

Medical Orders for Scope of Treatment: Implementation in North Carolina

North Carolina Institute of Medicine

2013

The Medical Orders for Scope of Treatment (MOST) document is a standardized form that patients can use to designate treatment preferences which can be used as medical orders across healthcare facilities. The form must be completed by both the patient (or his or her authorized representative) and the physician, nurse practitioner or physician assistant. The MOST form includes care preferences in regards to cardio-pulmonary resuscitation, antibiotics, intravenous fluids, and feeding tubes, including scope of care (full care, limited care, comfort measures only). These types of care preferences may be of particular use in nursing home settings. Studies have shown that the patients' preferences are more likely to be honored with use of similar forms.^{1,2} Despite generally high support of the MOST form by health professionals, there has been some concern regarding time, complexity, literacy level, and need for annual update. Nursing homes in NC are thought to have excellent compliance with documenting advanced care directives, but the type of process used by most nursing homes in NC is widely varied. In addition, we have no knowledge of the use of the MOST form in North Carolina, how it is perceived by staff in health care settings, and whether there are barriers to its use. Also, while we have some understanding of the use of advance care directives in nursing homes, less is known about the role of the MOST form and other types of advanced directives in adult care homes and assisted living facilities. Planning for advance care preferences often starts after a change in health status concurrent with an acute care hospitalization, therefore understanding the role of hospitals in advanced care planning and documentation is an important part of understanding the use of the MOST form in NC.

In 2007, the NC General Assembly passed a bill regarding advanced directives, which, among other things, authorized the creation of the MOST form for use across settings of care in North Carolina. This legislation codified the requirements that must be followed in using the MOST form, including when it will be used, what parties must sign the form, and how often it must be updated. In addition, the legislation set forth that the North Carolina Institute of Medicine (NCIOM) would study the process of end-of-life care in 2013.³ Specifically, the NCIOM was directed to:

“study issues related to the provision of end-of-life medical care in North Carolina. As part of the study, the Division of Health Service Regulation, Department of Health and Human Services, and the North Carolina Board of Medicine shall provide to the Institute non-identifying information regarding claims and complaints related to end-of-life medical treatment by health care providers that was contrary to the express wishes of either the patient or a person authorized by law to make treatment decisions on behalf of the patient. The Institute may review any other data related to end-of-life medical care and treatment the Institute determines is relevant.

The purpose of this study is to determine whether statutory changes related to advance directives and health care powers of attorney impact the type and quantity of end-of-life medical care provided to patients, whether the patient's or patient representative's express wishes regarding the provision of treatment at the end of life are being honored, and whether there is any change in the number of persons who request continued treatment at the end of their lives, but do not receive that treatment.”

The North Carolina Institute of Medicine took two approaches to study the use of the MOST form in North Carolina. First, we conducted a series of interviews with key informants to better understand how the MOST form was perceived and whether or not there were any formal complaints about the use of the MOST form. The second part of the study was a web-based survey of professionals involved in hospital discharge planning and ongoing care in a long-term care facility (e.g. nursing home, assisted living, or adult care home) to better understand their advanced care planning process generally and their use of the MOST form more specifically.

Methods:

Key informant interviews

The key informant survey included discussions (face to face or by telephone) or email dialogues with 20 stakeholders knowledgeable in end-of-life care and the delivery in NC. This included directors or representatives of the NC Medical Board, the NC Medical Society, the Office of Emergency Medical Services, the NC Bar Association, the NC Division on Aging, the NC Health Care Facilities Association, hospice agencies, physicians (geriatric/palliative care), attorneys, and ethicists. The interviews were framed around three issues: 1) perceptions around the use of MOST forms, DNR forms, and health care power of attorney, 2) claims or complaints that the MOST form was used contrary to the express wish of the patient regarding end-of-life care, and 3) changes in end-of-life care related to the 2007 statute.

Web-based survey

To gather more broad-based input on the use of the MOST form in clinical settings, we conducted a web-based survey of health professionals that are often involved in or supervising advanced care planning. This was done using Qualtrics, a commercial platform for administering web-based surveys.

Subjects

Representatives of four organizations agreed to send a link to a web-based survey: the NC Health Care Facilities Association (representing nursing facilities in North Carolina), the NC Association of Long Term Care Facilities (representing assisted living and adult care homes), the NC Assisted Living Association (representing assisted living facilities), and the NC Chapter of the American Case Management Association (representing hospital discharge planners). The lists were not provided directly to the NCIOM. We included professionals from all four of these organizations to gain a better understanding of the advance care planning across the spectrum of long-term care facilities and from the perspective of the hospital-based discharge planning professional.

Survey instrument

Staff from the NCIOM wrote the first draft of the survey instrument. The items were based on the findings of a qualitative study of experience with the MOST form by nursing home professionals.⁴ Additional items were added to assure that we addressed the questions raised by the North Carolina General Assembly in the authorizing statute. A draft survey was reviewed by representatives of the participating organizations and by several members of the North Carolina Partnership for Compassionate Care (a group of healthcare and community leaders dedicated to improving communication and education about end-of-life care through local and statewide initiatives). The survey was revised based on their feedback.

The survey included questions on the respondents' familiarity with the MOST form, the types of advanced care planning forms used by the institution, whether the MOST form is honored in the institution, and any barriers or concerns about use of the MOST form. The survey specifically asked respondents whether they had received complaints that treatment was provided in excess of the wishes expressed by the patient on the MOST form, and if so, whether care was less aggressive or more aggressive than wishes expressed on the MOST form. The survey sent to administrators of various ongoing care organizations was nearly identical. The survey of the hospital-based care managers differed somewhat to capture the perspective of a patient upon being discharged from the hospital, but included most of the same concepts regarding use of the MOST form, barriers and complaints with the MOST form, and tools used for advance care planning more generally.

Procedures:

A link to an online survey was sent to the four previously mentioned groups of professionals. If they followed the link and agreed to the study conditions on the consent, they were directed to a brief (<5 minutes) online survey. The survey was anonymous. After one week, the surveys were re-sent to encourage participation. The study was approved by the UNC Committee on Human Subject Research.

Results:

In the key informant interviews, stakeholder expressed varied perspectives on the uptake of MOST forms. Generally, stakeholders felt that other forms were more common, including Don Not Resuscitate (DNR) and 5 Wishes (a combined living will and healthcare power of attorney that address comfort care and spirituality). Several informants mentioned that use of the forms was dependent on the local physicians, most of whom were unfamiliar with the form or felt that it was too cumbersome. When the form was being used, it was often due to local champions who spread the use of the form in their communities. Several informants mentioned that the biggest problem with the MOST, DNR, and other forms is when a family wants to override the wishes of a critically ill loved one, creating conflict at the time of crisis. One respondent noted that at his/her facility they did not accept the most form as an 'order' but stated that admitting physicians generally reviewed the form and translated it into similar parameters available in the institution's computerized order entry system. Several informants commented that the law posed challenges because it requires the use of original signed forms (e.g., copies are not valid). This necessitated the patient to keep multiple originals at different locations. No stakeholder could provide data on how often the forms were being used in their organization or facility.

The authorizing legislation required that the Division of Health Service Regulations, Department of Health and Human Services, and the NC Medical Board provide the NCIOM with non-identifying information regarding claims and complaints related to end-of-life medical treatment by health care providers that was contrary to the express wishes of either the patient or a person authorized by law to make treatment decisions on behalf of the patient. The NCIOM staff interviewed the executive director of the NC Medical Board and the Director of Complaints for the NC Medical Board. The Board receives approximately 1300 complaints per year, but the complaints are not searchable in a way to conclusively examine the issues raised in the authorizing legislation. However, the Director of Complaints has worked for the medical board for 15 years, and reviews all complaints. She reported no increase in complaints regarding end-of-life care since the authorizing legislation. She had vague recollection of one complaint in which care exceeded that which was desired by the patient. She recalled that no action was taken on this complaint, and could not recall whether or not this was related to any type of advanced directive. The Executive Director and Director of Complaints reported that the Board gets infrequent complaints about end-of-life care in which family members report that their wishes are not met for end-of-life care when all family members are not in agreement or when there is a disagreement between physician and family members. The Director of the Division of Health Services Regulation and the Director of the Office of Emergency Medical Services reported that they had not received specific complaints about the MOST form. They did report that they maintained a record of the number of forms ordered and by which institutions, but they have no way of knowing how many are completed. In a personal communication with the director of the Office of Emergency Medical Services, she reported that 110,846 MOST forms were distributed in 2012-2013 (compared to 185,829 DNR forms). The number of forms given to patients/clients and the number of completed forms remain unknown. Though there is an option for keeping DNR forms, living wills, and healthcare power of attorney forms online in a registry for a small fee, there is no such registry option for MOST forms in NC.

The web-based survey yielded 242 responses. It is important to note that the number of potential respondents is unknown and no response rate is reported. The respondents were well distributed across the four organizations, representing responses from a spectrum of levels of care.

The general approach to advanced care planning and use of the MOST form is summarized in Table 1. Advanced care planning is required or strongly recommended by the majority of ongoing care organizations. DNR forms, living wills, and health care power of attorney forms are more common than the MOST form. The majority of respondents have heard of the MOST form, but the majority report that few residents or patients at their organization have a MOST form. The overwhelming majority of organizations honor a MOST form completed elsewhere. Respondents reported that they had heard few complaints with the MOST form, and the majority of complaints were in regard to difficulty in understanding the form. Three respondents reported that they had received complaints that more aggressive care was delivered in excess of care wishes expressed on the MOST form. No respondents reported care that was less aggressive than care wishes expressed on the MOST form, a finding consistent with previous research on the POLST form.² (Reported complaints are summarized in Table 2.)

Table 1: Advanced Care Planning and Use of MOST Form

	NCHCFA ¹	NCALA ²	NCLTCF ³	NCCM ⁴	Total
Respondents (N)	76	41	61	64	242
Use MOST (%)	64	28	30	47	45
Use 5 Wishes (%)	5	3	3	6	5
Use DNR (%)	99	100	90	100	97
Use HCPOA (%)	66	95	77	94	81
Use Living Will (%)	65	87	60	87	74
Advanced Care Planning required (%)	33	23	15	NA	24
Strongly recommended (%)	46	41	37	NA	42
Report >50% have plan (%)	73	55	34	23	47
Heard of MOST (%)	97	76	63	94	84
Report >50% have MOST (%)	17	6	6	4	9
26-50% Have MOST (%)	9	3	0	12	7
1-25% Have MOST (%)	54	76	51	48	55
None MOST (%)	13	14	43	36	27
Honors MOST (%)	80	100	91	86	88
Received complaints about MOST (N)	1	6	2	5	14

¹ NC Health Care Facilities Association

² NC Assisted Living Association

³ NC Association of Long-Term Care Facilities

⁴ NC Chapter of the American Case Management Association

Table 2: Problems with MOST FORM (reported providers in an organization)

	NCHCFA ¹	NCALA ²	NCLTCF ³	NCCM ⁴	Total
Form difficult to understand (N)	1	4	2	5	12
Scary to discuss end of life(N)	-	1	-	2	3
Form too comprehensive (N)	1	2	1	1	5
Form too specific/not comprehensive enough (N)	-	1	-	1	2
Care provided in excess of wishes on MOST form (N)	-	2	-	1	3
Care less aggressive than wishes on MOST form (N)	-	-	-	-	0
Other (N)	-	4	-	2	6

¹ NC Health Care Facilities Association

² NC Assisted Living Association

³ NC Association of Long-Term Care Facilities

⁴ NC Chapter of the American Case Management Association

The perceived barriers to the use of the MOST form are summarized in Table 3. The common concerns included: the form takes too much time, it is hard to match treatment goals to the form, the review requirements are cumbersome, the form is difficult to understand, the form is redundant of other paperwork, the form might be lost in transfer, and the form might not be accepted upon transfer to other agencies. Closer look at the response by organization type reveal some possible additional information. For example, time requirement is a much bigger problem for hospital-based care managers than at ongoing care organizations. This may reflect the short duration of relationship with patients and families in an acute care facility, the high acuity of medical need, and the short duration of stays. Administrators at ongoing care facilities may feel like admission to a long-term care facility is too late to start the discussion of advanced care planning, but the feedback from care-managers may reflect the unique challenge of that environment, indicating the need to start advanced care planning before acute illness or decompensation of chronic disease. Concern that a form might be lost or not honored seems to be a bigger problem for ongoing care organizations than for hospitals.

Table 3: Identified Barriers (reported by providers in an organization)

	NCHCFA ¹	NCALA ²	NCLTCF ³	NCCM ⁴	Total
Takes too much time (%)	34	22	34	68	41
Hard to match goals to treatment (%)	13	30	29	42	28
Review requirements (%)	26	22	17	26	23
Difficult for patients and families to understand (%)	33	48	40	32	37
Redundant paperwork (%)	20	37	20	14	21
Concern form would be lost during transfer (%)	38	37	20	8	25
Concern form would not be honored (%)	16	33	29	14	22
Other (%)	18	4	9	26	16

¹ NC Health Care Facilities Association

² NC Assisted Living Association

³ NC Association of Long-Term Care Facilities

⁴ NC Chapter of the American Case Management Association

Discussion:

This study of MOST implementation should serve two purposes. First, it provides assurance that the authorizing statute requiring this study did not lead to large numbers of complaints about ongoing care. There are no complaints that we could identify that the MOST form or its authorizing legislation resulted in treatment being withheld at the end of life or treatment being given in excess of that which was desired by the patient or his/her family. Likewise, concerns about matching end-of-life treatment with wishes, and navigating family discord at the end of life were not problems created by the MOST form nor will they be entirely solved by the MOST form. Unfortunately, there was no baseline by which to examine a change in these problems over time.

The second purpose of this study is to help providers of medical and long-term care in NC to better understand the role, application, and limitations of the MOST form. The study points to a number of possible program and policy changes that may improve the use and utility of the MOST form. Similar barriers and challenges were identified after implementation of the POLST form in California.⁵ Universal acceptance of a MOST form upon transfer would be an important solution to one perceived barrier. Also, efforts to simplify the form and processes may be important solutions to improving utilization of the form. For example, if a copy of the form could be honored, this would safeguard against losing the form. Another option would be the creation of an electronic MOST form with accessibility between electronic health systems. In Oregon, completed POLST (Physician Orders for Life Sustaining Treatment) health care providers who complete a POLST form are required by law to enter the POLST form elements into a registry which represents a valid order and is available 24 hours a day to emergency personnel and hospitals unless a patient opts out.⁶ This is quite different from the system in North Carolina, where a MOST form can be sent to the Secretary of State by a patient, but the documents housed in this registry do not represent valid orders as only the original documents can be used as valid orders.

Perhaps the most important finding from this study is that advanced care planning is incorporated at high rates at hospital discharge and admission to ongoing care facilities, at least those represented by respondents to this study. Patients and providers at these facilities use a variety of forms, incorporate advanced care planning into discharge and admission processes at high rates, and report that high proportions of their clients have advanced care plans. Forms, processes and regulations that facilitate discussion between family members, clients, and care providers will help to maximize the chance that care preferences are honored at the end-of-life. The forms and processes that encourage clients to consider a broader range of issues and options are likely to lead to care that is more closely aligned with their wishes.

References

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