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SB 413 – MOLST
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Public Health Committee,

SB 413 would start a trial program under DPH to create a new detailed form of medical orders that would be used across different medical settings. This pilot program would be conducted in a specific geographic area of Connecticut. MOLST is an acronym for “Medical Orders for Life Sustaining Treatment” and is part of a nationwide movement. To date, the form is mostly in use in specific geographic areas of specific states. In a very few minority of states, the form is used statewide.

What Problem Does this Law Attempt to Address:

This form essentially codified existing living wills into medical orders and would be an expansion of current DNR orders already in common use. Proponents of this bill say that the problem this bill seeks to remedy is over treatment of patients who do not want medical interventions which would prolong their lives. For healthcare providers, the main benefit of the MOLST form is that it would be on a brightly colored form that can be easily found when needed. This would greatly assist patients when EMS arrives to assist at residences, or in care facilities with thick medical charts. DNR orders currently are printed on black and white forms, as are living wills.

In some circumstances, this form would adequately remedy this problem and assist patients. In others it would cause more stress for families. In many cases, it will cause significant new ethical issues where patients will be even more under-treated than today. Already, many healthcare mistakenly believe the presence of DNR orders believe they do not need to treat that patient. The reality is that DNR orders are specific only to when a patient's heart stops and no sooner.

To prevent a larger number of problems arising than are solved, we have several thoughtful recommendations:

- Recommend that DNR orders be printed on bright colored paper
- Institute a program where DNR orders, intubation, and POA contacts are included
- Conduct a study of families and healthcare providers (those who may sign a death certificate, actually perform an intubation or similar procedure) of what advanced directives currently are conveyed, if those requests are followed and why. Information as to whether such requests were in writing or verbal and the context of the reason would be helpful.
- If this program progresses, that a qualified bio-ethicist agreeable to interested parties be included with the formulation of the program
- Include EMS personnel with the development process
- Include criminal penalties for falsification or altering a MOLST form

There are several potential benefits and harms in this new program:

PRO:

- MOLST forms are on brightly colored paper. This would assist in quickly finding directives
- Creates a standardized document across different healthcare settings
- Requires medical advisement by healthcare professionals with an ongoing relationship with a patient on end of life decisions. This is preferable to the current system where lawyers create living wills absent the medical knowledge of accepting or declining specific treatment modules.

CON:

- MOLST doesn't follow traditional norms for informed consent within the context of a specific medical condition
- Withholding of hydration or food may leave a patient dying from dehydration or starvation instead of the underlying disease process
- Denying or even allowing a patient to deny themselves hydration at a future date removes respect for their right to live and removes dignity during death.
- Signed forms constitute an IMPLIED contract even if it does not have the same legal force
- History of misunderstanding and abuse of forms in other states (California, Delaware)
- Perceived and actual coercion of healthcare institutions to require inpatients to use the form. This existed at assisted living facilities during the Worcester pilot project.
- Form is used outside of intended “end of life” patient scenarios

Discussion:

As a paramedic and Legislative Affairs Vice President of Connecticut Right to Life, I have serious concerns with this bill.

The form is meant to be brightly colored (neon pink or hot green) so it isn't misplaced and can be found easily. As a paramedic, current DNR orders and living will directives are often misplaced because they are on black and white papers. A brightly colored form is therefore a great idea.

A recent conversation with a probate judge has revealed their admitted limiting understanding of the consequences of advising patients and families about what limiting treatments they would accept in a terminal illness. This really belongs in a medical realm which is why EMS providers today are not able to acknowledge advanced directives since they are not drafted by healthcare personnel.

The MOLST concept takes a step in improving this problem and attempts to introduce a formal method where patients and families know their wishes would be respected. However, this proposal goes beyond DNR or intubation orders already commonly in use.

Problems

While MOLST implies providing life sustaining treatment, the proponents really are suggesting these forms be provided to limit that treatment. (In many forms, check-boxes for declining treatment precede boxes for affirming it). The medical and ethical implications for withholding treatment is not frequently discussed. Withholding such treatment has become influenced by pop culture and television dramas rather than basic medical and biological science.

The perceived problem that has led to this bill has not been studied either. DPH should investigate **if** and **why** healthcare providers actually are over-treating or ignoring the wishes of their

patients today. Is the proper documentation presented? Are there extenuating circumstances? Were the wishes known? If those wishes already are documented and known, would an additional form in the form of MOLST really change the outcome?

Rather than implement a new program that can cause many new patients to be inadequately treated, let's make sure we clearly understand the problem and if this proposed solution would fit.

Ethical Concerns

MOLST in many states have been expanded to limiting antibiotics, restricting hydrating fluids, or prohibiting someone from being transported to a hospital for new diagnosis. This is troubling. When patients are presented with advanced directives, an assumption is made that it would only apply to the presently known illness. However, healthcare professionals almost always apply it to conditions that may occur down the road perhaps months or years after they are discussed. Once a legal form is filled out, it is almost never voided or loosened.

In the age where healthcare decisions are often dictated by insurance companies, there are often competing interests between the best interests of a patient and cost. I have frequently encountered Hospice patients who delayed or worried that any transport to a hospital would make them ineligible for further Hospice care. I am not sure if this is true or not.

MOLST changes the way that we look at informed consent. Informed Consent requires a patient to reasonably appreciate and understand their medical condition in context. Because new and unforeseen conditions may develop months or years after signing a medical directive, this prohibits such patient from reasonably understanding the potential benefits or side effects within that context. While potential treatments might be predictable in the course of terminal cancer or advanced respiratory disease, normally preventable and treatable problems such as dehydration, UTI's and other infection are not foreseeable.

Many lay persons are not well informed as to the implications of withholding medical interventions. A probate judge told me that he prefers to advise people seeking his advice to talk to their doctor instead for this very reason. It is easy to ask if someone may want an IV today when they feel perfectly, fine, but if they are actually uncomfortable at a future date, they may change their mind.

Without proper hydration, patients become confused. This takes that patient out of the decision-making process to give consent for their care or communicate to loved ones during a critical time period. People who are older, frail and especially those with disease (as well as the very young) are especially prone to increased confusion when their bodies lose even a small amount of fluid (i.e. through fevers, vomiting or diarrhea symptoms which likely point towards an underlying infection). Re-hydrating or giving antibiotics can often restore their function fairly quickly.

Conversely, treating a pervasive pneumonia might not be in a patient's interest in some circumstances. Patients also probably do not intend to be maintained on constant IV use for long periods of time. Yet, denying their use on a form with check-boxes also limits their short term use.

Here's my point: Making these decisions months or years ahead outside the context of a medical condition when they might be needed is problematic. It defies current standards of informed consent when a patient cannot appreciate the potential benefits or harms of accepting or denying a treatment. The State has an interest in not steering patients in this way.

Anecdotes:

I will present a few anecdotes from my experience with advanced directives as a paramedic.

People obtain DNR orders for many reasons. Similarly, “do not intubate” requests are fairly common as well. An intubation means the placement of a plastic tube into the trachea to facilitate breathing. It is often done while under anesthesia and once a patient is intubated, they are often sedated. An ET tube can always be removed if a patient becomes more aware and is able to control their own gag reflex again. In my experience, patients with advanced airway disease sometimes are intubated several times. At some point, they may decline to have it done again and request a DNI order to be written into their records.

However, even if the presence of such an order exists, EMS and hospital personnel always ask a patient if they want to be intubated if its necessity is imminent. I recently had a patient who had been intubated several times in the past, was intubated again and coded. Doctors revived him for the second time in his life.

I've also responded to several hospice patient homes where a patient's heart stopped. Hospice staff is usually not on site when we arrive. More often than not, family members lose paperwork or are unsure what to do when we arrive. We are often caught with the following problems:

- “I can't find the paperwork”
- A relative off-site has the paperwork, even though the relative present lives with the patient.
- “We would like a DNR, but the paperwork isn't signed yet” - either by family or physician
- A living will is present. EMS personnel often do their best to follow these wishes by consulting medical control even though technically these orders are not valid in the medical setting.
- “I don't know what to do. Hospice is supposed to take care of this”
- “We signed something, but I'm not so sure about it”
- “if they go to the hospital, we were told we can't be on Hospice anymore”
- “Insurance won't let us _____”

I have been to homes where the wife of a Hospice patient wanted “something” done even though it was clear to us that her husband who had severe cancer – was deceased. The man had advanced directives (which took about 10 minutes to find among piles of other paperwork) The man fell in the bathroom and had been otherwise mobile. Our cardiac monitor showed that there was no cardiac activity or hope for recovery. At this point, our role goes towards caring for surviving loved ones. In this scenario, we elected to perform CPR for ten minutes.

I have also responded to the home of a patient who had developed a fever. This patient was also in the care of Hospice. Family did not know what was causing the fever and EMS tools are limited and unable to determine such a cause either. I contacted the Hospice agency and coincidentally talked with a former co-worker of mine who had become a nurse with the agency. His response was “What does family want to do?”

Whenever I have contacted Hospice agencies in the past where it is unclear what our course of action should be, their response is always “What does family want to do”. They clearly want family and loved ones to have control in decision-making. I explained to the family that a hospital can more definitively determine if the patient had a treatable or non-treatable condition. After they knew what that was, they could further decide to administer treatment for that condition or leave it be. They understood and we transported them.

I fear that a MOLST order in this scenario could further bind the family into thinking “well we signed this form with the Hospice agency..” implying that such a form was an agreement and breach of it would nullify further care from that agency.

In this era of rapid change within our state and nation's healthcare system, I would caution the Public Health Committee and Legislature in considering this legislation, the problem it seeks to solve, and the potentially unanticipated impacts its implementation may have. Testimony has yet to show how widely the problem of over treatment is, or if families are informed enough or have concerns about under treatment.

I invite you as legislators to contact me anytime to discuss this issue further. I would also like to make myself available to work on a compromise or assist in developing this proposal further if it moves forward.

Thank you.

- Chris O'Brien
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