

Key Role of Social Work in Effective Communication and Conflict Resolution Process: Medical Orders for Life-Sustaining Treatment (MOLST) Program in New York and Shared Medical Decision Making at the End of Life

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In this article, the authors review the development of the Medical Orders for Life-Sustaining Treatment (MOLST) Program and recent landmark legislation in New York State in the context of advance care planning and shared medical decision making at the end of life. Social workers are central health care professionals in working with patients, families, practitioners, health care agents, and surrogates in the health systems and in the communication and conflict resolution process that is integral to health care decision making. The critical importance of ethics and end-of-life training and education for social workers is also addressed. Data from a pilot study evaluating interdisciplinary ethics training on legal and ethical content in communication and conflict resolution skills in health care decision making are reported. Recommendations are made for research on education and training of social

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workers, and investigation of the role and influence of systems in shaping social work involvement in end-of-life and palliative care.

KEYWORDS advance care planning, communication, conflict resolution, end-of-life care, health care agent, health care proxy, medical orders, palliative care, shared medical decision making, surrogate

INTRODUCTION

In this article, we explain the development of the Medical Orders for Life-Sustaining Treatment (MOLST) Program in New York State, integration of the Family Health Care Decisions Act and the Palliative Care Information Act, and the critical role of social work and ethics training in advance care planning and end-of-life decision making. In March 2010, a 17-year effort to enable legislation that would improve end-of-life decision options culminated in passage and signing of the Family Health Care Decisions Act (FHCDA), a New York State law that enables a patient's family member to make health care decisions when the patient is not able to do so. The key provisions of the FHCDA became effective on June 1, 2010. The New York State Department of Health also revised the MOLST form (DOH-5003) in June of 2010 to make it more user-friendly and to align the form with the procedures and decision making standards set forth in the FHCDA.

The FHCDA was followed by the enactment of the Palliative Care Information Act in New York State. This legislation will ensure that patients and their family members and loved ones will be provided with information regarding the key pillars of palliative care: advance care planning, pain and symptom management, and caregiver support.

The implementation of the MOLST program together with family health care decision making and palliative care legislation in New York State dramatically changes the landscape for patients with advanced chronic illness as well as for dying patients and their families, and serves as an emerging model of shared medical decision making for the nation. Social workers have a tremendous opportunity to build on this model in helping patients and families prepare for and deal with the anxiety of death. There are multiple roles for social workers at all stages of the health care decision making process and in all settings.

NEW YORK RECOGNIZES FAMILY HEALTH DECISION MAKING

The FHCDA (Public Health Law Article 29-CC) marks a major shift in health policy in New York State as it formally recognizes family health decision making in the state statutory scheme. In essence, the FHCDA gives health care decision making authority to surrogates for patients who have lost decision

making capacity and did not leave prior instructions or appoint a health care agent. This authority extends to all health care decisions, including the withholding or withdrawal of life-sustaining treatment, subject to certain standards and restrictions. The law only applies to decisions for patients in hospitals or nursing homes; however, it is likely to be amended to include community settings such as a patient's home, clinic, or physician's office.

The FHCDA is a critically important law for numerous reasons. First, prior to its enactment, unless a health care agent had been appointed or prior instructions had been left (by a living will or the completion of a MOLST form, or orally in a hospital) it was almost impossible for family members to make health care decisions for patients without capacity. This was because court decisions in New York State required "clear and convincing" evidence of a patient's wishes, a very difficult legal standard to meet. Additionally, as the vast majority of patients in New York State (as elsewhere) had not taken steps to make their health care wishes known, decisions to forgo or stop treatment even when such treatment was clearly burdensome and not beneficial, could not be made by loved ones. Even decisions to consent to treatment that may have been beneficial and likely to improve a patient's quality of life were subject to legal challenge.

Key Provisions

Under the FHCDA, decisions for those who have lost capacity can be made by the person highest in the following priority list, once a determination has been made that a patient lacks decisional capacity: Mental Hygiene Law Article 81 court appointed guardian; spouse or domestic partner; adult son or daughter; parent; adult sibling; or close friend (who could be another relative). The responsibility to notify at least one person on the surrogate list in order of priority rests with the hospital or nursing home. If there is more than one eligible person in a category highest on the priority list, it is assumed that if the eligible persons cannot reach agreement themselves, the hospital or nursing home will generally be able to determine which one is better suited to be the surrogate. In cases where conflicts may arise among family members or eligible persons who are surrogates, the social worker can play a key role in effective communication and in resolving such conflicts informally even at this early stage of the process, or if the conflict needs to be referred to such a committee, as a member of an ethics review committee.

Capacity Determinations

The attending physician makes capacity determinations (Bomba & Vermilyea, 2006). In nursing homes a concurring determination is required; in hospitals a concurring determination must be made only for decisions to withhold or

withdraw life-sustaining treatment. The concurring practitioner can be a registered nurse, nurse practitioner, physician assistant, another physician, a psychologist, or a licensed clinical social worker. Licensed clinical social workers who have met the training and credentialing requirements under hospital and nursing home policy may qualify to perform concurring capacity determinations within their scope of practice. This is especially important in nursing home settings in which social workers serve a large population of frail elderly residents who suffer from various cognitive impairments and dementias.

Decisions for Patients who Lack Capacity

The law is very broad in allowing the surrogate to make all health care decisions; however, there are certain clinical criteria that must be met and stringent limitations on some decisions. The surrogate is required to make treatment decisions in accordance with the patient's wishes, including the patient's religious and moral beliefs, or if the patient's wishes are not reasonably known and cannot be ascertained, in accordance with the patient's best interests. An assessment of the patient's best interests must include the following subjective and objective considerations: (a) dignity and uniqueness of every person; (b) possibility and extent of preserving the patient's life; (c) preservation, improvement, or restoration of the patient's health or functioning; (d) relief of the patient's suffering; and (e) other values that a reasonable person in the patient's circumstances would wish to consider.

While relief of pain and suffering is broadly the goal of palliative care, the express language written into the FHCDA regarding relief of patient suffering provides a new legal basis for assessment of patient suffering as integral to the surrogate decision making process. Social workers are properly trained and qualified to perform this assessment because it is multidimensional in nature and involves evaluation of cognitive, emotional, interpersonal, social, spiritual, cultural, and other aspects of the patient's experience. While social workers are not part of the formal assessment process of patient's best interests, they will need to provide a supportive role to surrogates, physicians, and other health care team members in facilitating their understanding of the patient's experience of suffering.

Decisions to Withhold or Withdraw Life-Sustaining Treatment

Although the standard for decisions based on a patient's wishes or best interests might reasonably be considered sufficient for all health care decisions, other standards must be met in certain situations. Decisions to withhold or

withdraw life-sustaining treatment, including DNR orders, must meet one of the following standards:

- treatment would be an extraordinary burden to the patient and an attending physician, with the concurrence of a second physician, determines to a reasonable degree of medical certainty that the patient is terminally ill (expected to die within 6 months) or the patient is permanently unconscious; or
- treatment would cause such pain, suffering, or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome and an attending physician, with the concurrence of a second physician, determines to a reasonable degree of medical certainty that the patient has an incurable or irreversible condition.

Each of these standards involves a two-pronged determination. The assessment of burden to the patient is made by the surrogate and is primarily non-clinical in nature, although the surrogate will in most cases be consulting with the physician; the second part of the determination is clinical and is made by the physician and concurring physician.

In a nursing home, the surrogate may make a decision to refuse life-sustaining treatment for a patient with an irreversible or incurable condition only if the ethics review committee or a court reviews the decision and determines that the standards set forth above are met. This requirement does not apply to a decision to withhold CPR. If an attending physician in a hospital objects to a surrogate's decision to withhold or withdraw artificial nutrition and hydration for a patient with an irreversible or incurable condition, the decision cannot be implemented until the ethics review committee or a court reviews the decision and determines that the standards set forth above are met.

These standards impose limitations upon decisions to withdraw or withhold life-sustaining treatment to which other health care decisions made by surrogates are not subject. For surrogate decisions under the inhumane/extraordinary burden standard for patients with incurable or irreversible conditions, there is language of pain and suffering written into the clinical criteria that has to be operationalized in facilities in order to make a determination about treatment. In New York State, a health care agent appointed under the health care proxy law is subject only to the limitation that the agent needs to know the patient's wishes about artificial nutrition and hydration, either expressed orally or in writing. Therefore, there is still a strong incentive for individuals to appoint a health care agent whom they trust under New York State law. However, assessment of pain and suffering as burden to patients at the end of life is critically important. This statutory requirement should lay a foundation for consultation not only with physicians, but

with social workers about the patient's pain and suffering experiences and appropriate assessment processes.

Decisions for Minors and for Adults Without Capacity and Without a Surrogate

The FHCDA authorizes parents of minor children to forgo life-sustaining measures in accordance with the same standards that apply to surrogate decisions for adults, but only with the minor's consent if the minor has capacity. Emancipated minors can make life-sustaining treatment decisions under the statute without parental consent subject to ethics review committee approval.

The statute also wisely sets forth a procedure for making health care decisions for adult patients without capacity who have no available persons to serve as a surrogate. Social workers have the professional training and experience to work with both minors and their parents, and to serve as advocates for the most vulnerable and isolated adults in the health systems in discussing end-of-life decisions with physicians. In nursing homes, social workers are also authorized under the statute to make concurring determinations recommending major medical treatment that would involve the use of restraints for residents without capacity who have no health care agent or surrogate.

Ethics Review Committees

Ethics review committees must be established to provide advice upon request or in the event of disputes and to review certain sensitive decisions by surrogates to withdraw or withhold life-sustaining treatment. At least three of the committee members must be health or social service practitioners. Social workers have traditionally served an important role as members of ethics committees in health care institutions in working with the other review committee members to understand patient needs, values, and preferences, and the nature of conflict. In addition to this formal role, social workers have an equally important role, however, in working with patients, families, and practitioners to help resolve disputes informally before cases are referred to an ethics review committee.

PALLIATIVE CARE INFORMATION ACT BECOMES LAW IN NEW YORK STATE

The New York Palliative Care Information Act (PCIA; 2010) is a significant new law in New York State that will serve as a model for the nation. Its goals are to ensure quality clinical practice and appropriately empower dying patients. Patients will be given the opportunity to receive information and

counseling about their palliative care and end-of-life options, including hospice, so that they can make informed decisions about their treatment and care. The law provides that a terminally ill patient's attending health care practitioner shall offer to provide the patient with appropriate information (either verbally or in writing) regarding the patient's options with respect to both palliative and end-of-life care. Such options may include but are not limited to a discussion of the patient's prognosis, risks and benefits, as well as the patient's legal rights to pain and symptom management. (New York Public Health Law Article 29-D).

The obligation to provide this information can be fulfilled by the patient's attending physician or nurse practitioner, as well as by referral or transfer of the patient to another appropriate health care practitioner; however, this information shall not be provided to patients who do not want it. If the patient lacks the capacity to make decisions, the information must be provided to the person with authority to make decisions for the patient.

The PCIA, which will become effective February 2011, was needed for many critically important reasons. The patient's right to receive information and counseling under this new law expands the well-established right of patients to have information sufficient for them to make informed decisions about their treatment under existing New York State laws including the FHCDA (Public Health Law Art. 29-CC, §2994-d3[c]) and the Health Care Proxy Law (Public Health Law, Art. 29-C, §2982.3). In addition, at the end of life, physicians have sometimes been reluctant to discuss with patients or make disclosures to them about diagnosis, prognosis, and end-of-life treatment options (Csikai & Martin, 2010). In a retrospective study of bereaved hospice caregivers, Csikai and Martin (2010) found that caregivers expressed a desire for more information about disease course and the dying process much earlier in the decision-making process.

The SUPPORT study (SUPPORT Principal Investigators, 1995) of physicians in five U.S. hospitals reported that physicians did not have a high level of involvement with their patients concerning patients' end-of-life decision making, even with the support of a specially trained nurse who had multiple contacts with the patient and family. The investigators concluded that greater individual and societal commitment and stronger incentives were needed to improve the experience of seriously ill and dying patients.

Effective communication is viewed as critical to hospice referrals which frequently occur very near death or not at all. While research studies show that the timing of hospice referral involves a mix of factors influencing hospice care at the end of life, better communication between physicians and patients to document and support patient evaluations and Medicare Hospice Benefit eligibility decisions is likely to increase access to hospice care, especially for terminally ill persons who have serious noncancer chronic illnesses (Miller, Kinzbrunner, Pettit, & Williams, 2003; Miller, Lima, Gozalo, & Mor, 2010).

The implementation of the PCIA in New York will involve dissemination of information about the law's mandates to all health care professionals. Social workers will serve an important function in supporting attending practitioners in providing counseling to their terminally ill patients about end-of-life care options. Historically, health care professionals have not been trained or trained well in palliative and end-of-life care, or on how to have effective communication on palliative and end-of-life care with terminally ill patients and their families. Practicing social workers can take the initiative to ensure more and better training, pre- and post-graduation. Additionally, they can, as integral members of the interdisciplinary team, play a key role in having and ensuring good communication with patients and families.

RESEARCH ON ADVANCE CARE PLANNING AND END-OF-LIFE CARE

In its 1998 report *Approaching Death: Improving Care at the End of Life*, The Institute of Medicine stated that end-of-life care must improve on all levels (Institute of Medicine, 1998). The need for improvements in the quality of this care is growing. By 2030, 20% of the American population, or 70 million people, will be over the age of 65 (Robert Wood Johnson Foundation, 2002, p. 39). Since 75% of individuals dying each year are over the age of 65 (Robert Wood Johnson Foundation, 2002, p. 16), there will be greater need for appropriate end-of-life care.

Humane care for those approaching death is a social obligation not adequately met in the communities we serve. Too often death is viewed as a medical failure rather than the final chapter of life. As a result, many people fear a protracted, technologically over-treated death, abandonment during a time of need, and profound suffering of self and family. Currently, conversations about death are too frequently avoided until a crisis occurs, resulting in inadequate advance care planning and patient preferences not being known or honored. Surveys reveal that more than 70% of surveyed Americans indicated that they wish to die at home. Yet, only 25% of Americans die in their homes and 75% die in institutions (Robert Wood Johnson Foundation, 2002, p. 13).

Providing quality medical care is more than supplying appropriate, timely medical interventions without error. Quality medical care is person-centered and respects an individual's wishes, values, and beliefs. This is more difficult when the person requiring care is unable to communicate his or her own wishes, which is often the case in end-of-life care.

Advance Care Planning Discussions

Since passage of the Patient Self-Determination Act in 1990 (Pub. L. No. 101-508), the current system of communicating end-of-life care wishes solely

using traditional advance directives, such as the living will, has proven insufficient. Traditional advance directives require individuals to recognize the importance of advance care planning, understand medical interventions, evaluate personal values and beliefs, and communicate their wishes to their agents, loved ones, physicians, and health care providers.

A study by Tierney et al. (2001) found that elderly patients with chronic illnesses who discussed advance directives with their primary care physicians showed significantly greater satisfaction with their care than those who did not have advance care planning discussions. The strongest predictor of satisfaction with care was the presence of advance care planning discussions. In a retrospective study of over 1,500 decedents, bereaved family member reports showed an association between completion of an advance directive and greater hospice use as well as fewer issues with communication (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). However, there were unmet pain needs and concerns about emotional support for both the patient and family.

Unfortunately, traditional advance directives like the living will apply to future circumstances, require further interpretation by the agent and health care professionals, and do not result in actionable medical orders. The situation is further complicated by the difficulty in defining “terminal” or “irreversible” conditions and accounting for the different perspective that physicians, agents, and loved ones bring to the situation. For example, a patient with dementia who is nearing the end of life eats less, has difficulty managing secretions, aspirates, and often develops pneumonia. While end-stage dementia is “terminal,” pneumonia may be potentially “reversible.” Decisions regarding care depend on interpretations of prior conversations, physician estimates of prognosis; and, possibly, the personal convictions of the physician, agent, and loved ones. The presence of the living will does not help clarify the patient’s wishes in the absence of antecedent conversations with the family, close friends, and the patient’s personal physician.

Traditional advance directives like the health care proxy focus on proactive discussions of personal values, beliefs, and goals of care. It is extremely important to choose the right health care agent who will make decisions in accordance with the patient’s current values and beliefs, and that the chosen health care agent is able to separate his or her personal values from the patient’s values. Two studies on surrogate decision making reported the inaccuracy of surrogates in predicting patient preferences at the end of life, even among family member surrogates who are more likely to choose over-treating versus under-treating the patient (Coppola, Ditto, Danks, & Smucker, 2001; Ditto et al., 2001).

A study published in 2008 revealed that end-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with poorer patient quality of life and more difficult bereavement adjustment (Wright et al., 2008).

A randomized study of 151 patients with newly diagnosed non-small-cell lung cancer examined early palliative care plus standard oncologic care or standard oncologic care. Quality of life and mood were assessed at baseline and at 12 weeks. The primary outcome was change in quality of life at 12 weeks. The study revealed fewer patients in the early palliative care group received aggressive end-of-life care (33% vs. 54%, $p = .05$). Further, the median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $p = .02$; Temel et al., 2010).

Completion Rates of Advance Directives

Sadly, the advance directive completion rate in our nation has not significantly increased since the passage of the Patient Self-Determination Act in 1990. At that time, 75% of Americans approved of the notion of patient self-determination and 20% had completed a living will. More than a decade later, only 15–20% of Americans had completed some form of advance directive (Robert Wood Johnson Foundation, 2002, p. 9). It is likely that even fewer have had the open, honest conversations regarding end-of-life care wishes, the critical element of the advance care planning process. Documents cannot account for every circumstance; therefore, the family and health care agent need to know the patient's general wishes for the end of life. Such knowledge is best attained through open conversations.

Subsequent to the intense media pressure surrounding the Terry Schiavo case, a nationwide poll conducted by the Pew Research Center in 2005 found that 95% of adults were aware of the need for advance directives, but only 29% of Americans had completed one, specifically a living will; health care proxy completion rates were not assessed (Pew Research Center, 2006).

POLST Paradigm, a Model for Ensuring Patient Preferences are Honored

A growing body of literature supports the efficacy of the Physician Orders for Life-Sustaining Treatment (POLST) approach in honoring and communicating patient's wishes (Dunn et al., 1996; Lee, Brummel-Smith, Meyer, Drew, & London, 2000; Tolle, Tilden, Nelson, & Dunn, 1998). For example, approximately 6 months after implementation of the POLST program in Washington State, a chart review study conducted in nursing facilities in two eastern Washington counties found POLST forms included in 21 charts at these facilities. Chart reviews and analysis of interviews with staff and residents/surrogates found evidence that the POLST form accurately conveyed treatment preferences 90% of the time. Most charts contained documentation regarding an informed consent process (76%) and there was evidence that

residents' wishes were honored in a majority of cases (90%). When patients had advance directives in their charts, the POLST form was congruent with the advance directive 100% of the time (Meyers, Moore, McGrory, Sparr, & Ahern, 2004).

In another study, emergency medical technicians in Oregon reported that the POLST form provided clear instructions about patient preferences, and was useful when deciding which treatments to provide (Schmidt, Hickman, Tolle, & Brooks, 2004). In contrast to the single intervention focus of out-of-hospital do-not-resuscitate (DNR) orders, the POLST form provides patients with the opportunity to document treatment goals and preferences for interventions across a range of treatment options, thus permitting greater individualization (Hickman, Tolle, Brummel-Smith, & Carley, 2004). The multi-state study of POLST published in 2010 consisted of a stratified random sample of 90 Medicaid-eligible nursing facilities that included a comprehensive review of nursing facility residents' medical records. POLST was compared with traditional advance care planning in terms of the effect on the presence of medical orders reflecting treatment preferences, symptom management, and on use of life-sustaining treatments. The study found residents with POLST forms had significantly more medical orders about life-sustaining treatments than residents with traditional advance directives. There were no differences between residents with or without POLST forms on symptom assessment or management measures. POLST was more effective than traditional advance planning at limiting unwanted life-sustaining treatments. The study suggests that use of POLST offers significant advantages over traditional advance directives in the nursing facility setting (Hickman et al., 2010).

In summary, more than a decade of research has shown that an emerging national model, the POLST Paradigm Program, like New York's MOLST, more accurately conveys end-of-life care preferences for patients with serious, life-limiting conditions, and yields higher adherence by medical professionals.

Cost of Care

Further, there are significant regional variations in the cost of care, percentage of deaths occurring in hospitals, and other measures of end-of-life care. Dollars are wasted on unwanted, unnecessary, and futile treatments. Reducing the amount spent on ineffective treatments will help reduce the total cost of end-of-life care.

A study published in 2009 showed that only 31% of patients with advanced cancer at the end of life had had discussions with physicians about end-of-life care. Patients who had end-of-life conversations had significantly lower costs in their final week of life (over \$1,000 less). Further, higher costs were associated with worse quality of death (Zhang et al., 2009).

The MOLST Program may remove some of the financial burden of traditional end-of-life care from families and the health care system by reducing the number of unnecessary or unwanted procedures, referrals, or visits to the intensive care unit. A study comparing high-cost medical care regions to low-cost care regions in the United States found that additional spending on more intense medical care at the end of life, such as additional referrals to specialists or additional testing, did not materially impact life expectancy (Wennberg, Fisher, Goodman, & Skinner, 2008). Many individuals face an altered quality of life and other unpleasant burdens as a result of this additional medical care that has little to no benefit. Honoring preferences regarding end-of-life care will reduce the propensity to follow this unproven “more is better” approach. Advance care planning, when coupled with hospice, is estimated to save up to 10% of the cost of the final year of life, 10–17% of the last 6 months of life, and 25–40% of the final month of life compared to traditional end-of-life care (Robert Wood Johnson Foundation, 2002, pp. 16–17).

MOLST AND ADVANCE CARE PLANNING

Advance care planning is a key pillar of palliative care and is recognized as a critical process. Prior to 2010, as previously discussed, New York State had been one of the few states that did not authorize family members to make health care decisions for incapacitated loved ones, except for decisions related to cardiopulmonary resuscitation when the patient’s heart and/or breathing stops. No one, not even a concerned family member, had the right to make decisions about medical treatment for patients who lacked capacity, unless the patient had signed a health care proxy or left “clear and convincing evidence” of his or her treatment wishes. As a result, the value of a properly completed health care proxy linked with conversation has long been recognized in New York State (Bomba, 2005; Bomba & Sabatino, 2009).

Patient preferences for care at the end of life are not consistently followed, despite the presence of advance directives completed in accordance with state law. In New York State, two types of advance directives protect a patient’s right to request or refuse medical treatments if a patient loses the ability to make medical decisions: the health care proxy (created by statute), and the living will (not a creature of statute in New York State).

The New York State health care proxy is a legal document that allows an individual to name a person whom he or she trusts to make decisions about his or her medical care, including decisions about life support. The health care proxy form appoints that person called the “health care agent” to speak for an individual not only at the end of life, but at any time that person is unable to make medical decisions.

The living will allows individuals to state their wishes regarding medical care in the event that they develop an irreversible condition that prevents them from making their own medical decisions. The living will becomes effective if a patient becomes terminally ill, permanently unconscious, or minimally conscious due to brain damage and will never regain the ability to make decisions. Persons who want to indicate under what set of circumstances they favor or object to receiving any specific treatments utilize the living will. Increasingly, however, many individuals are being counseled that appointing a health care agent is best practice due to the clear limitations of the living will as an advance care planning tool.

Studies have shown that most patients either do not have advance directives or, for those patients who do, advance directives like the living will do not adequately provide health care professionals with explicit instructions for making critical decisions. This finding is consistent with the reality that what really happens to patients in hospitals and other health care settings normally depends on physician orders. Patients' advance directives, or their spoken wishes, and their surrogates' voices often get lost in the regimented hustle and bustle of clinical convention.

The POLST Paradigm is an evidence-based program supported by a decade of research that affirms that it more accurately conveys end-of-life care preferences for patients with serious, chronic, life-limiting conditions. POLST is followed by medical professionals because POLST contains medical orders. Known by a different name, the New York State *Medical Orders for Life-Sustaining Treatment* or "MOLST" Program was developed by the Community-wide End-of-life/Palliative Care Initiative (2001) in Rochester, New York, and is among the first six programs in the country and shares common core elements with other endorsed programs (Bomba & Sabatino, 2009; Community-wide End-of-life/Palliative Care Initiative, 2001).

The MOLST Program is designed to improve the quality of care received by seriously ill patients at the end of life. It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored pink form, and a promise by health care professionals to honor these wishes. MOLST enables physicians and other health care professionals to discuss and convey the wishes of patients with serious life-limiting illnesses who have a life expectancy of less than 1 year, or anyone interested in further defining their end-of-life care wishes. MOLST is outcome-neutral and may be used either to limit medical interventions or to clarify a request for all medically indicated treatments. Qualified and trained social workers are ideally suited to participate in discussions leading to completion of a MOLST in all settings, particularly along the long-term care continuum, including the nursing home.

MOLST provides resuscitation instructions if the patient has no pulse and/or is not breathing. Additionally, the medical orders provide direction about other types of life-sustaining treatment that the patient may or may not want such as decisions about intubation and mechanical ventilation,

transport to the hospital, ICU care, artificial nutrition and hydration, and antibiotics. Key features of the program include education, training, and a quality improvement process.

There is a role for both traditional advance directives and the MOLST in a two-step approach to advance care planning, as planning for future medical care in case a patient is unable to make decisions is critically important. Advance care planning begins with conversations among families and other trusted individuals, such as friends and doctors. The process builds trust and establishes relationships among family, close friends, health care professionals, and others who will care for the patient or be with them as they approach death. Advance care planning permits peace of mind for the individual and family by reducing uncertainty and helping to avoid confusion and conflict over care.

Two-Step Approach to Advance Care Planning

The two-step approach to advance care planning originated as a project of the Community-wide End-of-life/Palliative Care Initiative (2001), a health care and community collaborative based in Rochester, New York (Community-wide End-of-life/Palliative Care Initiative, 2004). The Community-wide End-of-life/Palliative Care Initiative focuses on implementation of a set of broad end-of-life/palliative care projects that result in quality improvements in the lives of those facing death.

In the absence of surrogate decision making laws in New York State prior to the FHCDA, this innovative two-step approach to advance care planning was successful in increasing completion rates for health care proxies across upstate New York and also in development and implementation of the MOLST program. The two-step approach to advance care planning encourages all persons 18 years of age and older to complete a health care proxy while they are healthy and to update this advance directive across the health-illness continuum from wellness until end of life. Seriously ill individuals with advanced chronic illness who may die in the next year and those interested in further defining their wishes are encouraged to have more intensive conversations on goals of care as part of the MOLST program. The two evidence-based programs include:

- Community Conversations on Compassionate Care (CCCC), an award-winning, nationally recognized program developed to help individuals over 18 years of age complete health care proxies. The CCCC program focuses on “Five Easy Steps” to complete a health care proxy, as outlined in the CCCC Advance Care Planning booklet, the “Five Easy Steps” webpage the community web designed by the Initiative, and the CCCC videos (Community Conversations on Compassionate Care Advance Care Planning booklet, 2010; Community Conversations on Compassionate Care

“Five Easy Steps, 2007; Community Conversations on Compassionate Care Videos, 2007).

- Medical Orders for Life-Sustaining Treatment (MOLST), a program designed to improve the quality of care people receive at the end of life based on effective communication of patient wishes, documentation of medical orders on a brightly colored pink form, and a promise by health care professionals to honor these wishes.

Community Conversations on Compassionate Care (CCCC) Program

In January 2001, the Rochester (New York) Community End-of-Life Report (based on a response rate of 50%) revealed that only 38% of hospital patients, 40% of clients in one home care agency, and 72% of residents in our communities' skilled nursing facilities had advance directives in place (RIPA/Blue Cross End-of-life Professional Advisory Committee, 2001). Less than 20% of patients receiving home care services had a health care proxy. Thus, prior to the initiation of the CCCC Program, statistics for the communities in upstate New York mirrored national statistics on end-of-life care.

In developing the CCCC Program, it was recognized that education is the first step in behavioral change and an important step in overcoming functional health illiteracy regarding advance care planning. Since behavior is too complex to systematically and consistently respond to one type of intervention or another, solely measuring completion rates of health care proxies may not adequately measure the effectiveness of the CCCC Workshop (Bomba & Vermilyea, 2006). Thus, the Health Care Proxy Readiness Form (Bomba, Doniger, & Vermilyea, 2004) establishes a baseline and follow-up by asking the individual to select responses regarding their readiness to complete a health care proxy form.

The report, *Community Conversations on Compassionate Care (CCCC) Pilot Study Results, 2002–2004* (2004), showed that a workshop format motivated individuals to complete an advance directive. For those who attend a CCCC Workshop, 48% of those in attendance had an advance directive; 55% had an advance directive 6–8 weeks later. The difference is statistically significant ($p = .01$).

The CCCC Program was shared across upstate New York. The *End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report* (Excellus BlueCross BlueShield, 2008), described results of the most comprehensive survey ever done in upstate New York to assess consumer attitudes and actions regarding two advance directives (health care proxy and living will.) A random sample of 2,000 adults, 18 and older, living in a 39-county area of upstate New York, was selected for phone interview using the random digit dialing (RDD) sample. Nearly 90% surveyed signified that it is very/fairly important that they have someone who could make medical decisions on their behalf if they had an

irreversible terminal condition and were no longer able to make medical decisions on their own. Yet, only 42% indicated they have actually designated a health care proxy. Significant regional variations were observed in completion rates for health care proxy forms, from a low of 35% in Utica to a high of 47% in Rochester. Attitudes toward health care proxies, on the other hand, showed little variation across regions—85% to 90% saying it was very/fairly important (Excellus BlueCross BlueShield, 2008). Evidence suggests that the difference is driven, in part, by physician communications with patients as the highest rate of discussion with doctors occurred in Rochester (47%) vs. Utica (27%). Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives. Further, community education plays a role as the highest rates occurred where the CCCC Program was initiated.

Medical Orders for Life-Sustaining Treatment (MOLST) Program

The MOLST Program began with creation of the original MOLST form by the MOLST Creation Workgroup, as a project of the Community-wide End-of-life/Palliative Care Initiative in fall 2001. The form was completed in November 2003. MOLST was adapted from Oregon's POLST form and integrates New York State Public Health Law. Implementation began on a voluntary basis in Rochester health care facilities shortly thereafter. A broader regional launch in January 2004 resulted in expansion to surrounding counties (Community-wide End-of-life/Palliative Care Initiative, 2005).

As regional adoption ensued, simultaneous collaboration with the New York State Department of Health (NYSDOH) began in March 2004. As a result, a revised form consistent with New York State law was approved by the NYSDOH for use as an institutional DNR in all health care facilities throughout New York State in October 2005. NYSDOH sent a "Dear Administrator" Letter (DAL) on January 17, 2006 confirming its approval. This approval did not require legislative action but achieved significant growth in the MOLST Program across the state. Implementation of the MOLST Program began in health care facilities, including hospitals and nursing homes, and has spread to assisted living facilities, enriched housing, and the community.

With passage of the MOLST Pilot Project Legislation (Public Health Law §2977[13]) in 2005 and the Chapter Amendment in 2006, NYSDOH approved the MOLST for use in the community as a Nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) in Monroe and Onondaga counties. In addition to collaboration with the NYSDOH, the MOLST Community Implementation Team partnered with the Medical Society of the State of New York (MSSNY), the Healthcare Association of New York State (HCANYS), New York State Health Facilities Association (NYSHFA), the New York Association of Homes and Services for the Aging (NYAHS), the Hospice and Palliative Care Association of New York State (HPCANYS), New York State

Office for the Aging (NYSOFA), New York State Society on Aging (NYSSA), New York State Bar Association (NYSBA), the Greater New York Hospital Association (GNYHA), and other professional associations, health care facilities, systems, and agencies across the state.

A successful MOLST Pilot Project resulted in Governor David Paterson signing into law a bill that made MOLST permanent and statewide, thereby changing the scope of practice for EMS across New York State. MOLST was consistent with Public Health Law §2977(3) at the time the Public Health Law was amended (this section has since been repealed and a new Public Health Law Article 29-CCC created to govern Nonhospital DNR Orders), is consistent with the new FHCDA law and cannot be altered. MOLST has been reviewed annually since 2005, complies with New York Public Health Law, and has been adapted to meet clinical needs (Bomba & Sabatino, 2009).

The NYSDOH updated the MOLST form in June of 2010 to make it more user-friendly and to conform to the procedures and decision-making standards set forth in the FHCDA. The MOLST Statewide Implementation Team was launched in May 2010 to oversee effective statewide implementation of the MOLST Program and to support NYSDOH implementation of the FHCDA and revision of the MOLST form.

SOCIAL WORK ROLE IN ADVANCE CARE PLANNING AND MOLST

There is an important role for social workers as central health care professionals in advance care planning and the MOLST program in all settings working with individuals, families, health care agents and surrogates, caregivers and members of the health care team. Research on social work and professional involvement in advance care planning has focused on measurement of professional attitudes and barriers to completion of advance directives (Neuman & Wade, 1999; Solomon et al., 1993; SUPPORT, 1995). Studies have also examined social work communication practices and interventions (Black, 2004, 2005; Gutheil & Heyman, 2005), and system level interventions (Pearlman, Starks, Cain, & Cole, 2005; Morrison et al., 2005).

In an early study of health care professionals' experience with advance directives across care settings, social workers as a group reported lower levels of satisfaction with advance directive laws and systems than nurses and other professionals, even though 63% of all respondents expressed no confidence in the effectiveness of advance directives in assuring patients' wishes were honored (Neuman & Wade, 1999). Positive attitudes toward end-of-life planning have been reported by Heyman and Gutheil (2003, 2006) for social workers and social work students. Social workers identified education as one of their principal roles in end-of-life planning (Heyman & Gutheil, 2006). In a study of nurses and social workers who were members of the New York State professional associations, Heyman (2008) reported that

social workers had more positive attitudes than nurses toward the New York State health care proxy, with a statistically significant mean difference ($p < .05$). Both professional and end-of-life training were factors in predicting attitudes.

Social workers were also found to have a more active role than nurses and physicians in advance directive communication practices in a study with patients located at hospitals in upstate New York (Black, 2005). Social work involvement in five out of seven phases of communication remained fairly consistent, however, at moderate levels in such critical activities as discussing treatment options ($M = 3.5$) and interacting with family ($M = 3.4$), measured on a 5-point Likert scale ranging from 1 (lowest score) to 5 (highest score; Black, 2005).

Christ and Sormanti (1999) and Csikai (2004) reported findings demonstrating low to moderate levels of involvement by social workers in discussing patients' wishes or facilitating such discussions. These findings are generally consistent with the results of a study of a random sample of NASW members in health and aging by Heyman and Gutheil (2006) which showed that less than half of social workers were involved in end-of-life planning roles: 44% of social workers were involved in discussing health care proxies with clients; 37.3% were involved in counseling clients about health care proxies; and 23.8% were involved in completing health care proxies. The total health care proxy involvement scores for social workers ranged from 0 to 12 within a possible range of 0 to 16 ($M = 7.42$). This total score reflects a low level of involvement by social workers in end-of-life planning, despite the influence of the federal Patient Self-Determination Act and the New York State Health Care Proxy laws which have been in effect for almost a decade. Social workers have been identified as key health care professionals in the implementation of these laws.

Two studies involving social work advance directive interventions at the systems level reported positive outcomes for patients in nursing homes and in Veterans Affairs outpatient clinics, including improved documentation of treatment limitations and preference-concordant care (Morrison et al., 2005; Pearlman et al., 2005). The role and impact of systems in the delivery of end-of-life and palliative care, including the social work role and process at the end of life, may not be sufficiently accounted for in previous studies. Bern-Klug and colleagues (2004) recognized the relationship between organizational delivery systems and the achievement of consensus-based end-of-life care.

In a study of advance care planning in Program of All Inclusive Care for Elderly sites, researchers reported that program effect, including local provider practice styles, accounted for substantial variation in end-of life treatment choices (Temkin-Greener, Gross, & Mukamel, 2005). This evidence is consistent with research done by Wennberg and colleagues (2008) on the relationship between regional health care spending and practice patterns, and outcomes.

It is noteworthy that health care industry trends of the last two decades have to a large extent marginalized social workers in the health systems, in part due to health care financing and reimbursement structures. Csikai and Martin (2010) pointed out that reduced visibility and access to social workers present a potential barrier to improvements in the end-of-life communication process.

Research evidence suggests that social workers are not receiving the comprehensive education and training they may require in ethics and other domains of end-of-life and palliative care in order to provide competent and well-informed care to seriously and terminally ill patients (Christ & Sormanti, 1999; Csikai, 2004; Csikai & Raymer, 2005; Social Work Policy Institute, 2010). The lack of attention to developing educational curricula and training may be responsible in part for the slow adoption by social workers of appropriate roles in discussions with patients and their families and other discussion and facilitation activities related to end-of-life planning and decision making. Csikai and Raymer (2005) identified the biggest gaps in content in MSW programs and continuing education in the areas of cultural and religious/spiritual differences, research, psychosocial interventions, and both state and federal legislation and legal issues associated with practice in end-of-life care.

Education and training in end-of-life and palliative care remain issues of concern for the social work profession. Gwyther and colleagues (2005) have called for broad dissemination of best practice information to social workers in all practice settings about end-of-life and palliative care including competencies in advance directives and decision making. The Social Work Policy Institute (2010) of the National Association of Social Workers Foundation recommends that researchers develop a curriculum track for social workers to prepare them for work in hospice and end-of-life care and also target infusion of end-of-life content into curricula.

Role of Social Work in MOLST Program

As health care professionals and members of the health care team, social workers are appropriately involved in the implementation of the MOLST program, especially in nursing homes and community settings. A critical part of the MOLST program is process-oriented and based upon having conversations with the patient, the patient's family, health care agent or surrogate, and health care professionals. Essential skills competencies for social workers such as assessment, treatment planning and interventions, including family counseling and conflict resolution, advocacy for patient and family needs, and interdisciplinary teamwork (Gwyther et al., 2005) form the foundation of social work practice. These same skills are important to the goals of the MOLST program in initiating dialogues with patients and their loved about the goals of care, understanding values and preferences as well as cultural differences in care and decision making styles, negotiating conflicts at the bedside, and counseling patients and families about ethical dilemmas that

arise in connection with decisions such as withholding and withdrawing life sustaining treatment. Social workers are also important members of ethics review committees in reviewing cases.

In addition to participating in conversations with the patient, family, key decision makers, team and ethics committee members, the trained and qualified social worker plays a key role in educating these individuals about advance care planning and shared medical decision making as well as in resolving conflict. Shared medical decision making must be well-informed. The decision maker (patient, health care agent, or surrogate) must weigh the following questions:

- Will treatment make a difference?
- Do burdens of treatment outweigh benefits?
- Is there hope of recovery? If so, what will life be like afterward?
- What does the patient value? What is the patient's goal of care?

It is exactly this kind of in-depth discussion with patients, family members, and surrogates for which social workers need to be available. They also need to facilitate and coordinate with other members of the health care team. Patients, family members, and surrogates are often reluctant to ask these questions and afraid to discuss the dying process. Even if they are informed of a diagnosis and prognosis, they do not know what they mean in terms of their everyday experience and future. The social worker has the skills to work with individuals in diverse environments, understand their social ecological contexts, and help them make meaning of their medical decision-making experiences. The social worker can perform an assessment of the patient and family situation and probe the psychosocial, emotional, and multidimensional aspects of what is at stake for the patient. Assessment should include evaluation of pain and suffering. The charge of social work to initiate, facilitate, and support end-of-life discussions with patients, families, and surrogates, and coordinate discussions with other members of the health care team is a dynamic process role that positions the social worker as a central health care professional in the health systems.

Social workers can be helpful in educating patients and families about the goals of palliative care at the end of life. For example, artificial nutrition and hydration, especially tube feeding, is one area of decision making for patients and families that has been fraught with tension and conflict. Due to their often frail medical conditions, residents in nursing homes are at high risk for feeding tubes. Research has demonstrated that feeding tube interventions are a medical treatment that is associated with poor outcomes for frail elderly persons (Finucane, Christmas, & Travis, 1999; Mitchell, Teno, Roy, Kabumoto, & Mor, 2003; Mitchell et al., 2009; Teno et al., 2010). Consistent with the MOLST process for documenting discussions and decisions about artificial nutrition and levels of care, social workers can explain care options

to families, including the option to provide “comfort only” feeding to patients for whom tube feeding may not be medically or ethically appropriate (Teno et al., 2010). This discussion and preference-sensitive treatment decision can be documented on the MOLST form and reviewed periodically by the patient’s physician and other health care professionals. One of the strengths of social work involvement in the MOLST program is improving communication between the patient and the patient’s physician, family members, caregivers, health care agents, or surrogates. Communication has been identified as central to patient-centered care, the shared decision-making process, and preference-concordant care.

The trained and qualified social worker who has completed his/her own health care proxy (in some states, known as durable power of attorney for health care) is comfortable in educating on advance care planning in the community as well as in the professional workplace. In the long-term care continuum, advance care planning education is provided to patients, families, and loved ones and all are encouraged to complete a health care proxy, as any individual may face a sudden and unexpected acute illness or injury and risks becoming incapacitated and unable to make his or her own medical decisions. In New York State, decision standards are higher for surrogate decision making. The FHCDA is a law of last resort and encourages everyone 18 years and older to engage in advance care planning discussions early and engage in dialogue with family and loved ones. In the end, it is the conversations that sustain us when we lose our own loved ones.

FHCDA INTERPROFESSIONAL ETHICS TRAINING: PILOT CASE STUDY

Ethics training is central to the roles social workers and other health care professionals play in interdisciplinary teamwork, advance care planning, and health care decision making. For this reason, a research investigator at one university center for aging designed a pilot project to develop appropriate interprofessional ethics training for social workers and other health care professionals in connection with the implementation of the FHCDA in New York State. There is little data available on ethics committees, ethics consultations, and the evaluation of ethics training for ethics committee members and health care professionals working in health care settings and the impact of such training on outcomes for patients. The enactment of the FHCDA in New York State provided a unique opportunity to launch such a pilot project at a time when health care providers would be changing their policies and instituting training programs to bring their staff into compliance with the new statutory requirements.

In the pilot phase of this project, health care professionals at a 180-bed suburban community hospital in the New York metropolitan area were

invited to attend an educational training program on the FHCDA which provided both legal and ethical content on the statute and related content areas in health decision making (Morrissey, Heyman, Jennings, & Leven, 2010). Study methods and training materials were developed by interdisciplinary professionals including social work researchers, an ethicist, and attorneys practicing in end-of-life and palliative care. Results are based on 31 participants who attended the training and completed both the pretest and posttest. Participants were from multiple professional disciplines including medicine, nursing, social work, and chaplaincy. The University Institutional Review Board approved the protocol.

A one-group pretest-posttest design was used to determine if the training impacted participants' self-rated knowledge. Knowledge questions were based on provisions of the new FHCDA in New York State as well as existing health decision making laws including the Health Care Proxy law. Questions also examined participants' training, and involvement in case consultation.

Results from the pilot study showed that less than one half of the participants had prior training or work in palliative care (41.9%) and well under two thirds of the participants had prior training in ethics (58.1%). There was a statistically significant difference between pretest and posttest on knowledge items ($p < .001$). Morrissey et al. (2010) used Csikai's (2004) involvement scale which asked professionals about how often they were involved in 10 different case consultation activities related to the discussion of difficult cases involving ethical dilemmas. Responses could range from 1 = *never involved* to 5 = *almost always involved*. Results showed the highest mean rated activities included: helping promote communication between health care professionals and patient/family ($M = 3.16$), offering support to health professionals following discussions ($M = 3.16$), offering support to patient/family following discussion ($M = 2.97$), and facilitating discussion of the case ($M = 2.77$).

The results from this study, while not generalizable, demonstrate the importance of interprofessional ethics training for health care professionals. This research project is being expanded to other health care providers and settings, and to community social work professionals.

CONCLUSION

The MOLST Program, together with the implementation of family health decision making and end-of-life counseling about palliative care and end-of-life options, are shared medical decision-making models that promote more effective communication and end-of-life discussions for patients, families, surrogates, and health care practitioners. Social workers have a key role in the process of end-of-life discussions and in advance care planning. Research evidence supports the need for improved communication in these areas and

for heightened involvement of social workers with patients, families, and caregivers. There is also evidence that education and training in ethics and end-of-life issues for social workers in all practice settings is a priority. Social workers need to reclaim their role and standing as central health care professionals in the health systems in which they provide critical services to patients and families, and support other members of the interdisciplinary team. Research is also urgently needed to investigate the influence of systems and systems-level factors in shaping social work involvement with the care of seriously ill and dying patients.

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