SUPPORT FOR A STANDARD OPERATING PROCEDURE FOR THE USE OF MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT (MOLST) FORMS IN A COMPREHENSIVE CANCER INSTITUTE

by

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This is to certify that

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Abstract

**Problem under investigation:** For adult palliative care patients at a Comprehensive Cancer Center, how did having an active Medical Orders for Life Sustaining Treatment (MOLST) form affect advance-care planning? Under this same service, how did having an active MOLST form impact the care provided by the palliative care team?

**Objective:** Provide support for MOLST forms which enhance patient- and family-informed care regarding end-of-life orders at a Comprehensive Cancer Center.

**Background literature and theoretical framework:** As of 2008, a MOLST form must be accepted and recognized as the legal equivalent of a do-not-resuscitate (DNR) form in New York State. The MOLST conveys the patient’s end-of-life wishes beyond resuscitation and intubation. However, it remains largely underutilized. The framework is supported by Ruland’s Peaceful End of Life Theory that developed a standard for care provided at end of life.

**Project Methods:** Qualitative thematic analysis conducted via interviews with both the palliative care team and adult patients admitted to the inpatient palliative service.

**Results:** Patients and palliative care providers expressed feelings of obligation in completing patients’ MOLST forms in an abbreviated period of time to avoid life-saving measures.

**Potential Significance:** Aid in the development of a standardized operating procedure for the use of MOLST in the healthcare setting.

**Implications:** Introducing the MOLST form prior to an inpatient admission alleviates making compulsory end-of-life care decisions. With a standardized approach, MOLST forms can enter a patient’s care at a time that allows for collaboration with their physician, overall enhancing patient-informed care and improving quality of life at end of life.

*Keywords: medical orders for life sustaining treatment, MOLST, palliative care*
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Introduction

The Patient Self-Determination Act, passed in 1990, mandated that health care facilities receiving Centers for Medicare and Medicaid Services funding inform patients on admission about advance healthcare directives (Evans, Ball, & Wicher, 2016). Nevertheless, despite policies and initiatives enacted in an effort to effect change regarding end-of-life decisions, barriers to widespread use of advance-care planning remain (Effern, 2017). The National POLST (physician’s order for life sustaining treatment) Paradigm was established as an approach to end-of-life planning based on conversations between individuals, family members, and health care providers to determine what critically ill patients do or do not want, and to honor their wishes (Clemency, Cordes, Lindstrom, Basior & Waldrop, 2017). Since its initiation, the POLST paradigm has been implemented in 17 states, with developing programs in 28 states, under 14 different names, including medical orders for life-sustaining treatment (MOLST) in New York State (Nogler, 2014).

In New York State, the medical orders for life-sustaining treatment (MOLST) form was introduced in 2006 by the Rochester Health Commission for initial use in Onondaga and Monroe Counties (Vo, Pekmezaris, Guzik, Nouryan, Patel, Vij, Tai, Wolf-Klein, 2011). MOLST became statewide and permanent in New York in 2008 when Public Health Law No. 2977 was signed. As a result, when a MOLST form is presented by a patient to any facility in the state, the form must be accepted and recognized as the legal equivalent of an inpatient DNR form (Aultman, 2010). In addition to a DNR order, the MOLST form conveys the patient’s wishes regarding intubation, artificial nutrition and hydration, hospitalization, and other advance-care orders (Vo et al., 2011). Statewide attempts have been made to implement both POLST and MOLST
(depending on the state) programs to improve, and possibly one day eliminate, do-not-resuscitate orders, which are often confusing to patients, and their families (Bomba & Orem, 2015). The use of a MOLST form clearly identifies medical interventions that should or should not be used based on the patient’s medical needs and values, and on what the physician can reasonably do to provide adequate comfort without significant harm, eliminating the subjective nature of the terms “end-of-life care” and “comfort care” (Bomba & Orem, 2015).

**Relevance to Current Practice**

The POLST program adopted by New York is approved by the New York State Department of Health in all healthcare settings across the state and is intended for patients with a limited life expectancy, although it should be recognized that this form can be completed with anyone who wants to specify his or her wishes regarding end-of-life medical decisions (Evans et al., 2016). POLST paradigm requirements differ from state to state; at this time, some states require a physician’s signature while others accept the signatures of nurse practitioners (Vo et al., 2011). Although New York’s POLST program requires that the physician ultimately sign the MOLST form, a healthcare professional can complete or change the MOLST form prior to physician signature, based on the patient’s medical condition, values, and wishes. Nurses, particularly those with advanced training, have a role in ensuring education is being provided to empower patients and their families regarding end-of-life decisions, advocating for informed patient care to improve overall quality of care delivered in the final stages of life (Vo et al., 2011). In having open and honest conversations with patients, and addressing questions that may arise, advance-care nurses can succor patients and their health care proxies to make appropriate, individualized, and comprehensive advance-care planning decisions (Effern, 2017).
The American Association of Colleges of Nursing (AACN) states that doctoral education in nursing is designed to prepare nurses for the highest level of leadership in practice and scientific inquiry in a profession that influences health care outcomes for individuals and populations including direct care, care management, administration of nursing and health organizations, and the development and implementation of health care policy (AACN, 2006). The Essentials of Doctoral Education for Advanced Nursing Practice defines eight competencies for all nurses practicing at the Doctorate of Nursing Practice (DNP) level. This project will use the integration of nursing science to develop and evaluate new practice approaches based on nursing theories to assess current care delivery approaches that meet the needs of patient populations based on scientific findings in nursing outlined in Essentials I and II (AACN, 2006). The use of analytical methods to critically appraise the literature will be employed to determine and implement best practice through the evaluation of current patient outcomes, and to apply relevant findings to develop practice guidelines for evidence-based improvement of patient-centered care delineated in Essential III. (AACN, 2006). Essential IV will be met as this project will use health care information systems and demonstrate the conceptual ability to execute an evaluation plan involving data extraction from practice information systems and databases (AACN, 2006).

Through the development of a standardized operating procedure, DNP Essential V will be achieved as this project demonstrates leadership in the development and implementation of institutional health care policy that will directly impact nursing and provides leadership to shape health care delivery (AACN, 2006). This capstone project will employ the use of effective communication and collaboration with interprofessional teams through the use of a focus group with the palliative care team to improve current practice models and develop practice guidelines
in order to create change in health care delivery systems outlined in Essential VI (AACN, 2006). Essential VII will be achieved as all collected data will be analyzed and used to improve health status and address gaps in current care models to that are being used under the palliative care service (AACN, 2006). Lastly, through the demonstration of advanced clinical judgment in designing, delivering, and evaluating evidence-based care to improve patient outcomes, interprofessional collaboration and support for nursing excellence will facilitate optimal patient care and outcomes defined by Essential VIII (AACN, 2006).

**Objective and Aims**

The question this project investigated is, for adult palliative care patients at a comprehensive cancer institute, how did having an active Medical Orders for Life Sustaining Treatment (MOLST) form affect advance-care planning? Under this same service, how did having an active MOLST form impact the care provided by the palliative care team? This project’s first goal was to identify how the MOLST form is utilized for adult patients under the palliative care service, and potential barriers to its use. Then, the goal was to improve the form’s utilization with the input gathered from the perception of the palliative care team. By combining patient and palliative clinician perceptions of MOLST, the project had the potential to enhance the development of a standard operating procedure for this document, and to improve the utilization of a form that enhances patient- and family-informed care pertaining to medical decisions about life-sustaining treatments.

**Review of the Literature**

The Institute of Medicine (IOM) released “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,” a comprehensive review of end-of-life care stating that the U.S. health care system is poorly designed to meet the needs of patients near
the end of life (2014). The IOM concurred that changes to the health care system are needed to meet patients’ end-of-life care needs in a high-quality manner with a patient-centered, family-oriented approach to care (Institute of Medicine, 2014). Medical Orders for Life-Sustaining Treatment (MOLST) forms document a patient's treatment preferences and transform them into actionable orders that have the ability to change with the patient's evolving clinical disposition (Tarzian & Cheevers, 2017). Despite its documented benefits, the MOLST form remains underutilized among patients and their health care proxies.

The MOLST form is intended to clarify patient’s wishes to a greater extent than that of do-not-resuscitate or do-not-intubate (DNR/DNI) orders or living wills, and yet research has commonly found either an incomplete form or the absence of one in patients’ charts (Clemency et al., 2017). In the MOLST form’s absence, emergency medical services and emergency medicine providers are compelled to treat patients with the highest interventions, leading to incongruences between patients’ wishes and the treatment they receive, as well as patients receiving unnecessary interventions that can be both painful and ineffective (Clemency et al., 2017). The high proportion of patients with an incomplete MOLST form - or without one entirely - suggests the possibility that patients and their proxies may be leaving forms incomplete because they are unable to understand the treatment decisions they are being asked to make or that they may be unaware of the implications of patients’ wishes not being documented (Clemency et al., 2017).

**Literature Search**

An extensive review of the literature exploring the perception and use of the MOLST form was conducted, using the following keywords both singularly and in multiple combinations: **MOLST, palliative medicine, end of life, Medical Orders for Life Sustaining**
Treatment, advance directives, and attitudes of health care professionals. Databases searched include: CINAHL Plus with full text, PubMed, MedLine, and Web of Science. After title and abstract screen, 17 were chosen for inclusion in the review. Relevant findings among articles and common topics have been synthesized to support the need for this capstone project.

Advance-Care Planning

Advance-care planning is “a process of planning for future medical care in the event an individual is unable to make their own medical decisions” (Bomba, & Orem, 2015, p. 10). Patients with chronic illnesses who were given the chance to discuss advance directives with their primary care physicians showed considerably greater satisfaction with their care than those who did not undergo those same discussions (Bomba, Morrissey, & Leven, 2011).

Unfortunately, advance directive completion rate in our nation has remained stagnant since the passage of the Patient Self-Determination Act in 1990, with only 15-20% of Americans having some form of advance directive in place (Bomba, et al., 2011; Evans, Ball, Wicher, 2016).

Discussions of advance-care planning fail to occur in a large percentage of patients. Research demonstrates that half of patients cannot identify the meaning of DNR/DNI, coupled with a statistically significant number of healthcare providers having the same misunderstanding, making effective advance-care discussions difficult (Pirinea, Simunich, Wehner, & Ashurst, 2016). In an ICU setting, 51.3% of patients reported having set up either a power of attorney or an advance directive or both, while an astonishing 48.7% had not completed either document (De Heer, Saugel, Sensen, Rübsteck, Pinnschmidt, & Kluge, 2017). In addition this, the literature shows that many oncology patients with an advanced trajectory of disease receive aggressive treatment near the end of life which puts quality of care in question (Pedraza, Culp, Knestrick, Falkenstine, and Moss, 2017). Aggressive care includes hospitalization in the last 90 days of life,
intensive care unit admission in the last 30 days of life, death in the inpatient setting of the hospital, a care setting transition in the last 3 days of life, hospice enrollment for a minimum of 4 days or no hospice enrollment prior to death (Pedraza et al., 2017). However, research shows that caregivers report excellent end-of-life care for their kin with an advanced cancer diagnosis if their end-of-life care did not include the above measures outlined as aggressive treatment (Pedraza et al., 2017). It is for this reason that The Institute of Medicine’s Committee on Approaching Death, recommended the use of advance care planning and Medical Orders for Life-Sustaining Treatment forms to improve care for patients with serious illness such as those with advanced cancer (Pedraza et al., 2017).

The POLST paradigm provides a vehicle for end-of-life discussions in which patient preferences can be converted into medical orders making this an effective form of advanced care planning. The Institute of Medicine’s committee goes on to recommend that in order to make the MOLST form readily available states should implement POLST programs and internet-based registries linked to patients’ electronic health records (Pedraza et al., 2017). It has been noted, though, that while there remains vast room for improvement, there has been growth of advance-care planning, end-of-life care, and palliative care across New York following the release of the IOM report with the implementation of MOLST (Bomba & Orem, 2015; Institute of Medicine, 2014).

Use of the MOLST Form

Traditional advance directives like the living will apply to future circumstances, are subjective, do not result in actionable medical orders, and are complicated by subjective terms such as ‘‘terminal’’ or ‘‘irreversible’’ conditions (Bomba et al., 2011). Solely having a health care proxy relies on an individual who is not the patient to separate his or her personal values
from the patient’s pre-discussed wishes (Bomba et al., 2011). A growing body of literature supports the POLST approach in honoring and communicating patients’ wishes as an alternate option for advance directives (Lee, Brummel-Smith, Meyer, Drew, & London, 2000). The MOLST form accurately conveys treatment preferences, and was found to be congruent with the advance directives (Meyers, Moore, McGrory, Sparr, & Ahern, 2004). Advance care planning with completion of POLST forms, as opposed to advanced directives alone, in patients with advanced cancer was associated with greater achievement of two metrics for quality end-of-life care: out of hospital death and hospice admission (Pedraza et al., 2017). In contrast to DNR/DNI orders, the MOLST form provides patients with treatment goals and preferences for interventions across a range of treatment options, permitting individualization (Hickman, Tolle, Brummel-Smith, & Carley, 2004). Literature shows that residents with POLST forms had significantly more medical orders regarding life-sustaining treatments than residents with traditional advance directives, and POLST was more effective than traditional advance planning at limiting unwanted life-sustaining treatments (Hickman et al., 2010).

More than a decade of research has shown that the POLST Paradigm Program, like New York’s MOLST, precisely conveys end-of-life care preferences for patients, in addition to increased adherence by medical professionals (Bomba et al., 2011). The literature continually shows that goals-of-care discussion with MOLST form completion represents an actionable approach to improve end-of-life care for patients with advanced cancer. As a result of these conversations, in which the patients’ preferences for end-of-life care are elicited and recorded on the MOLST form, the POLST program converts patients’ end-of-life treatment wishes into medical orders that are immediately actionable across care settings.
Staff Perceptions

Among emergency medical technicians, the guide for orders of life-sustaining treatment was reported to provide clear instructions about patient preferences (when filled out entirely) and to be useful when deciding which treatments to provide (Waldrop, Clemency, Maguin, & Lindstrom, 2014; Clemency, Cordes, Lindstrom, Basior, & Waldrop, 2017). MOLST forms have also been found to be implemented under younger healthcare providers and are believed to provide better pain management for patients, yet the length of the MOLST form deterred some healthcare professions from aiding in its completion (Vo et al., 2011). It is understood among healthcare professionals that a MOLST form has to be signed by a physician to be valid, however there remains confusion regarding the role other members of an interdisciplinary team play in assisting with the process of MOLST completion. Specifically, staff reports that it is either the social worker or physician who is responsible for MOLST discussion (Vo et al., 2011), but only half of physicians report having goals of care discussions or having knowledge of whether or not their patients have an active MOLST form (Ganguli, Chittenden, Jackson, & Kimball, 2016). Advanced practitioners were no more likely to make end-of-life recommendations, as only a quarter of a given sample felt comfortable completing this task (Ganguli et al., 2016).

A MOLST form should be completed following a discussion between patient, proxy, and physician. However, it is most commonly someone other than the physician who reviews and witnesses the MOLST form with the family, and the physician's signature merely activates it. Regardless of who initially prepares the forms, it is essential that the signing physician reviews the patient's wishes with the patient and healthcare proxy to ensure that any inconsistency or incomplete information is addressed (Clemency et al., 2017). The literature currently suggests
that there is a need for education of all advance-care providers in regards to goals of care conversations and the use of standardized forms, such as MOLST, to facilitate appropriate end-of-life conversations. Studies show that 44.0% of physicians and 33.0% of advanced practitioners reported that they discussed goals of care with all patients with serious, life-limiting illness, and that advanced practitioners were more likely than physicians to report awareness of MOLST forms at 55.1% vs. 45.1% respectively (Ganguli, Chittenden, Jackson, & Kimball, 2016). However, advanced practitioners were less likely to feel comfortable making recommendations regarding end-of-life care with just 25.3% of advanced practitioners versus 41.0% of physicians recommending against resuscitation and 35.1% vs. 55.7% recommending for resuscitation respectively (Ganguli et al., 2016)

**Need for Integration of MOLST form under Palliative Care**

Palliative care aims to improve quality of life for patients and their families by focusing on reducing and managing pain, stress, and anxiety, while improving daily function for patients with life-limiting illnesses (Schreibis-Baum, Xenakis, Chen, Hanson, Ahluwalia, Ryan, Lorenz, 2016). Although all patients at an oncology center can benefit from such services, palliative care typically intervenes when symptom management is at the forefront - in end-of-life care patients. End-of-life discussions are associated with less aggressive medical care near death, as aggressive care is associated with poorer patient quality of life (Bomba et al., 2011). Most patients either do not have advance directives or, for those who do, advance directives do not sufficiently provide health care professionals with explicit instructions for making critical decisions. Patients’ advance directives, spoken wishes, or health care proxies’ voices have the potential to be overlooked in a treatment-oriented situation, an unfortunate circumstance that can be eliminated with an active and written MOLST form (Bombe et al., 2011; Efferen, 2017).
Conflicting Evidence

Conflicting evidence was found in one article regarding the differences between residents with or without POLST forms on symptom and management measures. This particular article states that there was no difference among these measures for patients with or without a POLST form (Bomba et al., 2011). This finding was discovered to be inconsistent among all other reported findings.

Gaps in the Literature

Major gaps in the literature that were discovered through this review were the lack of patient perception regarding having an active MOLST form on file and the lack of evidence suggesting when is most appropriate for a MOLST form to be initiated into a patient’s care.

Conceptual Framework

With permission from the author herself, the theory that provided the framework for this capstone project was a mid-range theory: Ruland’s Peaceful End of Life Theory (see figure in Appendix A). As a mid-range theory, it offers a bridge between grand nursing theories and nursing practice, allowing for guidance of both and allowing it to be verified through testing (Alligood & Marriner-Tomey, 2010). Cornelia M. Ruland developed the peaceful end-of-life theory based on two general systems theories: the Donabedian’s model and Brandt’s preference theory. The Peaceful End of Life Theory for terminally ill patients was developed based on a group of clinical expert nurses in a surgical gastroenterologic unit in a university hospital in Norway (Higgins & Hansen, 2017). It was on this specific unit that half of the patient population was diagnosed with cancer and had a terminal diagnosis; however, no clinical guidelines were in place to provide direction for the care of this specific population of patients (Ruland & Moore, 1998). This lack of guidance for appropriate nursing care for this specific patient population was
identified as a large barrier to quality nursing care. This ultimately led to an initiative to develop a standard for care provided at end of life. The new standard would not be based on death itself, but a focus on peace and quality of living in the time that remained for the patient. Ruland explains that the theory not only requires knowledge related to pain relief and symptom management, but also caring attitudes, awareness, sensitivity, and compassion of the staff caring for the patient (Ruland & Moore, 1998).

Ruland’s focus is on improving shared decision-making between patients and their provider regarding difficult decisions following screening or treatment options, and helping patients understand potential risks and benefits. Ruland, through her theory, also remained cognizant of the importance of patients’ values when managing chronic illness over a period of time (Higgins & Hansen, 2017). Ruland adapted Donabedian’s model of structure, process, and outcomes to her own theory. She identified the structure as terminally ill patients and all significant others involved in the care; the process as the nursing interventions; and the outcomes including being free from pain, being at peace, and experiencing comfort, dignity, respect, and a closeness to significant others and those who care (Higgins & Hansen, 2017).

The second theoretical underpinning is the preference theory developed in 1979 by Richard Brandt. This theory has been used by philosophers to explain and define quality of life. Under this specific theory, a “good life” is defined as getting what one wants, which could be applied specifically when evaluating end-of-life care practices. The theory is applicable for both responsive persons and incapacitated persons who have previously provided documentation related to end-of-life decision making. Quality of life, therefore, is defined and evaluated under the preference theory as a demonstration of satisfaction through outcomes, including symptom relief, and satisfaction with personal relationships (Higgins & Hansen, 2017).
Applying this theory provided a framework for the proposed project; the use of a MOLST form allows for patient-informed care in order to improve *quality of life at end of life*. The form goes beyond the DNR/DNI component and outlines comfort measures versus full medical interventions, the use of antibiotics, artificially administered fluids and nutrition, and hospital transfer, and allows for the family and patient to spell out their specific wants and wishes when end of life is presumed to be near (Vo et al., 2011). One aspect of Ruland’s theory that was found to be especially applicable to the MOLST form is the component of experiencing dignity and respect. Ruland goes on to state that this is supported by including the patient and significant others in decision making, and being attentive to the patient’s expressed needs, wishes, and preferences (Ruland & Moore, 1998). The outcomes of her theory are based on the patient not being in pain, but experiencing comfort, having dignity and respect, being at peace, and allowing for closeness to significant others. Refer to Appendix A for a depiction of the relationship between the concepts and the theory (figure has been included with the permission of the author of the theory, Cornelia Ruland).

When patients and their family members are encouraged to guide and be a part of the patients’ end-of-life decision making with the use of a tool such as a MOLST form, we are honoring the aspects outlined in the peaceful end-of-life theory, providing the framework for exceptional quality of life and positive outcomes for those with a terminal diagnosis. This capstone project, with the framework provided by Ruland’s theory of peaceful end of life, investigated what leads patients and their families under our inpatient palliative care service to complete a MOLST form, and more so how this impacted the inpatient palliative care team.
Project Design and Method

A qualitative description method is an exceptional methodological choice for the healthcare environments, designer, practitioner, and/or health science researcher because of the method’s ability to provide rich descriptive content from the participant’s perspective (Colorafi & Evans, 2016). It is this method, the qualitative description that guided the collection and analysis of data. A qualitative study employed non-probabilistic, purposeful sampling of the convenience type to develop a sample of participants for this capstone project in addition to a focus group with the palliative care team at Roswell Park Comprehensive Cancer Center. A minimum of ten patient interviews with adult patients under the inpatient palliative care service were conducted based on the expected, reasonable coverage of the phenomenon given for the purpose of this study. However, the sample size was fully determined based upon the point of saturation.

Face-to-face, semi-structured, individual interviews with adults solely under the inpatient palliative service were conducted. Inclusion criteria for patients stipulated that the patient must be an inpatient under the palliative care service with a diagnosis of cancer and were able to understand and speak the English language. There was no outlined inclusion or exclusion criterion for stage of disease process, ethnicity, or gender. Patients that are under the pediatric service were excluded from the interview process, as were patients who were seen by the palliative service exclusively in the outpatient setting. Qualitative data was collected with the use of semi-structured interviews. One-time interviews consisting of open-ended questions were conducted in a one-on-one fashion. Patients were asked 10 open-ended questions. See Appendix B for a patient interview guide.
The focus group was held with members of the palliative care team. This team consists of two Medical Doctors, one Doctor of Osteopathic Medicine, one Nurse Practitioner, one Fellow, and one Case Manager. The palliative care team was walked through questions provided in Appendix C to gather their perception of the use of the MOLST form in regard to palliative and end-of-life care interventions. All interviews and the focus group were recorded with a tape recorder and then transcribed for coding of data in order to determine emerging themes throughout.

**Data Analysis**

Qualitative description is especially amenable to health environments research because it provides factual responses to questions about how people feel about a particular space, what reasons they have for using features of the space, who is using particular services or functions of a space, and the factors that facilitate or hinder use (Merriam & Tisdell, 2016). Data analysis, in qualitative data, is described as “the classification and interpretation of linguistic material to make statements about implicit and explicit dimensions and structures of meaning-making in the material and what is represented in it” (Merriam & Tisdell, 2016 p. 195). This was a conventional content analysis with the goal of identifying the underlying themes gathered from the responses of the participants and how they related to the current use of the MOLST form with the goal of developing a standardized operative procedure for hospital staff.

In qualitative research, ensuring “trustworthiness” and “authenticity” is essential in the same way quantitative research strives to ensure validity and reliability of the research study. Ensuring the validity and reliability of this qualitative project involved conducting the interviews in an ethical manner to enhance the trustworthiness of this capstone. Quality and legitimacy of this capstone was achieved through meeting the five standards of objectivity, dependability,
credibility, transferability, and application associated with a properly conducted qualitative analysis. Internal validity was achieved by checking interpretations with the individuals interviewed for respondent validation, being available on site over a period of time, adequately engaging in data collection, and clarifying research biases and assumptions. Reliability, or the extent to which a research finding can be replicated, can be problematic in social sciences. However, this study employed aspects such as peer review and an in-depth audit trail by describing in detail how this qualitative project was conducted in order to enhance project reliability (Merriam & Tisdell, 2016 p. 237). Dr. Mary Ann Meeker, Associate Professor of the School of Nursing at the University at Buffalo, was consulted in the process of this project in an effort to eliminate bias, as her expertise is in both palliative care and qualitative analysis. She also assisted by reviewing the developed interview questions and by aiding in the interpretation of data to enhance overall validity and reliability. As the validity and reliability of a study greatly rely upon the ethical considerations of the investigator, it was of the utmost priority to protect the vulnerability of the population of subjects in this project.

Protection of Human Subjects

Prior to beginning this capstone project, approval was granted from both Roswell’s Institutional Review Board and The University at Buffalo’s Institutional Review Board. All participants were provided an informed consent that outlined exactly what the collected information was used for, and that their identity was protected throughout the course of the project. All patients were assigned numbers to eliminate the use of identifiable information. All collected data was protected by the interviewer, as the interviewer will be the only one that has access to the data. Interviews and recorded information were kept in a lock box and all electronic
information remained on a laptop under a security login. Information collected was solely used of this capstone in order to answer the question outlined by this project.

**Scope and Limitations**

This project investigated the perceptions of adult patients admitted to the inpatient palliative care service on their perceptions of having a MOLST form. Members of the palliative care team were also included in this study. Pediatric patients or patients under the outpatient palliative care service were not included in this study. Any employee of the institute that is not part of the palliative care team was not asked to participate. The study was conducted at a single site with a qualitative design that included one-time, face-to-face interviews with adult patients admitted under the palliative care service as well as a focus group with members of the palliative care team. The study relied on truthfulness of interview participants and self-reports of clinician behavior that may not accurately represent true behavior outside of the focus group. The study was interpreted in the context of the above limitations.

**Results**

The study sample included a total of ten participants, although twelve interviews were conducted. Two participants were removed from the study, one due to an inaudible interview attributable to tumor burden and another after admitting they were not entirely certain they knew what a MOLST form entailed during the interview. All participants included in the study were admitted under the care of the inpatient palliative care service and had an active MOLST form on file. Interviews were conducted one time in a face-to-face manner over a one month period. The sample consists of six males and four females. As stated previously, a focus group consisting of the palliative care team members was also conducted to discuss the perception of the institute’s
use of MOLST forms. Themes describing means for improving the use of MOLST forms and developing a standard for their use in a comprehensive oncology center are presented below.

Participant Interview Results

Introduction to Form from Institute Staff (n=8)

Participants stated that introduction to the MOLST form came from a Roswell Park Comprehensive Cancer Center employee (n = 8). Of these eight participants, three stated that the form entered their care by way of a member of the palliative care department. Another three participants mentioned having the form initially brought to their attention by their primary oncologist (at Roswell) and two members explained it was a nurse in the institute that first discussed the MOLST form with them.

Limited Knowledge (n=7)

When discussing prior knowledge of the MOLST form, participants stated that prior to initial introduction to the MOLST form, they did not know that a form depicting different options for end-of-life care existed (n= 5). Other participants stated they only knew what the form symbolized and “what it was intended to do,” knowing that the form had a box for “Do not resuscitate” (n=2). These participants did not elaborate on whether or not they had prior knowledge of the other options the form offers including artificial nutrition, hospital transfer, or trial intubation.

Worsening Prognosis (n= 9)

Many of the participants explained that the MOLST form entered their care due to worsening prognosis (n=9). Patients stated that it was when they found out they had disease progression that the MOLST form followed, typically during their current inpatient admission. Participants reported that the MOLST form entered their care on their current admission within
the last 24-48 hours (n=5) and felt it “had to be done before something happened.” They also felt it was important to have their “wishes known”. Of these nine participants, six went on to explain that their ultimate goal of completing the MOLST form was to avoid being “put on machines.”

Positive Perception (n = 7)

Although participants acknowledged the difficulty of the realization that the MOLST form was necessary in their care (n = 6), they reported a positive opinion of the MOLST form (n = 7). The form allows them to have control in their “end-of-life wishes” (n= 6), alleviating their family members’ burden of having to make those decisions (n = 2) (although it should be noted many participants identified a family member as being active in their care, typically as their healthcare proxy (n= 6)). Additionally, participants stated that the form allows them to have control over how they leave this world, providing dignity to the patient in their last hours (n=6).

Updates to the MOLST Form (n = 10)

When asked what changes have been made to their MOLST form since its initial completion, all participants stated they have not made any changes to their MOLST. It should be noted that several of the participants’ MOLST forms entered their care within 24-48 hours prior to their interview (n =5).

Focus Group Results

Caring for a Patient with a MOLST Form

When discussing situations with the palliative care team in which they cared for a patient in the inpatient setting who had a MOLST form, all members of the palliative care team expressed their view that it made their consultation easier. The ease was identified as their having a framework for the patient’s values and the ability to identify the patient’s end-of-life wishes. Having an active MOLST form redirects the focus from a form that needs to be
completed on a “teetering” patient to avoid drastic and arguably unnecessary measures, to a focus of symptoms management and achieving comfort measures. This allows a patient to have an improvement in quality of life. It was also identified by the team that approximately 50% of the time, the form is completed incorrectly, either without patient or physician signature, or the patient does not fully understand what they have signed. The members also stated that when they come across forms that are completed correctly, this is typically because a member of the palliative care team is the one that completed the form with the patient.

The members of the palliative care team also discussed instances in which they introduced a MOLST form to a patient and the patient stated they have been given multiple MOLST forms and all remain incomplete in a pile at home. In these instances, the team felt that a true conversation regarding the purpose of the form and the patient’s prognosis did not occur to an appropriate extent. Cases of incomplete or incorrect information provided on the form has in turn caused patients to want to revoke their MOLST form at a later date because it was not thoroughly reviewed and an informed conversation, including patient prognosis, did not take place. This thorough review and informed conversation have been shown in the research to guide a patient’s decision for end-of-life care. The team members then expressed their belief that having a standardized approach to the implementation of the MOLST form would contribute to a reduction in these issues.

**MOLST Form for all Palliative Care Patients**

The palliative care team did not feel that all patients admitted under the palliative care service should have a MOLST form. The clinicians’ primary reasoning was that beginning with a conversation regarding code status is very difficult and is not an appropriate first encounter for all patients. A large percentage of patient referrals to palliative care are solely for symptoms
management. The team feels that it is important to avoid the inaccurate notion that palliative care equates exclusively to end-of-life care and Hospice referrals. Therefore, bringing this form to patients who are referred to palliative and supportive care exclusively for symptoms management may create confusion and distrust in that the patient may surmise that death is imminent and information had been withheld from them regarding their disease and prognosis. However, this is where the other providers can intervene and implement the MOLST form under their own service—such as primary oncology—to eliminate this form exclusively coming from the palliative care team.

The palliative care team did, however, express the importance of having end-of-life care conversations without bringing out the “pink form,” and the symbolic meaning this form holds for patients and their family. Collectively, the group felt that initiating conversations and speaking openly with their patients about what they would want if their disease were to progress is a much more natural segue into the process of obtaining a written advanced directive such as the MOLST, as opposed to walking in and simply filling out a form. All clinicians agreed that they try to avoid introducing a MOLST form on their first encounter with a patient but identify that unfortunately, once the patient is admitted inpatient, it becomes a difficult task to avoid due to inpatient nature and necessity of interventions completed when a patient’s health deteriorates and their wishes are not documented. This makes the completion of the form an acute obligation or something that simply “has to be done,” a mutual feeling identified by the participants interviewed.

**Comfort Level of Caring for Patients with a MOLST**

When patients are admitted to the inpatient census in the institute with a MOLST form, the clinicians identified a sense of relief, as this is a current quality improvement goal. Many
times, when a patient meets end-of-life care criteria, they are wavering on needing intensive care. The Chief of the palliative care service explained that when attempting to obtain a MOLST in the inpatient setting at a time when the patient’s prognosis is worsening, the patient is angry, in denial, and grieving; this is the worst time to force a decision of this magnitude on them because it becomes a situation where “time is of the essence.” Current measures show that approximately 50% of patients have a palliative care referral prior to dying, however only 17% of these patients have a DNR in place prior to the admission during which they expired. Therefore of the 50% of patients that have a palliative care referral, 33% are signing a MOLST form immediately prior to their passing in the inpatient setting or going to Hospice.

The Chief of Palliative Care went on to explain that she felt it was derisory for the palliative care team to then come in as strangers to obtain the appropriate advanced directives when this could have been done by a clinician who knows their patient best, whether that be by the patient’s nurses, social workers, therapists, primary oncologist or primary care provider. This feeling is mutual among the palliative care team. The group also stated that when the MOLST form is in place and completed correctly, they are able to complete a full palliative care consult of assessing symptoms, addressing psychological and spiritual issues, ensuring healthcare planning has been addressed and discussing prognosis. This alleviates the sense that a clinician’s “agenda” consists of merely obtaining written documentation of code status before the patient deteriorates and higher interventions are implemented. It should be noted that the team identified the fact that there will always be select cases wherein, despite how many times end-of-life conversations occur with a patient and their family, the patient and family may never be ready to sign a MOLST form prior to an inpatient admission in which the patient’s death is imminent.
Identifying Barriers to Use of MOLST

When discussing potential barriers to the use of a MOLST form, the team identified two recurring themes: that patients may not understand their prognosis (whether due to denial or not having had proper discussions regarding their disease process) or patients do not want to complete a MOLST form because they fear they will be treated differently if they have a DNR in place and confuse the term DNR for “Do not treat.” The team spoke about different instances in which patients, either in long term rehab or a nursing facility, had an instance occur that required a higher level of medical intervention and the facility would not call an ambulance because the patient had Do Not Resuscitate or do not intubate marked on their MOLST form. These instances led to all restrictions on code status being revoked and an overall distrust in the healthcare system from these patients, making it significantly more difficult to obtain a written DNR/DNI consent from them in the future.

The team also discussed the issue of the institute’s own nursing staff in having a difficult time navigating the “areas of gray” that accompany a DNR/DNI order with full treatment. In healthcare, there tends to be a misconception that if a patient is DNR/DNI then they are automatically to be treated with “comfort measures only”. Many times, this is not the case. The team has identified instances where orders were not followed as written or the team was questioned because the staff felt the orders did not align with “comfort measures”, despite the fact that the patient was not on the suspected comfort measures; they simply had signed their MOLST stating that they did not want to be resuscitated should their heart stop beating. The discussion led to the need to clarify the different terminology that is associated with end-of-life in healthcare in order for patients to feel confident that they are receiving best practice and evidence-based care despite having also a signed DNR/DNI.
Responsibility for MOLST Form Conversations

Unanimously, the group felt that it is the responsibility of all of the hospital staff to start “the conversation” and create a culture and environment for patient-informed care in efforts to enhance discussions of end-of-life wishes. One need not be a member of the palliative care team, nor the primary oncologist, nor a physician to have these discussions. Nurses, social workers, physical therapists, respiratory therapists, and others all have the ability to initiate these conversations and provide education regarding the MOLST form; a doctor’s signature simply activates it.

One of the Medical Doctors in the focus group also acknowledged that it is too much to assume that the primary oncologist would be able to obtain a MOLST form on all patients. Many patients do not feel comfortable thinking ahead in their disease and want to be present in the “here and now.” Asking those patients to walk through their disease process and the “unknown” can be too traumatic. These patients may not be ready to complete a MOLST form until an admission due to disease progression or worsening overall condition. Therefore, with this knowledge, all members of the hospital staff can help in these instances. The members of the focus group also identified the need for training on completing goals of care with patients and how this might encourage more members of the interdisciplinary staff to take part in goals of care and end-of-life care discussions with patients.

Discussion

The POLST Paradigm developed a medical order set in efforts to improve end-of-life care. It sought to accomplish this by ensuring that documented patient wishes are not only consistent with their preferences and goals of care, but are also as honored across healthcare settings (Waldrop, McGinley, Clemency, 2017). Advance directives allow individuals to
communicate preferences for future circumstances while do-not-resuscitate orders specify which life-sustaining treatments to withhold now in patients who are unresponsive (Waldrop et al., 2017). MOLST orders were developed through the POLST paradigm as a response to the limitations of both advance directives and do-not-resuscitate orders for patients with advanced progressive illness (Waldrop et al., 2017).

National campaigns have been launched to encourage conversations about what matters at the end of life, specific care choices, the identification of surrogate decision makers, and the completion of documents to establish directions when the person is unable to speak for him or herself. However, despite recent increased nationwide emphasis on the promotion of advanced care planning and the use of MOLST, there remain challenges associated with implementation and utilization of such orders (Waldrop et al., 2017). This study adds to the larger body of research on the POLST paradigm by examining how MOLST forms impact patients in an inpatient setting, and aims to contribute to a standardized operating procedure for the use of the forms in a local oncology center.

“The convergence of medical treatment that can extend life with written medical orders that make it possible to refuse such treatment brings the differential dynamics of contemporary end-of-life decision-making into sharp focus” (Waldrop et al., 2017, p.1). This evolution in medicine makes conversations regarding end-of-life care an essential component in healthcare, in that all members of the interdisciplinary team should feel competent when contributing to providing best practice for our patients. The authors also acknowledge that “all too often, the process becomes reductionist resulting in simply the completion of a form and checking a list, with little or no meaningful conversation or protracted avoidance of any conversation about dying, which leave families with more questions and uncertainty than answers” (Waldrop et al.,
The research has shown that patient-family-clinician communication can be confusing, uncertain, and pressured when death is imminent. A reciprocal feeling aligns them with the members of the palliative care team and patients included in this study.

An identified theme gathered from both the individual interviews and the palliative care team focus group was that patients often complete the MOLST form because they “had to do it” given their current situation. The patient’s worsening prognosis, coupled with the fact that they were in the inpatient setting, left the participants with little choice when their ultimate goal was to “avoid being put on machines.” The palliative care team explained that when patients are admitted to the hospital without a MOLST form and death is imminent, an admission to the intensive care unit is usually soon to follow. Under the intensive care unit, interventions that a patient may not wish to receive could occur if the team is unable to reach the patient in time to obtain written documentation detailing the patient’s wishes. These situations detract from the palliative team’s ability to complete a full palliative consult with a focus on symptom management, to a focus of ensuring that the patient is not resuscitated and placed on mechanical ventilation. These pressured and hurried situations can create distress not only for patients and their families, but also for care providers. Further, that distress ultimately influences the end-of-life experience for those who are dying and those who care for them (Waldrop et al., 2017).

Another prominent theme gathered through this study is patients stating they had no prior knowledge that a form outlining wishes regarding different medical interventions existed. This is coupled with the fact that the palliative care identified the need for more healthcare professionals to feel competent in discussing goals of care and introducing MOLST forms to patients. These finding aligned with the literature that continually shows room for improvement in how often clinicians discuss prognosis and goals of care (Pedraza et al., 2017). Research shows that
physicians and advanced practitioners alike felt more comfortable giving recommendations for resuscitation when they believed it would be helpful for a patient than when they felt it would not, a finding that supports reports of clinicians’ discomfort with confronting the limits of medical intervention (Ganguli et al., 2016). These findings correspond with the recently published Institute of Medicine report entitled “Dying in America,” which noted the unfortunate inconsistency of clinician–patient informed conversations about end-of-life care (Ganguli et al., 2016).

Despite the importance of advance care planning to patients with cancer as documented in the literature, only a minority of oncologists have such discussions with their patients. In a study of 1,985 cancer decedents from 2000 to 2012, researchers found that there was an increase in patients with cancer who had completed a durable power of attorney for health care but no increase in the percentage of patients who had completed a living will or participated in end-of-life care discussions (Pedraza et al., 2017). Adding to this ongoing issue is the dispute among healthcare providers whose duty it is to have advanced care planning conversations with their patients. The New England Journal of Medicine polled its readers on the question of who should take the lead of advanced care planning at end of life. Of the 938 responses, 52% responded that the primary care physician should do it, 27% the oncologist, and 21% the palliative care specialist (Pedraza et al., 2017). Many of the respondents mentioned a multidisciplinary approach, a finding that was also consistent with the palliative care team focus group’s consensus that all members of the patient’s care team should be involved in discussions regarding advanced care planning. Interestingly, the research shows that patients with cancer have indicated the importance of continuity with their oncologists at the end of life because they value their oncologists’ expertise and ongoing therapeutic relationship (Pedraza et al., 2017).
Despite who it is that takes the initiative to discuss advanced care planning, including the introduction of the MOLST form, the data collected in this study aligns with prior published articles in regards to implementation of MOLST into a patient’s care. Research shows that goals-of-care discussions with patients with cancer occur late in the patients’ illness trajectory. Several participants in this study identified the MOLST form entering their care only within the last 24-48 hours due to significant disease progression. This parallels the literature that shows that POLST forms are entering a patient’s care a median of only 5.1 weeks before death (Pedraza et al., 2017). This leaves open As discussed with the palliative care team, introducing a MOLST form is a process that focuses on person-centered and family-oriented goals for care; it is not typically completed in one sitting on an initial visit. Depending on the patient’s readiness for advanced care planning, it may take more than one patient interaction to complete the MOLST form. Because of this, the team members feel these conversations need to be initiated in the outpatient setting prior to admission to the inpatient setting.

If advanced care conversations are initiated in the outpatient setting, the patient and their family members would have the necessary time to plan and have decisive conversations. This would also allow the form to enter the patient’s care while the patient is in a stable state of health and able to fully communicate their wishes without any looming factors impacting the decision. Taking the appropriate time necessary to introduce and complete MOLST allows for a person-centered, family-oriented care plan. It is also during this time that family and caregivers can be educated about what to do in an emergency in order to ensure that the patient’s wishes are being followed as outlined on the MOLST form (Bomba, & Orem, 2015).

The data was collected and analyzed in accordance with the framework provided for this capstone project, Ruland’s Peaceful End of Life Theory. Ruland’s theory was developed with the
intention of providing a standard of care for patients with an oncology-related or terminal diagnosis. Like the use of the MOLST form, Ruland’s focus is on improving shared decision-making between patients and their provider regarding difficult decisions while remaining cognizant of the importance of patients’ values when managing chronic illness over a period of time (Higgins & Hansen, 2017). In accordance with her theory, the application of the MOLST form allows for the family and patient to spell out their specific wants and wishes when end of life is presumed to be near (Vo et al., 2011). When patients and their family members are encouraged to guide and be a part of the patients’ end-of-life decision making with the use of a tool such as a MOLST form, we are honoring the aspects outlined in the peaceful end-of-life theory. This provides the framework for exceptional quality of life and positive outcomes for those with a terminal diagnosis.

It is also important to note the limitations of this study. Throughout the course of the study, there was difficulty in identifying participants at any given time in the institute, as there were very few patients who met the criteria of having documented code status and being a patient of the inpatient palliative care service. Also, as noted above, many patients had only been introduced to the MOLST form for the first time during their current admission, with some participants stating they filled out the MOLST form that day. Typically these patients reported they were then being discharged to end-of-life care services outside of the hospital in the next 24-48 hours. This created a very small window to conduct patient interviews for the purpose of this study. The above information further strengthened the need for this study and for a more structured approach to the implementation and use of MOLST forms. With a framework of patient and the palliative care team’s perspectives on the use of the MOLST form completed,
future studies could focus on implementing MOLST forms in the outpatient setting to further assess the conversations and perceptions of this particular advanced care directive.

**Implications**

Through the development of a standardized approach to the implementation of the MOLST form, patient populations will not have to sign a form with the magnitude of the MOLST form in a rushed or pressured situation where “time is of the essence” as an avoidance of what could happen. This will also alleviate concerns of the staff caring for the patient, namely the palliative care team. The focus group, comprised of members of the palliative care team, expressed their hope that more of these conversations will be moved to an outpatient setting when the patient is in stable health and is able to take the time necessary to make informed decisions regarding end-of-life. It is essential that patients are given the dignity to have been properly introduced to this form at a time when informed, stress-free conversations can be had so that patients and their families can confidently complete a form that allows for self-directed care at end-of-life. Several studies have suggested that patients with advanced cancer who have advance care planning discussions with the use of a MOLST form achieve better quality of life during the end of life and undergo unwanted medical care less often (Pedraza et al., 2017). This further supports the need to develop advance care planning best practices that can be implemented more widely in the care of patients with advanced cancer.

The provided evidence supports the development of a standardized operating procedure regarding the use of MOLST forms at a comprehensive cancer institute. A standardized approach to the utilization of this form will assist in meeting quality improvement measures by increasing the number of patients admitted to the inpatient setting with a MOLST form in place. Moving the conversation “upstream” to the outpatient setting will be beneficial for both patients and
providers when the correct documentation is in place outlining the patient’s preferences prior to an inpatient admission. By building a standardized approach to the implementation of a MOLST form into patients’ care, the institute can have a hospital-wide policy that will allow patients to have their end-of-life care wishes known in a timely and appropriate manner as well as enhancing the capabilities of the palliative care department to focus on the improvement of quality of life at end-of-life.
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Appendix A

Relationship between the concepts of Ruland’s Peaceful End of Life Theory

Appendix B

Interview Guide for Patients

1. I understand you have a MOLST form on file. Tell me how this form was originally brought to your attention.

2. Tell me about the time when the MOLST form entered your care.

3. What did you know about the MOLST form prior to filling it out?

4. How did you feel when you were initially asked about the MOLST form?

5. What motivated you to complete the MOLST form?

6. What was the hardest thing you experience when initially completing a MOLST form?

7. Who would you feel comfortable making decisions for you?

8. Have there been any changes to your MOLST form since initial completion

   1. Tell me about this

9. What other advance directives do you have in place?

10. What else would you like to share about the process of filling out the MOLST form?
Appendix C

Question Guide for Palliative Care Focus Group

1. Talk about a situation where you have cared for a patient with a MOLST form.

2. What are your feelings regarding having a MOLST form for all patients admitted to the palliative care service?

3. How does your level of comfort change in caring for a patient with an active MOLST form?

4. What kind of challenges or barriers do you feel hinder the use of a MOLST form for patients?

5. Whose responsibility do you feel it is to initiate conversations and assist a patient to fill out a MOLST form?

6. What else would you like to share regarding your views of the MOLST form under the palliative care service?
September 27, 2017

Dear Michelle Secrist:

On 9/27/2017, the IRB reviewed the following submission:

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<tr>
<th>Type of Review:</th>
<th>Initial Study</th>
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<td>Title of Study:</td>
<td>IMPLEMENTING A STANDARD OPERATING PROCEDURE FOR THE USE OF MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT (MOLST) FORMS IN A COMPREHENSIVE CANCER INSTITUTE</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Michelle Secrist</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>STUDY00001768</td>
</tr>
<tr>
<td>Funding:</td>
<td>None</td>
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<td>Grant ID:</td>
<td>None</td>
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<td>IND, IDE, or HDE:</td>
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<td>Documents Reviewed:</td>
<td>• Secrist_ResearchProtocol.docx, Category: IRB Protocol; • Secrist_FocusGroup_ConsentForm.pdf, Category: Consent Form; • Secrist_ConsentForm.pdf, Category: Consent Form; • Interview Guide.pdf, Category: Recruitment Materials;</td>
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</table>

The IRB approved the study from 9/27/2017 to 9/26/2018 inclusive. Before 9/26/2018 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 9/26/2018, approval of this study expires on that date. The Initial Study materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Initial Study Review. Before to 9/26/2018 inclusive. Before 9/26/2018 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 9/26/2018, approval of this study expires on that date. or within 30 days of study closure, whichever is earlier, you are to submit a continuing review application with required explanations.
You can submit a continuing review application by navigating to the active study in Click IRB and clicking Create Modification / Continuing Review. Studies cannot be conducted beyond the expiration date without re-approval by the UBIRB.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

UB IRB approval is given with the understanding that the most recently approved procedures will be followed and the most recently approved consenting documents will be used. If modifications are needed, those changes may not be initiated until such modifications have been submitted to the UBIRB for review and have been granted approval.

Prior to the expiration of this approval, you will receive notification that it is time for the UBIRB to conduct its periodic review of your study. Studies cannot be conducted beyond expiration date without re-approval by the UBIRB.

As principal investigator for this study involving human participants, you have responsibilities to the SUNY University at Buffalo IRB (UBIRB) as follows:

1. Ensuring that no subjects are enrolled prior to the IRB approval date.

2. Ensuring that the study is not conducted beyond the expiration date without re-approval by the UBIRB.

3. Ensuring that the UBIRB is notified of:
   - All Reportable Information in accordance with the Reportable New Information Form Smart Form.
   - Project closure/completion by the Continuing Review/Modification/ Study Closure smart form.

4. Ensuring that the protocol is followed as approved by UBIRB unless a protocol amendment is prospectively approved.

5. Ensuring that changes in research procedures, recruitment or consent processes are not initiated without prior UBIRB review and approval, except where necessary to eliminate apparent immediate hazards to subjects.

6. Ensuring that the study is conducted in compliance with all UBIRB decisions, conditions, and requirements.

7. Bearing responsibility for all actions of the staff and sub-investigators with regard to the protocol.
8. Bearing responsibility for securing any other required approvals before research begins.

If you have any questions, please contact the UBIRB at 716-888-4888 or ub-irb@buffalo.edu.
October 9, 2017

Michelle Secrist
michelle.secrist@roswellpark.org

Dear Ms. Michelle Secrist:

On 10/9/2017, the IRB reviewed the following submission:

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<tr>
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<tr>
<td>IRB ID:</td>
<td>STUDY00000442 / IRB 044217</td>
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<tr>
<td>Funding:</td>
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<td>IND, IDE, or HDE:</td>
<td>None</td>
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</table>
| Documents Reviewed: | • Interview Guide.pdf, Category: Recruitment Materials;  
|                  | • Secrist_GeneticsProtocol.pdf, Category: IRB Protocol;  
|                  | • Secrist_ConsentForm.pdf, Category: Consent Form;  
|                  | • Secrist_FocusGroup_ConsentForm.pdf, Category: Consent Form; |

The external IRB’s approval for this study will expire on 9/26/2018.

Please be advised that only the ORSP stamped consent form can be used to enroll subjects.

The principal investigator is responsible for ensuring that the research complies with all applicable regulations. Any modifications in the research project are subject to approval by the external IRB and acceptance by the ORSP prior to initiation by the investigator. The RPCI IRB reserves the right to stop the research for violations of regulatory or IRB requirements.
A progress report must be submitted to the ORSP at least ten days prior to the expiration date noted above for continuing review.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103), including the reporting of Unanticipated Problems and any other Reportable New Information.

Sincerely,
Donald Handley MSc, MBA
Camille P Wicher, PhD, Esq., RN, MSN
Capstone Defense
Support for a Standard Operating Procedure for the use of Medical Orders for Life Sustaining Treatment (MOLST) in a Comprehensive Cancer Center
Presented by: Michelle Secrist
University at Buffalo
Spring 2018

Purpose of Capstone
➢ Provide support for the development of a standard operating procedure for hospital staff in implementing the use of a MOLST form.
➢ Improve the utilization of a form that enhances patient- and family-informed care pertaining to medical decisions about life sustaining treatments.

Specific Aims
➢ To identify and evaluate how a MOLST form was utilized for adult patients under the palliative care service.
➢ Identify barriers to the MOLST forms use.
➢ Improve the use of the MOLST form.
➢ Engage the palliative care team to identify their perception of the use of a MOLST form.

Capstone Questions
➢ For palliative care patients at a comprehensive cancer center, how did having an active MOLST form affect advanced-care planning?
➢ Under this same service, how did having an active MOLST form impact the care provided by the palliative care team?
What is MOLST?

- Medical Orders for Life Sustaining Treatment.
- A MOLST form presented by a patient to any facility in the state must be recognized as the legal equivalent of an inpatient do-not-resuscitate (DNR) form.
- Includes patient’s wishes regarding intubation, artificial nutrition, artificial hydration, hospitalization, and other advance-care orders.

Background & Significance

- Passage of Patient Self-Determination Act in 1990 mandates healthcare facilities discuss advance directives with patients.
- Development of the National POLST (physician’s order for life sustaining treatment) Paradigm.
- New York State is 1 of 17 states that adopted the POLST paradigm under the name MOLST.
- Barriers to widespread use of advanced care planning remain.

Background & Significance

- Institute of Medicine releases “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.”
- Changes to meet patients’ end-of-life care needs in a high-quality manner with a patient-centered, family-oriented approach to care.
- Incomplete or absence of MOLST form in a patient’s chart.

Background & Significance

- MOLST conveys end-of-life care preferences for patients.
- Goals-of-care discussion with MOLST form completion represents an actionable approach.
- Increased education for all advanced-care providers in regards to goals of care conversations and the use of standardized forms, such as MOLST.
Theoretical Framework

- Ruland’s Peaceful End of Life Theory
- Based on two general systems theories: Donabedian’s Model and Brandt’s Preference Theory.
- An initiative to develop a standard for care provided at end-of-life.
- Improving shared decision making between patients and their provider.
- Focus on peace and quality of living in the time that remains for the patient.

Justification for use of Ruland’s Theory

- Use of a MOLST form allows for patient-informed care in order to improve quality of life at end of life.
- Encompasses importance of providing dignity and respect.
- Includes the patient and significant others in decision making.
- Outcomes of the theory include: patient not being in pain, experiencing comfort, having dignity and respect, being at peace, and allowing for closeness to significant others.
- MOLST form honors the aspects outlined in the peaceful end-of-life theory.

Contribution to Clinical Practice

- Activation of the MOLST form
- Advanced practitioners comfort in making recommendations of end-of-life care.
- Advanced practice practitioners role in education and empowering patients and their families.
- Assisting patients and their health care proxies to make appropriate, individualized, and comprehensive advanced-care planning decisions.
Study Sample

- Adult patients admitted to the inpatient palliative care service at Roswell Park Comprehensive Cancer Center with an active MOLST form.

Focus group with the palliative care team:
- Medical Doctor (2)
- Doctor of Osteopathic Medicine (1)
- Nurse Practitioner (1)
- Palliative Care Fellow(1)
- Social Worker(1)

Patient Study Sample

- Inclusion Criteria:
  - ≥ 18 age
  - Patient with a cancer diagnosis
  - Inpatient at Roswell Park
  - Patient admitted to the palliative care service
  - Patient with an active MOLST form
  - Ability to read/speak English Language

- Exclusion Criteria:
  - Patient under the pediatric service
  - Patient not admitted to the palliative care service
  - Outpatient at Roswell Park
  - Patient without a diagnosis of cancer
  - Patient that does not have an active MOLST form

Focus Group Study Sample

- Inclusion Criteria:
  - Member of the palliative care team

- Exclusion Criteria:
  - Employee not employed to the palliative care team

Design & Methods

- Qualitative study employed non-probabilistic, purposeful sampling.

- Convenience sample: Adult patients who had an active MOLST form under the inpatient palliative care service and the palliative care team.

- Minimum of 10 patient interviews.

- Continue to achieve point of saturation.

- Setting: Roswell Park Comprehensive Cancer Center.
Design & Methods

Data Collection

- Face-to-face, semi-structured, individual interviews with adult patients solely under the inpatient palliative service at Roswell Park Comprehensive Cancer Center with an active MOLST form.
- Focus group with the palliative care team
- Participant recruitment:
  - Participants will be sought out based on inclusion criteria.

Interview Guide for Patients

1. I understand you have a MOLST form on file. Tell me how this form was originally brought to your attention.
2. Tell me about the time when the MOLST form entered your care.
3. What did you know about the MOLST form prior to filling it out?
4. How did you feel when you were initially asked about the MOLST form?
5. What motivated you to complete the MOLST form?
6. What was the hardest thing you experience when initially completing a MOLST form?
7. Who would you feel comfortable making decisions for you?
8. Have there been any changes to your MOLST form since initial completion?
9. Tell me about your other advance directives.
10. What else would you like to share about the process of filling out the MOLST form?

Data Analysis

- Qualitative data is described as “the classification and interpretation of linguistic material to make statements about implicit and explicit dimensions and structures of meaning-making in the material and what is represented in it” (Merriam & Tisdell, 2016 p. 195).

Focus Group Questions

1. Talk about a situation where you have cared for a patient with a MOLST form.
2. What are your feelings regarding having a MOLST form for all patients admitted to the palliative care service?
3. How does your level of comfort change in caring for a patient with an active MOLST form?
4. What kind of challenges or barriers do you feel hinder the use of a MOLST form for patients?
5. Whose responsibility do you feel it is to initiate conversations and assist a patient to fill out a MOLST form?
6. What else would you like to share regarding your views of the MOLST form under the palliative care service?
Protection of Human Subjects

- Printed informed consent for each participant.
- All identifying participant information was removed to maintain anonymity and confidentiality.
- Survey was given ID number to correspond with patient data.
- Data was protected by the interviewer as the interviewer was the only one that had access to the data.

Scope and Limitations of Project

- Investigated the perceptions of adult patients admitted to the inpatient palliative care service on their perceptions of having a MOLST form.
- Members of the palliative care team were also included in this study.
- Conducted at a single site with a qualitative design that included one-time, face-to-face interviews and focus group.
- Relied on truthfulness of interview participants and self-reports of clinician behavior.
- The study was interpreted in the context of the above limitations.

Patient Interview Results

- Study sample included a total of ten participants.
- All participants were admitted under the inpatient service, were under the care of the palliative team, and had an active MOLST form on file.
- Interviews were conducted one time in a face-to-face manner over a one month period.
- The sample consists of four males and six females.

Patient Interview Results

- Introduction to Form from Institute Staff (n=8)
  - Participants stated that introduction to the MOLST form came from a Roswell Park Comprehensive Cancer Center employee (n = 8).
  - Of these eight participants, three stated that the form entered their care by way of a member of the palliative care department.
  - Three participants had the form brought to their attention by their primary oncologist (at Roswell).
  - Two members stated it was a nurse in the Institute that first discussed the MOLST form with them.
Patient Interview Results

- **Limited Knowledge (n=7)**
  - Participants stated that prior to initial introduction to the MOLST form, they did not know that a form depicting different options for end-of-life care existed (n= 5).
  - Patients stated they knew what the form “was intended to do” and that the form had a box for “Do not resuscitate” (n=2).

- **Positive Perception (n = 7)**
  - Participants acknowledged the difficulty of the realization that the MOLST form was necessary in their care (n = 6), they reported a positive opinion of the MOLST form (n = 7).
  - Allows patients control in their “end-of-life wishes” (n= 6).
  - Alleviates family members of having to make end-of-life care decisions for the patient (n = 2).
  - The form allows participants a sense of control and provides dignity to the patient in their last hours (n=6).

- **Worsening Prognosis (n= 9)**
  - The MOLST form entered care due to worsening prognosis (n=9).
  - The MOLST form entered their care on their current admission within the last 24-48 hours (n=5) and felt it “had to be done before something happened.”
  - Importance of having “wishes known”.
  - Of these nine participants, six went on to explain that their ultimate goal of completing the MOLST form was to avoid being “put on machines.”

- **Updates to the MOLST Form (n = 10)**
  - All participants stated they have not made any changes to their MOLST.
  - It should be noted that several of the participants’ MOLST forms entered their care within 24-48 hours prior to their interview (n =5).
Focus Group Results

- Study sample included a total of 6 participants.
- Focus group consisted of a Nurse Practitioner, two Doctors of Medicine, a Doctor of Osteopathic Medicine, a Palliative Fellow, and a Social Worker.
- Each focus group member was a member of the palliative care team.
- The focus group was a one-time session.

Focus Group Results

- **Caring for a Patient with a MOLST Form**
  - Members expressed their view that it made their consultation easier.
  - Redirects the focus from a form that needs to be completed, to a focus of symptoms management and achieving comfort measures.
  - Forms completed incorrectly.
  - Multiple incomplete MOLST forms.
  - Expressed belief that having a standardized approach to the implementation of the MOLST form would contribute to a reduction in these issues.

Focus Group Results

- **MOLST Form for all Palliative Care Patients**
  - Did not feel that all patients admitted under the palliative care service should have a MOLST form.
  - Large percentage of patient referrals to palliative care are solely for symptoms management.
  - Avoid the inaccurate notion that palliative care equates exclusively to end-of-life care and Hospice referrals.
  - Initiating end-of-life care conversations is a much more natural segue into the process of obtaining a written advanced directive such as the MOLST.

Focus Group Results

- **Comfort Level of Caring for Patients with a MOLST**
  - Clinicians identified a sense of relief.
  - Allow for a full palliative care consult.
  - No longer force a decision of such magnitude on patients because of a situation where “time is of the essence.”
  - Current measures show 50% of patients have a palliative care referral prior to dying, however only 17% of these patients have a DNR in place prior to the admission during which they expired.
Focus Group Results

- Identifying Barriers to Use of MOLST
  - Two recurring themes:
    - Misunderstanding of prognosis
    - Patients fear they will be treated differently
    - Difficult time navigating the “areas of gray.”

Discussion

- Providers and patients reported completing the MOLST form because they “had to do it” given the current situation.
- Patients stated they had no prior knowledge that a form outlining wishes regarding different medical interventions existed.
- The palliative care team identified the need for more healthcare professionals to feel competent in discussing goals of care with patients.
- Findings aligned with the literature that continually shows room for improvement in how often clinicians discuss prognosis and goals of care.

Focus Group Results

- Responsibility for MOLST Form Conversations
  - Unanimously, the group felt that it is the responsibility of all of the hospital staff to create a culture and environment for patient-informed care in efforts to enhance discussions of end-of-life wishes.
  - Cannot expect the primary oncologist to be able to obtain a MOLST form on all patients.
  - Identified the need for training on completing goals of care with patients and how this might encourage more members of the interdisciplinary staff to take part in goals of care and end-of-life care discussions with patients.

Discussion

- The data collected in this study aligns with prior published articles in regards to implementation of MOLST into a patient’s care.
- Research shows that goals-of-care discussions with patients with cancer occur late in the patients’ illness trajectory.
- Participants in this study identified the MOLST form entering their care only within the last 24-48 hours due to significant disease progression.
- Focus group members feel these conversations need to be initiated in the outpatient setting prior to admission to the inpatient setting.
Discussion

- Advanced care planning conversations initiated in the outpatient setting allow patient and their family members the necessary time to plan and have decisive conversations.
- The form will enter the patient’s care while the patient is in a stable state of health and able to fully communicate their wishes without any looming factors impacting the decision.
- Introducing a MOLST form is a process that focuses on person-centered and family-oriented goals for care.

Discussion

- Difficulty in identifying participants at any given time in the institute, as there were very few patients who met the criteria of having documented code status.
- Many patients had only been introduced to the MOLST form for the first time during their current admission, with some participants stating they filled out the MOLST form that day.
- This further supported the need for this study and for a more structured approach to the implementation and use of MOLST forms.
- Future studies should focus on implementing MOLST forms in the outpatient setting to further assess the conversations and perceptions of this particular advanced care directive.

Implications

- Patients will not have to sign a form with the magnitude of the MOLST form in a rushed or pressured situation.
- Alleviating concerns of the staff caring for the patient in instances where the patient’s health status deteriorates.
- Patients with advanced cancer who have advance care planning discussions with the use of a MOLST form achieve better quality of life during the end of life and undergo unwanted medical care less often.
- Building a standardized approach to the implementation of a MOLST form into patients’ care, the institute can have a hospital-wide policy that will allow patients to have their end of life care wishes known in a timely and appropriate manner as well as enhancing the capabilities of the palliative care department to focus on the improvement of quality of life at end-of-life.

References

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