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RESEARCH ARTICLE

A Practical Method to Protect Patient Autonomy Using Conditional Medical Orders

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ABSTRACT

Throughout the world, patients have the right to determine what is done to their bodies, and to have their wishes recorded and honored when undergoing medical interventions. Unfortunately, many patients receive treatment that does not concur with their goals. Many patients are reluctant to discuss advance care planning because they are intimidated by the need to contemplate their own serious illness and/or death. Even if patient preferences are elicited, they may not be understood or clearly recorded, and if recorded, may not be accessible when needed. Conditional Medical Orders are one efficient way to concisely record patients' preferred modes of treatment in a form that can be prominently placed in patients' medical records and carried with them for use in outpatient medical care. It requires provider signatures because it combines an advance directive with treatment orders, providing assurance that the medical record accurately reflects patients' preferences. Unlike most order sets that reveal little about patients and force them to make rigid binary choices, this order set identifies patients' values and offers them more realistic options that stipulate the conditions under which each procedure is desired. Although only a single page, this order set is more complete than other forms. It is partly standardized and partly editable so it can be adapted to patient and provider preferences. The flexibility of this order set makes it more acceptable to many patients who have been averse to traditional approaches to advance care planning that they consider too rigid and insensitive to their evolving healthcare needs. Providers appreciate both the efficiency with which the orders can be completed and their specificity which facilitates delivering treatment that concurs with patients' treatment goals.

Keywords: Conditional Medical Orders, advance care planning, goal-concurrent treatment, critical care, palliative care, end-of-life treatment.

Introduction

Patients vary widely in the scope of medical care that they want as their health declines. Among other codes of ethics, the European Code of Cancer Practice¹ stipulates that “patients have a right to discuss with their healthcare team, their preferences to achieve the best possible quality of life”. The goal is to arrive at treatment decisions through shared decision making in which patients, key members of the healthcare team, and selected significant others participate.²

These discussions are often routine in palliative and critical care settings, but highly desirable for all patients because no one can know when illness or accidents will pose major healthcare crises. When treatment received differs from treatment desired as stated in these documents, patients and their families report greater pain and distress, dissatisfaction with their care, and have more profound bereavement issues.³ Therefore, failure to deliver care concordant with patient goals can be regarded as a “medical error that can harm patients and families.”⁴

What type of care do patients want?

Many patients desire limited treatment or comfort care only,⁵ wishing to prioritize pain and symptom control over the additional survival time that disease specific therapy might provide.⁶ Furthermore, these patients may be aware of the burden of meeting the needs of someone with a serious illness, and by choosing palliative and/or hospice care they hope to reduce the physical, emotional, and time commitment of their caregivers.⁷

Despite the common preference for less rather than more treatment, at the end of patients’ lives, physicians often continue to focus medical

care primarily on extending life rather than emphasizing quality of life. For example, one study reported that as many as 91% of European cancer patients continue to undergo aggressive treatment that compromises the quality of their end of their lives.⁸ Overtreatment is defined as treatments in which risks are greater than benefits. It is morally justified only if the patient has a clear understanding of the treatment burden relative to the likelihood of measurable success, a choice some seriously ill patients are willing to make. In European countries that rely on the fee-for-service model, up to one third of critical care intervention is excessive.⁹ This is supported by a study in Sweden that found that “about one-third of decedents received at least one treatment or procedure indicative of ‘potential overtreatment’ during their last month of life”.¹⁰ It is considerably less common for patients to receive less care than they desire at the end of life, although this possibility clearly exists. If someone wants aggressive medical intervention, all members of the treatment team should appreciate this. Offering too little treatment is as serious an error as offering too much treatment.

How can we account for non-goal-concordant care?

A number of system-level factors contribute to over-treatment: time constraints of critical care may allow few opportunities to discuss advance care planning; providers may choose active treatment because they regard death as failure or because of their religious convictions; patients may lack the assertiveness needed to express their concerns; family members, not knowing the patient’s wishes, may wish to prolong life as a default; and routine institutional protocols may be oriented at maximizing intervention.

For example, although it acknowledges Do Not Attempt Resuscitation orders, the European Recommendations for End-of-Life Care for Adults in Departments of Emergency Medicine¹¹ stipulates that “prolonging life and not hastening death is the duty of ED personnel”. Increasing opportunities for patients to express their preferences and then receive goal-concordant care will require changes in both medical culture and in various standard practices. Here we focus on one practical challenge related to recording advance care documents and making them available when needed. We suggest that using a simple form can ensure both accurate documentation of patient wishes, with easy accessibility and portability.

The need for easily-interpretable, easily-accessible testaments of a patient’s wishes

Patients may expend considerable time and energy in producing clearly stated and appropriately certified advance care documents, but their existence does not guarantee that providers will read, understand, or act on them. It is not uncommon in hospital systems to learn long after a patient is admitted that an advance care plan exists. Either the family cannot find it or has trouble delivering it to the hospital, or staff do not communicate about its existence. After it is uploaded into the electronic medical record, providers may be unable to locate the document, read it, and accurately interpret what it means to the patient in the current clinical setting. Uncertainty may still persist about what the patient wanted.

Advance care planning documents should be immediately accessible in patients’ medical records. It has been suggested that documents expressing patient wishes should be

consolidated in one place in the records, rather than being “scattered across multi-disciplinary notes”.¹² In addition, they should be portable, so patients have them available in multiple settings in which they receive care, e.g. pre-admission to hospitals, clinics, and providers’ offices, and at home and while traveling. The documents should also be standardized and concisely stipulate the goals and limitations of the desired critical illness treatment.¹³

Conditional Medical Orders

The Conditional Medical Orders (CMO) form (Figure 1) meets these requirements efficiently by summarize patient preferences in one page. Using decision aids can greatly improve communication with patients about end-of-life wishes.¹⁴ There are also other excellent guides to goals of end-of-life care discussions.¹⁵ In our experience, a CMO can be completed in an average of 14 minutes with patients who have sufficient capacity and health literacy. Including the patients’ surrogates when creating the CMO, which may not add additional time, can both help to reduce patients’ anxiety and minimize costly delays in care when stakeholders debate goals and options during critical care crises.

Figure 1

Conditional Medical Orders

Patient: _____ DOB: _____ Pt. IID#: _____

Name of surrogate _____ Phone: _____ E-mail _____

2nd surrogate: _____ Phone: _____ Email: _____

Patient demonstrated sufficient capacity: ___ Yes and sufficient health literacy to understand choices ___ Yes

Personal values: 1 _____ 2 _____ 3 _____

For context. I believe life has value for me: under all circumstances _____ OR only if I can think and act independently_

Scope of treatment desired.

___ To live as long as possible regardless of the quality of my life. I want all potentially helpful treatments.

___ To try a limited course of treatments only as long as there is a reasonable chance of my being able to live a life I value. If that is unlikely, I would like comfort care only.

___ To die naturally. I want comfort measures, but no interventions that can delay natural death. I want medication and other procedures including surgery only to make me comfortable and not to prolong my life (I would rather make the mistake of moving to comfort care too soon than risk waiting so long that my functioning deteriorates below the quality of life I am willing to lead.)

Options for Conditional Resuscitation Orders

___ ACPR: Always attempt resuscitation whenever deemed necessary.

___ DNAR-X: DO NOT Attempt resuscitation EXCEPT when due to an event that has reversible effects in the opinion of providers at the scene.

___ DNAR: DO NOT attempt resuscitation under any conditions.

Options for Conditional Ventilation Order

___ AV: Always ventilate by any means for any duration recommended.

___ IVM-C: Use invasive ventilation methods ONLY if they are needed for resuscitation or for the treatment of an acute event with reversible effects. OTHERWISE use Non-invasive Ventilation as needed.

___ DNI: DO NOT use invasive ventilation methods ever. Provide oxygen via canula as needed.

Options for Conditional Artificial Nutrition and Hydration Orders

___ AANH: Always Administer artificial nutrition and hydration by any method for as long as recommended.

___ NAH-X: DO NOT administer artificial nutrition and hydration EXCEPT for a short time to achieve a specific goal.

___ DNANH: DO NOT Administer artificial nutrition and hydration. Only provide nutrition and hydration orally.

Additional medical procedures:

VCED: Allow my Voluntary Cessation of Eating and Drinking, making me as comfortable as possible while awaiting death. Do not attempt to provide food or liquid orally other than ice chips or lozenges for comfort. ___ YES. ___ NO (Initial)

If I meet the legal requirements for medical aid in dying in the jurisdiction in which I am receiving treatment:

1. I would like this service if my condition has worsened to the point at which I would rather die than continue living: _ YES. _ N) _ (Initial)

2. I would like this service if I develop moderate dementia, e.g. if I do not recognize people, often appear confused. and need constant help in meeting personal needs, and therefore need 24 hour care, _ YES. _ N) _ (Initial)

Further additions _____

Physician, RN, ARNP,, PA-C: _____ Date _____

Patient: _____ Date _____

Surrogate _____ Date: _____

The CMO should be administered by a healthcare professional or a trained facilitator who is qualified to assess each patient's capacity to render informed consent. Since it is both an advance directive and an actionable medical order, it must be signed by a professional who is qualified to enter orders into patients' records. Combining both documents in a single page also saves time for providers by reducing their workload. Given the finding that providers sometime falsely report that shared decision making has taken place,¹⁶ the existence of a CMO signed by both patients and providers offers evidence that ethically mandated discussion of goals of care has actually occurred.

To orient the discussion on personal perspectives, the CMO asks patients to identify three personal values. For example, patients who choose autonomy, connection, and learning may prefer to end their lives when their conditions no longer make these things possible. In contrast, those who consider life a divine gift that should be preserved at all costs, may be more likely to choose to undergo all available treatment options regardless of their burden.

As an added way to understand their values, patients are asked to express a preference for quantity versus quality of life. This is followed by asking patients to declare a general preference for curative, limited, or comfort care only treatment. These answers provide a context for helping patients express preferences for the most common critical illness treatment procedures: resuscitation (CPR), ventilation, and artificial nutrition and hydration (AHN). Acknowledging that medicine rarely offers simple dichotomous choices, the CMO offers

a range of actions in each category, i.e. always, sometime, and never, that allows patients to stipulate the conditions under which they are willing to accept each procedure. This is in sharp contrast to the various iterations of the highly flawed POLST (Portable Orders for Life Sustaining Treatment) that cling to problematic dualistic choices. If patients who have a binary DNR suffer cardiac or respiratory collapse due to a medical error or reversible condition, e.g. anaphylactic shock resulting from a medication error or consuming a food to which they are allergic, providers are faced with two very bad choices. They can allow the patients to die, which at the least would be medical negligence, or they could disregard the patients' request, which would be an ethical error. Conditional orders avoid these harsh choices by providing a more viable alternative. In our experience, the pragmatic flexibility of the CMO helps overcome many patients' resistance to ACP by offering options that are more personalized and less limiting than the more common dichotomous choices.

As a measure of patients' capacity and health literacy, providers can examine the consistency of patients' answers. For example, patients who deeply value autonomy and who completely accept their grave condition are unlikely to choose full treatment that includes CPR because they know that survival after resuscitation is poor, and their QOL is rarely the same, and usually worse than before the procedure. They would feel the same about mechanical ventilation, and intubation if they are helped to understand the common use of restraints and poor outcomes when these procedures are used long-term.^{17,18,19} Inconsistency in these responses would signal the need to assess and the patient's capacity to understand the

decisions before finalizing the document. If the patient does not understand, further discussion would be warranted. Soliciting preferences in multiple formats can also help overcome another problem with other ACP documents that providers may fail to understand exactly what their patients want.²⁰

It is suggested that providers keep the first two-thirds of the CMO intact for standard use, but because this form is open-source, i.e. not copyright protected form, they are free to change or delete any of the Additional Medical Orders, e.g. those pertaining to VSED (Voluntary Stopping Eating and Drinking) and those pertaining to medical aid in dying. For example, recognizing that mortality is associated with both stage and type of cancer²¹ and patients' general state of health, some oncologists might strike these and offer patients an option along the following lines:

Specifically regarding treatment of my cancer:

__Rather than assuming that I will accept all treatments offered, I ask that whenever a change in my treatment regimen is suggested, my provider discuss the pros and cons of the treatment with me. Knowing that changes in treatment often correlate with changes in treatment outcome, I ask that my provider review the impact of these changes on my preferences recorded on this CMO.

_I do not want to undergo any treatment for my cancer other than supportive comfort care.

An option like this sets the state for ongoing collaborative reviews of treatment plans.

Buffering Conditional Medical Orders

One additional form can increase providers' opportunity to deliver appropriate care. One of the many challenges to the delivery of goal concordant care is the fact that many patients see multiple providers at the end of their lives, with no one provider having the responsibility to coordinate the well-intended, but occasionally conflictual interventions. Moreover, most providers have very large panels of patients and cannot be expected to recall important details about all of them. To increase the likelihood that providers will know essential facts about them, it is helpful for patients to complete, regularly update, and bring to all medical encounters, the two-page "Important Information to Give Your Provider" (Figure 2). This form can be downloaded at no charge from www.6stepslivingwill.org. Doing so can improve the quality of care that patients receive while also lowering the risk of medical errors by providers who lack important information about their patients, including their allergies, current conditions and the medications taken to treat them that may have been prescribed by other providers, and other important elements of their health histories.

Figure 2

Step 5: Important Information to Give to Your Provider

Name: _____ Date of Birth: _____

1. To introduce myself, here are three things that I consider important for you to know about me.

- a) _____
- b) _____
- c) _____

2. I have the following allergies: _____ None.

- a) _____ b) _____ c) _____
- d) _____ e) _____ f) _____

3. I have been diagnosed with the following current major physical and/or psychological conditions. _____ None.

- a) _____ b) _____
- c) _____ d) _____

4. I have I currently take the following prescribed and over-the-counter medications.

Name of Medication	Dose (mgs, drops etc.)	How often? (times per day)	Prescribed by?	When?

5. I have the following metal devices or supports implanted in my body.

- a) _____ b) _____
- c) _____ d) _____

6. If this is an emergency contact, the provider who I see regularly now is:

- a) Name of Provider: _____
- b) Provider's contact information: _____
- c) Provider's organization: _____

7. My healthcare representative (surrogate or DPOA) is:

Name: _____ Phone: _____ E-mail: _____
Address: _____

8. If this person is unavailable, my backup healthcare representative is:

Name: _____ Phone: _____ E-mail: _____
Address: _____

9. I currently live with (Initial ONE): _____ my spouse _____ a domestic partner _____ or live alone

Name: _____ Phone: _____ E-mail: _____
Address: _____

I DO _____ DO NOT _____ (Initial ONE) grant this person access to my medical records and participation in discussion of my medical treatment.

10. I DO _____ DO NOT _____ (Initial ONE) have an advance directive and/or Conditional Medical Order, dated: _____

- a) Not an advance directive. In general, if I have a terminal condition, I am likely to prefer: (Initial ONE)
_____ Full treatment _____ Limited treatment _____ Comfort care only

11. I, and my significant others, will hold you blameless for meeting community standards for the level of care I requested in my advance care planning documents. (Initial if accepted, write "X" if not) _____

12. Additional important information about you that you would like your provider to know:

Need for further research

Research on goal-concordant care is still in its infancy. Answers to key questions would be of value to palliative and critical care providers as well as health care planners. A barrier has been difficulty in determining exactly what patients desire. Use of the CMO facilitates precise identification of patients' general scope-of-treatment wishes and their preferences for specific procedures. Providers can code intervention using the same language to facilitate comparing treatment desired with treatment delivered. The existence of a CMO would also validate that ACP was offered and make it possible to study the demographics of patient choices and provider offerings.

Conclusion

Ethical codes around the world require providers to identify, record, and honor patients' requests for the scope of treatment they are willing to undergo. However, it is challenging to deliver care concordant with the treatments patients prefer. One obstacle is the difficulty that some patients have in declaring their goals in a way that providers understand. This is a particular problem when patients experience a pressing medical crisis. The CMO is an optimal way to create and record patients' requests through efficient shared decision-making meetings involving patients, providers, and surrogates. The form offers cues to patients' values, their general scope of treatment preferences and specific requests for resuscitation, ventilation, and artificial nutrition and hydration. Because it is an open-source document, parts of the CMO can be customized to reflect specific provider protocols and patient preferences. Placed prominently in patients' records and in

their hands, the orders are available when and where needed. When paired with the useful "Information to Give Your Provider" form, healthcare workers can be better equipped to deliver care concordant with their patients' requests. As a final note, further validation of the role of the CMO in promoting goal-concurrent care is a very useful area of further research.

Conflict of Interest Statement:

The authors report no conflicts of interest.

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