Thinking Ethically:
Who’s in Charge When The Patient is Not?
Advance Directives, Surrogate Decision-makers, and DNR Orders

Center for Biomedical Ethics and Humanities
University of Virginia Health System
Donna Chen, M.D., M.P.H., and Lois Shepherd, J.D.
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These slides were created as a reading for a Mind, Brain, and Behavior TBL session on March 23, 2012. Viewing them before the Geriatrics-Palliative Care Ethics Workshop may be helpful, as we invariably discuss one or more aspects of surrogate decision-making or advance care planning in connection with the stories or events students bring to the workshop. The content in the slides should largely be review, although this version may differ slightly from the version you read in MBB because there have been minor changes in the applicable law.
Case 1: DNR orders—what do they mean?

Mr. Yamaguchi, a 79-year-old Japanese-American man with severe dementia, has a DNR order.

He develops an aspiration pneumonia. The antibiotics are starting to work but breathing is difficult, and his physicians realize that he may need intubation to allow the antibiotics time to work.

Should his physicians discuss this treatment option with his daughter, who is his surrogate decision-maker? Or, does DNR mean that intubation is no longer an option?
The physicians should discuss this treatment option with his daughter

- A DNR (Do Not Resuscitate) Order does not mean “do not treat.” Instead, it has very specific, and limited, application. It is a doctor’s order to withhold cardiopulmonary resuscitation (CPR) from a particular patient in the event of cardiac or respiratory arrest.

- DNR orders are institution-specific orders signed by a doctor and issued only with the consent of the patient or the patient’s surrogate, as appropriate.

- In this case, even though the patient’s daughter has authorized the DNR order, she should be given the opportunity to make the decision about intubation in this situation. In some cases, the physicians will have anticipated this situation ahead of time and have a decision noted in the medical record. If this is the case, the physicians do not need to obtain another decision, but should inform the daughter of what is going on clinically.
Is a DNR an advance directive?

- No, a DNR order is not considered an advance directive. A DNR is a doctor’s order, whereas an advance directive is a statement made by a patient (although often made before the individual becomes a patient).

- The term “advance directive” refers to an oral or written statement regarding medical care that serves to express the patient’s preferences in the event the patient is later determined to lack decision-making capacity.

- Please note, the term is “advance directive,” not “advanced directive.”
Advance directives, continued

• Written advance directives include
  – Instructional directives (sometimes called “living wills”)
  – Appointment of an agent to make medical decisions (sometimes called “durable power of attorney for healthcare”) [Note: a “health care agent” may also be referred to as a “proxy” or “surrogate”]

• One or both components may be present in a written advance directive

• “Oral advance directives” are discussed in a bit.

• The schematic on the next slide shows the relationships between the different kinds of advance directives.
Advance Directives, continued

- Advance directives
  - Written advance directive
  - Oral advance directive
    - Appointing a health care agent
      (durable power of attorney for healthcare)
  - Instructional directive ("living will")
Advance Directives, continued

- While it is important to understand these terms for effective communication, what is important for purposes of legal and ethical application, is the content of the document, not its name.

- At the same time, health care providers need to be aware of the many different terms used by other providers, patients, and families.

- If you are trying to determine whether a patient has an advance directive, you might ask whether she has an “advance directive,” “living will,” or “durable power of attorney,” or ask “did she appoint someone to make decisions?” “a proxy?” “an agent?” “a surrogate?” or “did she leave written instructions?”
Case 2: DNR Orders and Advance Directives

Ms. Yu, an 80-year-old Korean-American woman, is brought into the hospital’s ED by her daughter who reports that her mother is experiencing weakness.

Her daughter mentions that Ms. Yu has an advance directive and that she will bring it when she comes back from parking the car.
While the daughter is parking, Ms. Yu’s heart stops.

Before this time, the ED doctor had pulled up her clinic notes and learned that she has terminal cancer. The patient has never been admitted to the hospital before.

Must the ED staff perform CPR?
Must the ED staff perform CPR?

• Yes, performing CPR is the default rule.

• In this case, there is no evidence yet of what the advance directive form says and whether the patient would want an attempt at resuscitation. Physicians need some evidence that a patient would want to avoid resuscitation before issuing a DNR order.

• In order for a patient to avoid unwanted resuscitation in the event of cardiac or respiratory arrest, a doctor must issue a DNR order. An advance directive alone is not sufficient, even if it says “DNR” on it.

• With other medical treatment as well, in order for an instructional advance directive to have practical effect, a physician’s order is required.

• There is a good reason for this: interpreting and determining appropriate application of an advance directive takes time and may involve multiple individuals.
How could Ms. Yu have avoided CPR in this situation if that is what she wished?

- With a **Durable DNR** — A Durable DNR (DDNR) is a written order by a doctor on a specific state-mandated form that is also signed by the patient or, if appropriate, the patient’s surrogate decision-maker. DDNRs are effective across settings and time.

- If the doctors had a copy of Ms. Yu’s DDNR (or, in some states, special DDNR bracelets and necklaces that substitute for the actual form), the ED staff would not have performed CPR.

- Emergency medical personnel (EMTs, paramedics, etc.) must perform CPR unless a patient has a DNR or DDNR. This is why some individuals post their DDNRs on their refrigerator door, so the document is easily spotted by EMTs.
But, be careful…

• Many people confuse advance directives and DNR orders. For example, family members might believe that CPR would not be performed if their relative has an advance directive that expresses a wish to die naturally.

• The following slide shows a schematic of the relationship of advance directives to DNR orders, both “facility DNRs”—which are DNR orders written in a specific institution for a specific admission, and Durable DNRs—which are effective across settings and time.
Relationship of advance directives to DNR orders, continued

Instructional advance directive expressing patient wishes to avoid CPR requires translation into DNR orders.

- Facility DNRs
- Durable DNRs (DDNRs)
Advance Directives do NOT need to be on a specific form in Virginia

- As shown on the next couple slides, there are several valid, preprinted advance directive forms in Virginia. People can also modify forms as they like, or even not use a form.

- However, many state laws require that advance directives be witnessed in order to be valid. Some require notarization.

- In Virginia, two witnesses must sign for an advance directive to be valid.
There are many Advance Directive forms in Virginia.
People can also modify forms as they like, or even not use a form.
Advance directive forms vs. DDNR forms

• While a written advance directive can be in almost any form (as long as it’s appropriately witnessed), there are official **Durable DNR (DDNR)** forms in each state.

• Official forms and the most up-to-date information can be found at Virginia’s DDNR program website [http://www.vdh.virginia.gov/OEMS/DDNR/index.htm](http://www.vdh.virginia.gov/OEMS/DDNR/index.htm)

• The following slide shows a picture of Virginia’s DDNR form (downloadable from the web) and samples of DDNR-approved jewelry
Authorized Virginia DDNR Form and samples of DDNR approved jewelry (as of July 2011)

Form comes with 3 copies: (1) for patient, (2) for permanent medical record, and (3) to order DDNR approved jewelry

Until recently, Emergency Personnel and other health care providers could only rely on the original DDNR order (a yellow form, shown to the right).

The law on this changed in July 2011. Now the form shown on the previous slide is the official form. However, the yellow forms are still valid.

Also, photocopies of a signed DDNR on either the old or new state-authorized form now may be honored.

Many clinicians may not know about these changes in the law.
New POLST/POST Paradigm

• In addition to DDNR orders, a new way of recognizing “out of facility” doctor’s orders is gaining recognition in many states.

• Under this new paradigm, patients with terminal conditions can secure a doctor’s order to be recognized by emergency personnel and other health care providers regarding CPR, hospital transfer, antibiotic use, artificial nutrition and hydration, and other types of medical treatment.

• This new paradigm is called, variously, POLST (Physicians Orders on Life-Sustaining Treatment), POST (Physicians Orders on Scope of Treatment), and MOLST or MOST (Medical Orders on …).

• In Virginia, a pilot “POST” project is ongoing in certain regions of the state. This project uses a distinctive pink POST form.
New POLST/POST Paradigm

- Up-to-date information about what is happening nationally in this area can be found at [www.polst.org](http://www.polst.org)

- The following are examples of forms from different states (these and more available at [www.polst.org](http://www.polst.org)).

Sample POST form from West Virginia (front and back)

(from [http://www.ohsu.edu/polst/programs/documents/PostForm2010d demographicinfolinksample.pdf](http://www.ohsu.edu/polst/programs/documents/PostForm2010d demographicinfolinksample.pdf))
More POLST paradigm forms

Oregon POLST form (2 page form)

New York MOLST form (4 page form)
As you may have already picked up or known from before, state—rather than federal (or national) law—determines many of the rules about advance directives, DNR orders, and surrogate decision-making generally. (And, institutions also develop specific policies and guidance to help healthcare providers apply the laws.)

So... what happens when patients cross state lines?
Case 3: The out-of-state advance directive

A terminally ill, now incapacitated, patient has an advance directive that refuses all life-prolonging procedures in the event of terminal illness. The patient is in Virginia, but the advance directive was executed in Florida, in accordance with Florida law.

Is it valid in Virginia?
Yes, or at least most likely...

• In Virginia, an advance directive executed in another state is valid if it complies with the laws of Virginia or the other state. Most states have a similar "portability" provision.

• There is a possible exception: if the request in the advance directive is specifically prohibited by law in the state the patient is in, then it would not be effective on that point. Virginia has very liberal standards for advance directives, making this outcome very unlikely in our state.

• IN ANY EVENT, even if the written advance directive were not legally effective, it would contain very good evidence of what the patient would want—the key factor for surrogates to consider.
But DDNRs do **not** cross state lines

- But note that DDNRs, which are executed on very specific, authorized forms, do NOT cross state lines like advance directives.
- Out-of-state DDNRs, however, can still be treated as evidence of what the patient would have wanted, although a new medical order would need to be written before emergency personnel and other health care providers could avoid CPR.
Case 4: The “oral advance directive”

Late one night, a hospitalized terminally ill patient with decision-making capacity tells her nurse that she does not want any life-prolonging procedures, including the feeding tube that her team had discussed with her earlier that day.

The nurse notes this conversation in the hospital chart and notifies the covering intern. Soon after, the patient loses capacity and during morning rounds the issue of a feeding tube arises.

What is the significance of the patient’s statement to the nurse?
Case 4: The patient’s statement to the nurse should be...

1. Considered irrelevant, because it was not made in the presence of an attending physician and two witnesses

2. Shared with family members as they determine whether to authorize the feeding tube.

3. Strictly followed as an “oral advance directive.”
The correct answer is 2.

- No. 3 is incorrect because to be a valid “oral advance directive” in Virginia, the patient’s instruction must be made in the presence of her physician and two witnesses, following a diagnosis of a terminal condition (“terminal condition” under the Virginia law means death is imminent due to injury, disease, or illness, or the patient is in a persistent vegetative state).

- If the physician had come to hear her statement, and two others were present as witnesses, a notation of this conversation in the medical record would have qualified as an “oral advance directive.”

- No. 1 is incorrect; although the patient’s statement is not an “oral advance directive,” it is also not irrelevant. It is very good evidence of what the patient would want and should be shared with and considered by surrogate decision-makers.
Surrogate decision-making

- Surrogate decision-making ideally allows persons who know the patient best to participate in making medical decisions for the patient when the patient is not able to do so herself.

- When an incapacitated patient has not appointed an agent to make decisions for her, state law designates who has decision-making authority.

- We now turn to the rules regarding surrogate decision-making when a patient has not designated a health care agent through an advance directive.
Case 5: State hierarchy for surrogate decision-making authority

Mr. Henley is a 65-year-old man who is hospitalized following a sudden collapse. He lacks decision-making capacity but has not appointed someone to be his surrogate decision-maker. His wife is no longer living, and he has three adult children.

One of them would like for him to receive palliative care only, and to stop aggressive treatment measures. This is the course of action recommended by his doctors.

The other two ask the doctors to “do everything.”
Under Virginia law, who has authority to make treatment decisions for Mr. Henley and why?

1. The child who wishes to discontinue aggressive treatment because this is the course of action recommended by the physicians.

2. The two children who wish to continue aggressive treatment because when anyone who could qualify as a surrogate opposes withdrawing life-sustaining treatment, such treatment cannot be withdrawn.

3. The two children who wish to continue aggressive treatment because they are a majority of the highest category of surrogate available.
The correct answer is 3.

- The two children are the legally authorized surrogate decision-makers because they are a majority of the highest category of surrogate available under the law.

- Neither of the other two answers is correct because authority for decision-making is not generally based on the actual decision that a potential surrogate would make (for example, being for or against treatment withdrawal or in agreement or disagreement with the physicians). Instead, it is based on a hierarchy established by statute.
Virginia statutory hierarchy for surrogate decision-making

- In Virginia, as of 2010, a physician may rely on the authorization of the following persons, in order of priority, if not aware of any available, willing, and competent person in a higher class:
  - Legal guardian, if there is one
  - Spouse
  - Adult child
  - Parent
  - Adult brother or sister
  - Any other relative in descending order of blood relationship
  - In certain limited circumstances, another close adult, as long as the decision does not involve withholding or withdrawing life-sustaining treatment.
As in our case scenario, when there is disagreement among members of a particular category...

The physician may rely on the authorization of a majority of the reasonably available members of that category.

But, the law does not require the physicians to do whatever the legally authorized decision-makers say to do...
Surrogates are not given free rein to decide whatever they would like.

- They must follow the decision-making standards adopted by state law. Most states require surrogates to make decisions based on what the patient would want, if this can be determined. This standard is called “substituted judgment.”
Evidence on which to base “substituted judgment”

- In Virginia, a surrogate is supposed to make treatment decisions based on . . .
  - Guidance from the patient’s advance directive, if there is one and it provides information relating to the issue at hand.
  - In the absence of clear direction from an advance directive, the surrogate should make decisions on the basis of the “religious values, basic values, and previously expressed preferences of the patient.”
  - This order reflects that some types of evidence of the patient’s wishes are generally thought to carry more weight than others.
  - Oftentimes, people have spoken little about their medical wishes or have done so only in a casual way, such as in response to watching a movie. Such statements can still provide some evidence of the patient’s wishes and can usually be considered within the mix of all of the evidence that may exist.
The patient’s “best interests”

• In Virginia, if the surrogate does not have a good basis on which to make a “substituted judgment,” he or she should make a decision based on the patient’s “best interests.”

• This typically involves weighing the benefits and burdens of various options, along with the likelihood of their occurrence.

• As you can imagine, surrogates are also weighing benefits and burdens in determining what the patient would want (substituted judgment), so that these two standards for decision-making often (and appropriately) overlap in practice.
Medically or ethically inappropriate treatment requests

- Virginia law *does not require* physicians to follow a decision by a surrogate that they believe is medically or ethically inappropriate.

- In such instances, physicians should first try to resolve the matter with the surrogates; then they might consider involving the ethics consult service, the chaplaincy service, and/or the hospital lawyer.

- The involvement of these services might lead to a mediated resolution of the issue. If the matter cannot be resolved through these channels, a transfer to another physician or facility should be considered.

- Ultimately, if all else fails, the physician and hospital might seek a judge’s determination about how to proceed in a case in which agreement cannot be reached.
Court involvement—rarely sought but sometimes necessary

- Any person can ask a judge to step in when there is reason to believe that the wrong surrogate has been chosen or the chosen surrogate is not properly exercising his or her duties.

- This step would typically be taken only after attempted resolution of the issue through extended communication, family meetings, and ethics consultation.
The involvement of people other than legally authorized surrogates in decision-making processes

- While the statutory hierarchy gives greater legal authority to a particular person or persons, other people may still have important information that should be taken into consideration and their voices should be heard.

- Physicians should not feel inhibited from appropriately involving people other than the legally authorized surrogate as they work toward a good treatment plan.
Explicit limitations on surrogate decision-making in Virginia

- It is important to note some limitations in the Virginia surrogate decision-making statute
  - It does not allow a surrogate to restrict visitors to the patient unless this power is explicitly given to the surrogate in an advance directive.
  - It does not allow surrogate authorization of non-therapeutic sterilization, abortion, or psychosurgery, and
  - There is a notable absence of some important relationships in the legal hierarchy, such as common-law marriages, domestic partnerships, and same-sex marriages legally recognized in other states.
Case 6: Limitations on who can serve as a surrogate

Ms. Williams is in the hospital about to undergo a surgical procedure. Her physician, Dr. Paul, talks with her and her partner of 25 years, Cathy Simmons, about the risks and benefits of the procedure, alternatives, and so on. Unfortunately, the outcome of the procedure is less successful than desired, and Ms. Williams is now seriously ill and lacks decision-making capacity. Dr. Paul needs to know who should make decisions for Ms. Williams. Her only blood relative is a nephew whom she hasn’t seen in seven years and who lives in Nevada.

According to the Virginia statute, who should Dr. Paul turn to for decision-making on behalf of Ms. Williams? Who has legal authority to act as Ms. Williams’ surrogate?
In Virginia, who has legal authority to act as Ms. Williams’ surrogate?

1. The nephew only; and if he’s not available, a court-appointed guardian would be required.

2. Only Ms. Williams’ partner, because she knows Ms. Williams the best.

3. Under certain conditions, Ms. Williams’ partner may be able to serve as the surrogate, but consultation with the “Patient Care Consulting Committee,” a subcommittee of the hospital ethics committee would be necessary.
The correct answer is 3.

- The medical team should try to reach the nephew by phone, if possible, to see if he is willing to serve as a surrogate decision-making.

- If the nephew is not reasonably available or under the circumstances is unwilling to act as the surrogate, then the statutory hierarchy can be followed to the last remaining option, which is: an adult “who (i) has exhibited special care and concern for the patient and (ii) is familiar with the patient's religious beliefs and basic values and any preferences previously expressed by the patient regarding health care”

BUT NOTE

- a quorum of a “patient care consulting committee” of the facility must determine whether a person meets these criteria and

- this surrogate cannot make a decision in favor of withholding or withdrawing life-sustaining treatment.
How could Dr. Paul have helped Ms. Williams to avoid this situation?

• Before the procedure, or better, as a part of routine patient care, Dr. Paul could have explained this limitation in the statute so that Ms. Williams could have chosen who she would like to make decisions for her in the event of incapacity. She could have done this by executing an advance directive that named her partner as her health care agent if she wished.
Note that this issue goes beyond domestic partnerships

- The Virginia statute treats all potential surrogates who are not the spouse or a blood relative of the patient in the same way.

- This could mean that a beloved daughter-in-law, for example, who has cared for the patient for many years, would be overlooked as a surrogate in favor of a distant blood relative.

- As with most of the issues surrounding surrogate decision-making, this is a matter of state law. The law of other states may give greater or lesser recognition to close friends or partners as potential surrogates.
Case 7: When family members wish to supplant an appointed health care agent

Mr. Charlton has appointed his partner of many years, Rosita Garcia, as his health care agent in an advance directive. Mr. Charlton is now in a terminal condition and lacks the capacity to make decisions for himself. Ms. Garcia, following Virginia’s surrogate decision-making standards, decides to discontinue ventilator support, but Mr. Charlton’s mother (who has never approved of her son’s relationship with Ms. Garcia) disagrees.

Mr. Charlton’s mother would be his surrogate decision-maker by the statutory hierarchy if he had not named a health care agent. She reports to the medical team that she is seeking to remove Ms. Garcia as decision-maker and asks them to ignore Ms. Garcia’s authority in favor of her own and to restrict Ms. Garcia from visiting.

Can the doctors do that? Yes or no?
The correct answer is no.

• In general, the only individual who can revoke an appointed healthcare agent is the person who named the agent (here, Mr. Charlton).

• Also, even legally authorized surrogate decision-makers can only restrict visitors if given this authority in an advance directive. So, for example, even though Ms. Garcia, the healthcare agent appointed in the advance directive is the legally authorized surrogate decision-maker here, she could not restrict Mr. Charlton’s mother from visiting unless given this authority in the advance directive.

• If asked, a court might agree to review the situation and decide to revoke Ms. Garcia’s agency, but would have to have grounds for doing so other than the mother’s disapproval (e.g., if Ms. Garcia were making clearly inappropriate decisions about treatment, which is not the case here).
How have these many rules been established? State Law and the U.S. Constitution

- Federal constitutional law sets the basic minimal right -- a patient with decision-making capacity has a right to refuse medical treatment, even life-saving medical treatment; a patient who lacks that capacity continues to retain that right, although it must be exercised by others.

- The more detailed rules for exercising the right for patients without capacity usually come from state law, through a combination of state statutes and legal cases.

- Although the right to refuse treatment exists in every state as a matter of federal constitutional law, there is wide variation among states about the means of exercising that right. It is therefore important to know the law of the state in which you live.
The law does not have all the answers.

- Generally, the law of surrogate decision-making, by statute, provides a “safe harbor” (legal immunity) for physicians, facilities, and individuals making medical treatment decisions involving people who lack capacity, so long as the situation they are facing is specifically dealt with in the statute.

- However, as depicted in the next slide, there are many situations on which there is little legal guidance, for example, to deal with the situation when the advance directive gives conflicting instructions or the surrogate challenges the advance directive or there is uncertainty about when is death “imminent.”
When the situation you are facing is specifically dealt with in a statute, following it provides you a “safe harbor”… this means you will have immunity from liability. Many situations you will face, however, are simply not answered by looking at the statutes; they require careful judgment.
Filling in the gaps

- In sorting through these situations, it is important to use the various resources available to you—discussion with colleagues, ethics consult service, chaplaincy service, patient and family educational resources, hospital counsel, among others.

- As noted before, while courts and legislatures prefer that these issues are handled outside of courts, sometimes it is necessary to resort to the courts.
Further Resources

Medical Center Policies 0024, 0079, 0142, and 0191 summarize both Virginia law and the policies of the Medical Center about informed decision-making, DNR orders, advance directives, and refusal of treatment.

A link to the Medical Center Policy Manual can be found on the website of the Center for Biomedical Ethics and Humanities

http://www.medicine.virginia.edu/community-service/centers/biomedical-ethics-and-humanities/resources