people with serious illness can access health care in a wide variety of ways, through private physician offices, public health clinics, emergency departments, or through community screening and health surveillance, blood pressure and cholesterol check stands at health fairs, mammography programs, community public health nursing, and parish nursing. If research reveals that a whole-community process is lacking, for example if many of these health care access sites are not providing assistance with advance care planning, this gap between what is valued and what is available can become a target for improvement of end-of-life outcomes.

Similarly, the ways in which people access and use legal counsel, ministerial or pastoral care, and burial and memorial services are elements of whole-community processes that significantly impact end-of-life experience. Other formal processes include the administration of social services that range from welfare to public medical coverage, to special transportation, to meals delivered in the home (through agencies such as Meals on Wheels or church-based committees.) Delivery of some formal services is indirectly related to end-of-life experience. For instance, the delivery of formal instruction regarding issues of aging, illness, death, grief and loss within the primary and secondary school classrooms fits within this category.

Communication between clinicians and patients and their families includes giving and receiving information about diagnoses and poor prognoses, decision-making and advance care planning, and death notification. The units of communication are individual patients, families and their clinical caregivers; however, in aggregating and triangulating data across sites, specific patterns of communication may be discerned. For example, how doctors in a given community tend to deliver bad news, and common ways by which people convey bad news to their families are relevant and potentially important foci for quality improvement.

Independent of clinicians, ill persons and families often engage in other processes that influence clinical care and end-of-life experience. Individual planning and preparation for care, completion of advance directives, naming of legal surrogates, providing instructions for future care at a time when the individual may be unable to communicate, and the planning and preparation for funerals and burial or cremation are all pertinent processes. Common patterns of accomplishing these individual activities, and the extent to which people commonly engage in discussion of these topics, have relevance at a community level of analysis.

Informal processes are not restricted to goal-directed activities but may include discussions and casual interactions between family members, friends, coworkers, members of faith communities and neighbors that involve content related to end-of-life experience. Also included are "non-interactions" such as avoidance by others of ill or grieving individuals, or avoidance of any mention of an affected individual's illness, grief or caregiving despite knowledge of these situations.

Informal care by family and friends and support for family caregivers' hands-on services of administering medications, changing wound dressings, and assisting with feeding, dressing and toileting are also categorized as processes. Informal support for the ill person and family can include assisting with errands such as grocery shopping, or with chores such as cutting the lawn or raking leaves. Friends or a volunteer may provide assistance with medical insurance forms and applications for welfare or Medicaid on an informal basis. One community may have one or more established programs (structures), perhaps based in churches or senior centers, to provide such services, while another community of similar size and demographics may not.

When the above behaviors and formal and informal interactions represent common patterns, the concept of "normative behaviors" applies, referring to accustomed modes of interaction considered to be "natural" and thought of by those involved simply as, "the way we do things." Often "the way we do things" is the process outgrowth of whole-community culture. When research indicates that processes are not in accordance with widely-held values, expectations, and desired outcomes, interventions can be implemented in community institutions or associations to raise community-wide awareness of the discrepancy.

COMMUNITY OUTCOMES

Within the conceptual framework for end-of-life experience, outcomes are the results of the interaction between characteristics, structure and processes. Since the purpose of this framework is to enable study and improvement of end-of-life experience, by definition, outcomes concern satisfaction with and the observed and reported quality of the following domains: 1) life with illness; 2) dying; 3)

experience of formal care; 4) experience of informal care; and 5) experience of grieving. For initial descriptive studies these are the baseline outcomes or starting points. Following quality improvement efforts, these same categories are assessed for improvement. Thus, as a cumulative result of interventions, the improved outcomes may come to represent the idealized, highest achievable quality of life during illness, caregiving, dying or grief, and quality of formal and informal care and support.

Although these outcomes are experienced at the individual and family level, we are proposing that the highest, idealized quality of life is achieved community-wide when dying, caregiving and grieving are recognized as important aspects of life. A cultural shift of this nature is required for normative behaviors to support individual values and expectations. Unless and until such a shift occurs, unsatisfactory outcomes will persist. We are suggesting that whole-community indicators of this cultural shift include: 1) an adult population comprised of individuals who have prepared for dying through discussions with family, friends, neighbors, and healthcare and other professionals; 2) a population in which people support, and feel supported by, one another during times of caregiving and grief; and 3) schools, faith communities, businesses, associations, and social clubs that commonly include issues and activities pertinent to dying, caregiving, and bereavement in their agendas. When acting otherwise would seem unnatural, these community attributes will comprise the social and cultural norm and will be self-sustaining. All of these components of the community are measurable.

Moving from documented baseline outcomes to improved outcomes entails a process of: 1) collecting and analyzing baseline data; 2) developing interventions that address community characteristics, structures, and processes that are at variance with professional standards of best practices or community values and hopes; 3) evaluating programmatic effect; and 4) determining if end-of-life outcomes are improved. This process is described below.

CONTINUOUS QUALITY IMPROVEMENT COMMU NITY-WIDE

The continuous quality improvement (CQI) model works with manageable sequential interventions that start with discrete units of analysis, for example one floor of a nursing home, or the cardiac unit in a hospital. This model comprises: 1) identifying problems through data gathering and analysis; 2) designing and implementing an intervention; 3) assessing the impact of the intervention; and 4) if the intervention is effective, establishing it system-wide. Based on the evaluation results, the intervention is revised, or a new one is developed to further improvement. This subsequent intervention is then implemented and evaluation is repeated. Improvement efforts can continue in this serial or iterative fashion. In the CQI model this cycle is referred to as the "plan, do, check, act" process. (14)

This model can be adapted to a whole community where the units of analysis are sub-components of the whole-community, for example faith communities, neighborhoods, employees, schools, attorneys, health care providers. Although these units of analysis are larger than those typically addressed in the CQI model, the process is the same. Data is used to identify problematic community characteristics, structures, and processes. Interventions are developed and implemented to address the problems. These interventions are evaluated and revised, or additional programs are developed and implemented. In this manner,

efforts to shift end-of-life outcomes in a direction consistent with a community's values, expectations and stated standards of best practice can be ongoing. The fundamental approach of sequential quality improvement based on measurable outcomes is common to institutional quality improvement programs. The time course for change of community characteristics, structures and processes, particularly those with strong cultural roots, is naturally much longer than the "plan-do-check-act" cycle of standard CQI goals.

Developing Programmatic Objectives and Interventions

We refer to the specific desired results from each intervention as *programmatic objectives*. Following is an example of a series of distinct, complementary programmatic objectives that target specific community characteristics, processes, and structures all related to improving advance care planning: 1) increasing the proportion of attorneys who understand and can counsel clients regarding advance directives and out-of-hospital do-not-resuscitate orders (characteristic); 2) doubling the percent of adults who say they are able to discuss end-of-life planning and preferences for care with their family (characteristic); 3) establishing a single form for advance directive documents for all health care institutions in the county (structure); 4) developing a volunteer, advance care planning mentor program (structure); and 5) recruiting volunteer mentors to assist people in thoughtfully completing advance directives (process.)

The objectives of programmatic interventions may converge to comprise *intermediate objectives*, such as, "having health care choices honored," "improved pain management" and "having spiritual needs met." Over time, and through impact on various sub-communities, these discrete components of progress can collectively contribute to achieving the conceptual goals of "best possible" outcomes of formal care and quality of life with serious illness.

A myriad of whole-community intervention activities, events, and programs exist as avenues for quality improvement. Some may focus on whole-community components, such as professional practice. (Table 1) Others may target changes in public knowledge, beliefs, attitudes and behaviors. (Table 2) Professional quality improvement activities may include education, such as grand rounds or other professional presentations on topics pertaining to pain management, advanced care planning, ethics of decision making, or anticipatory guidance for issues of life completion. Similarly, education forums related to health consequences of the stress of family caregiving and ways of supporting family caregivers may attract a multi-disciplinary clinical audience. Such presentations can draw upon data from local research and evaluative efforts that document the status quo in these aspects of practice.

Table 1
Community-based Quality Improvement: Targets for Intervention

- Communication related to dying, caregiving, death and grief

- Advanced care planning
- Symptom management
- Spirituality
- Healthy aging
- Issues of life completion
- Caregiving
- Bereavement
- Support for caregivers
- Advocacy – develop and skill-building

Table 2
Community Interventions: Professional and General Public Programs and Events

- Professional continuing education:
  - medical, nursing
  - pharmacists
  - legal
  - social work and pastoral care education
  - psychologists
  - therapists
  - funeral directors
  - teachers
  - administrators
- Programs for public education and community discussion forums
- Inter-generational activities
  - in assisted living
  - long-term care settings
  - childcare settings
  - school settings
- News media and local media programming
- Arts and entertainment programs and events with "talk-back" sessions

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Although the topic of end-of-life experience leads many to think exclusively in terms of clinical professions and institutions, these same concepts are applicable to the legal profession and the education profession. Quality improvement concepts likewise can be applied to improve the ways schools, churches, synagogues, and other faith communities, funeral homes and directors deal with end-of-life experiences.

Quality improvement efforts directed toward the whole community can take many forms. Efforts might focus on the news media or local cultural or civic events that attempt to educate and raise awareness of end-of-life issues of the community as a whole. Events such as town meetings convened to consider baseline data related to end-of-life experience can directly educate and engage the participants, as well as having important secondary impacts on a wider audience through media coverage. Such town meetings can be convened by a local hospice program, an individual health system, or may be organized as a collaborative effort of local health systems, perhaps in association with a local media outlet such as a newspaper or television

station. A good example occurred during the fall of 2000, when nearly 300 communities nationally held locally organized activities in conjunction with a nationally televised documentary, *On Our Own Terms*. (25) (26) (27)

Elements of the whole community can also be engaged through efforts that use data to call attention to the need to improve the quality of some aspects of community life. Thus, employers may respond to evidence documenting the effects of caregiver stress including missed days at work, secondary use of health services and filing of health insurance claims. Employee health benefit committees and health benefit managers can use this information in redesigning employee leave policies, health plans, and employee assistance programs. Committees of employees may decide on optional efforts to support coworkers, such as the "banking" of comp time or personal leave, or volunteering to support a coworker who is, or whose family is, experiencing terminal illness. Such support can range from providing a hot meal to helping with yard work or respite care that gives a primary caregiver a few hours of relief, or to the provision of hands-on care.

Depending on information obtained from the evidence base, whole-community intervention might include efforts to build or expand counseling services in the community schools for children experiencing grief through death, and to offer courses that integrate the experiences of grief and loss – whether engendered by death, parental separation, or relocation of the student or friends – as part of the standard curriculum. Such efforts attempt to normalize the inevitable facts of mortality, grief and loss within human life. School boards and school curriculum committees can use data to assess the current level of support provided to grieving students and their classmates, as well as the level of content germane to end-of-life experience within this curriculum, tracking it over time. Such interventions ultimately stand to affect change on whole-community culture. The quality of spiritual and pastoral support to members of a church, synagogue, prayer group or other faith community can be assessed in a structured or semi-structured manner. Resulting data can be used to stimulate and inform efforts to improve support at times of illness, care giving and grief. Likewise, spiritual care assessments in nursing homes, hospitals, and assisted living facilities can also be used to improve these institutions' capacity to meet dying residents' spiritual needs. These interventions are directed toward the whole-community process of end-of-life spiritual care.

Evaluating and Expanding the Evidence Base

Within this conceptual framework, we anticipate that the evidence base will expand in two ways. (Figure 1) The first is through on-going program evaluation, using a variety of methods, for example monitoring and documenting programmatic challenges and solutions when developing and implementing interventions. Methods to measure programmatic outcomes are conducted at differing levels of rigor. Individual education programs, for instance, can be evaluated using pre- and post-tests to assess participants' knowledge, attitudes and skills. Follow-up tests that are administered six months or more after the program's completion can determine its likely impact on participants' practice. Additionally, programs can be evaluated more rigorously using experimental or quasi-experimental designs. Program evaluations can both assess the impact of a specific intervention and expand the database for developing or refining other community-initiatives.

The second way in which evidence may expand involves serial, cross-sectional studies of the characteristics, structures, processes and outcomes defined by this conceptual framework. Baseline descriptive data can be collected, for example by administering a survey regarding end-of-life attitudes, values, and experiences to a random sample of community residents, or by surveying clinical health care providers regarding their pain management knowledge and practice, or by conducting after-death interviews with a random sample of bereaved family members. After various interventions have been implemented, re-administration of the initial data collection protocols expands the evidence base descriptively and through comparison with baseline data, by determining the collective effects that the combined interventions have had on end-of-life outcomes. The conceptual framework presented here supports such serial, cross-sectional data collection and analyses. The domains and specific aspects of experience delineated also support the integration of both quantitative and qualitative data. The various data sets can be combined or triangulated around foci of interest, such as pain experience and management, communication, or advance care planning to arrive at a more comprehensive picture of specific aspects of end-of-life experience. The quality improvement processes then proceed anew from this expanded evidence base, again targeting areas that are indicated by the data to be problematic.

THEORY IN ACTION: APPLYING THE CONCEPTUAL FRAMEWORK IN A REAL COMMUNITY

Community efforts to improve end-of-life care can be conducted in a variety of ways involving a range of sponsors. Efforts can be organized by a health care institution, a coalition of health-related organizations, an ad hoc committee of civic leaders, a branch of local government or a community-based organization formed with the specific focus of improving end-of-life care experience. An example of the latter is the Missoula Demonstration Project, a community-based project established to study and enhance the quality of end-of-life experience in Missoula County, Montana.

This project had its inception in discussions among citizens from a number of walks of life, including health care, health administration, elder services, faith communities, public education, university education, funeral services and the arts, who shared an interest in improving care for terminally ill persons, and support for families during caregiving and in grief. Prior to the development of the conceptual framework presented here, the initial steering committee and subsequent founding board of directors recognized the importance of establishing a comprehensive baseline of data. Early attention was directed toward designing a set of descriptive studies that would capture data prior to assessing the effects of major community-wide interventions.

Twelve distinct studies comprised the initial Community Profile of baseline descriptive research. The initial questions for descriptive research included the following:

- How do people die in Missoula?
- How do people in Missoula view death and dying?
- How do people in Missoula experience or perceive medical and social care at the end of life?
- How do people in Missoula prepare for death, dying and care at the end of life?

- How do people in Missoula care for and support one another, clinically and socially, during dying and grief?
- What is the quality of end-of-life care in Missoula?

The Community Profile employed a variety of methodologies to collect various types of data and included both quantitative and qualitative analyses. Objective data included state death statistics, funeral records, medical chart reviews, and a community audit of pertinent services and providers. Subjective data included responses to mailed surveys of public attitudes, beliefs and behaviors, and surveys of clinician attitudes, knowledge and practices. One study employed structured interviews about care and end-of-life experience with family members or friends of people who had died in Missoula in a defined two-year period, while another used semi-structured interviews to explore issues of quality from the perspective of bereaved family members. A participant-observer study followed nine patient-caregiver dyads during the last months of life and developed ethnographic data. (22) A series of modified focus groups was conducted with Native Americans to explore this ethnic population's perspective on end-of-life experience.

Pending completion of the Community Profile, the collective professional and personal experience of providers of service and recipients of services, constituted an initial base of local experience from which to interpret national data, such as that from the SUPPORT study. (1) (28) (29)(30)(31) This empirical base gave rise to a set of "working assumptions" about existing needs and valuable activities. Included among these was a shared recognition of the need and value of improving pain management, spiritual care, and advance care planning.

The Missoula Demonstration Project (MDP) began convening and providing administrative support and technical assistance to a number of task forces comprised of professional and lay members of the community. These task forces focused on improving specific aspects of care, both formal and informal; public awareness; and knowledge. As task forces were developed, it was their responsibility to determine what interventions would be implemented in their topic area. The Missoula Demonstration Project provided resources and staff assistance, but the direction of efforts and specific activities were decided by task force members. Consistent with the conceptual framework presented here, each task force used data from the Community Profile as it became available and, as needed, gathered additional information about the prevailing status of resources, services and resulting experiences in Missoula. These findings have reinforced and extended the empiric evidence of need for improvements and have provided an organizing framework for extending the efforts of local task forces. In the broadest sense, the data have revealed areas of discordance between widely-held community values and expectations and experienced end-of-life outcomes. Common patterns of practice, behavior, and social interaction often are inconsistent with desired goals.

The task forces have used the various data sets to develop program objectives. Interventions address relevant areas of knowledge, attitude and behaviors. The task forces then implement interventional programs and evaluate the short-term results. For instance, the MDP's Pain as a Fifth Vital Sign Task Force reviewed national data regarding deficiencies in pain management (28) (29), and examined MDP's Community Profile data, which indicated a significant percentage of the local population have misconceptions regarding pain management that may adversely impact treatment. The task force decided they needed additional information

regarding Missoula's clinician attitudes, knowledge, and skills related to pain management. They developed and implemented a survey of physicians, nurses, pharmacists, emergency medical technicians, physical therapists, and occupational therapists. The data identified areas of deficiencies with regard to knowledge, attitude and skill of pain management. As a result, program objectives were developed, and various professional and community education programs were designed, planned and implemented. As a result pain assessment has become a priority in Missoula's two hospitals and each institution has developed a pain management team. A programmatic outcome of these efforts has been that both hospitals received commendations from the Joint Commission on Accreditation of Healthcare Organizations. Surveys were re-administered, and indicated measurable improvement in professional attitudes, knowledge, and skills, while also reflecting that continued efforts were warranted. Symptom-focused quality improvement programs are ongoing in area hospitals and nursing homes. (32) These programmatic outcomes represent milestones toward the ultimate goal of improved end-of-life outcomes.

To date, a number of community-based task forces have been convened: An Advanced Care Planning Task Force, a Faith Community Task Force, a School's Task Force, a Life Stories Task Force, an Arts Task Force. Each of these groups comprises a diverse membership who share their expertise and experiences. In so doing, members learn from one another and take that knowledge back to their respective organizations, neighborhoods, or families. We observe a ripple effect that is raising awareness of end-of-life issues community-wide. With MDP staff and advisors support, the task forces have designed studies, collected and analyzed data, developed and implemented quality improvement interventions and evaluated the results of their activities.

DISCUSSION

This conceptual framework outlines community characteristics, processes, structures, and outcomes that describe how whole communities perceive and experience the end-of-life. Following the Stuart, et.al (10) model, quality of life for dying people and their families is the framework's principal focus. The framework offers a map for whole-community baseline research, intervention, and intervention evaluation with the goal of understanding that quality of life for dying people is governed, at least in part, by community-wide characteristics, structures, and processes. We are proposing that improving community-wide end-of-life outcomes requires integrating end-of-life care within the continuum of individual, family and community life. The social fabric of the community must be re-woven.

Social change does not come easily or quickly. Yet we know from various public health campaigns that research and interventions can successfully occur at the whole-community level. For example, cigarette smoking has drastically changed over the last ten years in large part due to the cultural attitude change toward smoking. No longer is it acceptable behavior to smoke anywhere one pleases. Community-wide campaigns systematically targeted various units of analysis, for example, employers, insurance companies, pregnant women, and teens. (7) By raising public awareness regarding the health risks of second-hand smoke, the problem no longer resided just with the smokers, it also became a community problem. We suggest that this type of model is necessary to significantly improve the quality of end-of-life experience. We also suggest that social marketing techniques

used in public health campaigns can be used and enhanced by organizing and supporting groups of community members who use research to develop, implement and test interventions. We propose this community-wide, community-driven framework to advance social change and a cultural shift regarding end-of-life experience and care. Absent changes of significant social and cultural breadth and depth, normative behaviors will remain at variance with a community's values and expectations, and unsatisfactory outcomes will persist.

Using this conceptual framework is not without its challenges. Considerable effort is required to gather baseline data. Appropriate outcomes must be well conceived and measurable. Tools for measuring community indicators are scarce. Rigorous research designs within whole communities are difficult at best. Random sampling, control groups, and treatment contamination are particularly problematic for community research and interventions. Evaluation of specific interventions is more manageable, but when several initiatives are concurrently underway, determining which intervention is responsible for outcome change is difficult. Community-wide research and interventions influence people who belong to more than one group. For example, a physician can become a patient, may also be part of a faith community, and likely resides in a neighborhood. Thus units of analysis are no longer mutually exclusive. Standardized, validated tools for measuring end-of-life quality of care and experience are in their infancy, and most are targeted for individuals and families. (16)(17)(18)(19)(20) Comprehensive and feasible measures need to be developed and validated for the whole-community, as well as the targeted sub-communities.

Community-wide programs targeting public health care, youth problems, hate crimes, and other social problems are becoming increasingly common. Researchers are now beginning to address the problems in evaluating community-wide initiatives. (15) Our goal in developing this conceptual framework is to assist initiatives across the country working to improve the quality of end-of-life experience and care throughout their communities. We believe the challenges of conducting whole-community quality improvement can be met. The proposed conceptual framework is a significant step in this endeavor.

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Endnotes

10[1]The term "*end-of-life experience*" is here used to convey the experiences of terminal illness, sudden death, family caregiving, and grieving.

11[2]The term *"end-of-life care"* is used to denote both professional and informal care to treat medical conditions or meet basic human needs such as bathing or eating.

12[3]The term "*community*" here refers to a defined geographic town, city or county and its residents. The term will also be used in reference to component sub-communities that exist within a city or town. In its most general sense, we define "*community*" as (a) formal associations of people who are valued by one another and (b) informal social structures and processes (discussions, activities, affiliations, responsiveness to one another) that reflect or advance some recognized commonality of history, culture, or perspective that is of value to the participants.

13[4]"*Caregiving*" denotes physical and emotional care provided by family, friends and volunteers.

14[5]"*Family*" is here defined as a set of relationships – established by blood or emotional bonds – in which individuals find identity and fulfill mutual obligations of domestic affairs, such as maintaining a household, raising a child, or providing care for each other.

15[6]"*Social support*" refers to both formal (paid) and informal (unpaid) help of a practical or emotional nature.

16[7]"*Quality of care*" refers to care that meets recognized standards of professional service and that conforms to the values and preferences of the individuals, families, and professionals within the community.

17[8]"*Normative behavior*" refers to accustomed modes of interaction that are often unrecognized by those involved. These interactions include formal (professional) and informal social interactions pertinent to end-of-life outcomes.

18[9] "*Culture*" refers to the set of attributes that collectively characterize a community: commonly held values, attitudes, assumptions, history, expectations, hopes, fears, and customary modes of professional, social and personal interactions.