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## End-of-Life Conversations and Hospice Placement: Association with Less Aggressive Care Desired in the Nursing Home

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### ABSTRACT

Education about end-of-life care and treatment options, communication between family and health care providers, and having advance directives and medical orders in place are important for older adults with chronic, progressive decline and end-stage disease who spend their last days in the nursing home. This study used retrospective data (6 months before death) of long-stay nursing home decedents ( $N = 300$ ) taken from electronic health records to capture the end-of-life experience. Findings showed for almost all decedents, Do Not Resuscitate and Do Not Intubate orders were in place, and just over one-half had Do Not Hospitalize and No Artificial Feeding orders in place. A small proportion had No Artificial Hydration or No Antibiotic orders in place. Overall, there was congruence between documented medical orders and treatment received. Findings showed that use of hospice and discussions about particular life-sustaining treatments each had significant associations with having less aggressive medical orders in place. These results can inform best practice development to promote high quality, person-directed, end-of-life care for nursing home residents.

### KEYWORDS

Health care; hospice;  
long-term care; palliative  
care

### Introduction

Improving quality of life for people with advanced serious illness may be considered one of the most serious challenges of today's health care system. One setting where this challenge is most evident is in the nursing home, as residents often experience chronic, progressive decline in end-stage disease including dementia. Additionally, this is often compounded by comorbidities and acute events such as pneumonia and influenza. In this setting, conversations about end-of-life (EOL) health care choices regarding treatment goals, advance care planning, and preferences about life sustaining treatments (LSTs) are critically important. Having health care "choices" implies having more than one option, and these options can only be made known through

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conversation. Importantly, not making a decision, even when not done intentionally, can become a choice for treatment by default.

Research documents poor EOL care in U.S. nursing homes (Oliver, Porock, & Zweig, 2004) with family perception of quality of care in this setting ranking lowest regarding last place of care for relatives (Teno et al., 2004). Dying in nursing homes is often associated with aggressive treatment such as hospitalization, unmet needs for pain and symptom amelioration, physician communication, and emotional support (Gozalo et al., 2011; Oliver et al., 2004; Mitchell et al., 2009). Hospitalization for residents with advanced chronic impairment has limited clinical benefit, and is costly in terms of both personal and financial burden. Nonbeneficial treatments at the EOL are widespread in hospital care (Cardona-Morrell et al., 2016). EOL care in the United States makes up a disproportionate amount of health care expenditures, yet it does not necessarily reflect patients' values and preferences (Riley & Lubitz, 2010). EOL family conferences are key for excellent EOL care (Lautrette, Ciroidi, Ksibi, & Azoulay, 2006) and are associated with less aggressive care near death (Molloy et al., 2000; Wright et al., 2008). In addition to having critical conversations and guiding decision-making, the integration of these decisions must become part of a nursing home resident's treatment plan.

Many states are using concise, recognizable forms to discuss and document LST decisions and translate them into medical orders (Biola, Sloane, Williams, Daaleman, & Zimmerman, 2010). The Physician Orders for Life-Sustaining Treatment (POLST) paradigm, initiated in 1991 and currently used in 22 states in some format (National POLST Paradigm, 2016), provides the methodology and tools for health care providers to document treatment preferences of patients with advanced disease and frailty as portable, actionable medical orders, not conditional on a loss of capacity to make one's medical decisions. The specific name and content of this paradigm varies by state. In New York State, the Medical Orders for Life Sustaining Treatment (MOLST; Bomba & Karmel, 2015; Bomba & Orem, 2015; Karmel & Lispo, 2011) paradigm invites discussion and clarification of goals of care, to decide whether or not a person wants treatments provided to attempt to extend life, to receive limited medical intervention, or to let nature take its course allowing death to occur naturally. No matter what is chosen, comfort measures are always provided as defined on the NY MOLST. Treatments that can be addressed on the MOLST include resuscitation, intubation, hospitalization, artificial feeding, artificial hydration, and the use of antibiotics. As stated above, if medical orders that state treatment preference are not in place, acute care default treatment procedures according to state law take precedence. Medical orders provide a way to ensure person-directed care, providing life-sustaining treatments residents want to receive, and not providing life-sustaining treatment they want to avoid (Bomba, 2011; Bomba, Kemp, & Black, 2012; Teno et al., 2011).

With education by health care professionals about burdens and benefits of LSTs and having current, evidence-based information, informed decisions including decisions about medical orders can be made and documented. For example, families may consider feeding tube insertion for relatives with advanced dementia who are no longer eating because it seems this will prolong life and prevent aspiration pneumonia. Yet, available evidence shows that those outcomes have not been found for persons with advanced dementia (Compassion and Support, 2009; Resnick, Schuur, Heineman, Stone, & Weissman, 2009). Use of a feeding tube in this situation conflicts with informed, shared medical decision-making, current medical evidence, and support of the standard of a restraint free environment (insertion of a feeding tube may require physical/pharmacologic restraints). Prior research has shown that family members of nursing home residents with dementia who have informed discussions about potential life sustaining treatments have higher care satisfaction, and are more likely to have medical orders in place that limit treatment for resuscitation, intubation, hospitalization, and feeding tube placement (Reinhardt, Chichin, Posner, & Kassabian, 2014). Also, having a greater frequency of discussion over time regarding these LSTs in the nursing home is associated with greater care satisfaction (Reinhardt, Boerner, & Downes, 2015).

Barriers to good EOL care include the difficult nature of conversations, inadequate staff training, and reimbursement favoring skilled over personal care (Leahman, 2004; Meier, Lim, & Carlson, 2010). Having conversations only at a crisis point, such as when an elder's health condition worsens, indicates inadequate advance care planning (Bomba, Morrissey, & Leven, 2011). While some elders do complete directives and medical orders, especially with a significant health status change (Hirschman, Abbott, Hanlon, Bettger, & Naylor, 2012), nursing home residence itself is a risk factor for wishes not heeded (Biola et al., 2010). Ongoing communication with health care providers is necessary for families and residents to have time to consider care options and to understand prognosis. When EOL care discussions are poorly managed, remaining life quality is jeopardized (Larson & Tobin, 2002). Although these conversations can be challenging, researchers have found evidence that increased use of advance directives and medical orders, and reduced use of aggressive treatments in nursing homes were not likely to have a negative effect on satisfaction or morbidity (Meyers, Moore, McGrory, Sparr, & Ahern, 2004; Molloy et al., 2000; Schmidt, Hickman, Tolle, & Brooks, 2004) and actually lowered cost (Nicholas, Langa, Iwashyna, & Weir, 2011; Zhang et al., 2009), and improved survival, perhaps by better symptom management (Temel et al., 2010). Higher cost has also been associated with lower quality of death (Zhang et al., 2009).

In addition to having informed EOL conversations, research is needed to determine what other factors are associated with decisions for less aggressive

care for nursing home residents with advanced chronic comorbidities. For example, having hospice care concurrent with nursing home care was associated with less aggressive care receipt at the EOL (Miller, Lima, & Mitchell, 2012). Due to prognostic difficulties with advanced chronic disease, hospice care is not always possible, thus we may look at cognitive and functional status variables indicating poor functioning and variables such as weight loss as potential indicators of desire for less aggressive treatment at the EOL. Also, characteristics of residents may be potential predictors including race/ethnicity. Barriers exist to provision of quality care for minority elders who were less likely to change the aggressive care default at the EOL (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009) that may then result in poorer quality of death (Smith, Davis, & Krakauer, 2007). The aim of this study was to identify specific care indicators that are significantly associated with having each of the six medical orders on the MOLST in place. Retrospective data (6 months before death) of long-stay nursing home decedents ( $N = 300$ ) from electronic health record were utilized.

## Methodology

### Research questions

Because less aggressive treatment near death has been associated with better EOL care and higher care satisfaction for nursing home residents with advanced chronic comorbidities (Molloy et al., 2000; Temel et al., 2010), the aim was to identify the predictors of each of the six medical orders written using NY MOLST that indicated avoidance of aggressive treatment: (a) Do Not Resuscitate (DNR)/Accept Natural Death, (b) Do Not Intubate (DNI), (c) Do Not Hospitalize (DNH), (d) Do Not Use Artificial Hydration, (e) Do Not Use Artificial Feeding, and (f) Do Not Use Antibiotics. It was hypothesized that poorer cognitive and functional status for decedents, having a discussion (between any health care provider and family member) about the particular life sustaining treatment, family attendance at a care plan meeting (another indicator of conversations), and use of hospice would be significantly associated with greater likelihood of having each of the six particular, less aggressive medical orders in place. Descriptive information will also be provided regarding the congruence between having medical orders in place for less aggressive care, and actual treatment received (for example, if a decedent had a DNH, was she hospitalized?).

### Sample and procedures

A secondary analysis was conducted using retrospective medical record data (6 months prior to death) of long-stay nursing home decedents to capture

actual EOL experience. The sample included all long-stay decedents over a 1-year period (beginning August 2013) from a large long-term care facility in New York State that utilizes the MOLST paradigm. This study was approved by the Institutional Review Board in this facility.

### **Measures**

All data items for this project were pulled electronically into an analytic data set for the study sample of decedents. Items (described below) were taken from the Minimum Data Set 3.0 (MDS 3.0; Centers for Medicare and Medicaid Services, 2016), and supplemented with additional sources of information that also exist electronically (scanned MOLST forms, clinical notes from physicians, nurses, social workers). The look back period for decedents was 6 months prior to date of death. Data items were taken from the last MDS that was conducted for the decedents. The MDS is completed quarterly. The MDS 3.0 is a standardized tool to provide information for conducting comprehensive assessment of nursing home elders including physical (e.g., diagnoses), functional (activities of daily life), and psychosocial (preferences, interests). It informs treatment planning, provides a payment mechanism, and also provides data used to monitor system-wide quality.

### **Resident characteristics**

For descriptive purposes, the following data items were examined: age, sex (female = 1; male = 0), race/ethnicity (dummy codes were computed as follows with White, non-Latino as the reference group—Black, non-Latino = 1; else = 0; and Latino = 1; else = 0), diagnoses, length of time living in the facility, length of time on hospice, and site of death (nursing home; hospital).

### **Predictor variables**

There are five categories of predictor variables. The first variable is Clinical Resident Status: *dementia diagnosis* (yes = 1;  $n = 0$ ); *functional status*: 0–18; high = high disability (Section G; MDS 3.0); *weight loss* ( $y = 1$ ;  $n = 0$ ), and *cognitive status score* for self-reported status (Brief Instrument of Mental Status [BIMS] score; Chodosh et al., 2008) or staff assessment (Cognitive Performance Scale [CPS] score; Morris et al., 1994). BIMS and CPS scores were recoded (Chodosh et al., 2008; van der Steen et al., 2006) to 1 = mild impairment (BIMS = 13–15; CPS = 0–2); 2 = moderate impairment (BIMS = 8–12; CPS = 3), and 3 = moderate to very severe impairment (BIMS = 0–7; CPS = 4–6) to create one variable that could be used for the entire sample. The second category is Communication—Discussions between Clinicians and Families: documented discussion between clinician and family member (each scored yes = 1; no = 0) about six treatments including Resuscitation, Intubation, Hospitalization, Feeding Tube, Hydration, and Antibiotics. Also,

provider type and relationship type of family member were coded for each discussion. The third variable is Family Attendance at Care Plan Meeting ( $y = 1$ ;  $n = 0$ ). The fourth category is Discuss Resident-Centered Goals for Care with Family: from clinical notes documented—e.g., discussed treatment guidelines (e.g., limited medical interventions), hospice care; palliative care ( $y = 1$ ;  $n = 0$ ). The final variable is Hospice placement ( $y = 1$ ;  $n = 0$ ).

### **Outcome variables**

The first group of outcome variables are Medical Orders in Place: The decision to “not” conduct a particular life sustaining treatment was coded yes (1) and any other decision (do the treatment, trial, and no decision made) was coded 0. The six medical order outcome variables were: Do Not Resuscitate (DNR), Do Not Hospitalize (DNH), Do Not Intubate (DNI), No Artificial Hydration, No Artificial Feeding, No Antibiotic Use ( $y = 1$ ;  $n = 0$  for each). While this information was taken from scanned MOLST forms, some additional electronically signed physician orders regarding life sustaining treatments that had not yet been transferred to updated MOLST forms were also included in the medical record, and thus, these data were also included in analyses. In order to look at congruence, the second group of outcome variables—interventions provided (coded yes = 1; no = 0)—were also included (Resuscitation, Intubation, Hospitalization, Artificial Hydration, Feeding Tube, and Antibiotics).

### **Data analysis**

Data were analyzed with IBM SPSS Statistics for Windows, Version 20 (IBM Corp., Armonk, NY, USA). Descriptive data are presented for all study variables. Concordance between each specific medical order in place and related interventions was also reported (e.g., was a resident with a DNH in place hospitalized?). Bivariate statistical analyses were conducted to examine the associations among variables. Each set of predictor variables (clinical status variables, communication variables, hospice placement) was examined for associations with each of the six medical order outcome variables. Multicollinearity was also examined.

Study hypotheses were examined by testing the relationships between predictor variables and outcome measures with a series of multiple logistic regression models. Predictor variables included both continuous measured and nominal variables. The number of predictor variables for each equation was limited by the convention of having at least 10 cases per variable for the smallest of the proportions of negative or positive cases in the sample (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996). This rule affected the inclusion of DNR (only 10% had no DNR) and No Antibiotics (only 10% had a directive for No Antibiotics) outcomes. That is, the regression analyses for each of these outcomes could be based on only three predictor

variables. The predictor variables that had significant correlations with outcome variables ( $p < .05$ ) were used in regression analyses. For DNR and No Antibiotics, variables with the highest significant correlations ( $p < .05$ ) were used as predictor variables. Nonsignificant associations with  $p < .10$  are identified in Tables presenting correlation and regression analysis results, but not specifically discussed in the text.

## Results

### Sample

The sample ( $N = 300$ ) was primarily made up of female decedents (68%); with a mean age of 87 and varied race/ethnicity with 47% White, non-Latino; 31% Black, non-Latino; and 21% Latino. The majority had a dementia diagnosis (82%) and moderately severe to severely impaired cognitive status (mean score = 2.6; range = 1–3). The mean score (27;  $SD = 4$ ) for functional disability was high (range = 2–33), and participants had a mean of 7 ( $SD = 3$ ) health conditions (not counting dementia). Just over one-quarter (28%) experienced significant weight loss prior to death. Cardiovascular diseases represented the most frequent health conditions in the sample including hypertension (68%), coronary artery disease (36%), and heart failure (26%). Just over one-quarter had arthritis (28%) or diabetes (27%), and 15% had a cancer diagnosis. Over one-half of decedents (62%) were on hospice at the time of their death, with a median length of stay on hospice of 33 days. One-half of those on hospice were on for 1 month or less, with 30% on hospice from 2 to 6 months, and 20% on hospice for more than 6 months (data on length of stay was available for 139 of those on hospice). Decedents had lived in the nursing home for a median of 2.8 years. Almost all deaths occurred in the nursing home (92%) with a small proportion occurring in the hospital (8%).

### Descriptive information

Treatment preferences are summarized in Table 1 including the proportion of decedents who had particular medical orders in place. There are multiple

**Table 1.** Summary of treatment preferences.

	Frequency (%)			
	In place	Trial	DO	Not in place
Do-Not-Resuscitate (DNR)	271 (90%)	NA	12 (4%)	17 (6%)
Do-Not-Intubate (DNI)	218 (73%)	3 (1%)	6 (2%)	73 (24%)
Do Not Hospitalize (DNH)	160 (53%)	NA	24 (8%)	116 (39%)
No Artificial Hydration	47 (16%)	33 (11%)	11 (4%)	209 (69%)
No Artificial Feeding	159 (53%)	2 (1%)	7 (2%)	132 (44%)
No Antibiotic Use	28 (10%)	11 (4%)	49 (17%)	197 (69%)

Note.  $N = 300$  for all except antibiotic use  $N = 285$ . "DO" indicates, Do resuscitate, intubate, hospitalize, use artificial hydration or feeding, or antibiotics.



choices that can be made. For example, findings showed that for those with an order in place regarding artificial hydration, the choices are No Artificial Hydration (“In Place”), a Trial of Artificial Hydration, or “Do” Artificial Hydration; while others had no documented decision in place regarding Artificial Hydration (“Not in Place”). Also, completion of a MOLST form was not synonymous with having care preferences documented for each of the six potential treatment interventions. Some of the treatments may have been discussed, yet no decision was made to date, and some of the treatments may not have been discussed.

Almost all decedents (90%) had a Do Not Resuscitate (DNR) order. The majority of decedents (73%) also had a Do Not Intubate (DNI) order. The next highest proportions for a “do not” order were for Do Not Hospitalize (54%) and No Artificial Feeding (53%). There were smaller proportions for No Artificial Hydration (16%) and No Antibiotic Use (10%) orders. Also, the proportion with no medical orders in place was highest for the latter two decisions. There were a few cases counted in the “do not” percentages above that were taken from electronically signed physician orders. This ranged from 14 cases for Do Not Hospitalize to one case for Do Not Resuscitate. Again, it is noted that for logistic regression analyses, all six types of medical order outcome variables were scored in the direction “Do Not” order = 1; else = 0. Thus, use of or a trial of artificial feeding, for example, would each be coded (0).

Descriptive information regarding discussions that occurred in the 6 months prior to date of passing between family members and health care providers is provided in [Tables 2](#) and [3](#). Less than one-quarter of regular care

**Table 2.** Care discussions.

Discussions between family members & providers (Yes)	Frequency	Percentage
Care discussions		
Family at care plan meeting	62	21
Discuss goals of care	199	66
<i>N</i> = 300		
“Goals of care” discussion participants		
Provider type		
MD	150	75.4
NP	34	17.1
SW	27	13.6
Nurse	11	5.5
Hospice	2	1
>1 professional	72	36.2
Relation to resident		
Child	143	71.8
Family	55	27.6
Niece/nephew	28	14.1
Spouse	18	9
Sibling	15	7.5
Resident (self)	9	4.5
Court appointed HCP	10	5
<i>N</i> = 199		

**Table 3.** Treatment discussions.

Discussions between family members & providers (Yes)		
	Frequency	Percentage
Resuscitation	75	25
Intubation	61	20
Hospitalization	118	39
Artificial Hydration	78	26
Artificial Feeding	68	23
Antibiotic Use	45	15
<i>N</i> = 300		

plan meetings included family members. However, resident-centered goals for care were discussed in 66% of cases. Table 2 also provides information regarding who had the discussions about resident-centered goals for care. The majority of health care providers that conducted care discussions were physicians (75%), and the majority of family members were adult children of the decedent (72%). Table 3 provides information on the proportion of discussions about each of the six types of life sustaining treatments. The highest proportion of the sample having a discussion within the last 6 months before death about a treatment decision occurred for hospitalization (39%), with about one-quarter having had discussions about artificial hydration (26%), resuscitation (25%), and artificial feeding (23%). There were fewer discussions about intubation (20%) or antibiotic use (15%). Table 4 provides detail on the dyads having the discussions about the six types of life sustaining treatments. Results showed that across all types of discussions, the majority of health care providers having discussions were physicians (ranging from 50 to 65%) with the next largest category being more than one health care provider speaking together to a family member (ranging from 7 to 33%). Regarding family members, most discussions about treatments were conducted with adult children (ranging from 34 to 45%), with the next largest group being multiple family members (ranging from 12 to 28%).

Regarding treatments in the 6 months prior to death, the highest proportion was for antibiotic use (68%) followed by artificial hydration (44%) and hospitalization (32%). Resuscitation (1%), intubation (1%), and artificial feeding (5%) were almost nonexistent.

### ***Congruence between medical orders and treatment interventions***

Results showed that there was no incongruence regarding medical orders and treatment for resuscitation, intubation, or artificial feeding. Regarding hospitalization, of the 160 elders with a DNH order, six (4%) of them were indeed hospitalized. For these six persons, clinical notes showed that the hospitalizations were due to conditions such as stroke or fracture. Hospitalization was appropriate and consistent with the MOLST order “Do not send to the

**Table 4.** Treatment discussion participants.

	DNR (N = 75) (%)	DNI (N = 61) (%)	DNH (N = 118) (%)	No Art. Hydration (N = 78) (%)	No Feeding- Tube (N = 68) (%)	No Antibiotics (N = 45) (%)
Provider type						
MD	50	54	58	65	53	64
NP	7	10	8	10	12	11
Nurse	3	2	8	7	3	9
Social worker	7	6	3	1	9	7
Hospice	0	0	1	1	0	2
>1 professional	33	28	22	15	23	7
Relation to resident						
Child	43	34	45	37	40	36
Family	15	28	19	12	16	22
Niece/nephew	8	7	9	13	7	11
Spouse	11	8	6	10	10	7
Sibling	3	2	4	8	3	9
Resident (self)	7	3	8	0	4	0
Friend	7	8	2	4	4	4
Other	5	8	5	12	12	9
Court appt. HCP	1	2	2	3	3	2

hospital unless pain or severe symptoms cannot be otherwise controlled.” These decisions were discussed with family members at the time of hospitalization to affirm the decision to hospitalize was consistent with the resident’s preferences. Also, 26 (16%) elders had both a DNH order and they were hospitalized in the last 6 months of life; however, the medical order was put in place *after* the experience with hospitalization. Regarding artificial hydration, of the 47 elders with an order for No Artificial Hydration, three (6%) did receive artificial hydration, but this was with family agreement. Also, nine (19%) elders had both a No Artificial Hydration order put in place and received artificial hydration within the last 6 months of their lives. However, the treatment came before the order was put in place. Regarding antibiotics, eight of the 17 elders (47%) with a No Antibiotics order in place received antibiotics, but again, the treatment preceded the date of the No Antibiotics order.

### ***Bivariate correlations and regression analyses***

The correlations between the clinical status and communication variables with each of the six medical order outcome variables are reported in Table 5. Overall, the communication variables had more significant associations with the medical order outcome variables than the clinical status variables. Almost all of the communication variables were associated significantly with each of the medical order variables with the exception of family at the care plan meeting. Having discussions relevant to the medical order in question was significantly associated with “Do Not” for each medical order with the exception of Do Not Resuscitate. For example, having a discussion about intubation was associated with having a “No Intubation” order. Having

**Table 5.** Pearson correlations for medical orders.

	Do Not Resuscitate	Do Not Intubate	Do Not Hospitalize	No Artificial Hydration	No Feeding Tube	No Antibiotics
<b>Clinical status</b>						
Age	.24***	-.01	.12*	.06	.08	.03
Sex (female)	.04	-.04	.05	.06	-.02	-.02
Black (yes)	-.05	.13*	.02	.05	.08	.01
Latino (yes)	-.05	.11*	-.05	-.11 <sup>+</sup>	-.04	-.12 <sup>+</sup>
Dementia (yes)	.14*	.02	.08	.09	.05	.02
Cognitive status	.19***	.06	.23***	.00	.07	-.01
Disability	.02	.10 <sup>+</sup>	.09	.08	.06	-.01
# medical conditions	-.13*	.09	-.03	-.02	.08	.02
Weight loss (yes)	.10 <sup>+</sup>	.13*	.08	.13*	.11 <sup>+</sup>	-.04
<b>Communication</b>						
AD discussion (yes)	.01	.16**	.23***	.23***	.19***	.18**
Family at CPM (yes)	.00	.00	-.12*	-.02	.00	.04
Care goals disc. (yes)	.10 <sup>+</sup>	.10 <sup>+</sup>	.24***	.07	.18**	.13*
Hospice (yes)	.29***	.19***	.22***	.17**	.29***	.14*

Note. <sup>+</sup> $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Medical order variables are scored "1" for "Do Not" decisions and "0" for other decisions/no decision.  $N = 300$ .

a Discussion About Care Goals was significantly associated with Do Not Hospitalize, No Tube Feeding, and No Antibiotics orders. Being on Hospice was significantly associated with having each of the six medical orders in place. Alternately, few of the clinical status variables had significant associations with any of the six medical order outcome variables. Age was associated with Do Not Resuscitate, and cognitive status was associated with Do Not Hospitalize orders. Also, race/ethnicity was associated with Do Not Intubate orders.

The multiple logistic regression results for medical order outcome variables are presented in Tables 6 and 7. For each of these outcome variables, yes = 1 and no = 0. For the Do Not Resuscitate (DNR) outcome, age, being on hospice, and cognitive status were entered as predictor variables. The first two of these variables emerged as significant independent predictors of having a DNR order. For each year of advancing age, there was a 7% increased likelihood of having a DNR order in place. Compared to those who are not on hospice, those who were on hospice were 10 times more likely to have a DNR order.

There were seven variables tested as predictors of having a Do Not Intubate order (DNI). Results showed that Blacks and Latinos were each about three times more likely to have a DNI order in place compared to study participants not in each group. Those who were on Hospice were twice as likely as those not on Hospice to have a DNI order in place.

Six variables were tested as predictors of having a Do Not Hospitalize (DNH) order in place. Results showed that those with poorer cognitive status were about twice as likely to have a DNH order than those with better cognitive status. Also, families who had a discussion about hospitalization and a discussion about goals of care were each twice as likely to have a DNH order,

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**Table 6.** Multiple logistic regression of predictors on medical orders.

	Do Not Resuscitate		Do Not Intubate		Do Not Hospitalize	
	OR	95% CI	OR	95% CI	OR	95% CI
Clinical status						
Age	1.07**	[1.02, 1.12]			1.03 <sup>+</sup>	[.99, 1.06]
Sex (Female)						
Black (Yes)			2.76**	[1.40, 5.42]		
Latino (Yes)			3.01**	[1.42, 6.74]		
Dementia (Yes)						
Cognitive status	1.24	[0.73, 2.13]			1.72**	[1.18, 2.50]
Disability			1.02	[0.95, 1.09]		
# medical conditions						
Weight loss			1.6	[0.81, 3.17]		
Communication						
AD discussion (Yes)			2.16 <sup>+</sup>	[0.92, 5.06]	2.23**	[1.28, 3.90]
Family at CPM					.37**	[0.20, 0.69]
Care goal discussion (Yes)			1.1	[0.60, 2.01]	1.96*	[1.10, 3.50]
Hospice (Yes)	10.41***	[2.99, 36.31]	2.27**	[1.26, 4.09]	1.87*	[1.10, 3.16]
Nagelkerke $R^2$	.27		.15		.23	
Chi-square	39.12***		32.03***		54.83***	
	$N = 296$		$N = 288$		$N = 300$	

Note. <sup>+</sup> $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

and decedents who had been on hospice were twice as likely to have a DNH order in place. Those with a family member at a care plan meeting were about one-third as likely to have a DNH order in place.

Four variables were tested as predictors of having a No Artificial Hydration order, and two of these emerged as significant predictors. Those who had a discussion about artificial hydration were almost three times as likely to have

**Table 7.** Multiple logistic regression of predictors on medical orders.

	No Artificial Hydration		No Feeding Tube		No Antibiotics	
	OR	95% CI	OR	95% CI	OR	95% CI
Clinical status						
Age						
Sex (Female)						
Black (Yes)						
Latino (Yes)	.41 <sup>+</sup>	[0.15, 1.11]				
Dementia (Yes)						
Cognitive status						
Disability						
# medical conditions						
Weight loss	1.64	[0.82, 3.28]	1.01	[0.57, 1.80]		
Communication						
AD discussion (Yes)	2.97**	[1.51, 5.85]	2.23*	[1.18, 4.23]	2.67*	[1.08, 6.64]
Family at CPM						
Care goal discussion (Yes)			1.31	[0.75, 2.28]	1.95	[0.61, 6.23]
Hospice (Yes)	2.10*	[1.00, 4.39]	3.04***	[1.81, 5.11]	1.96	[0.73, 5.31]
Nagelkerke $R^2$	.14		.15		.09	
Chi-square	23.85***		35.13***		12.58**	
	$N = 288$		$N = 288$		$N = 281$	

Note. <sup>+</sup> $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

this order in place compared to those who did not have a discussion. Those on hospice were twice as likely to have a No Artificial Hydration order in place compared to those who were not on hospice.

Four variables were also tested as predictors of having a No Artificial Feeding order, and the same two variables were significant in predicting this outcome as in the prior outcome. Those who had a discussion about artificial feeding were twice as likely to have the order in place, and those on hospice were three times as likely to have this order in place.

Finally, three variables were tested as predictors of having a No Antibiotics order. Those who had a discussion about a No Antibiotics order were almost three times more likely to have the order in place compared to those who did not have this discussion.

Overall, predictor variables that were significantly associated with less aggressive medical order outcomes included being on hospice and having had discussions about particular life sustaining treatments.

## Discussion

The goal of this study was to understand the current status of EOL care in the nursing home as documented in existing medical records, and to set the stage for developing more effective processes, mechanisms, and reporting tools aimed at improving clinical care in this important area. Descriptive information for medical orders in place showed that for almost all decedents, DNR and DNI orders were in place, and just over one-half had DNH and No Feeding Tube orders also in place. Only a small proportion had No Artificial Hydration or No Antibiotic orders in place on the MOLST. In comparison, a study of current nursing home residents in California where the POLST form is used, less than half (47%) had a DNR order in place, but a similar proportion (52%) had limits on artificially administered nutrition (Rahman, Bressette, Gassoumis, & Enguidanos, 2016). The content of POLST forms can differ by state. The California POLST has a category for medical intervention, but it does not have separate categories that match all of those on the New York MOLST form. Current study findings showed that there was variability in the number of specific MOLST decisions that were made and documented. The vast majority of medical orders that indicated a preference to avoid life-sustaining treatment were documented on the NY MOLST form, but there were also some additional signed physician orders in the medical records as reported above. This finding stresses the necessity of reviewing procedures around the proper use of MOLST paradigm including updates and review of orders over time. Review of existing medical orders is important, not only to document decisions that have been made, but to also review and potentially edit existing orders. For example, upon review of current medical orders, there are some preliminary research findings of discordance

between existing Wisconsin Physician Orders for Life Sustaining Treatment (POLST) orders and current preferences (Hickman, Hammes, Torke, Sudore, & Sachs, 2017).

It is recognized that having conversations and making decisions takes time. However, when no decision is made to withhold a particular life-sustaining treatment, full treatment is implied and received. As per the New York State Department of Health instructions, if a patient or decision-maker can reach a decision on one or more treatment options, but not others, the physician may cross out the portion of the form with the treatment option(s) for which there is no decision and write “Decision Deferred” next to those treatment option (s). If the patient or decision-maker reaches a decision concerning that treatment option(s) at a later time, a new form must be completed and signed by a physician, indicating all of the patient’s or decision maker’s decisions” (New York State Department of Health, 2010a, 2010b).

In terms of documented discussions regarding each of the specific life-sustaining treatments in the last 6 months of life, hospitalization was most often discussed, with all other treatments discussed in about a quarter of cases, while antibiotic use was rarely discussed. Most discussions were between physicians and adult children. Regarding communication, not quite a quarter of family members were documented as present in a care plan meeting. It is not known whether or not family members were reached for these invitations and they declined, or if they were unable to be present at the specific time of the meeting. A higher proportion of discussions with family were reported concerning care goals (e.g., longevity, functionality, comfort measures only) as well as discussion of a palliative care plan and/or hospice to support the resident decisions and MOLST orders. Overall, these findings showed that the number of discussions about life-sustaining treatments were not very high in the 6 months before death, and when they occurred, they were largely between physicians and family members. Physicians can discuss an elder’s condition, including prognosis, with family members, as outlined in the eight-step MOLST protocol and physicians complete the MOLST after decisions are made. However, all members of the interdisciplinary team interact with the elders and their families and can assist with these important conversations that may be ongoing until a decision is actually made and documented.

Regarding treatments received in the last 6 months of life, the low occurrence of resuscitation, intubation, and artificial feeding supported the use of less aggressive treatment that is recommended for this population (Wright et al., 2008). The highest treatment usage was for antibiotics, followed by artificial hydration, and hospitalization.

The congruence between documented MOLST orders and actual treatment received for resuscitation, intubation, and artificial feeding showed good communication. Regarding findings for congruence for hospitalization, an important comparison can be made with a recent study where death records

of 58,000 people who died of natural causes in 2010 and 2011 in Oregon were analyzed (Fromme, Zive, Schmidt, Cook, & Tolle, 2014). Nearly 31% of the people who died had POLST forms entered in Oregon's POLST Registry. Oregon has mandatory submission of OR POLST forms. The location of death was compared with the treatment requested. Results showed that 6.4% of people with POLST forms who selected "comfort measures only" died in the hospital, while 34.2% of people without POLST forms in the registry died in the hospital (Fromme et al., 2014). Regarding hospitalization, of the 160 decedents in this study with a DNH order, a very small percentage were hospitalized and hospitalization was appropriately indicated by their health condition.

In the last 6 months of life, some orders to avoid specific life-sustaining treatment were put in place *after* treatment occurred including hospitalization, artificial hydration, and antibiotics. Thus, MOLST orders may have been updated over time and decisions to withhold life-sustaining treatment may change during times acute care episodes. The value of MOLST comes from planning in advance of acute decompensation and/or symptom exacerbation, as it is more advantageous and can give family members more time to discuss and consider treatment wishes. When decisions are made during times of a medical crisis, there is less time to be sure patients and families are guided in conceptualizing and expressing their values and goals (Farber & Farber, 2014). Furthermore, the focus may be on interventions, rather than on resident values, beliefs, and goals for care. Prior research shows that family members faced with medical decision-making for relatives with advanced dementia at the end-of-life find that decisions to not treat are more difficult than decisions to treat (Rabins, Hicks, & Black, 2011). Thoughtful MOLST discussions begin with reviewing the resident's current health status and prognosis, followed by a discussion of personal values, beliefs, and goals for care, and then a review the benefits and burdens of life-sustaining treatment for the individual resident. These discussions take time. They often require more than one session to ensure shared medical decision-making that is well informed, resolve potential conflicts, and achieve consensus. Study results supported the idea that decisions change over time as health status, prognosis, and goals change in the last year of life.

Logistic regression analyses showed that the most significant predictors of having individual medical orders in place were having a discussion about particular life-sustaining treatments and receiving hospice care. This supports the importance of communication which sets the stage for these vital decisions to be made. Discussing an elder relative's prognosis and the pros and cons of multiple, potential treatment interventions likely involves multiple discussions over time before a decision can be made and recorded. While previous research has shown that greater frequency of discussion of EOL treatment wishes is positively associated with higher care satisfaction scores among family members of nursing home residents with dementia (Reinhardt



et al., 2015), the current study showed that such discussion is also associated with actionable medical orders being put in place. This further sets the stage for person-directed care practices.

In terms of the significance of receiving hospice care, making the determination that an elder will utilize hospice services likely ensures more discussions are taking place, eventually resulting in more orders being put in place. Background characteristics of the elder did not seem to have guided the efforts to have MOLST orders in place. Only one outcome variable, having a DNH in place, was significantly associated with a physical or cognitive status variable (poor cognitive status). Also, two of the six outcome variables had a significant association with a demographic variable, having a DNR (older age) or DNI (being Black or Latino) directive in place. The latter finding showed decedents who were Black or Latino had a higher likelihood of having a Do Not Intubate order in place. This finding differs from prior research that shows racial/ethnic disparities in end-of-life care with minorities having lower likelihood of expressing treatment wishes, fewer completed advance care planning documents, and problematic communication with physicians (Trice & Prigerson, 2009; Welch, Teno, & Mor, 2005). This association needs to be explored further in future research. Finally, family attendance at care plan meetings was only associated with one of the medical order outcome variables, Do Not Hospitalize, and it was in the opposite direction than expected. That is, having family at a scheduled care plan meeting was associated with lower likelihood of having a Do Not Hospitalize order. Further investigation is needed regarding the nature of what is covered in care plan meetings including how that differed from impromptu goals for care discussions between individual care providers and family members.

### ***Study limitations***

Study limitations included the use of cross-sectional data, thus causation cannot be addressed. A prospective study would be better able to establish temporal effects. Also, in terms of the “discussions” variables assessed, only the presence of a discussion was assessed, as the content was unavailable. Knowing the content of conversations is important in order to determine whether or not nursing home residents and their family members were educated regarding the burden and benefits of treatments, and if they were able to express their values and preferences. Additional research in this area with larger samples is warranted.

### ***Implications for practice***

The decedents in this study were largely characterized by poor physical and cognitive status, with high functional disability and receipt of hospice services. There was variability in the proportion of MOLST orders in place for different

types of life-sustaining treatments. Documented discussions around the different types of treatment decisions available were not frequent, and few family members participated in care plan meetings. However, those discussions that were documented were largely between adult children and physicians. These conversations with physicians can be helpful in terms of discussion of prognosis, care goals, and the pros and cons of life-sustaining treatments for relatives in the nursing home, and discussing/completing medical orders. Documentation of discussions can ensure individual preferences for treatment are followed in an emergency. However, study results also emphasize the need to get all members of the health care team, that is, other than physicians, more involved in EOL care discussions. Physicians or nurse practitioners can reach out to other members of the interdisciplinary team to guide the process of engaging nursing home residents and families in discussion.

Social workers, trained in communication, have a role to play regarding interdisciplinary team interactions. For example, social workers can assist other professionals to understand and follow the laws related to end-of-life care as they become increasingly attuned to patient or resident rights. Nursing home residents tend to have multiple comorbidities and dementia with varying severity levels which, in turn, affects their decision-making capacity. Social workers also have an important role in working with families and residents in terms of understanding and supporting residents' best interests. Making decisions to understand and consider withholding or withdrawing potential life-sustaining treatments can be challenging for everyone involved. Disagreements can further complicate these processes. If surrogates of equal status have conflicting viewpoints regarding treatment, social workers are in a position to facilitate effective communication and potentially resolve conflicts, avoiding a formal ethics review (Bomba et al., 2011).

Study findings showed that many decedents and their families chose to avoid cardio-pulmonary resuscitation, intubation, and feeding tubes; these choices are consistent with the evidence-based medicine for these interventions in this population. Almost one-third of decedents had been hospitalized in the last 6 months of their lives, and larger portions received artificial hydration and antibiotics during this time. However, there seemed to be little incongruence between treatment wishes and treatment received. Also, some orders were put in place *after* treatment had occurred indicating discussions had occurred affirming the value of the review and renew process. Goals for care often change as a result of a decline in health status; prognosis and care transition and MOLST orders are revised. In this population, earlier discussions may have avoided the hospitalizations. When predictor variables were considered together in logistic regression analyses, discussions of treatment interventions were significant predictors of putting almost all types of medical orders in place.

More effective processes and reporting tools are needed to further inform practice moving forward. Next steps include moving toward the development

and implementation of a three-part strategy to complete medical orders that follows the recommendations of the IOM Report *Dying in America* (Institute of Medicine, 2015). First, enhance clinician training in advance care planning and communication skills that support the MOLST process and form, using a team-based interdisciplinary approach within scope of practice. Staff need to keep each other informed regarding the content and outcome of conversations regarding end-of-life care in order to document and meet personal preferences for care. This training aligns with the Core Elements for NY MOLST and eMOLST Education developed by Dr. Pat Bomba and approved by the MOLST Statewide Implementation Team. Second, integrate public education of residents, families, medical decision-makers (health care agents and surrogates), and caregivers using the standardized advance care planning tools developed to support advance care planning in New York, including MOLST. Third, work toward implementation of eMOLST, an “electronic form completion and process documentation system for the NYSDOH-5003 MOLST form which also functions as New York’s eMOLST registry (Bomba & Orem, 2015).” eMOLST includes programming to eliminate errors, guides conversations between clinicians and the medical decision-maker and family, the ethical framework and legal requirements for making decisions regarding CPR and life-sustaining treatment, and documentation of the discussion. This will facilitate the proper use of the MOLST paradigm including documentation of multiple, ongoing conversations, updates and review of orders over time, and the use of preferred treatment at all times.

## Conclusions

This examination of existing standardized data regarding the experience of decedents in the nursing home the last 6 months of life can inform plans for systemic change, and best practice development. Further social work research may focus on the best ways to implement such practices that encompass working with nursing home residents, their families, and interdisciplinary colleagues within the scope of policy and legal requirements in support of learning, documenting, and following residents’ wishes for care at the end of life.

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