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Advance Directives and Code Status Information Exchange: A Consensus Proposal for a Minimum Set of Attributes

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Abstract: Documentation of code status and advance directives for end-of-life (EOL) care improves care and quality of life, decreases cost of care, and increases the likelihood of an experience desired by the patient and his/her family. However, the use of advance directives and code status remains low and only a few organizations maintain code status in electronic form. Members of the American Medical Informatics Association's Ethics Committee identified a need for a patient's EOL care wishes to be documented correctly and communicated easily through the electronic health record (EHR) using a minimum data set for the storage and exchange of code status information. After conducting an environmental scan that produced multiple resources, Ethics Committee members used multiple conference calls and a shared document to arrive at consensus on the proposed minimum data set. Ethics Committee members developed a minimum required data set with links to the HL7 C_CDA Advance Directives Module. Data categories include information on the organization obtaining the code status information, the patient, any supporting documentation, and finally the desired code status information including mandatory, optional, and conditional elements. The "minimum set of attributes" to exchange advance directive / code status data described in this manuscript enables communication of patient wishes across multiple providers and health care settings. The data elements described serve as a starting point for a dialog among informatics professionals, physicians experienced in EOL care, and EHR vendors, with the goal of developing standards for incorporating this functionality into the EHR systems.

Introduction and Background

Resuscitation is the default option in the event that a patient arrests. Other medical treatments (e.g., surgery or chemotherapy) require a provider to deem it necessary and a patient to consent. Resuscitation is presumed to be consented to (unless explicitly not) and always considered appropriate in the event of an arrest. As a result, many patients are overtreated with CPR resulting in unnecessary and unwanted resuscitations.[1]

Discussion and documentation of end-of-life (EOL) decisions prior to clinical deterioration is labor intensive and potentially stressful for patients and clinicians and frequently is avoided.[2] However, appropriate documentation of advance directives for EOL care can improve care and quality of life,[3] decrease cost of care,[4] and increase the likelihood of an experience desired by the patient and his/her family.[5,6] Patients who have prepared advance directives receive care that is strongly

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associated with their preferences.[7] Properly documented and complete advance directives aid families in having important conversations about EOL preferences and increase their confidence that they know what the patient would want.[8]

Preference for "code status," especially in hospitals, can be an essential part of the advance directive. Clarity regarding an individual's preferences for intervention in the event that s/he is unable to make medical care decisions can protect the individual's autonomy or right to self-determination.[9] Congress passed the Patient Self-Determination Act in 1990,[10] mandating that patients receive information concerning decisions at the end of life, and confirming the patient's right to draft an advance directive. One of the Patient Self-Determination Act provisions is to document the existence/execution of an advance directive in the patient's medical records. The instructions for EOL care, as documented in the advance directive, are to be translated into appropriate code status by a health care provider.[11] A patient's resuscitation management in hospitals is thus driven by a documented code status that represents a patient's desires for EOL care.

The use of advance directives and code status, usually documented on paper, has remained low.[12,13] Also, only a small proportion of facilities maintain code status in electronic form for select populations.[14-18] The Ethics Committee of the American Medical Informatics Association (AMIA) identified a need for a patient's EOL care wishes to be documented correctly and easily communicated to those caring for the patient in various care settings, preferably through the electronic health record (EHR). Currently, many EHRs lack appropriate functionality to document decisions at the end of life. Further, there is a lack of clarity on what should be documented, leading to low rates of documentation of EOL preferences.

The "advance directive" document is generally understood to include (1) a living will that declares an individual's EOL preferences, including code status, desires for other aggressive treatments, and the role of physicians in providing prognoses; and (2) designation of a surrogate or proxy, which assigns someone to guide medical decision making—including decisions at the end of life—in the event of the patient's incapacity. Living wills often include language rejecting interventions described as "nonbeneficial," "heroic," or "likely to prolong the dying process." Even if code status is not explicitly addressed in a living will, clinicians can infer an appropriate code status from other declarations. Rarely, living wills proclaim a desire for aggressive treatment, even if the medical team regards such treatment as ineffective or inappropriate.

The goal of this white paper is to describe a minimum data set required for the storage and exchange of code status information in EHRs. The data set was developed by consensus of the members of the AMIA Ethics Committee.

Environmental Scan

For the purpose of identifying the minimum data set for advance directive / code status (AD/CS) documentation, we explored existing resources that could potentially support the documentation, and possibly exchange, of an individual's end-of-life wishes.

1. The Minimum Data Set 3.0 is a standardized primary screening and assessment tool of health status for long-term care nursing home residents developed at the Research Data Assistance Center (ResDAC).[19] It provides "life care

wishes" as one set of the attributes documented. A search of minimum data set attributes for "advance directive," "code status," or "EOL care" terms in the data elements[20] did not yield any results.

2. The Health Information Technology Policy Committee of the Office of the National Coordinator for Health Information Technology held a care planning hearing[21] in November 2013 and listed resources that may aid patients in expressing and documenting their advance directive independently in an electronic format. Those resources that may help to exchange the AD/CS data in EHR include the following:
   a. The myDirectives[22] web service enables individuals to create, update, and retrieve an advance directive. It can also be integrated with electronic medical records (EMRs), electronic health records (EHRs), personal health records (PHRs), and health information exchanges (HIEs).[23]
   b. Physician orders for life-sustaining treatment (POLST) or medical orders for life-sustaining treatment (MOLST) registries are created at the state level to document advance directive for patients. The POLST/MOLST can function as a repository for the code status for patients treated at facilities in those states. Currently, Oregon and West Virginia have mature POLST programs, while many other states have either endorsed or are developing POLST registries.[24] A sample POLST tool for Oregon can be found at http://www.polst.org/wp-content/uploads/2013/01/Printing-POLST.pdf.
3. Commercial EHR systems currently do not have a standardized representation to document and exchange AD/CS.

Although a few of the sources listed above (POLST/MOLST and myDirectives) may facilitate the documentation of EOL care wishes, currently neither a standard format for AD/CS and its data elements nor a standard communication protocol exists.[25] However, the HL7 Consolidated-Clinical Document Architecture (C-CDA) document standard does contain an advance directives module for data exchange of an advance directive section within a health summary.[26] The section is described as "contain[ing] data defining the patient's advance directives and any reference to supporting documentation" and "data such as the existence of living wills, health care proxies, and CPR and resuscitation status." This module further contains a number of data elements with some bindings to standard terminologies, for example LOINC 42348-3 for the section title "Advance Directives." The module also contains SNOMED value sets for AD/CS types (e.g., CPR, resuscitation, and intubation) and the status of the advance directive itself (e.g., current and verified, verified by medical record only, etc.).

Moreover, in addition to do-not-resuscitate order status, information of potential significance in EOL care includes preferences regarding mechanical ventilation, artificial hydration and nutrition, and the use of antibiotics and cardiovascular medication (such as epinephrine). Because clinicians serving gravely ill patients often need to access more detailed data and information than mere code status preference, a comprehensive EOL utility for EHR would provide all such data and information in addition to easy access to living will

documents from which the data, sometimes free text, are drawn. In at least some EHRs, the actual documents are stored (often as PDFs) in directories several clicks away from the main code status information. Efforts should be encouraged to develop machine readable or electronic versions of living wills and surrogate/proxy designations.

Source Authenticity

An important aspect that must be resolved is the source of EOL information. Though the information interchange can take place as per "*a standard data structure,*" there could be multiple, conflicting sources of this information (e.g., myDirectives, a state registry, last medical care facility visited by the patient). Identifying the source that should receive preference is critical and should be done using agreed-upon rules. Ascertaining the authentic source of the AD/CS data is also important for backward data flow in case the patient asks for any changes (e.g., at the time of or even after admission). Institutions should ensure that patient preferences are up-to-date and accurately represented in the EHR.

Key questions to address concerning source include

1) Are there sources that a receiving entity should consider as reliable (and therefore would always be approached or supersede any other source), or should the most recent update be taken as accurate, rather than a specific source?
2) Could there be a hierarchy of the sources (e.g., surrogate, centralized source, state level registries, last update) so the seeking entity would go down the hierarchy until it receives the AD/CS information?
3) What is best practice in case of discrepancy or conflict between or among sources?

Methods

The AMIA Ethics Committee used multiple conference calls and a shared document to arrive at consensus on the proposed minimum data set. All authors had the opportunity to review and revise the final document.

Results

The AMIA Ethics Committee developed a minimum required data set developed with links to the HL7 C_CDA Advance Directives Module. Data categories include information on the organization obtaining the code status information, the patient, any supporting documentation, and finally the desired code status information. This data set includes mandatory, optional, and conditional elements.

Mandatory data elements include

- Organization name—This is the institution or organization where the code status is obtained and documented. The corresponding C-CDA element is *information source for advance directive* (subdata elements of author ID, represented organization ID, and represented organization name).
- Patient (unique) identifier—This may be a medical record number. This identifier would be unique within the institution of origin, but may not be unique universally.
- Patient last name
- Patient first name
- Patient date of birth
- Date of code status—This is the date the code status was last obtained or updated and confirmed.
- Provider recording the code status—This is the name of the practicing provider who discussed and recorded the patient or family's code status wishes.

- Provider's phone number—This is the phone number where the provider recording the code status can be reached.
- Provider phone number type—This indicates whether the provider's phone number is an office, pager, or cell phone number. [multiple entries possible]
- Patient's ability to consent—This describes the patient's ability to discuss and consent to the code status. Possible entries include "unable to consent" and "able to consent" or "capacitated," "incapacitated," and "episodic capacity."
- Patient's proxy phone number—This is the phone number where the patient's proxy can be reached.
- Code status type—This element typically will be "full code," "do not resuscitate" (DNR), or "limited resuscitation."

Conditional data elements include

- Patient's assent—This element indicates whether a minor patient has assented to the actions outlined in the advance directive.
- Patient's proxy, surrogate, and/or guardian—This element is mandatory if the element "ability to consent" is "unable to consent."
- Relationship of proxy, surrogate, and/or guardian to patient (mandatory if "patient's proxy" field is populated)—This element indicates the relationship of the proxy to the patient, e.g., parent, child, sibling, legal guardian, other relative.
- Code status limitations (mandatory if the "code status type" is set to "limited resuscitation")—This element indicates various limitations that are in place. Limitations to interventions could include DNR if no pulse and not breathing or full code otherwise, and DNR if no pulse and not breathing with limited intervention otherwise. These limited interventions include, but are not limited to, withhold antiarrhythmic medications, withhold intravenous vasoactive drugs, withhold defibrillation/cardioversion, withhold chest compression, withhold ventilation by mask, withhold endotracheal intubation, withhold mechanical ventilation, withhold transfusion, withhold dialysis, withhold admission to intensive care unit, withhold administration of vasopressors, withhold artificial feeding (nutrition/hydration), withhold administration of antibiotics, and withhold diagnostic procedures.

Optional data elements include

- Organization address—This is the address of the medical record department or equivalent of the institution or organization where the code status originated.
- Organization phone number—This is the phone number of the medical record department or equivalent of the institution or organization where the code status originated. [multiple entries possible]
- Organization fax number—This is the fax number of the medical record department or equivalent of the institution or organization where the code status originated.
- Patient middle name
- Patient e-mail address
- Patient address
- Patient phone number
- Living will—This element describes an existing living will and how to obtain it.
- Designation of surrogate—This element describes an existing designation of a surrogate will and how to obtain it.

- POLST form—This element describes an existing POLST form and how to obtain it.
- General comments—This element allows further narrative descriptions of the code status.
- Witness—This element includes the full name of the witness to the discussion of the patient or family's code status wishes.

Discussion

The AMIA Ethics Committee identified the need for a patient's EOL care wishes to be documented correctly and communicated easily in patient care settings through the EHR. Recognizing that currently no data standard exists to support this functionality, the AMIA Ethics Committee created a proposed minimum required data set. This data set is intended for use by EHR implementers and vendors to include it in their future products, thus enabling the recording, transmission, and exchange of patients' EOL wishes.

This minimal data set emphasizes the importance of a "limited resuscitation.," recognizing that the default action of "full code"—i.e., resuscitate by any measure—may not always be reflective of a patient or family's wishes and desires. Studies have revealed that a majority of patients who survive after CPR either do not regain previous functional status or die in a short span of time.[27,28] Since aggressive resuscitation may result in several harms (e.g., physical distress, loss of dignity, family suffering with complicated bereavement) and since the benefits or harms of resuscitation are best assessed from a patient's perspective,[29,30] we assured that the data set contains sufficient elements to document the individual options that may go into a "limited resuscitation" choice.

Similarly, it is important for patients to make informed decisions about their code status and establish one a priori (in the form of an advance directive document or code status instructions at the time of admission).[31] However, the capture of code status has remained low even among terminally ill patients.[32] It is the hope of the AMIA Ethics Committee that the publication of a minimum data standard will lead to more tools incorporated into EHRs to document EOL choices.

Conclusion

Despite the challenges involved and the limited time available to discuss and gather the code status details for a patient in certain conditions, it is important to have a better understanding of patient and family perspectives. Research has shown that EOL preferences are often not well documented, leading to failures in communicating such information from patient to physician, as well as among physicians and health care settings. Although failures of communication in the clinician-patient relationship will impede any attempts to document and access preferences regarding EOL care, such communication can be influenced by the design of the EHR. EHR systems can assist with this communication task if they are designed to provide user-friendly, complete, and accurate documentation of EOL preferences and can even facilitate the discussion between physicians and their patients about this important issue. Because few EHR systems currently have clearly designed functionality for advance directives, this paper identified core attributes for such functionality. The "minimum set of attributes" to exchange AD/CS data described in this manuscript enables communication of patient wishes across multiple providers and health care settings. The data elements described should serve as a starting point for a

dialog among informatics professionals, physicians experienced in EOL care, and EHR vendors, with the goal of developing standards for incorporating this functionality into the EHR systems. Given the key role that EHRs now play in clinical care at all levels, we believe that incorporating such standards can play a major role in improving both documentation and communication about patients' EOL preferences.

Notes

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