Discussing Patient Preferences and End of Life Care

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A two-step approach to advance care planning originated as projects of the Community-Wide End-of-life/ Palliative Care Initiative (2001), a healthcare and community collaborative based in Rochester. The 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 NYS prior to Family Health Care Decisions Act (FHCDA), this innovative two-step approach to advance care planning has been successful in increasing completion rates for health care proxies across Upstate New York and in development and implementation of the Medical Orders for Life-Sustaining Treatment (MOLST) program. Physicians in the Rochester Region played a critical role in establishing these “best practices” in understanding patient preferences and discussing end-of-life care. A partnership with the Medical Society of the State of New York has been instrumental in moving these best practices across New York State.

Family Health Care Decisions Act

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 FHCDA , a NYS 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 NYS Department of Health (NYSDOH) 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 (PICA) in NYS. Passage of the PCIA will ensure that patients and their family members and loved ones will be provided information on 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 healthcare decision-making and palliative care legislation in NYS dramatically changes the landscape for both patients with advanced chronic illness and dying patients and their families, and serves as an emerging model of shared, informed medical decision-making for the nation.

Physicians have an opportunity to collaborate with other health care professionals on ensuring thoughtful advance care planning discussions, while maintaining accountability for the process and the end result, the MOLST form, a set of actionable medical orders that travels across care transitions and ensures patient preferences for care are honored. Further, physicians provide leadership to build on this model in helping patients and families prepare for and deal with the anxiety of death, while living actively until the end of life. There are multiple roles for all health care professionals at all stages of the medical decision-making process and in all settings.

Best Practice - The Two-Step Approach

- Community Conversations on Compassionate Care (CCCC), a program designed to help individuals over eighteen years of age complete health care proxies when healthy and update this advance directive across the health-illness continuum from wellness until end of life.
- Medical Orders for Life-Sustaining Treatment (MOLST), a program designed to improve the quality of care seriously ill patients receive at the end of life that is based on effective communication of patient goals for care and 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

Community Conversations on Compassionate Care (CCCC), an award-winning , nationally recognized program, was developed by the CCCC Workgroup. The CCCC program integrates the behavioral readiness to complete a health care proxy and focuses on choosing the right spokesperson and discussions that focus on values, beliefs and what is important to the person. “Five Easy Steps” are outlined in the CCCC Advance Care Planning booklet , the CCCC videos , and the “Five Easy Steps” web page , interactive Advance Care Planning Clinical Pathways, and other web pages on www.CompassionAndSupport.org, the community website designed by the Initiative. The CCCC videos, housed on the website, are based on successful CCCC workshops conducted with patients and families across Upstate New York and with employees at Excellus BlueCross BlueShield.

The CCCC Program was shared across Upstate NY. *The End-of-Life-Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report (2008)* describes results of the most comprehensive survey ever done in Upstate New York to assess consumer attitudes and actions regarding health care proxies and living wills to assess impact of the CCCC Program.

A random sample of 2,000 adults, eighteen and older, living in a thirty-nine county area of upstate New York were selected for a phone interview using the random digit dialing (RDD) sample. Nearly 90 percent surveyed signified "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 percent indicated they have actually designated a Health Care Proxy. Further, significant regional variations were observed in completion rates for Health Care Proxy forms, from a low of 35 percent in Utica to a high of 47 percent in Rochester. 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 (forty-seven percent) vs. Utica (twenty-seven percent). Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives. Additionally, community education plays a role as the highest rates occurred where the CCCC Program was initiated.

Medical Orders for Life-Sustaining Treatment

Physicians should consider consulting with the patient about completing a MOLST form if the patient: wants to avoid or receive life-sustaining treatment, resides in a long-term care facility or requires long-term care services, or might die within the next year.

The MOLST form must be completed based on the patient's current medical condition, values, and wishes. Completion of the MOLST begins with a conversation or a series of conversations between the patient, the health care agent or the surrogate, and a qualified, trained health care professional that defines the patient's goals for care, reviews possible treatment options on the entire MOLST form, and ensures shared, informed medical decision-making.

The MOLST 8-Step Protocol was developed in 2005 to outline the process of shared, informed medical decision-making and was updated with passage of FHCDA.

1. Prepare for discussion
    - Review what is known about patient goals and values
    - Understand the medical facts about the patient's medical condition and prognosis
    - Review what is known about the patient's capacity to consent
    - Retrieve and review completed advance directives and prior DNR/MOLST forms
    - Determine key family members and if the patient lacks medical decision-making capacity, identify the health care agent or surrogate
    - Find uninterrupted time for the discussion
2. Begin with what the patient and family knows
    - Determine what the patient and family know regarding condition and prognosis
    - Determine what is known about the patient's values and beliefs
3. Provide any new information about the patient's medical condition and values from the medical team's perspective
    - Provide information in small amounts, giving time for response
    - Seek a common understanding; understand areas of agreement and disagreement
    - Make recommendations based on clinical experience in light of patient's condition /values
4. Try to reconcile differences in terms of prognosis, goals, hopes and expectations
    - Negotiate and try to reconcile differences; seek common ground; be creative
    - Use conflict resolution when necessary
5. Respond empathetically
    - Acknowledge
    - Legitimize
    - Explore (rather than prematurely reassuring)
    - Empathize
    - Reinforce commitment and non-abandonment
6. Use MOLST to guide choices and finalize patient/family wishes
    - Review the key elements with the patient and/or family
    - Apply shared, informed medical decision-making
    - Manage conflict resolution
7. Complete and sign MOLST
    - Get verbal or written consent from the patient or designated decision-maker
    - Get written consent from the treating physician, and witnesses
    - Document conversation
8. Review and revise periodically

To ensure shared, informed medical decision-making, 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 for care?

An in-depth discussion with patients, family members, and surrogates is needed. 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. This is why an interdisciplinary approach to advance care planning is effective.

Although the conversation(s) about goals and treatment options may be initiated by any qualified and trained health care professional, a licensed physician must always, at a minimum: (i) confer with the patient and/or the patient's health care agent or surrogate about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker, and (ii) sign the orders derived from that discussion.

Decision-making standards, procedures and statutory witness requirements for decisions to withhold or withdraw life-sustaining treatment, including DNR, vary depending on who makes the decision and where the decision is made. Accordingly, the New York State Department of Health has developed different legal requirement checklists for different types of decision-makers and settings. There are five different checklists for adult patients, one for minor patients and one for patients with developmental disabilities who lack medical decision-making capacity. If a patient has a developmental disability and does not have the ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

The physician should briefly summarize pertinent content of the discussion and document core patient values and/or goals for care. MOLST Chart Documentation Forms align with the NYSDOH Legal Requirements Checklists for Adult Patients and Minor Patients were developed as tools to document the MOLST discussion and help providers comply with documentation requirements under FHCDA.

Functional Health Literacy

The Community-wide End-of-life/Palliative Care Initiative recognized the importance of functional health literacy as an essential element in the advance care planning process as well as improving end-of-life care. Functional health literacy is based simply on a "need to know" and a "need to do" with respect to being informed about medical information. With a lack of knowledge about medical care and medical conditions, functional health illiteracy results in a decreased comprehension of medical information and a lack of understanding and use of appropriate services, from preventive to end-of-life services, like palliative care and hospice. Patients experience poorer health status, poorer self-reported health, and poorer compliance rates. As a consequence, increased hospitalizations and increased health care costs result.

The community website, www.CompassionAndSupport.org is another project of the Community-Wide End-of-Life/Palliative Care Initiative. Initially developed as a resource for patients and families, the website is dedicated to educating and empowering patients, families and professionals on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. A key goal of the website is to provide community education that aims to overcome functional health illiteracy and ensure shared, informed medical decision-making. The website houses information on both the CCCC and MOLST Programs.

Conclusion

Caring for patients and families at the end of life is the ultimate in professionalism. Shared, informed medical decision-making is a patient-centered process that is critical to ensuring patient preferences for care are honored at the end of life. Providers must be trained, qualified and comfortable with the discussions needed for effective shared, informed medical decision-making. Health care professionals will find the two-step approach to advance care planning including the Community Conversations on Compassionate Care (CCCC) and Medical Orders for Life-Sustaining Treatment (MOLST) Programs is helpful in engaging all adults eighteen years of age and older to complete a health care proxy and in initiating discussions with seriously ill patients about the MOLST. For all adults, the discussion should focus on choosing the right health care agent and sharing values, beliefs and what is important to the individual. For seriously ill patients appropriate for the MOLST, these discussions should focus on understanding the patient's goals for care in light of the patient's health status and prognosis and ensuring a clear understanding of the benefits and burdens of life-sustaining treatment. Functional health literacy regarding advance care planning, a key pillar of palliative care, must be achieved by patients, families, health care agents and surrogates to assure shared, informed medical decisions. Community data and recent landmark legislation in New York State support the value of implementation of the CCCC and New York's MOLST. Development, implementation and sustainability of the CCCC and MOLST Program highlights the success of healthcare and community collaborative initiative focused on improving care at the end of life.

NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female eMOLST NUMBER **(THIS IS NOT AN eMOLST FORM)**

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing

Check one:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

SECTION B Consent for Resuscitation Instructions (Section A)

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION-MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decision? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate

SECTION C Physician Signature for Sections A and B

PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

PHYSICIAN LICENSE NUMBER PHYSICIAN PHONE/PAGER NUMBER

SECTION D Advance Directives

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

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