End-of-Life

TOOLKIT

This toolkit is free to EMS agencies interested in implementing an end-of-life program. The materials have been developed to provide step-by-step instructions for implementing programs and serve as a resource to assist you in that process. This and other toolkits may also be found at: http://resuscitationacademy.org/.

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Introduction

Emergency providers are routinely faced with end-of-life situations in the field.
To respond appropriately to challenging circumstances, EMS providers need to be trained and prepared for numerous situations. Physicians are increasingly receiving education on end-of-life decision making processes, yet a large proportion of cardiac arrests occur outside of a medical setting, leaving these situations in the hands of EMS providers.

The response of EMS providers to death in the field has been changing in recent years. Some of the reasons for this change include: an aging population, more terminal illnesses and chronic health problems, and more effective in-hospital intervention.

In addition, changes in society are occurring that affect our attitudes and practices surrounding death and dying. These include greater respect for patient autonomy in critical care decisions that weigh the importance of quantity of years remaining versus quality of those years. There is also growing understanding of, and support for, those who decide to die at home, and greater recognition of the needs of friends and family in end-of-life events. The result is higher expectations on field providers to act in accordance with the wishes of the patient.

The term "resuscitation" suggests CPR (Cardiopulmonary Resuscitation) and the multiple other interventions that are necessary to save a life. While this remains a primary focus, it is also important to recognize situations in which a resuscitation effort is unwanted and inappropriate.

Implementing end-of-life protocols may be met by some amount of resistance. Fear of litigation and fear of "gray areas" are the two largest barriers to implementation. In King County, such resistance is rare. Yet it is important for EMS personnel to understand personal biases that may impact professional decisions. The issue is well summarized in the following quote:

> " … Everything my mother had feared ultimately was done to her, and even though I was aware of her wishes, I was unable to prevent any of it. …Our experience has opened our eyes, that as a society, we need to do more in respecting the wishes of those who have definite feelings regarding their own care and treatment or the declining thereof, and we share the desire that Society return to compassionate discretion, humanity, and common sense."
>
> *- Anonymous*

There are many ways to address resistance and achieve buy-in. Most importantly, establish clear and concise protocol that emphasizes liability protection. After drafting a protocol, it should be presented to the following groups:

- Representative group of EMTs and paramedics
- Representative group of local physicians involved in prehospital oversight
- Medical directors of the local EMS agencies
- Fire chiefs and training officers of the local fire departments
- County risk management
- County medical examiner

Additionally, King County learned through a pilot study that it could assess the effectiveness of its protocol and make appropriate data-based modifications.

Key talking points

- Patient self-determination/autonomy
- The nature of CPR and its probable outcomes under various conditions
- No liability according to Washington State law (if not in Washington State, refer to individual state laws/regulations)
- Minimal gray areas if protocol is written clearly

Community buy-in

Despite growing interest in advance care planning and the proliferation of "death cafes", death and dying still remain taboo subjects in much of society today. One way to broach this subject is to inform the community of what your agency is doing to respect patient wishes. A press release or interview with local media can go a long way to helping the community understand the issues surrounding life-threatening situations and emergency personnel. This publicity may also reach physicians who have aging or terminally ill patients and spark them to discuss advance care planning.


The Seattle Times | HEALTH

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EMTs are listening to patients' dying wishes

By Carol M. Ostrom

Seattle Times staff reporter

The following toolkit is meant to assist EMS providers and administrators in creating clear and concise guidelines for the issues that surround end-of-life care.

Ethical Considerations

On autonomy

As our population ages, the clinical aspects of out-of-hospital cardiac arrest are also changing. Increased comorbidities and terminal conditions can lead to difficult ethical questions that are incredibly time sensitive in the prehospital setting.

The ethical principal of autonomy (or self-determination) plays heavily in the end-of-life debate. Patients with the capacity to do so have the right to choose which medical interventions they are and are not willing to undergo. Unfortunately, most Americans do not have advance directives in which these choices are defined, so determining what their wishes truly are becomes more challenging.

For a variety of reasons, EMS providers are often called to assist patients even though neither the patient nor the family desire EMS resuscitative intervention. Historically, this has caused confusion and anxiety in situations where EMS personnel must make treatment decisions in a matter of seconds. Family discomfort with the home dying and death process, a lack of timely outpatient advance care planning, and a societal aversion to discussing death and dying continue to place EMS personnel in the difficult position of having to make critical decisions with virtually no time to sort out the situation.

Most states and many countries have some form of recognition of patients' wishes regarding CPR in the form of a health care power of attorney, living will, or Do Not Resuscitate (DNR) order. Additionally, numerous studies have demonstrated that most EMS providers as well as the public believe that a patient's end-of-life wishes should be honored.

Major unavoidable complications arise when even patients who stated their preferences may want something different when faced with life-threatening conditions, when advance directives are often vague and difficult to interpret, and/or when significant others have preferences that conflict within themselves and/or with patients' wishes.

On medical futility

When deciding to initiate resuscitation, continue resuscitative efforts, or cease efforts, providers may take into consideration medical futility. Medical futility, in essence, means there is virtually no chance of reversing the dying process. Bear in mind, however, that "futile" is a subjective judgement. If any chance of success exists, no matter how small, some nevertheless want CPR attempted. Although that prolongation of life in this way may increase a person's suffering, some people are willing to endure suffering because they value life at any cost.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report, "Deciding to Forego Life-Sustaining Treatment," in which it stated: "A health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options … or to reject all options. No one, however, has an obligation to provide interventions that would, in his or her judgment, be counter-therapeutic."

The Society of Critical Care Medicine's Task Force on Ethics published a consensus report declaring that **"treatments that offer no benefit and serve to prolong the dying process should not be employed."**

Local and State Guidelines and Law

When creating an end-of-life program from scratch or amending a current program, the following components must be considered.

Local and state guidelines/law

Most states have some form of legislation authorizing emergency providers to honor out-of-hospital DNR orders. Each piece of legislation is written differently, so it is important to learn and understand the law in your state. Some are very explicit, recognizing only one official state DNR form, while others allow varied ways in which patients express their preferences and allow EMS providers to use discretion "in good faith" to honor a patient's wishes.

On the federal level, there is no specific regulation regarding out-of-hospital DNR orders although The Patient Self-Determination Act (PSDA) of 1991 has acted helped many state legislatures develop out-of-hospital DNR laws.

The Patient Self-Determination Act (PSDA) 1991

Under this federal law, health care providers are required to provide adult patients the opportunity to participate in their own future health care decisions. Enacted in 1990, the PSDA applies to Medicare and Medicaid patients when provided care by institutions such as hospitals, nursing homes, home health care agencies, hospice programs, and HMOs. These institutions must ask patients whether they have ADs and must provide patients with educational materials about their rights under state law. If there is an AD, it is entered into the patient's medical record at that institution.

Washington State Laws

RCW 18.71.210

Emergency medical service personnel-liability.

The Washington State EMS liability law protects EMS personnel from litigation pertaining to end-of-life issues when EMS personnel act in good faith.

No act or omission of any physician's trained emergency medical service intermediate life support technician and paramedic, as defined in RCW 18.71.200, or any emergency medical technician or first responder, as defined in RCW 18.73.030, done or omitted in good faith while rendering emergency medical service under the responsible supervision and control of a licensed physician or an approved medical program director or delegate(s) to a person who has suffered illness or bodily injury shall impose any liability upon:

The physician's trained emergency medical service intermediate life support technician and paramedic, emergency medical technician, or first responder;

1. The medical program director;
2. The supervising physician(s);
3. Any hospital, the officers, members of the staff, nurses, or other employees of a hospital;
4. Any training agency or training physician(s);
5. Any licensed ambulance service; or
6. Any federal, state, county, city or other local governmental unit or employees of such a governmental unit.

This section shall not apply to any act or omission which constitutes either gross negligence or willful or wanton misconduct.

RCW 70.122.030

Directive to withhold or withdraw life-sustaining treatment.

The Washington State Natural Death Act allows for patient self-determination in medical decisions.

(1) Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining treatment in a terminal condition or permanent unconscious condition. The directive shall be signed by the declarer in the presence of two witnesses not related to the declarer by blood or marriage and who would not be entitled to any portion of the estate of the declarer upon declarer's decease under any will of the declarer or codicil thereto then existing or, at the time of the directive, by operation of law then existing. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the declarer is a patient, or any person who has a claim against any portion of the estate of the declarer upon declarer's decease at the time of the execution of the directive. The directive, or a copy thereof, shall be made part of the patient's medical records retained by the attending physician, a copy of which shall be forwarded by the custodian of the records to the health facility when the withholding or withdrawal of life-support treatment is contemplated.

Protocol

Once state-specific laws have been reviewed, it is important to create a protocol or set of protocols that are clear and concise. A well thought out protocol will give EMS providers clear guidelines to refer to in difficult situations.

Compelling Reasons

Compelling Reasons

"Compelling reasons" is a King County protocol regarding withholding resuscitation when written information is not available yet the situation suggests that the resuscitation effort will be futile, inappropriate, or inhumane.

Protocol

Patients who have legal capacity to make this decision have the right to refuse medical care, including CPR. EMS providers have the responsibility to determine a patient's resuscitation wishes and honor them if possible.

Compelling Reasons Protocol: EMS personnel may withhold resuscitation from a patient in cardiac arrest when two criteria are BOTH present. These are:

1. End stage of a terminal condition
2. Written or verbal information from family, caregivers or patient stating that patient did not want resuscitation

- If both criteria are not met, a resuscitation effort should be initiated.
- If both criteria are met, a resuscitation effort should be withheld.
- If resuscitation was already started, it should be stopped.
- If there is discomfort among family members, begin resuscitative efforts while attempting to achieve consensus.
- When there is doubt, resuscitate.

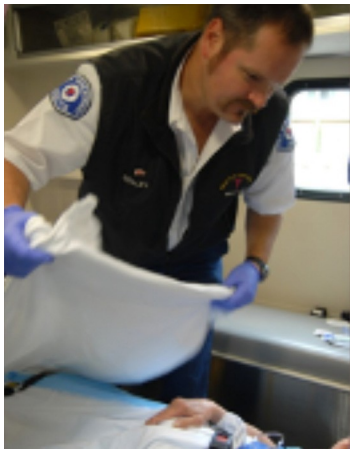
Documentation of compelling reasons when they are used as a basis for withholding resuscitation is mandatory.

Justification for Compelling Reasons Protocol

Several incidents highlighted this issue in the late 1980s, in which written documentation did not exist and patients' wishes were clearly disregarded—not by intent, but simply because EMS personnel felt that, lacking written documentation, they were not able to make the decision to withhold a resuscitation effort. In response to these incidents, King County developed a pilot program that trained EMTs in about half the agencies in the county on issues around death and dying, including the protocol that allowed EMTs to make decisions to withhold a resuscitation effort even in the absence of standard written DNR orders.

The program continued for 2 years and then a retrospective study was conducted which compared EMT resuscitation decisions before and after implementation of the new guidelines. The program was highly successful in honoring patients' preferences, not only because it was well-received by the EMTs but also because of the ability of EMTs to follow the guidelines correctly in making decisions on withholding resuscitation.

Training



Multiple studies have demonstrated discomfort among field providers regarding end-of-life issues that have received little attention in textbooks and training curricula for emergency responders. For an EMS provider to be prepared for these situations, they must be adequately trained.

Before implementing a training program, it is essential to have clear and concise protocols as a basis for creating training modules. Without solid protocols, training programs will end up muddled and potentially create additional confusion and discomfort regarding end-of-life situations.

Training Topics:

Communicating about Death and Dying

One of the most challenging aspects of end-of-life situations is knowing how to communicate with the patient or patient's family members. During this stressful period, communication must be clear, concise, and compassionate. Clear communication is especially important when discerning patient wishes for end-of-life care. It is important to identify the legally sanctioned decision maker as named in a Durable Power of Attorney document (DPOA) in order to ask whether this person supports the intended actions. Time permitting, it is also useful to try to elicit support from significant others who might be present, all while preparing the patient for CPR in case timely initiation of the procedure is needed.

Guidelines for not starting resuscitation

Obvious signs of lividity (pooling of blood in lower body regions) or rigor mortis (a stiffening of the body's muscles after death) are indications to not start CPR. Additionally, if a patient's injuries are incompatible with life (such as decapitation), CPR should not be started.

Another situation in which you may withhold CPR is when a patient or family member presents an advance directive. The directive must state that CPR or resuscitation should be withheld. An example of an advance directive is a POLST (Physician's Orders for Life Sustaining Treatment) or other suitable document, e.g. MOELI-Medical Orders for End-of-Life Intervention) that contains specific instructions to withhold CPR.

Stopping a resuscitation due to medical futility

Studies have shown that prognosis is poor in certain situations. Unwitnessed, nonresponsive asystole may be reason to end resuscitative efforts in the field. Prolonged response time and asystole also have poor prognoses. No ROSC or transition to a shockable rhythm after a prolonged resuscitative effort may also be grounds for stopping resuscitation. Continuing CPR beyond these points can lead to increased risk for the providers and increased distress and expense for the patient and patient family, with little or no chance of meaningful recovery coupled with possible increased family trauma due to prolonging death.

In 1991, the American Medical Association's Council on Ethical and Judicial Affairs published Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders. The Council held that CPR efforts may be withheld, even if previously requested by the patient, "when efforts to resuscitate a patient are judged by the treating physician to be futile."

Providing comfort care to dying patients

When a valid reason for withholding resuscitation is present, EMS providers shall not resuscitate but should provide full palliative care and transport, as appropriate, including:

- Emotional support
- Airway suction
- Administration of oxygen
- Application of cardiac monitor
- Control of bleeding
- Splint
- Positioning for comfort
- Initiation of an IV line
- Administration of medication (such as morphine for pain or severe agitation)

Reasons 911 is initiated

Additionally, all EMS providers should understand why they are sometimes called to situations where resuscitation is to be withheld. Reasons for calling 911 for an expected death include:

- Confusion
- Uncertainty
- Guilt
- Inappropriate information from other agencies
- Need for confirmation of death
- Need for information about how to manage the body of the deceased person

Training should include coverage of the following issues:

- Recognizing signs incompatible with life
- Ceasing efforts due to medical futility
- Understanding the different types of advance directives-POLST, MOELI, DNR, DNI, Living Will
- Verifying the authenticity of advance directives
- Responding to verbal wishes of family members
- Limiting or withholding resuscitative intervention
- Comfort care
- Communicating with family members regarding end-of-life
- Actions after an out-of-hospital death such as contacting the Medical Examiner, funeral home, etc.

Withholding resuscitation due to patient wishes

Though the number is still low, some patients have an advance directive.

The challenge has always been translating patient wishes regarding end-of-life into a format that can be implemented by EMTs and paramedics in an emergency setting. There are many potential problems in the field setting: written powers-of-attorney may not be present, paperwork may be locked in a safe, or prehospital providers are unsure about whether they can honor non-standard expressions of patients' wishes. Clear, concise guidelines for providers will reduce the questions surrounding patient care and will speed the process of resuscitation, comfort care, or grieving.

Considerations in Overriding Patients' Wishes

An important consideration is the fact that patients who execute DNR orders seek to avoid long-term suffering resulting from irreversible conditions. Unfortunately, the CPR/DNR dichotomy in most versions of the POLST do not adequately address an important set of circumstances that would warrant over-riding that request. Patients who have DNR orders may suffer breathing and/or heart stoppage because of reversible or terminable events including adverse drug reactions, anaphylaxis, or traumatic events. If begun quickly enough, CPR is likely to restore patients to their prior level of functioning, but doing so technically violates the patient's stated wishes. Responders arriving on scene routinely ask observers, if any, for explanations of the event and can benevolently use this information to override the DNAR. One must weigh all available information and ultimately use good judgement in sorting through complex situations.

Prehospital Paperwork Considerations

Advance Directives (also known as a living will, personal directive, or advance decision documents), contain instructions, usually in writing, given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity. (See http://uslwr.com to access forms from all 50 states)

DNR/DNAR: A legal document informing medical personnel to respect the wishes of a patient to not undergo CPR or advanced cardiac life support if their heart were to stop or they were to stop breathing.

POLST (Physician's Order for Life Sustaining Treatment) and MOELI (Medical Orders for End of Life Intervention) were developed as an efficient way to communicate information about an individuals' preferences for end-of-life care including CPR. http://dying.about.com.

DNI (Do not Intubate) orders are similar to a DNR but developed to communicate patients' wishes concerning long-term intubation.

Feedback and Monitoring

Following up on end-of-life protocols is an important component of quality assurance, and helps administrators determine whether fine-tuning in training or implementation needs to occur. The first step is to identify incidents in which resuscitation has been withheld.

Strategies to identify these incidents may include:

- Check or add the unique code on the incident/type code section of the incident report form
- Review of each incident report form

Using a unique code works well in that it does not require any extra steps such as making a phone call or special notification. Reading and reviewing individual run reports may be the most accurate, but it is also the most time consuming.

It is important to note that continued attention to coding is essential; otherwise withheld or resuscitations tend to be coded as cardiac arrests, terminal illnesses, or with a code for the underlying illness. There are serious implications for erroneously coding withheld resuscitation as a cardiac arrest. The effect of such coding is to lower the overall survival rate from cardiac arrest.

Summary

The goal of EMS service is to make maximum effort to enhance patients' health and well-being. For many years it has been assumed that every patient suitable for the procedure should be resuscitated. However, changing social attitudes have given patients the right to request or decline resuscitation. In this changing environment, the following guidelines are useful.

1. DO attempt resuscitation if doing so has the possibility of restoring the patient's prior level of functioning—unless patient refused this intervention via a signed DNR.
2. DO attempt resuscitation even if a DNR exists if, in the judgment of the responder, heartbeat and/or breathing stopped due to a reversible short-term condition, e.g. airway obstruction or anaphylactic shock resulting from adverse drug effect, insect sting, or severe food allergy.
3. DO NOT attempt resuscitation if it clearly appears to be futile or if patient has a signed directive refusing the procedure.
4. TERMINATE resuscitation efforts if in the judgment of the responder, they appear to be futile.

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