Using Natural Language Processing to Evaluate Electronic Health Records of Patients with Ovarian Cancer for Documentation of Goals of Care

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Loyola University of Chicago Graduate School

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USING NATURAL LANGUAGE PROCESSING TO EVALUATE ELECTRONIC HEALTH RECORDS OF PATIENTS WITH OVARIAN CANCER FOR DOCUMENTATION OF GOALS OF CARE

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDACY FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

PROGRAM IN NURSING

BY
HILLARIE E. JOEHL
CHICAGO, IL
AUGUST 2023
ACKNOWLEDGEMENTS

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Dedicated to my dear friend Judy Lawrence who taught me so much and left us too soon.
You matter because you are you, and you matter to the end of your life.
Dame Cicely Saunders
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<td>ASCO</td>
<td>American Society of Clinical Oncology</td>
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<td>CMS</td>
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<tr>
<td>cNLP</td>
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<td>CNS</td>
<td>Clinical Nurse Specialist</td>
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<td>CUI</td>
<td>Concept Unique Identifier</td>
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<td>CPR</td>
<td>Cardiopulmonary resuscitation</td>
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<td>DNI</td>
<td>Do not intubate</td>
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<td>DNR</td>
<td>Do not resuscitate</td>
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<td>DPOA</td>
<td>Durable Power of Attorney</td>
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<td>ED</td>
<td>Emergency department</td>
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<td>EHR</td>
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<td>EOL</td>
<td>End of life</td>
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<td>HCPOA</td>
<td>Healthcare power of attorney</td>
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<td>ICD</td>
<td>International Classification of Disease</td>
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<tr>
<td>ICRG</td>
<td>Informatics &amp; Clinical Research Group</td>
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<tr>
<td>ICU</td>
<td>Intensive care unit</td>
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<tr>
<td>MDPOA</td>
<td>Medical Durable Power of Attorney</td>
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<td>NCCN</td>
<td>National Comprehensive Cancer Network</td>
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<td>NLP</td>
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<td>POA</td>
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<td>SIC</td>
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Advance Care Planning (ACP). Process of supporting adults in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

Advance Directive (AD). Legal document describing preferences for future care and appointing a surrogate to make health care decisions in the event of incapacity.

Aggressive medical interventions at end of life. Life-sustaining therapies including CPR; mechanical ventilation; dialysis; chemotherapy; radiation therapy; intensive care unit admission; surgery; feeding tubes; imaging; hospitalization; nonbeneficial medications.

Cardiopulmonary Resuscitation (CPR) Directive or Do Not Resuscitate (DNR). Documents preferences to avoid unwanted resuscitation attempts.

Durable power of attorney (DPOA). Legally recognized health care proxy.

Goals of care discussion. Discussion between patient and provider including these topics: understanding of prognosis; decision making and information preferences; prognostic disclosure; patient goals; patient fears; acceptable function; trade-offs; family involvement.

Healthcare power of attorney (HCPOA). Legally recognized health care proxy.

International Classification of Disease (ICD). Diagnosis codes used by health care providers to document diagnoses in patient health care records.

Living Will. Documents an individual’s wishes prospectively regarding initiating, withholding, and withdrawing certain life-sustaining medical interventions. Effective when the patient becomes incapacitated and has certain medical conditions.

Medical Durable Power of Attorney (MDPOA). Legal document that appoints an “agent” to make future medical decisions. Becomes effective only when the patient becomes incapacitated.

**Power of attorney (POA).** Legally recognized health care proxy.

**Primary palliative care.** Non-specialist palliative care.

**Serious illness communication.** Communication between patient with serious illness and provider including discussions about goals of care, ACP, and EOL discussions.

**Surrogate decision maker or health care proxy.** A decision maker that makes medical decisions when the patient becomes incapacitated, and the individual did not previously identify a MDPOA. Most states use a hierarchy system to designate a health care proxy. Some states appoint a proxy that is agreed on by all the interested parties.

(Bernacki & Block, 2014; Lum, Sudore & Bekelman, 2015; Sudore et al., 2017).
CHAPTER I
INTRODUCTION

For hospitalized patients, the primary orientation of healthcare systems is to deliver treatments and interventions to maximize life extension. As long as a patient’s and family’s preferences and goals align with this default orientation, the delivery of care will likely be concordant with the aim to prolong and preserve human life. Yet data show that when people are asked to think in advance about the medical care they desire as they approach the end of their lives, the overwhelming majority choose less aggressive medical interventions, preferring to avoid attempts at cardiopulmonary resuscitation and life-prolonging treatments in favor of a care plan focused on maximizing comfort (Silveira, Kim & Langa, 2010). Unfortunately, when a patient’s goals of care are focused on minimizing time in hospital, maximizing symptom control and comfort, spending time with family, and participating in activities that bring them joy, the healthcare system is less likely to deliver the care that will help them to achieve these goals. In fact, family members who described care their loved one received in their last months of life as inconsistent with patients’ wishes stated there were unmet needs for pain management and concerns with communication (Khandelwal et al., 2017). The implicit goals of cure and life prolongation are assumed by the healthcare system until there is some catalyzing event that results in a need to clarify, establish, and document explicit goals incorporating inherent trade-offs between hopes for life prolongation and supporting quality of life (Edmonds & Ajayi, 2019). Examples of catalyzing events include onset and diagnosis of irreversible conditions like
advanced cancer, progression of disease on treatment for advanced cancer, and loss of basic functions (walking, feeding oneself, swallowing, communicating ones needs). It is at these points along disease trajectories that discussions and documentation of patient goals of care are critical to ensure patients receive healthcare that best matches their preferences.

**Provision of Goal Concordant Care: A Comparison of Two Responses**

Consider the healthcare system’s potential responses to meeting Mrs. Jones, a 78-year-old retired teacher with a diagnosis of stage IV ovarian cancer. Mrs. Jones arrives in the emergency department feeling short of breath, fatigued and exhibiting hypotension. She is admitted to the intensive care unit (ICU) and started on intravenous antibiotics and fluid resuscitation for septic shock secondary to presumed community-acquired pneumonia. Within the first 12 hours of hospitalization, her oxygen requirements escalate from two liters per minute through nasal canula delivery to 15 liters per minute through non-rebreather mask; additionally, her mental status wanes and she is increasingly lethargic. The ICU team is concerned that she is at high risk for worsening hypoxemic respiratory failure and are prepared to intubate and place her on a ventilator.

**Response A**

The ICU nurse, ICU resident, pulmonologist and respiratory therapist meet with Mrs. Jones and speak to her husband by phone. They share their concerns that Mrs. Jones has a life-threatening pneumonia and in order to save her life, they want to intubate and place her on a ventilator. Both Mrs. and Mr. Jones agree with the medical recommendation, and she is promptly sedated, intubated and placed on full ventilator support. Over the next several days, Mrs. Jones develops acute renal failure and refractory shock. In the early morning hours of
hospital day 5, she has a cardiac arrest. The code team performs cardiopulmonary resuscitation (CPR) which is unsuccessful. Mrs. Jones dies in the ICU, surrounded by several nurses, physicians, and the on-call chaplain.

**Response B**

The ICU nurse, ICU resident, and pulmonologist meet with Mrs. Jones and speak to her husband by phone. They share their concerns that Mrs. Jones has a life-threatening pneumonia. They relate that they have also spoken with her oncologist. The Jones’ explain that she has undergone a course of radiation therapy, two years of immunotherapy and six months of chemotherapy, with her most recent imaging showing disease progression to her liver. Through open conversations with her oncologist, the Jones’ understand that she has no further treatments available to slow down her cancer. Mrs. Jones explains that over the past few weeks, she has been able to eat very little and has not left her home except to receive chemotherapy infusions. She has not been able to attend church or spend time with her children and grandchildren, both of which are important to her. The ICU team explains that Mrs. Jones’ pneumonia could get much worse and a decision needs to be made about how to proceed with her care in the event she gets sicker in the ICU. They share their worry that Mrs. Jones is sick enough to die during the hospitalization. They discuss two clinical pathways: 1) place Mrs. Jones on a form of life-support called a ventilator with the possibility that it can extend her life, or 2) initiate more intensive symptom supports like doses of morphine to treat Mrs. Jones’ cough and sensation of breathlessness. They explained that by pursuing the second pathway, her prognosis could be in the range of hours to days. Mrs. Jones clarifies her priority is to spend any remaining time with her family, and values this over having more time alive if that time would only be extended by
going on a ventilator. The ICU team recommends clinical pathway two because it seems most aligned with Mrs. Jones’ preferences. Mrs. Jones and her husband both agree with the medical recommendation, that if Mrs. Jones develops worsening respiratory failure the focus of her care will shift to her comfort with intensive symptom management. This conversation was documented by the nurse, resident, and pulmonologist in their respective electronic health record (EHR) progress notes; the code status was changed from FULL CODE to Do Not Resuscitate/Do Not Intubate (DNR/DNI).

Over the next 24 hours, Mrs. Jones develops more respiratory distress on non-invasive oxygen support and begins to require intermittent doses of morphine to alleviate this distress. Her pastor visits and prays with her and her husband. Her children and grandchildren visit. Hospice care is initiated in the hospital. Mrs. Jones spends more time sleeping, her breathing is non-labored with the continuation of oxygen support and morphine. She dies on hospital day six surrounded by her husband, her granddaughter, and her sister. The family convey their gratitude for the care that Mrs. Jones received and believe it was aligned with her preferences for care.

**Analysis of Goal Concordance**

The different responses to Mrs. Jones’ clinical scenario are clear. In response A, the healthcare team communicates the life-threatening nature of her condition and recommend aggressive interventions to save her life. Alternative actions are not offered, limiting an opportunity for shared decision-making. The patient’s goals, preferences and values are not explored. Prognosis is not addressed. The conversation is not documented in the EHR. The patient dies on a ventilator and undergoes CPR. The family is not present in the patient’s final moments or at the time of her death. In response B, the discussion between the healthcare team
and the patient and her husband includes communication around the seriousness of her medical problems within the context of her advanced cancer. Together they discuss alternate treatment courses including prognostic information, and her values and preferences are explored and considered. Shared decision-making results in a mutually agreed upon care plan that is documented in the EHR through both progress notes and a code status change. Treatments to support physical comfort are provided including hospice services; her family and pastor are present as she is dying; and they express feeling that Mrs. Jones received care consistent with her goals.

Response A demonstrates that without the direction provided through a goals of care discussion, the care provided even to patients with advanced and serious illness is by default focused on attempts to prolong life. Response A is devoid of evidence to inform whether the care Mrs. Jones received was consistent with her care preferences. Response B demonstrates that a goals of care discussion facilitates shared decision-making, establishes a care plan based upon shared understanding of medical context and personal preferences, and provides evidence to support the receipt of goal-concordant care.

Clarification of Concepts

Goals of Care

The concept of goals of care (GOC), while utilized widely by clinicians, researchers and policy makers who intend to provide the best care possible for patients with serious illness, lacks a consensus or operational definition (Stanek, 2017). Goals of care are the agreed on plans for care based on the clinical context and patient-centered values and priorities. While advance care planning (ACP) and the generation of advance directives (ADs) are related and complimentary to
GOC, they are future focused and intended to clarify and document one’s healthcare preferences at a point in their future when they encounter an irreversible condition. GOC are distinctly intended to align real-time treatment decisions with patients’ values and priorities within an existing clinical context.

**Goal Concordant Care**

As an emerging focus in quality and outcome measurements, clinicians and researchers are increasingly striving to deliver and demonstrate high-quality and goal-concordant care (GCC) for seriously ill patients. High-quality care in serious illness aligns treatment with patients’ known goals and values (Sanders, Curtis & Tulsky, 2018). The Institute of Medicine (2015) recommends that all individuals participate actively in decisions regarding their healthcare; that they receive services consistent with their known values; that clinicians initiate conversations; and that they are revisited over time as wishes and circumstances change. The organizations representing hospice and palliative care nursing and medicine use concordance, specifically “care consistency with documented care preferences,” as a quality metric in evaluating care for seriously ill patients (Unroe, Hickman & Torke, 2016, p. 453). GCC occurs when patient receive health care services and interventions in alignment with their values, priorities, preferences, and goals for care. Serious illness communication is a necessary condition to demonstrate care consistency with patients’ documented care preferences. Conversations between patients and clinicians addressing their health conditions and values must first occur to achieve goal concordance.

**Consequences of the Lack of Serious Illness Communication**

Earnest and well-intentioned attempts to cure or prolong life often result in lost
opportunities to provide care that help people and their families focus on what matters most, and may result in unintended suffering (Cassel, 1991). Yet when the healthcare system fails to deliver goal concordant care, medical errors result that are as critical as any other harmful error (Sanders, Curtis & Tulsky, 2018). When patients do not fully understand their illness, prognosis, and treatment options and when clinicians have not sufficiently elicited patients’ values or documented them, physical and psychological suffering worsens (Bernacki & Block, 2014). Inadequate communication about serious illness leads to lower patient quality of life at the end of life, higher use of invasive care near death, shorter hospice stays, worse bereavement outcomes for family and caregivers; and increased costs without benefit to patients (Bernacki & Block, 2014; Wright et al., 2008). Poor quality communication also contributes to clinician burnout (Thorne, Bultz & Baile, 2005).

**Importance of Goals of Care Discussions and Goal Concordant Care**

A growing evidence base supports the benefits of serious illness communication including goals of care discussions and their documentation in the EHR. Patients who discuss end-of-life (EOL) care with their clinicians, especially earlier in their disease trajectory, are more likely to have positive outcomes including better reported quality of life, less distress, and a higher likelihood of receiving care consistent with their preferences (Detering et al., 2010; Mack et al., 2010; Wright, et al., 2008). Decedent patients who participated in at least one billable ACP visit experienced less intensive EOL care as evidenced by fewer hospitalizations, emergency department visits, ICU stays within a month of death, and were less likely to die in the hospital (Gupta et al., 2020). While ACP is not synonymous with goals of care discussions (GOCD), the concepts overlap. Documentation and billing using ACP codes for payment by Medicare are
intended to reimburse clinicians for having conversations that include identification of patients’ values, preferences, and GOC (Jones et al., 2016). Patients who reported having a serious illness conversation including their GOC are more likely to report receipt of goal concordant care (Modes et al., 2019). Conversely, inadequate discussions and/or documentation of the goals of care is an error of omission, and this omission often results in more invasive care than is desired by the patient (Allison & Sudore, 2013; Heyland et al., 2013; Wright et al., 2008). Improving communication and decision making has the potential not only to improve patient-centered, goal-concordant care and reduce harm, but also to reduce healthcare costs (Sinuff et al., 2015).

**Measurement Challenges Associated with Goal Concordant Care**

Goal-concordant care has been prioritized as the most important outcome for ACP by a large panel of experts in a Delphi consensus process (Sudore et al., 2018). However, GCC has also been described as the holy grail outcome; a treasured and elusive quality outcome of interest and the rationale for engaging patients in ACP, serious illness communication and goals of care discussions (Halpern, 2019). Trusted experts in palliative care and serious illness communication question the long-accepted assumption that ACP will result in goal-concordant end-of-life care and recommend the focus of research and clinical efforts on improving current shared decision making between proxies and clinicians (Morrison, Meier & Arnold, 2021).

Researchers describe a variety of challenges to identifying and measuring goal concordant care. GOC change over time; with progression of illness, with different and fewer treatment options, with information shared about prognosis, with decline in function and independence, people with serious illness prioritize differently what is important to them and adjust their healthcare preferences and goals (Ditto et al., 2006; Hopping-Winn et al., 2018).
Researchers conducted a systematic review examining the stability of patient preferences over time. They demonstrated about 20-30% of people in each study changed their treatment preferences, including a change in desire for either more or less aggressive treatments (Auriemma et al., 2014). In order to capture evolving GOC, investigators have stressed the importance of longitudinal assessments of patient goals and preferences, over multiple time points during a hospitalization or ICU stay followed by subsequent measurement of receipt or withholding of preference-sensitive treatments as a means of objective GCC measurement (Turnbull & Hartog, 2017).

**Lack of Documentation**

EHR documentation of GOC serve as an important component of communication relating to patient preferences among care providers to improve EOL care (Sinuff et al., 2015). Even for patients who have expressed preferences, communication with health care professionals and documentation of these preferences is inadequate (Heyland et al., 2013). For patients with serious illness, GOC documentation including critical data, care options, prognosis and medical plan are not reliably recorded in the EHR (Bear & Thiel, 2018). These data give rise to question whether and when GOCDs are happening at all. Without establishing preferences through a GOCD and documenting a patient’s care preferences, determining whether the care provided was aligned with their expressed goals and preferences becomes impossible to determine. This poses another significant challenge in the identification and measurement of goal concordance.

**Accessibility of Documentation**

To measure whether care provided was consistent with preferences, clear, systematic, and standardized formats for documenting preferences must be used (Unroe et al., 2017). Significant
challenges present when attempting to uncover and track recorded care preferences to determine whether GCC was achieved including the variety of EHR products and lack of interoperability across healthcare settings (Institute of Medicine, 2015; Wilkinson, Wenger & Shugarman, 2007; Wilson et al., 2013). This concern is well reflected in a clinician’s pointed question: “It puzzles me that we are so careful in asking about and documenting information about allergies, but we don’t expect the same quality of retrievable, reliable information when it comes to conversation about care goals and values. How can that be?” (Lamas et al, 2018, p. 522). Specific treatment preferences, for example “no dialysis,” may be documented in a provider progress note but can be difficult to locate at a later time when relevant to patient care. Providing and assessing for GCC are inherently compromised when documented care preferences are inaccessible. This presents challenges both in the moment when clinical decision making is necessary, and retrospectively from a research lens or outcomes evaluation. The methods for retrospectively determining whether GCC is achieved rely upon the documentation of concrete, specific, and relevant information about care preferences. Additionally, the treatment preferences need to be relevant to an actual treatment decision. For example, if the only documented treatment preference is code status, preferences around artificial nutrition and dialysis, for example, are unknown if a patient experiences loss of consciousness and renal failure.

**Methodologic Challenges**

Whether goal-concordant care is achieved at end-of-life is one of the most challenging constructs to measure (Sanders, Curtis & Tulsky, 2018). Obtaining the patient’s opinion on whether the care they receive is aligned with their goals, especially as they die is even more challenging as patients lose capacity to engage with this question. Even when capacity is
preserved, few choose to spend their last days participating in research studies. Within the clinical research environment, the patients’ perception of whether the care they are receiving is goal concordant was assessed but in a population of patients with prognosis of approximately two years life-expectancy, arguably not the EOL population of interest (Curtis et al., 2018). When experts were asked, they preferred a bereavement measure of goal concordance by which family or surrogate decision makers (SDMs) are surveyed to report on whether their deceased relative received preference aligned EOL care (Sanders et al., 2020). This type of measurement relies upon proxy-reporting and does not directly reflect the perspective of the patient themself. The inclusion of reports from family members or SDMs who are often unprepared, uncertain, or incorrect about patient goals poses a challenge to the validity of this type of measurement (Majesko et al., 2012; Torke et al., 2014). Retrospective interview and survey data from family and SDMs risk introduction of both social desirability and recall bias, making these proxy measures of GCC potentially less valid (Turnbull & Hartog, 2017). Additionally, response rates of bereavement surveys have been low in some settings, limiting the utility of this type of measurement (Bernacki et al., 2019). Experts have also suggested consideration of patient experience measurement constructs as means of assessing goal concordance. They prioritized constructs that assess patients’ valuation of how well the care team understands their priorities and adequately supports their decision making (Sanders et al., 2020). Presently there are no psychometrically valid research instruments or quality measures that assess patient experience in this manner.

**Study Aims**

Establishing and documenting patients’ goals of care in the electronic health record
(EHR) is an essential means of communication that guides delivery of patient-centered healthcare. The EHR documentation of GOCDs identify patient values, preferences, and goals that can be used to analyze whether patients receive healthcare consistent with their established goals – whether they receive goal-concordant care. Assessing and measuring for receipt of goal-concordant care relies on retrospective chart review and survey instruments, which present both analytical and collection challenges. Experts in the measurement of serious illness communication agree that the EHR is an underutilized source of data and consider natural language processing a novel measurement strategy for the study of large unstructured data sets (Sanders et al., 2020). Before undertaking the research of measuring for goal concordance within the EHR, a helpful contribution to advancing the science is first to identify whether and how patients’ goals, values, and preferences are documented.

The research question addressed by this study is:

Does use of a novel NLP methodology to query structured and unstructured data within the EHR uncover documentation of patient values, goals and preferences that clarify or describe patients’ goals of care?

The aims of this study include:

1) Identify concept unique identifiers (CUIs) that reveal patients’ values, goals, and preferences documented in the EHR.

2) Sort, investigate, and describe documentation of goals of care including any differences or variability within documentation or its timing based on select variables.

A review of the literature addressing discussion and documentation of goals of care for patients with serious illness will be presented in the following section, chapter 2.
CHAPTER II

REVIEW OF THE LITERATURE

Chapter 2 is a focused review of relevant literature, providing background, context, and current state of the science around goals of care discussions (GOCD) for patients with serious illness. Key terms and concepts are defined, the conceptual frameworks guiding the study are presented, GOCDs and their impact are explored, and the challenges in measuring and evaluating concordance of identified goals with healthcare delivery are described. Interventional studies aimed at increasing the frequency of addressing GOC are presented. Patients with a diagnosis of ovarian cancer are offered as an important patient population about whom little is known regarding the documentation of their goals of care toward EOL, warranting further study. Finally, analysis of electronic health record (EHR) data using natural language processing (NLP) and research supporting this methodology are presented as means to describe and evaluate goals of care documentation for patients with ovarian cancer.

Defining Key Terms and Concepts

Advance Care Planning

Advance care planning (ACP) is the process of considering and communicating health care values and goals over time, regarding future healthcare (Lum, Sudore & Bekelman, 2015). A consensus definition describes ACP as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” (Sudore et al, 2017, p. 826). ACP includes the activities of communication,
documentation of communication, choosing and preparing a health care agent, and completion of legal documents including advance directives.

**Advance Directive**

Advance directives (AD) are legal documents describing preferences for future care and appointing a surrogate, or agent, to make health care decisions in the event of incapacity (Lum, Sudore & Bekelman, 2015). Examples of ADs include durable power of attorney for health care (DPOAHC), also known as a health care proxy or health care power of attorney (HCPOA); living will and orders for life-sustaining treatment (Walter, 2021). A living will prospectively documents a person’s wishes regarding initiating, withholding and withdrawing certain life-sustaining interventions, and is effective only when the person becomes incapacitated and has a terminal condition. Orders for life-sustaining treatment is a portable order set (transferable between health care settings) that translates patient preferences for life-sustaining therapies into medical orders.

**Serious Illness Communication**

Serious illness communication (SIC) occurs between a patient (and/or family, surrogate decision maker, health care agent) with serious and life-threatening illness and a healthcare provider and may include advance care planning, breaking bad news, prognostic information, discussions about goals of care and end of life discussions. These discussions are not just for the very end of life but for care throughout the course of serious illness (Bernacki & Block, 2014). Illnesses are defined as serious when they convey a high risk of mortality and contribute to negative effects on patient or caregiver quality of life (Sanders et al, 2020). The most common clinical conditions relevant to serious illness communication include cancer, congestive heart
failure, chronic obstructive pulmonary disease, chronic or end-stage renal disease, and advanced neurologic illnesses like dementia and Parkinson’s disease. Serious illness communication is intended to be an iterative process in which providers periodically check in with patients and their loved ones to convey health updates or revisit the risks, benefits, and alternatives of treatment options throughout a patient’s disease course. Ideally these discussions occur earlier in the illness, both in outpatient environments and continue during hospitalization or crisis situations (Jain & Bernacki, 2020).

**Goals of Care**

Explicit goals of care (GOC) are described as the establishment of agreed on, desired health expectations that are appropriate, documented and communicated. These goals are formulated through the thoughtful interaction between a person seeking medical care and the healthcare arena (Stanek, 2017). GOC are informed by physical, social, spiritual, or other person-centered values (Weissman & Meier, 2011). *Explicit GOC are distinct from implicit health care goals (cure and life prolongation) that are the presumptive or default goals until a catalyzing change in health condition occurs. Explicit goals are inherently personalized, and discussions commonly begin once the health care team, patient or family perceive the burdens of treatments are outweighing their benefits or when the patient experiences a critical decompensation. GOC are further clarified as the overarching aims of medical care for a patient that are informed by patients’ underlying values and priorities, established within the existing clinical context, and used to guide decisions about the use of or limitation on specific medical interventions (Secunda et al., 2019). Figure 1 illustrates the incorporation of patient and clinical components into GOC.*
The phrases GOC and ACP are commonly used interchangeably. For the purposes of this study, these terms have distinctly different definitions. Implied within the phrase itself, ACP occurs prospectively, in advance of serious illness, regardless of health status, and is intended to elucidate general patient preferences about health scenarios that may occur in the future. ACP is preparation and planning done in advance of serious illness. And as Morrison (2020) argues, the data around ADs and ACP do not support continuing funding of research efforts to demonstrate their linkage to provision of goal concordant care (GCC). Rather Morrison (2021) suggests the focus of research should be on different models of decision making that might include helping patients and proxies make better in the moment and real time decisions rather than planning in advance.

GOC reflect values, priorities and preferences and guide the provision of care within the context of a patient’s active diagnoses and current healthcare context. GOC influence and help guide in the moment decision making about provision or avoidance of specific interventions and treatments that may become imminently relevant, for example during a current hospitalization (Morrison, Meier & Arnold, 2021). GOC may change over time as patients reprioritize what matters most, particularly with progression of their disease, limitations in available treatment options, changes in their functional abilities and in consideration for the lives of their loved ones.
Conceptual Frameworks

This section of the paper describes the four conceptual frameworks that guide this study. The first three frameworks address key themes, variables, outcomes and organizing principles of serious illness communication and decision making centered around patient preferences, values, and goals. They support and guide selection of the key operational variables that will be studied; this is addressed in more detail in chapter 3. The final conceptual framework addresses the theoretical underpinnings of the methodologies used in the proposed study.

Framework 1: Improving End-of-Life (EOL) Communication and Decision Making

The conceptual framework for improving EOL communication and decision making describes the nonlinear process and communication activities used to inform decisions about treatment options at the EOL, including identification and documentation of goals of care (Sinuff et al, 2015). In Figure 2, the framework illustrates the relationships among ACP, goals of care discussions (GOCD), documentation, and the health care system that supports these processes. This framework also identifies specific elements of structure, processes, and outcomes of care related to EOL communication and decision making.
The Sinuff framework provides a macroscopic view of the inter-related concepts of ACP and GOC including the structures within which they take place, the processes and activities involved and the desired outcome – provision of care that is consistent with a patient’s values and goals. This model suggests documentation sources to be examined in the EHR – both unstructured sources including documented conversations about values, wishes and preferences, and structured sources including practitioner orders for life-sustaining treatment (POLST).

**Framework 2: Relationship Between Communication and Goal-Concordant Care**

Sanders, Curtis and Tulsky (2018) describe a conceptual model that illustrates the relationship between high quality communication and GCC. Their model, shown in Figure 3, suggests that clinician-patient communication improves patient and caregiver experience, enables shared decision making, and mediates GCC. It offers candidate quality measurement
domains for serious illness communication in both research and practice. The authors describe how communication in serious illness comprises four mutually reinforcing processes: information-gathering, information sharing, responding to emotion and fostering relationships. Information gathering includes the uncovering of a patient’s (or surrogate’s) understanding of the clinical context of their illness, as well as their goals, values, and preferences. Information sharing includes provision of health information including diagnosis, prognosis, and likely outcomes, as well as the clinician’s treatment and care plan recommendations. The communication components represented in this model reflect elements of GOCDs. It provides important direction for the inclusion of key words and phrases that describe GOC-related terms found within narrative content of the EHR, descriptors of data that will guide analysis, as well as target documentation sources like ADs.

Figure 3. Conceptual Model of the Relationship Between Communication and Goal-Concordant Care

Note. Taken from Sanders et al., 2018, p. S-21.
Framework 3: Organizing Framework of Advance Care Planning Outcomes

Methodological variations and weaknesses in ACP research have prevented meaningful comparisons between past studies or synthesis of their findings, demanding standardization of methods (Johnson et al., 2018). Addressing the lack of standard research variables and outcomes in serious illness communication and ACP, the organizing framework of ACP outcomes systematizes overarching ACP outcome domains and describes outcome constructs within those domains intended to direct future studies to utilize consistent variables and measures across studies (Sudore et al., 2018). The intent of the framework is to support future research that is pragmatic, accessible and translates to practice. The framework, illustrated in Figure 4, suggests moderator variables such as patient demographics that may influence the effectiveness or change the strength of an effect or relationship between two variables. The unit of analysis refers to identifying the outcome construct at the patient, surrogate, clinician, or by administrative data at the healthcare system level. ACP-specific action outcomes measure an individual’s completion of specific components of ACP such as a GOCD or documentation of a surrogate or care preferences. Quality of care outcomes measure the impact of ACP on quality of care such as care consistent with goals, also described as goal concordant care. The authors acknowledge the many challenges in measuring the outcome of GCC, recommending that future studies determine how best to define and assess for it. Finally, health outcomes measure the impact of ACP on outcomes including health status and healthcare utilization. In the framework, Sudore and colleagues point to key ACP outcome domains and constructs for use in operationalizing and defining key variables for future study.
Figure 4. Organizing Framework of ACP Outcomes

Note. Taken from Sudore et al., 2018, p. 248.

Framework 4: Relationship of data, information, knowledge, and wisdom and automated systems

Included in the American Nurses Association Nursing Informatics: Scope and Standards of Practice is a conceptual framework for using data and describing its relationship to generating nursing knowledge and wisdom (American Nurses Association, 2015; Englebardt & Nelson, 2002). The model was augmented by Nelson (2018), which describes the relationship of data, information, knowledge, and wisdom and automated systems. Seen in Figure 5, Nelson’s model demonstrates that as interactions and interrelationships increase among the key concepts, complexity also increases. This study is centered at the overlapping interrelationships between the concepts: Data (naming, collecting, organizing) and Information (organizing, interpreting).
Goals of Care Discussions

Clinicians commonly initiate goals of care discussions (GOCDs) when current therapies are not working or there has been a significant decline in a patient’s condition. A GOCD occurs between a patient (and/or family surrogate or proxy) and a clinician during which the following key elements should be addressed: understanding of prognosis, decision making and information preferences, prognostic disclosure, patient values and goals, patient fears, acceptable function, trade-offs, family involvement and patient-centered care plan recommendations (Bernacki & Block, 2014). GOCDs are a type of serious illness communication involving the patient’s
current medical context and relevant decision making as they approach EOL. This section of the chapter presents key elements and methods for conducting GOCDs and their documentation.

**Essential Elements and Methods for Conducting GOCD**

A recent systematic literature review found no validated tools to assist providers in completing or documenting GOCD (Myers et al., 2018). Experts in serious illness communication recommend that clinicians having GOCDs start these conversations by discussing prognosis, exploring patient values, attending to emotion, and then using this information to develop a plan with the patient or their surrogate decision maker (Bernacki & Block, 2014; Childers et al., 2017). Various methods have been put forth offering guidance for conducting GOCDs – two are described here.

**REMAP**

A useful framework or talking-map for both teaching and conducting GOCDs was developed with the mnemonic, REMAP: Reframe, Expect emotion, Map out patient goals, Align with goals, and Propose a plan (Childers et al., 2017; VitalTalk). The first step in REMAP is to provide both the new information and its meaning to the patient that reframes the clinical context into a bigger picture. Most patients will have an emotional response to hearing this news. REMAP encourages clinicians to both expect the emotion and respond empathically with reflective statements, allowing the patient to feel heard and to help them process their emotions.

The next step in REMAP moves the conversation toward a plan by first stepping back to explore the patient’s values before discussing therapeutic choices. The clinician should explore what matters most, their concerns, their fears, and any prior experiences that may shape how they think about their health care. Once the clinician has a thorough understanding of the patient’s
values, they align by reflecting back what they’ve heard their patient say, including any ambivalence. Aligning with goals and values is an opportunity for the clinician to reflect and summarize, and to further clarify what’s most important. In the last step of the REMAP framework, if the patient is willing to hear it, the clinician proposes a plan of care they believe has the best chance of maximizing the patient’s values and goals within the context of what is medically feasible. If there seems to be agreement with the proposed plan, exploring and clarifying what questions the patient has ensures that by the conclusion of the conversation, there is common understanding about next steps and the path forward.

**Serious Illness Conversation Guide (SICG)**

The SICG was similarly developed as part of a serious illness communication training program to foster, improve upon, and guide clinicians to have quality GOCDs (Bernacki & Block, 2014). The SICG functions as checklist and guide, providing a structure for the clinician to lead a meaningful, valuable, and important conversation. The SICG delineates a step-wise process during which the clinician addresses key concepts including: Understanding (what the patient understands of their illness), Information preferences (quantity and type of information helpful to patient), Prognosis (sharing of prognostic information), Goals (uncovering most important things to patient if health worsens), Fears/Worries (exploring biggest fears/worries about their health), Function (define critical abilities for patient’s quality of life), Trade-offs (clarify what patient is willing to undergo for possibility of longer life), and Family (how much family knows about priorities/wishes).

While both REMAP and SICG intend to support quality serious illness communication and identification of patient’s goals and values, there are two key differences: 1) The last step of
REMAP includes the planning step during which shared decision-making results in a mutually agreed upon plan of care between the patient and their healthcare team, and 2) SICG functions both as guide and template for documenting the discussion.

**Documentation of GOC**

At the conclusion of GOCDs, clinicians should establish a timeframe for subsequent check-in conversations with the patient and communicate the pertinent details and any outcomes of the meeting to all relevant health care team members. Quality communication importantly includes documenting the process and outcomes of GOCDs in the health record to ensure that all current and future care team members have access to this information (Jain & Bernacki, 2020). Documentation should include a list of those who participated in the conversation (both virtual and in-person) and a general summary of the encounter (Baran & Sanders, 2019). Inclusion of direct quotes helps illustrate the patient’s goals, values, and priorities that may inform treatment decisions.

Just as ACP is an iterative process, so too are GOCDs. These conversations occur throughout the course of serious illness and the resultant documentation of these discussions is housed in the EHR, sometimes in the form of an order for life-sustaining treatment document, a written AD, and/or a narrative note describing the discussion. It is argued that the ability of clinicians to find documentation of GOCDs is as important as their occurrence. This is especially important in the inpatient setting, where team-based care is common and long-term clinician-patient relationships are the exception (Steiner, Morse & Lee, 2020). If documentation of prior conversations are retrievable, they can be harnessed during future encounters, incorporating prior GOCDs into decision-making for acutely ill patients (Childers, White &
Arnold, 2020). When a critically ill patient with prior EHR GOCD documentation is brought to the emergency department (ED) in respiratory distress, the ED clinicians can utilize the documentation of the patient’s previous care discussions and decisions as a starting off point for a more focused and targeted emergency care planning discussion, instead of having to start from the beginning. The prior documentation can save valuable time by bringing the ED clinicians quickly up-to-date and can spare the patient energy and psychological distress from having to repeat themselves.

**Goals of Care: A Clinical Buzz Phrase**

Goals of care are not necessarily addressed or documented when the phrase *goals of care* is used in documentation without presence of the essential or key elements of a GOCD. In a study analyzing the clinical discourse in progress notes within the EHR, clinicians used the phrase GOC extensively in their documentation to indicate poor prognosis, to describe conflict with families, or to provide rationale for limitations on specific medical interventions (Kruser et al., 2019). Use of the phrase GOC was typically used only after there was documentation in the EHR acknowledging the “failure to achieve physiologic goals” (p. 788). An example of this is the following documentation: “Need to discuss GOC.” In this instance, the use of GOC does not represent the occurrence of a GOCD, rather the clinician author suggests the importance of addressing GOC in their documentation. The notation represents the author’s clinical suspicion or worry of future clinical deterioration, a professional hint or clinical buzz phrase that someone ought to have a GOCD with the patient or family (Klement & Marks, 2020). Therefore, when clinicians document the phrase *goals of care* in their clinical narrative, this phrase alone does not represent a GOCD and should not be credited as such. The necessary operational elements that
define the presence of GOC in clinical documentation are elucidated further in chapter 3. And the mere presence of the clinical buzz phrase goal of care is specifically not included and does not alone represent the presence of documented GOC.

**GOCD: Barriers and Facilitators**

This section of the chapter presents identified barriers to and facilitators of GOCDs. Barriers to GOCDs are divided into three main categories: Clinician-related barriers, healthcare system barriers, and patient-related barriers. Clinician and patient descriptions of GOCD facilitators are described.

**Clinician-Related Barriers**

Most published data around clinician barriers to GOCDs comes from qualitative studies of physician participants, specifically oncologists. Though two of the studies sampled a broader array of clinicians including nurses, advance practice nurses, and rehabilitation therapists.

**Protective Nature of Clinician-Patient Relationship**

In semi-structured interviews, oncologists revealed barriers to effectively communicating about EOL concerns with their patients: The challenge of balancing hope and reality, both respecting patients’ emotion and desire for longevity, in most cases, while also disclosing important information like prognosis and what to expect with their cancer (Granek et al., 2013). As part of a qualitative analysis of a communication support program, patients with advanced cancer reported their perceptions that the oncologist “was afraid or reluctant to initiate [GOC] discussions or provide prognostic estimates,” both elements important to these conversations (Walczak et al., 2015).
In a cross-sectional online survey, oncologists and oncology support staff described their perception of both patient and family discomfort as barriers to discussions (Chandar et al., 2016). This concern for suffering was cited by oncologists in another study, wanting to avoid the perceived infliction of harm (Robinson, 2017). Oncologists recognize the vulnerability of their patients and expressed concern that ACP discussions may increase fear and anxiety, as well as disrupt hope.

**Lack of Adequate Communication Training**

Oncologists explained that they had received no formal training or tools on how to discuss EOL issues with patients, describing this as “a significant barrier to effective communication” (Granek et al., 2013, p. e132). In another qualitative evaluation of serious illness conversations with patients with advanced cancer, clinicians were challenged by discussing prognosis and had difficulty in responding to emotional or ambiguous patient statements (Geerse et al., 2019). The authors suggested these deficiencies may be a result of limited training and thus confidence and experience in having these discussions with their patients. Physicians’ needs for training and support for GOCDs was similarly affirmed by more than half of the participating oncologists through focus group or individual interviews (Robinson et al., 2017). The need for education was echoed in a large, cross-sectional online survey in which 30% of the interprofessional team members expressed need for provider training in SIC (Arnett et al., 2017).

Clinicians miss opportunities to facilitate shared decision-making regarding GOC (Sharma et al., 2019). In their qualitative analysis of audio recorded GOCDs with hospitalized patients with advanced cancer, when discussing code status clinicians missed opportunities to
engage patients in information exchange to achieve a shared understanding of clinical context and to confirm the patient’s decision or choice. When discussing disease-modifying treatments like chemotherapy and hospice, clinicians failed to integrate patient preferences or make patient-centered recommendations. Their findings stress the importance of quality and completeness of GOCDs and the training necessary for clinicians to have high quality conversations.

**Avoidance**

Another barrier to EOL communication as described by oncologists is their focus on cure and overtreatment, described as “death-defying mode,” and thereby avoiding engagement with patients about planning for EOL. They also referenced their own frustrations when other physicians avoid having conversations with their patients (Granek, 2013). A culture of “shared avoidance” was revealed during analysis of semi-structured interviews of an interprofessional team of neuro-oncology clinicians (Llewellyn et al., 2018). They described the conditions for mutual avoidance: 1) difficulties being highly emotive in a time-intensive practice requiring the right ‘window of opportunity’; 2) challenges due to inexperience and lack of training with having structured conversations; and 3) outside one’s responsibilities, that SIC would be better if done by someone other than oneself.

**Healthcare System Barriers**

Healthcare systems are replete with clinicians, administrators and advanced technologies intended to provide, facilitate, and coordinate healthcare. Yet system barriers exist, making provision of streamlined and patient-centered care more challenging. Several system-related barriers to discussing GOC are discussed here.
Lack of Time

Time pressures, limiting clinicians’ ability to dedicate time for serious illness conversations, are widely reported as barriers (Sanders, Robinson & Block, 2016). Lack of time is cited by oncologists and oncology support staff as a barrier to having GOCDs with their patients (Chandar et al., 2016; Nedjat et al., 2017; Schulman-Green et al., 2018). This same concern, “lack of time for discussions” was noted by all interviewed providers; especially in relation to outpatient appointment time slots as brief as twenty minutes (Dillon et al., 2017, p. 7).

In a more recent study, lack of time or the misperception that discussing GOC with patients with advanced cancer requires significant time, is refuted as a barrier to conducting GOCDs. After receiving communication skills coaching to facilitate GOCDs, oncologists completed high-quality GOCDs (as rated by patients) during post-imaging visits in median time of 15 minutes (Pintova et al., 2020). Surprisingly, the length of the visit did not differ between high-quality GOCDs from those rated as lower in quality, suggesting that encounter times are similar regardless of whether the patients perceive a high-quality conversation. The results of this study affirm that with proper training, a GOCD can be completed without jeopardizing clinical workflow.

Shared Responsibility

There is a lack of consensus of whom is responsible for these conversations among healthcare providers, which can lead to role confusion, and incomplete or a complete void of SIC. In semi-structured interviews, patients with metastatic breast or gynecologic cancers reported communicating with various oncology clinicians (social workers, nurse practitioners, and oncologists) about SIC; those who named multiple clinicians were more likely to have
completed an AD, while they did not identify an individual clinician who took charge of the process (Clark et al., 2017). Not surprisingly, in busy outpatient oncology centers where a multitude of clinicians interface with patients, clinicians express uncertainty about who should lead and take ownership of GOCDs (Dillon et al., 2017). In a purposive sample of oncology chaplains, social workers, nurses, and physicians, most providers (64%) said it was partially their role to initiate these discussions (Nedjat-Haiem et al., 2017). A pertinent quotation from one clinician exemplifies this phenomenon of ambivalence, acknowledging responsibility without taking ownership: “I feel like it’s my role, but I don’t feel ownership over it, like other people shouldn’t do it…because I feel like it’s 100% my responsibility to do it, but it’s okay if other people do it too” (p. 311).

Electronic Health Record Design, Interoperability, and Workflow

Clinicians express general frustration at the lack of efficient, effective, and useful systems in place to facilitate, store, and retrieve the products of their serious illness conversations. Prominent barriers include electronic health record (EHR) design and lack of interoperability (Dillon et al., 2017). Clinicians note the real difficulties, and lack of standardized workflows, locating previously completed ADs and POLST forms that set limits on future aggressive medical treatments. Of the 118 inter-professional responders to a survey regarding clinical routines, system processes and policies related to SIC, 54% responded no, or unknown, when asked if GOC-related documents are systematically available/transferrable to another health care setting; 62% did not have, or did not know if they had, guidelines or policies (Arnett et al., 2018). Widespread clinician frustration was regrettably validated by the results of a cross-sectional study conducted in a large, urban Veterans Affairs Medical Center, that described
documentation practices and accessibility of GOCDs in the EHR (Walker et al., 2018). Most (55%) of the discussions were not easily accessible, even when expressed care preferences had changed. The grave patient safety concern is that patients are put at increased risk for receiving unwanted aggressive treatments at EOL because of systems that make retrieval of important information about their documented care preferences laborious, time intensive, and often impossible.

**Clinical Momentum Hijacks Opportunity for Timely Goals of Care Discussions**

Kruser, Cox and Schwarze (2017) introduce a novel concept, clinical momentum, that describes system-level practice patterns that strongly influence the provision of patient care. They describe the phenomenon of clinical momentum as a cascade of effects triggered by an inciting event, such as the automatic linking of an abnormal clinical sign or diagnosis and an intervention. Once triggered, multiple subsequent interventions proceed along a cascading path, rather automatically, without anyone stopping to consider alternative actions. Clinical momentum influences patients, families, and clinicians to accept or tolerate ongoing interventions without consideration of likely outcomes, bypassing opportunities to consider patient preferences through GOCDs, eventually leading to potentially unwanted treatment near end of life. The most vivid examples of clinical momentum’s influence occur in intensive care units where deteriorating critically ill patients are maintained on multiple forms of life support before there is consideration for having a GOCD. Chapple (2018) further explains that clinical momentum is “housed within sets of powerful cultural forces at work in the US health care system,” including ritual intensification of interventions, reimbursement patterns that reinforce continued technology-driven interventions, and a phenomenon she describes as actor network
theory in which the mere existence of a technology invokes its use (p. 733). Chapple adds yet another cultural force influencing clinical momentum, the notion that forgoing a technological intervention is viewed as doing nothing versus doing something – giving up versus giving the patient a fighting chance. The phenomenon of clinical momentum and existing cultural forces hijack opportunities for thoughtful consideration of the care plan, discussion of person-centered values and goals, and the shared decision making necessary to pause or retard the ongoing cascade of interventions that default to the most medically aggressive to prolong life. Clinical momentum serves as a barrier to holding GOCDs.

**Patient Related Barriers**

Hospital-based clinicians perceive family member- and patient-related factors as the most important barriers to having GOCDs (You et al., 2015). In this multicenter survey of nurses, internal medicine residents and staff physicians, interdisciplinary clinicians affirm the importance of their participation with seriously ill patients in GOCDs though cite several impediments to having them. The most consistently cited family member-related and patient-related factors impeding GOCDs were difficulty accepting a poor prognosis, difficulty understanding the limitations and complications of life-sustaining treatments, disagreement among family members about GOC, and patients’ incapacity to make GOC decisions. Clinicians perceived their own skills and system factors as less important barriers, though lack of time and language barriers were reported to limit GOCDs.

In a single center study in which oncology clinicians (physicians, residents, nurses, and advanced practice nurses) were surveyed about barriers to GOCDs, results were very similar (Piggott et al., 2019). The oncology clinicians reported the most important barriers to GOCDs
were patient and family factors: family members’ difficulty accepting poor prognoses, lack of
family agreement in the GOC, difficulty understanding the limitations of life-sustaining
treatments, lack of patients’ capacity to make decisions, and language barriers. Oncologists from
a broad array of practice settings who participated in semi-structured interviews expressed
additional patient-related barriers to conducting GOCDs (Schulman-Green et al., 2018). These
barriers to GOCDs include patient religion, patient culture, and patient denial.

**Patient Ambivalence and Avoidance**

As part of a lay patient navigator initiated GOCD program, lay patient navigators shared
the challenges they experienced with patients through semi-structured interviews that were
categorized thematically (Niranjan et al., 2018). “Fear of dying and consequently avoidance of
preparation for death was frequently and foremost in patients’ minds and led to reluctance in
having conversations” (p. 72). They encountered many patients pursuing cancer therapies with a
goal of life-prolongation, in “battle mode against cancer,” with hopes and plans to continue
cancer-directed therapies; preferring not to engage in discussions about EOL (p. 73).

While patients with advanced cancer reported interest in participating in goals
discussions, often motivated by prior experience with a loved one’s EOL and concern for their
family, many cited timing as a barrier; stating it was “too early” for such a conversation
(Walczak et al., 2015). In their special communication on best practices, Bernacki and Block
(2014) note patients’ desire to protect their family members as a barrier to ACP communication.

When patients receiving cancer-directed treatments through outpatient medical oncology
clinics were asked when they preferred to have EOL discussions, nearly half of the 203
respondents said when their cancer became incurable; and only 6.9% felt it should happen at
initial diagnosis (Waller et al., 2018). Yet these same respondents also indicated they wanted to write down their wishes in an AD (81.8%); and to appoint a HCPOA (90%); indicating conflicting and ambivalent desires.

In a randomized study of patients with heart failure who had GOCDs with their clinicians, patients identified their top barrier to having a GOCD as wanting to focus on staying alive rather than talk about death, and their top facilitator to having GOCDs was worry about quality of life in the future (Doorenbos et al., 2016). Despite the patient-reported preference to avoid GOCDs and their worry about their future, these same patients did not report significant evidence of psychological distress from these discussions.

In a qualitative exploration using semi-structured interviews, seriously ill patients valued the opportunity to discuss their preferences and GOC (O’Connor et al., 2020). Having a say and being heard were identified as important themes, with some expressing feelings of control and empowerment, being able to articulate what they wanted; being active rather than passive. Some stressed that stating their preferences would reduce the burden of decision-making on others. Like the results of the aforementioned study of heart failure patients, several patients with serious illness stated they were not ready to die and would prefer to focus on living provided there was reasonable quality of life; some were not ready or comfortable to have GOCD, describing death as unknown and scary and instead preferring to avoid a discussion. Others reported they had not previously talked with their family or general physician, assuming they would know the patients’ preferences. Patient-reported barriers to GOCDs included the provider’s poor communication skills or inexperience, the feeling that the provider had their own
agenda rather than focusing on the patient’s needs and preferences. Additionally, the lack of a private, quiet environment, without interruption negatively influenced the patient’s experience.

**GOCD Facilitators**

Schulman-Green and colleagues (2018) reported on oncologist-perceived facilitators of GOCDs from semi-structured interview data. Oncologists described having more ease with initiating GOCDs for patients with poor functional status, for patients with high health literacy, and when their families have both understanding and acceptance of a poor prognosis. Oncologists with more practice experience and with supportive practice environments including a strong palliative care service were also described as positively influential in conducting GOCDs with their patients.

A prominent theme revealed by a large convenience sample of interprofessional survey respondents regarding SIC was the importance of the involvement of different interprofessional team members to successfully facilitate these conversations in the clinic setting (Arnett et al., 2017). This diverse sample of clinicians stressed the value of involving multiple clinicians who interface with patients and families to support successful conversations. Longitudinal and trusting relationships with patients were also reported by lay patient navigators to promote the occurrence of such discussions (Niranjan et al., 2018).

The important theme of rapport and trust with providers was echoed by oncology patients through semi-structured interviews about communication with their clinician (physician or nurse practitioner) (Bires et al., 2018). They spoke positively about their interactions and felt the clinicians valued their needs and wishes. Patients also expressed appreciation when clinicians “took the lead” initiating the conversation and provided relevant medical information
(p. 1143). Through semi-structured interviews with seriously ill patients, O’Connor and colleagues (2020) describe that patient-reported facilitators of GOCs include the positive approach of the clinician, the clinician’s ability to normalize the topic, avoiding medical jargon, and spending time with the patient. Physicians affirmed the importance of developing rapport with patients in opening discussions (Johnson et al., 2016).

**Low Prevalence and Variable Quality Documentation of Goals of Care Discussions**

The findings of studies presented in this section demonstrate the low prevalence and variable quality of documentation of GOCs. In a prospective cohort study of patients diagnosed with stage IV lung or colorectal cancer, oncologists documented GOCs with only 27% of their patients, evaluated by manual chart review (Mack et al., 2012). And despite most of these patients desiring to have discussions earlier (as reported in patient and surrogate interviews), the majority of GOCs and discussions of EOL preferences did not occur until approximately one month before the patient’s death, and were frequently done by inpatient clinicians other than the oncologist.

Canadian authors studied outpatient clinical notes of patients receiving first-line palliative chemotherapy for metastatic pancreas or lung cancer to identify documentation of discussions of prognosis and GOC by chart review (Raskin et al., 2016). The content and quality of documentation was evaluated as poor, with only 4% of patients with documentation of GOC, and 64% of patients with documented discussion of their prognosis.

In a more recent retrospective study, researchers manually reviewed and qualitatively coded both structured and unstructured EHR data for documented GOCs of hospitalized patients with stage IV cancer (Ernecoff et al., 2021). They found that 42% of patients had EHR-
documented GOCDs. The EHR-documented discussions frequently described communication of cancer progression (89%), though rarely sharing of prognosis (22%). The narrative text often included patients’ goals and values (83%), and at least one treatment decision (82%), including about cancer treatment, hospice, resuscitation, or intensive care. Less than half (42%) of patients received recommendations from their provider that were documented, and rarely were their emotional or spiritual concerns addressed (15%). Ernecoff also found that use of a documentation template significantly increased the likelihood of documented GOC (80% vs. 61%, p < 0.01).

In a secondary qualitative analysis of outpatient visits audio-recorded between patients with stage IV cancer (life expectancy of less than one year) and their oncologist, only 5% of encounters included a GOCD (Knutzen et al., 2021). And in a random sample of 93 encounters, 38% included missed opportunities to address GOC and EOL concerns. Instead, oncologists responded inadequately to patient concerns about disease progression or dying, used optimistic language by discussing best case scenarios without addressing other possibilities in response to patient concerns, or expressed concern when patients opted to discontinue cancer treatment.

**GOCDs Associated with Lower Costs and Less Aggressive Healthcare Utilization**

Several studies presented here reveal positive associations between the occurrence of GOCDs and lower costs and utilization of healthcare as evidence by the following metrics: future acute care costs, average monthly expenses, days spent in hospital, receipt of critical care, hospital readmissions after 30 days, hospice use, and in-hospital deaths. Future acute care costs and healthcare utilization were evaluated in this secondary analysis of a retrospective cohort study, specifically comparing seriously ill patients who participated in GOCDs done as part of
inpatient palliative care consultation (PCC) encounters with propensity-matched patients without GOCDs (Starr et al., 2020a). There were significant differences between White patients who had GOCDs and those without in 30-day readmissions (10.2% vs. 16.7%, p < .0001), number of future days spent hospitalized (3.7 vs. 6.3 days, p < .0001), and accumulated mean future acute care costs ($8,095 vs. $16,799, p < .0001), resulting in an average reduction of $8,704 per patient. Similarly significant decreases in future costs and utilization were not seen with Black patients, though lower costs and less acute care use was demonstrated without reaching significance.

In a related study, the same authors performed a separate secondary analysis of the same retrospective cohort of seriously ill patients, this time to compare enrollment in hospice at discharge between patients with and without GOCDs as part of inpatient PCC encounters (Starr, et al., 2020b). The findings demonstrate that patients who participated in GOCDs as part of PCC were more likely to access hospice services after hospital discharge. Black patients were 15 times more likely to enter hospice after having in-hospital GOCDs than Black patients without GOCDs (36.5% vs. 2.4%, p < .0001); and White patients were 14 times more likely to enter hospice after having in-hospital GOCDs than White patients without GOCDs (42.7% vs. 3.0%, p < .0001).

As part of a robust systemwide prospective trial of the Serious Illness Care Program, Lakin and colleagues (2020) present an analysis of secondary expense outcomes for decedent seriously ill patients, comparing those who did and did not have GOCDs in primary care clinic. For patients in intervention clinics, seriously ill patients who had GOCDs had significantly lower
average monthly expenses compared to patients without GOCDs in their last 6 months ($6,297 vs. $8,876, p = .0363) and 3 months ($7,263 vs. $11,406, p = .0237) of life.

Apostol and colleagues (2015) conducted a cohort study describing patients’ and families’ perceptions of GOCDs and comparing health care utilization outcomes of patients who did and did not have discussions. Of the enrolled hospitalized patients with advanced cancer at risk for critical care interventions, 39% had reported GOCDs (study group). Patients/families reported their needs and goals were addressed moderately to quite a bit during the meetings. Study group patients were less likely to receive critical care (0% vs. 22%, p = .003) and more likely to be discharged to hospice (48% vs. 30%, p = .04) than the control group. More control group patients died in the hospital compared to those in the study group (17% vs. 3%, p = .08).

**Challenges in Measurement of Goal Concordant Care**

Goal concordant care (GCC) is the high-quality care that aligns treatments with patients’ known goals and values (Sanders, Curtis & Tulsky, 2018). GCC is the highest priority outcome for serious illness communication and advance care planning, while ironically described as a holy grail (Sudore et al., 2018; Halpern, 2019). Despite the positive associations demonstrated by the prior studies comparing the occurrence of GOCDs with both lower costs and less aggressive healthcare utilization, the science evaluating associations of GOCDs with individual patients’ receipt of high-quality care in alignment with their preferences is very challenging. This section will explore the measurement challenges around GCC.

A range of conceptual and practical challenges to measuring GCC have been reported. Turnbull & Hartog (2017) describe how measurement of GCC may require data on patient goals and preferences at multiple time points, and subsequent measurements to evaluate provision of
GCC at the level of the individual. They also describe various measurement reliability concerns including the use of next of kin as a proxy primary source, asked to report on the experience of their loved one. Turnbull & Hartog (2017) describe how next of kin may feel unprepared or uncertain to function as proxy reporters of a patient’s experience, increasing the risk of recall and social desirability biases in retrospective GCC assessments. Similarly, Halpern (2019) highlights conceptual barriers including need to establish baseline patient goals, capture of goals that change over time, and difficulty aligning goals with treatment experience. Heyland and colleagues (2017) have commented that patients’ expressed goals may be aspirational but not achievable, further complicating the pursuit of measuring for goal concordance. Several studies including those described here have operationalized GCC, but the field still lacks a gold standard or ideal method for GCC measurement, significantly limiting the evaluation of interventional studies in serious illness communication.

**Studies Evaluating Goal Concordance**

Studies evaluating goal concordant care were discovered using a combination of a PubMed search and review of references lists from relevant articles. Using the search term “goal concordant care,” PubMed was queried for clinical trials of adult populations, with full text available, published in the last five years. The resulting PubMed list of 19 publications was further scrutinized for studies evaluating goal concordance near end of life for patients with serious illness. The 4 relevant studies are presented in this section.

In a cluster randomized clinical trial of the serious illness care program (SICP) in outpatient oncology for patients with advanced cancer (SICP trial described elsewhere in this chapter), the investigators attempted to measure the intervention’s impact on GCC by matching
responses on a non-validated survey instrument (Life Priorities Survey, LPS) previously completed by decedent patients (n=278) against a Family Perception survey, completed by a family member pertaining to the patient’s final week and final 3 months of life (Bernacki et al., 2019). For surviving patients, their LPS survey was compared against self-reported measures included in the study. On the LPS, participants rated their life priority goals on a scale of 1 (not important) to 5 (very important); they also ranked their top five priorities from the same list. The LPS included the following goals: live as long as possible, no matter what; be at home; be physically comfortable; be mentally aware; not be a burden; be independent; have my medical decisions respected; provide support for family; be spiritually and emotionally at peace; and other. The results for the trial of this communication quality improvement intervention were null for GCC, meaning there were no significant differences found between the intervention and control groups in evaluation of GCC. In another publication, this same research group reflected on their null finding for GCC (Sanders et al., 2020). They describe how patient ratings of priorities were commonly incongruent with their rankings. Sanders and colleagues learned that ratings clarify how many things matter to patients, while rankings can better determine what matters most. They postulate that “rankings are more likely to help assess the degree to which care is goal concordant but may be best augmented by corollary measures that signal achievement of a given priority” (p. 889). The Bernacki study demonstrates some of the complexities in attempting to measure GCC.

In a descriptive cohort study of next of kin of decedents (n=715) who died at 65 years or older in an integrated health system, investigators used a non-validated survey to measure next of kin perception of GCC (Glass et al., 2021). Response rates for return of surveys were low, from
25-32%. Respondents reported that 80-90% of decedents had discussed preferences with next of kin, filled out an AD, or gave real thought to the care they desired. Respondents noted that high percentages of decedents received treatment that was concordant with their desires: 88.9% had their wishes met, 82.5% believed they received the right amount of care, and 5.9% received treatment they did not want. This study suggests that most decedents received care concordant with their wishes, as reported by proxy, but does not directly measure the patient experience. As Turnbull & Hartog (2017) suggest, proxy reports introduce uncertainty into measurement of patient goal concordance.

Using the Health and Retirement Study, a nationally representative, longitudinal cohort of adults over 50 years old, Haines et al. (2019) sampled the decedents’ family who completed a post-death interview on average approximately 12.6 months after the death (n=1175 respondents). The primary outcome of interest was proxy reported GCC using the proxy’s response to the question: “Thinking about their experiences with the health care system over the past year, how often were their preferences for care taken into account: never, sometimes, usually or always?” Receipt of GCC was defined by the authors as proxy responses of usually or always. As reported by their proxy, GCC was received by 76% of decedents. Again, while family experience is a worthwhile study outcome, it may not reflect the patient experience and therefore is a questionable measure of GCC, especially when measured more than a year post-death.

In a secondary analysis of patient enrollment surveys from a cluster-randomized trial of outpatients with serious illness (Jumpstart-Tips trial described elsewhere in this chapter), Modes and colleagues (2020) matched responses of their prioritized health care goal with the focus on
their current medical care to define receipt of GCC. Of the 405 patients with a prioritized health care goal, 58% reported receipt of GCC, 17% goal-discordant care, and 25% were uncertain of the focus of their care. For patients who prioritized extending life, 86% reported GCC; while for those who prioritized relief of pain and discomfort, only 51% reported GCC. Seriously ill outpatients who prioritized a goal of relief of pain and discomfort were more likely to report goal-discordant care than patients who prioritized extending life (relative risk ratio 22.20: 95% confidence interval 4.59, 107.38).

Lastly, a mixed methods study used both a post-mortem follow-back survey of next of kin of decedents (n=601) and in-depth interviews of next of kin (n=51) to characterize decedent wishes for care at EOL and to examine next of kin narratives to inform whether wishes were honored (Bandini et al., 2021). Next of kin responses to a survey question “Did your family member have specific wishes or plans about the types of medical care he or she did not want at the end of his or her life?” defined decedent care preferences. And responses to “Did the staff providing care to your family member do anything that went against his or her wishes?” defined goal-discordant care. Among those with stated wishes, 10.9% reported that the decedent received care that went against their wishes. The main theme from interview data revealed the primary reason that next of kin stated wishes were not honored was due to poor pain and symptom management, resulting in lack of comfort at EOL.

In these studies that attempt to measure GCC, there is not a consistent means of measurement among them and while creative, none of the investigators describe using a validated and reliable measurement tool. Similarly, each study uses a different means of defining GCC. All but two used a single means of measurement, while both Bandini and colleagues and
Bernacki and colleagues used two means of measurement. The results from Modes and colleagues and Bandini and colleagues, describing receipt of goal discordant care associated with prioritizing comfort are not surprising given the default priority of healthcare is pursuit of life extension. The results further demonstrate the need for translational research in this area to bring about the improvements necessary for provision of GCC, and the avoidance of unwanted, aggressive care at EOL. As suggested by Ernecoff et al. (2021), future insights on the measurement of GCC may come from triangulation across methods of measurement, with improvement in EHR application and documentation, and through natural language processing and machine learning to improve EHR queries and capture nuance for research purposes.

**Goals of Care Interventional Studies**

Studies evaluating goal of care interventions were discovered using a combination of PubMed searches and review of references lists from relevant articles. Using the search terms “goals of care,” “serious illness communication,” “goals of care conversation,” and “goals of care discussion,” PubMed was queried for clinical trials of adult populations, with full text available, published in the last five years. The resulting PubMed list of 42 publications was further scrutinized for studies evaluating interventional efforts to increase GOCDs for patients with serious illness.

The following section presents 15 interventional studies intended to increase the frequency and improve the quality of goals of care discussions for patients with serious illness. The first set of studies evaluate how communication skills training of providers influences GOCDs. In the following two sections, research is reviewed on the effectiveness and impact that comprehensive and system-wide practice change interventions have on documentation and
quality of GOCDs. Lastly, studies of interventions intended to prime or prepare patients and clinicians for GOCDs are evaluated.

**Communication Skills Training Impact on GOCDs**

In a randomized controlled trial involving solid tumor oncologists (intervention group n=11, usual care group n=11) and patients with newly diagnosed advanced cancer with less than two years life expectancy (n=265), Bickell and colleagues (2020) evaluated whether communication training using a coaching model to teach oncologists to elicit patient values for GOCDs would improve communication skills and increase the prevalence and quality of discussions. Pre- and post-training audio recordings of communication skills were rated by experts in serious illness communication on seven elements. Prevalence and quality of GOCD outcomes were assessed through patient perception surveys about their most recent post-imaging visit. Teaching intervention group oncologists to elicit patient values improved their skills to have GOCDs (from pre-intervention score 27% to post-intervention score 55%) compared to usual care oncologists (9% to 0; p = .01). The skills training did not increase the prevalence or quality of GOCDs between groups as perceived by their patients (global odds ratio, 0.84: 95% CI, 0.57 to 1.23).

In a similar study, a single-blind randomized controlled trial, Annadurai and colleagues (2021) tested a GOC communication skills coaching intervention based on the VitalTalk model. Practicing solid-tumor oncologists caring for advanced cancer patients from four different hospitals were randomized to intervention (n = 22) or usual care (n = 11). All oncologists received a one-hour didactic training during oncology grand rounds, presented by a trained VitalTalk facilitator. The intervention included additional training: an experiential learning
model that used a two-hour role-play and four individualized coaching sessions to further practice eliciting patient values intended to “promote alignment of treatment received and patients’ goals and values” (p. 839). Three blinded coders evaluated recorded encounters before and after the intervention using a validated tool to assess skill attainment. Post-intervention, intervention oncologists were significantly more likely to elicit patient values (55% vs. 0%; p = .01), suggesting that communication skill acquisition can occur even with less time-intensive training compared to the standard two-day VitalTalk course.

Robertson et al. (2021) conducted a randomized controlled trial to evaluate the preoperative GOC and code status discussion skills of anesthesiology resident trainees. The intervention group of trainees received communication skills training by watching a novel video curriculum and the non-intervention group was provided journal articles covering topics on communication strategies pertaining to GOC and code status discussions. Objective structured clinical examinations (OSCE) with standardized patients were scored both before and after skills training. The video formatted communication skills training led to significant increases in resident performance during simulated GOCDs with mean scores of 4.19 compared to 3.79 (OR 0.85, 95% CI 0.34-1.36), p = .002. These trials demonstrate that communication skills training is associated with improved GOCD communication skills. This is valid when the intervention is as simple as watching a novel video curriculum, and for more sophisticated trainings using the VitalTalk model. Each of these studies show significant skill acquisition though use different measures for analysis.

**Effectiveness of Comprehensive Efforts to Increase and Improve GOCDs**

The Serious Illness Care Program (SICP) is a system-level care delivery model created
by palliative experts that combines communication tools, clinician training, and system supports intended to increase and improve serious illness conversations between clinicians and patients with serious illness about their goals, values, and priorities to inform their care (Ariadne Labs, 2021). Many studies have been published describing the impacts of the SICP, featuring implementation of the previously described Serious Illness Conversation Guide (SICG) in various populations and settings; several are highlighted in this document. Paladino and colleagues (2019) conducted a cluster randomized clinical trial in outpatient oncology clinics involving providers (physicians and advance practice clinicians) and patients with cancer at high risk of death, evaluating the SICP on documentation, timing, quality, and accessibility in EHR of GOCDs. The robust SICP intervention involved 2.5-hour skills-based training and support to providers to use the SICG in patient encounters. Patients were given a pre-conversation letter introducing SICG and their families were provided a family guide, outlining how to continue SICs after clinic visits. System changes were also made as part of the intervention including patient identification prompts to providers, email reminders to providers, creation of a SICG documentation template in an accessible ACP module in the EHR, and coaching on use of the SICG by palliative care faculty was also available to providers by phone, email, or in person. Compared to the usual care patient group, manual EHR review after intervention and patients’ dates of death showed a significantly higher proportion of had documented GOCD compared with controls (96% vs. 79%, p = .005), and intervention GOCDs occurred a median of 2.4 months earlier (median, 143 days vs 71 days, p < .001). The documentation was significantly more comprehensive, patient-centered, and with greater focus on values or goals (89% vs. 44%, p < .001), prognosis or illness understanding (91% vs 48%, < .001), and life-sustaining treatment
preferences (63% vs. 32%, p = .004). The intervention group documentation was also significantly more accessible in the EHR (61% vs 11%, p < .001).

Ariadne research partners published a secondary analysis of the original study by Paladino and colleagues (2019), assessing concordance between documentation and audio recordings of GOCDs, and evaluating adherence to the SICG (Geerse et al., 2020). Two researchers independently compared audio recordings with corresponding EHR documentation, both narrative and EHR template notes. Providers were well-adherent to the SICG, addressing 87% of the conversation elements, though documentation was fully concordant with the audio recording only 43% of the time. Most conversations (64%) were documented using the EHR template, a minority (28%) in narrative notes, and only 8% were not documented.

Lakin et al. (2017) conducted a nearly identical study to Paladino and colleagues (2019) with the following differences: primary care clinics were the targeted settings; the involved clinicians included physicians, nurse care coordinators, and social workers; and the intervention clinics and comparison clinics were conveniently selected from primary care clinics with high volumes of patients at risk for dying within two years. Deceased patients from intervention clinics were significantly more likely than deceased patients from comparison clinics to have GOCDs documented in the EHR (62.4% vs. 42.9%, p = .002) including discussion of values and goals (44.4% vs. 3.0%, p < .0001). There were no significant differences between intervention and comparison groups in those who accessed hospice before death.

Lally et al. (2020) conducted a quality improvement project in which a modified version of the SICG was used in nursing assessments by nurse case managers trained in geriatric assessment and GOCDs for community-dwelling adults with serious illness. Every three
months, nurse case managers were prompted by the EHR to utilize the modified SICG in routine telephone patient encounters. After receiving training and use of the modified SICG, they showed substantially increased rates of documentation of GOCDs from 33% of patients in the first month, to 86% of patients having documented GOCDs in the EHR by the twelfth month of the program.

In yet another project involving use of the SICG, a retrospective chart review was published describing GOCDs for patients with the novel coronavirus (SARS-CoV-2) known as “COVID-19” seen by an inpatient palliative consultation service. Reidy et al. (2021) describe how their health system mandated the assessment of COVID patients’ GOC within 48 hours of hospital admission, and how they felt the hospital-based clinicians were prepared to meet this mandate given prior training and embedded practice patterns using the SICG including a dot phrase/structured template in the EHR to document GOCDs. They report nearly all (97%) patients with COVID-19 had GOCD documentation in the EHR within 48 hours of admission. Remarkably, palliative clinicians did not lead the majority of the GOCDs, rather they were conducted by a variety of clinicians including social workers, nurses, physicians, and advanced practice providers.

The Veterans Health Administration’s (VHA) Life-Sustaining Treatment Decisions Initiative (LSTDI), another enterprise-wide project involving novel and comprehensive staff training, standardized EHR documentation tools, monitoring and information technology tools to support and enhance proficiency of GOCDs, is described in a published report by Foglia and colleagues (2019). Initial results are presented in a retrospective observational study evaluating completion of life-sustaining treatment (LST) templates of all veterans with VHA utilization over
a seven-month period (Levy et al., 2021). Among 5,576,279 veterans, LST templates were documented for 108,145 veterans. Higher rates of completion were associated with veterans with highest risk for hospitalization and mortality (OR 8.61, 95% CI 11.99-13.10), and with veterans with a stay in a VHA nursing home (OR 14.5, 95% CI 14.12-14.97).

Gradwohl and colleagues (2019) report on a sequential, multicohort design of a yearlong mentored implementation approach supporting non-palliative care clinicians (nurses, physicians, advance practice providers, social workers, chaplains, and other clinical staff), including 29 different hospital teams, in both communication skills training to have GOCDs and implementing site-specific interventions to promote GOCDs. Specific projects varied by hospital as did the results, however they reported increases in GOCD documentation, life-sustaining treatment order completion, new screening and documentation methods, and increased support from leadership. After project completion, the majority (89%) of hospitals continued efforts to expand GOCD initiatives either by training new staff and/or developing new GOC education modules.

**Novel and Comprehensive Intervention Increases GOCDs**

In a single site, randomized clinical trial, Patel et al. (2018) describe how a longitudinal structured coaching and ongoing support model is effective in an outpatient oncology setting. Lay health workers were formally trained (80-hour online training and 4-week clinical observation of a palliative team) to serve as liaisons and provide support to older adults with advanced cancer through a systematic protocol that involved a series of twice-monthly telephone and in person conversations over a period of six months during which time they discussed GOC and ACP. Within six months of enrollment, patients randomized to the intervention had much
greater documentation of GOC in the EHR by an oncology clinician than control group (92% vs. 17.5%; p < .001). The intervention group also demonstrated larger increases in satisfaction with care (difference-in-difference, 1.53; 95% CI 0.67-2.41, p < .001), greater hospice use (76.7% vs. 48.3%, p = .002), fewer emergency department visits (mean [SD], 0.05 [0.22] vs. 0.60 [0.76], p < .001), fewer hospitalizations (mean [SD], 0.05 [0.22] vs. 0.50 [0.62], p < .001), and lower costs (median [interquartile range], $1048 [$331-$8522] vs. $23482 [$9708-$55648], p < .001) than patients in the control group.

**Priming Interventions Increase GOCD Occurrence**

This multicenter cluster-randomized trial in outpatient primary care clinics targeting physicians or nurse practitioners and patients with a qualified serious illness was designed to evaluate a patient-specific pre-conversation communication priming intervention (Jumpstart-Tips) and its effect on GOCDs (Curtis et al., 2018). Jumpstart-Tips first surveyed patients to identify their preferences, barriers, and facilitators for communication about EOL care. Based on their responses, an algorithm was used to create an abstracted version of their preferences, identify the most important barrier or facilitator, and provide communication tips based on VitalTalk methodology (VitalTalk). A 1-page Jumpstart-Tips was sent to the clinician days prior to the patient’s target clinic visit. One week prior to this visit, patients also received a patient-specific one-page Jumpstart-Tips summarizing their survey responses and recommendations for discussing GOC with their clinician. The intervention was associated with a significant increase in patient-reported GOCDs (74% vs. 31%; p < .001), increased EHR documentation (62% vs. 17%; p < .001), and increased patient-rated quality of communication (4.6 vs. 2.1; p = .01). In their invited commentary about this intervention, Paladino and Bernacki (2018) highlight that
personalized, actionable information at the point of care increases the likelihood that communication will occur and inspires the conversation to happen earlier, before inevitable crises arise.

A secondary analysis of the initial Jumpstart-Tips study examined three methods to assess occurrence of GOCDs at a primary care visit: patient report, clinician report, and documentation in the EHR (Modes et al., 2019). Self-reported surveys completed by patients and clinicians two weeks after a clinic visit assessed for occurrence of a GOCD. Documentation of a GOCD was abstracted from the EHR. Clinicians reported GOCD at 66% of visits, patients reported at 52% of visits, and EHR documentation occurred in 42% of visits. Patients who reported having had GOCDs were also more likely to report receipt of goal concordant care ($\beta$ 0.441, 95% CI 0.190-0.692, $p = .001$). The authors demonstrate methodologic challenges in measuring serious illness communication; highlight that patient-clinician pairs may not have a shared understanding of what constitutes a GOCD; and hypothesize that without a streamlined, standardized, and centralized location in the EHR to document GOCD, clinicians may be less likely to document them.

In a single-blind cluster randomized clinical trial, Hanson and colleagues (2017) evaluated a GOC decision aid intervention in nursing home settings for dyads of persons with advanced dementia and their family decision makers. The intervention for the family decision makers consisted of an 18-minute GOC video decision aid, a print copy of the decision aid and guide, plus a structured discussion with the nursing home team (nurses, social workers, therapists, and dieticians). The decision aid provided information on dementia; descriptions of life prolonging care, care supportive of patient function, care intended to improve comfort; and
how to prioritize care goals. To prepare the nursing home staff, investigators gave a one-hour training session during which they 1) watched the video-decision aid, 2) reviewed principles for family communication, 3) observed a role-play of a GOCD, and 4) received a written discussion guide. They also received reminders from the research staff to meet with decision makers. Differences in documentation of GOC in treatment plan notes between GOC intervention and control groups were significant, with greater GOC documentation at six months (91% vs. 42%, p < .001), and at nine months (95% vs. 52%, p < .001) in the intervention group. The GOC intervention group also achieved better quality EOL communication ratings from the family decision maker, with longitudinal improvements in ratings over the course of the study.

In a randomized study conducted in an academic, outpatient heart failure (HF) clinic, Doorenbos and colleagues (2016) tested a GOC intervention in patients with a diagnosis of advanced HF and their HF clinicians including physicians, nurse practitioners, cardiology and HF fellows, and nurses. Patients in the intervention group received 1) telephonic pre-visit coaching by a nurse addressing patient perceived communication barriers and facilitators with their cardiology providers, education about standard HF therapies, patient communication preferences about EOL care, and guidance to complete an AD document, 2) a 1-page activation outline of personalized information summarizing the pre-visit telephonic encounter, and 3) patient-centered recommendations and demonstrations to help initiate a GOCD with their HF provider. The HF provider intervention included 1) a personalized patient activation outline summary, 2) patient-specific mortality estimates, and 3) communication tips relevant to the patient’s identified barriers and facilitators. Providers were asked to conduct a GOCD at the next clinic visit with corresponding documentation in the EHR. The study resulted in significant
increases in GOCDs in the intervention group compared to usual care using both patient self-report and documentation in EHR (73% vs. 2.6%, p < .001), and higher quality of EOL communication (F = 5.09, p = .03). Of note, despite the significant increase in GOCDs in the intervention group, there was not an increase in HF patients’ anxiety or depression which affirms prior research that patient participation in GOCDs does not promote psychological distress.

While the interventional studies presented here all demonstrate how GOCDs can be encouraged, their frequency increased, and that the requisite communication skills are learnable, significant challenges remain in reproducing and scaling these interventions in the variety of regions, systems, conditions and with the persons that populate the healthcare domain. Interventions involving the SICP and VHA LSTDI programs are both massive and comprehensive undertakings involving time-intensive skills training of clinicians, system-wide EHR improvements and modifications, and ongoing support available to clinicians. The Jumpstart-Tips and outpatient HF program priming interventions are similarly complex, utilizing the support of highly skilled research staff to facilitate priming. And lastly, the intervention involving intensely training a lay healthcare worker who provided ongoing communication and support to patients over many months may be equally if not more challenging to reproduce. These interventions provide a window into the complexity of the problem, and how investment in sophisticated, thoughtful, robust, and sustainable solutions will be required to improve person-centered care for patients with serious illness.

GOCD in Patients with Ovarian Cancer

Of the gynecologic cancers, ovarian cancer is the most lethal (National Cancer Institute, 2021). Understood to be a silent killer, ovarian cancer is often diagnosed at an advanced stage
owing to its vague symptomatology; therefore, treatments are directed at life prolongation and palliation rather than cure (Jayson et al., 2014). As of 2018, ovarian cancer is the eighth most common cancer worldwide in women, with around 300,000 new cases diagnosed each year (World Cancer Research Fund, 2021). In the United States, there are over 21,000 new cases of ovarian cancer diagnosed, and nearly 14,000 deaths related to ovarian cancer annually. Women of all ages are affected by ovarian cancer, though it is most diagnosed in women between the ages of 55 and 64 years (NCI, 2021). Unfortunately, over 70% of ovarian cancers are not diagnosed until the disease has reached stage III or IV (Stewart, Ralyea & Lockwood, 2019).

Relative survival data demonstrate that only 49.1% of women diagnosed with ovarian cancer will still be alive five years after diagnosis (NCI, 2021).

Despite the advances in therapeutics including tumor debulking surgery, chemotherapy, new monoclonal antibodies and multidisciplinary care, the majority of women with ovarian cancer diagnosed with advanced disease will eventually develop recurrence, become resistant to platinum chemotherapy agents, and receive palliative treatments (Cliby et al., 2015; von Gruenigen et al., 2018). Women with advanced ovarian cancer suffer considerable physical and emotional symptoms that negatively impact their quality of life. The most common disease-related symptoms include fatigue, pain, abdominal problems, worry about worsening condition, and trouble sleeping. They also experience distressing treatment side effects, especially nausea and hair loss (von Gruenigen et al., 2018). Additionally, many women with ovarian cancer receive aggressive care in the last month of life, characterized by intensive care unit admissions, hospitalizations, repeated emergency department visits, and health care transitions (Mullins et al., 2021; Wright et al., 2014).
The American Society of Clinical Oncology issued consensus guidelines for core clinician communication with a strong recommendation that clinicians address patients’ goals and priorities to inform treatment decisions (Gilligan et al., 2017). Similarly, the clinical practice guidelines in oncology developed by the National Comprehensive Cancer Network state that patients and their families should be asked about their personal goals, priorities, and expectations for treatment (Dans et al., 2021). There is a paucity of research describing or evaluating serious illness communication between clinicians and patients with ovarian cancer including EOL discussions and GOCDs describing values and preferences. Lopez-Acevedo et al. (2013) conducted a retrospective manual review of health records for women who died of ovarian cancer (n=220), describing the prevalence, timing, and setting of documented EOL discussions. EOL discussions were broadly defined as a documented discussion with the patient during which any of the following was mentioned: comfort care, resuscitation status (DNR), and hospice. One hundred seventy-seven (80%) patients had a documented EOL discussion; the median interval time between EOL discussion and death was 29 days. The occurrence of an EOL discussion at least 30 days before death was associated with a lower incidence of several quality indicators: receipt of chemotherapy in the last 14 days (1% vs. 12%, p = .003), more than one hospitalization in the last 30 days (3% vs. 27%, p < .001), ICU admissions in the last 30 days (3% vs. 16%, p = .005), dying in acute care setting (3% vs 13%, p = .001), and hospice admission less than 3 days (2% vs. 11%, p = .02). An EOL discussion at least 30 days before death was also associated with decreased healthcare utilization: lower likelihood of being hospitalized in the last month of life (18% vs. 89%, p < .001), longer hospice enrollment (53 vs. 11 days, p < .001), and fewer invasive procedures in the last month of life (13% vs. 59%, p <
.001). Even without evidence that these discussions considered patient values and goals of care, the occurrence of any EOL discussion was associated with higher value, less intensive, and more comfort-focused care near end of life. Regrettably, in gynecologic malignancies including ovarian cancer, GOCDs are happening late, if at all (Davidson, Havrilesky, & Lefkowitz, 2021).

In a focus group of women who had ovarian cancer, 100% of participants identified communication with their provider as an essential element in determining treatment plans (Frey et al., 2014). Yet only 14% of patients reported having a discussion about their goals, values, and perceptions prior to making treatment decisions. Participants desired an individualized approach to cancer care, focused on how anti-cancer treatments impact their quality of life, as opposed to hearing their clinicians use common research outcome terminology such as progression free and overall survival in describing expectations for their cancer treatment (Frey et al., 2014). Importantly, when ovarian cancer survivors are involved in decision-making about their treatment, it is associated with better quality of life (Andersen et al., 2012).

These data reinforce the importance of conducting EOL and GOCDs with patients dealing with ovarian cancer. The paucity of research around goals of care in the ovarian cancer population warrants further study. Patient values and priorities are crucial to decision-making processes between patients and clinicians as treatments are planned, evaluated, and augmented along the course of illness. Without exploration and clarification of their goals of care, provision of care that is both patient-centered and aligned with patients’ preferences is only achieved by chance. In their editorial, Davidson and colleagues (2021) reinforce and expand on the critical role GOCDs have in the development of high-value care plans for patients with ovarian cancer, declaring, “what we should be striving for near the end of life is goal-concordant care, focused
Electronic Health Record: Untapped Data Repository

Measuring serious illness communication quality and outcome variables including GOC has until recently been dependent on manual chart review or use of survey instruments that present analytical and collection challenges, respectively (Sanders et al., 2020). The electronic health record (EHR) is an underutilized source of existing and ever-growing data for palliative care research and novel measurement strategies, including natural language processing and machine learning, that are beginning to show promise as powerful research tools (Bush et al., 2018).

EHR Offers Opportunities

The EHR is a comprehensive record of clinical and administrative data on all individuals cared for within health care systems, containing information about both intended healthcare and actual healthcare. It offers a repository with vast size and depth to support analyses of specialized clinical care and assessments of important subgroups of patients, such as those with serious illness (Curtis et al., 2018). EHR data are recorded directly from documentation of healthcare delivery and utilization without requiring additional data entry on top of what is required for routine care. Additionally, the EHR is a key component of effective serious illness communication because it offers the opportunity for both centralized and context appropriate access to the most up-to-date information and discussions (Wilson et al., 2020). The EHR captures social determinants of health, which are important for provision of high-quality, accountable care for seriously ill persons (Adler & Stead, 2015).
EHR Presents Challenges

Coupled with the strengths of the EHR as a critical database for future research, it also has important limitations. Information captured from the EHR reflects care documented, not necessarily care delivered or care perceived by patients and families since documentation is solely performed by clinicians. GOCDs highlight this potential mismatch. While clinicians may report having these discussions with patients, they may fail to document them, their documentation may not reflect the actual communication, or they document them in ways that are not readily accessible (Mack et al., 2012; Moody et al., 2004). The contrary may be true, that aspects of care are documented in the EHR but were not delivered (Dimick, 2008). The common phenomena of the “copy and paste” feature and documentation duplication make it difficult to determine how many GOCDs truly occurred (Hammond et al., 2003). Another commonly encountered challenge both in clinical care and research is that even if all serious illness communication, GOC and ACP discussions are documented, the relevant data may be buried within other events or inappropriately filed making it virtually irretrievable or inaccessible to the clinician and researcher (Wilson et al., 2020).

The collection of EHR data are used for a wide range of purposes and may compromise its validity for use in quality and accountability. These purposes include documentation of care delivery, communication between clinicians, billing, care coordination, quality improvement, and administrative reporting (Curtis et al., 2018). With each purpose idiosyncrasies in the data are introduced that may weaken its reliability and validity. An example of this is the use of acknowledgement forms that most health systems require patients complete indicating they were asked about ADs, as required by the Patient Self-Determination Act (Teno et al., 1997). These
forms are often erroneously uploaded into the same data field under which actual copies of ADs are filed, causing confusion, and making it difficult to determine what the record holds. Lastly, the lack of interoperability between EHRs of different healthcare systems and vendors creates challenges in standardizing research methods for data collection and analysis (Mandl, Khorasani, & Kohane, 2012).

**Natural Language Processing**

Expression of natural language through narrative clinical notes in the EHR is an essential form of communication within healthcare. Relative to the generically coded and structured data elements, narrative notes provide a detailed and personalized record of patient histories and evaluations, and they provide the context for clinical decision making (Rosenbloom et al., 2011). Manual abstraction and classification of this free-text, narrative data is time-consuming, prone to human error, and difficult to execute at scale (Lucini et al., 2021). Natural language processing (NLP) is a subfield of artificial intelligence that studies the ways in which the analysis and synthesis of information expressed in a natural language can be automated (Spasic & Nenadic, 2020). NLP is more simply described as computer identification of phrases within electronic records (Udelsman et al., 2020).

The feasibility of NLP has been shown to unlock evidence buried in clinical narratives, making it accessible for large-scale analyses by automating abstraction and classification of free-text, unstructured data (Spasic, Uzuner & Zhou, 2020). NLP has enabled the secondary use of EHRs to analyze patient data, advance research, and better inform clinical decision making (Sheikhalishahi et al., 2019). NLP is being used by investigators within oncologic research in the areas of case identification, staging, and outcome determination (Yim et al., 2016).
Researchers are using machine learning technology to evaluate EHR data for proactive identification of hospitalized patients who would benefit from palliative care consultation (Avati et al., 2018). Another research group built a predictive machine learning model to predict patients in need of inpatient palliative care consultation and was integrated into practice to refer new patients to palliative care services (Murphree et al., 2021).

Machine learning is the scientific discipline that focuses on how computers learn from data. It occurs at the intersection of statistics, which seeks to learn relationships from data, and computer science, that utilizes efficient computing algorithms (Deo, 2015). Deep learning is a subset of machine learning, where data representations are adaptively learned by computer systems instead of fed directly into the program (Chan et al., 2019). Deep learning uses neural networks, a series of statistical algorithms capable of modeling and processing nonlinear relationships between inputs and outputs in parallel and real time. The algorithms generate rules to associate sequences of words or images on a prespecified concept, such as care preferences, and become more accurate with more data over time (Udelsman et al., 2020). When NLP is combined with a neural network, it is referred to as deep natural language processing.

**Unstructured Data and the Unified Medical Language System (UMLS) Metathesaurus**

EHRs capture three types of data: structured, semi structured, and unstructured (American Nurses Association, 2015). Structured data include laboratory tests, vital signs, diagnosis codes, assessment checklists, and dropdown lists. Semi structured data include information on medications, procedures, and working medical diagnoses. Unstructured data exists in the narrative notes and represent approximately 80% of all data housed in the EHR (Kong, 2019). In addition to the inherent challenges of manual data abstraction, word choice and
terminology representative of specific concepts differ between providers internationally, nationally, regionally, locally, and even within the same health system (Oosterhouse et al., 2021).

The UMLS Metathesaurus is a database that contains information about biomedical and health related concepts, their various names, and the relationships among them (United States National Library of Medicine, NLM). The NLM certifies classification systems and dictionaries for approved use for EHRs in the United States to achieve meaningful use, and the UMLS links standardized ontologies by health-related concepts (ANA, 2015). Ontologies are descriptions of concepts and categories in a subject area or domain that demonstrate relationships. When used in artificial intelligence, common ontologies assist in the sharing and reuse of the knowledge that is represented (Chandrasekaran, Josephson & Benjamins, 1999).

Historically, extracting rich and person-centered data from the EHR has been challenging. The UMLS provides a robust index of terminologies and standards in one framework that enables incorporation of data regardless of how the data are originally structured and stored. For example, each health-related and biomedical concept or meaning has a unique and permanent concept unique identifier (CUI) (NLM). The UMLS concept (CUI) can be matched to free text extracted from an unstructured clinical note that exactly or closely matches the text contained in the concept description (Reimer & Milinovich, 2020). Thus, the UMLS Metathesaurus can be used to identify and standardize data from the EHR, using CUIs as the primary data organizer, enabling semantic analysis of the unstructured narrative data for secondary analysis.

**Natural Language Processing in Goals of Care Research**

Within the past few years there have been a flurry of published investigations using NLP
as a means of analyzing narrative notes from the EHR to reveal information about goals of care for patients with serious illness. Studies using NLP were discovered using a combination of PubMed searches and review of references lists from relevant articles. Using the search terms “natural language processing,” “machine learning,” “deep learning,” and “goals of care,” PubMed was queried for studies of adult populations, with full text available, published in the last five years. The resulting PubMed list of 18 publications was further scrutinized for studies using NLP to describe GOC for patients with serious illness. These 10 studies fall into two main categories, research describing the frequency of GOCD documentation using NLP extraction and NLP model validation studies.

**Frequency of GOCD Documentation**

Udelsman et al. (2019) used both administrative data and manual review to retrospectively identify hospital admissions during which palliative procedures were performed for patients with advanced pancreas cancer. They used NLP to identify the presence of palliative care (PC) process measures in associated free-text notes. PC process measures were found in 68% (n = 823) of admissions. Of the admissions for palliative procedures, 49% included documentation of a GOCD. And GOCDs were associated with decreased ICU utilization (HR 0.69; 95% CI 0.48-0.99, p = .046)

Using administrative billing codes and NLP review of magnetic resonance imaging reports, Brizzi and colleagues (2020) retrospectively identified a sample of patients with metastatic breast cancer with leptomeningeal disease (n = 183), and then used NLP to evaluate their clinical notes for the presence of PC process measures. They found that within six months of diagnosis of leptomeningeal spread, 88.5% of patients had documentation of at least one
process measure, including 63.4% with documentation of a GOCD. The presence of palliative care consultation was shown to be a predictor of subsequent documentation of discussions about GOC (OR 3.15; 95% CI 1.58-6.27) and hospice (OR 4.61; 95% CI 2.12-10.03).

**Model Validation**

Researchers in palliative surgery propose four quality measures for end-of-life care, described as processes of care: goals of care conversations, code status clarification, palliative care consultation, and assessment for hospice (Lilley et al., 2018). In preparation for this study and for future studies some of which are explored here, Lilley and colleagues created an NLP key term library intended to identify the presence of each of the four aforementioned processes of care in clinical notes. Manual chart review (considered the gold standard) was performed by a single researcher, reviewing 241 EHR notes for twenty patients with identified pancreas cancer who underwent palliative procedures. They pilot-tested the performance of the NLP key term library, applying NLP methodology on the same population. The NLP key term libraries successfully identified the four processes of care in narrative notes with high sensitivities and specificities that ranged from 93.8% to 100%. Additionally, the NLP search abstracted these records and provided a structured dataset in just 26 seconds. The manual chart review and data entry, by comparison, required twenty hours to complete.

A retrospective cohort study of adult cancer patients (n = 302) who had palliative gastrostomy tube placement was undertaken by Lindvall and colleagues (2019) to determine whether NLP of the EHR could 1) identify the desired patient sample, and 2) assess the documentation of palliative surgery EOL process measures. Their NLP process identified the correct patient sample with both 95.8% sensitivity and 97.4% specificity. NLP also identified
EOL process measures with high sensitivity and specificity. In the two months prior to palliative gastrostomy placement, 20.5% of patients had documentation of GOCDs; and during the hospitalization for gastrostomy placement, 67.7% of patients had GOCDs documented. Human chart abstraction took more than 2600 times longer than NLP (28 hours vs. 38 seconds).

K. Lee and colleagues (2020) set out to use NLP to identify palliative care (PC) delivery to patients 18 years or older with life-threatening trauma and compare NLP extraction performance to administrative coding and manual chart review. PC delivery was defined as documentation of any one of the four previously described EOL process measures during the trauma admission. NLP identified PC delivery in 33% of admissions compared with 8% using administrative coding. NLP performed 50 times faster and had a sensitivity of 93%, specificity of 96%, and accuracy of 95%.

A retrospective cohort investigation sought to compare frequencies of documented communication of code-status clarification and GOCDs between patients with advanced pancreatic cancer undergoing palliative procedures and patients admitted with life-threatening trauma (Udelsman et al., 2020). The study compares NLP-identified domains to manual extraction of domains. For patients with advanced pancreas cancer (n=523), NLP identified code-status clarification in 54% of admissions and GOCDs in 49% of admissions with associated sensitivities and specificities for both domains ranging between 93% to 100%. For patients with life-threatening trauma (n=2093), NLP identified code-status clarification in 25.9% of admissions and GOCDs in 6.3% of admissions. Though NLP had 100% specificity, the sensitivities for code-status clarification and GOCD was reduced to 86% and 50% respectively. Interestingly, the addition of phrases to the NLP key term library such as “ongoing discussions”
and “family meetings” increased the sensitivity of the NLP extraction for code status in the life-threatening trauma cohort to 98%, and for GOCDs to 100%.

Chan and colleagues (2019) set out to apply deep learning algorithms for automated identification of GOCDs documented in physicians’ notes during intensive care unit (ICU) admissions. Investigators first annotated all text documenting patient care preferences (GOC, code status limitations, full code status, communication with family) from a retrospective database of physician ICU notes, and then used the annotated text to train algorithms to identify the desired documentation and validate the algorithms. The algorithms were activated to evaluate the percentage of ICU admissions for patients 75 years or older who had care preferences documented within the first 48 hours in ICU. Evaluation of the algorithm was calculated by comparing deep learning-identified documentation to investigator-coded documentation. For detecting care preference documentation at the note level, the algorithm had an F1-score of 0.92 (95% CI, 0.89-0.95), sensitivity of 93.5% (95% CI, 90.0%-98.0%), and specificity of 91% (95% CI, 86.4%-95.3%). The algorithm performed in a fraction of the time compared to the investigator (18,000 times faster). For patients 75 years or older, 64.7% of ICU admissions were found to have documentation of care preferences within 48 hours of admission.

In a retrospective analysis of unstructured Veterans Health Administration EHR free text notes (n=778), Razjouyan et al. (2021) intended to develop and validate an NLP model that reliably measured documentation of patient priorities. Their NLP model utilized statistical machine learning approaches, requiring two essential words, “goals” and “values,” in all notes representing patient priorities for older patients with multiple chronic conditions. The automated NLP model reliably measured with high precision (0.84, 95% CI 0.77-0.91), recall (0.84, 95% CI
and accuracy (0.92, 95% CI 0.90-0.94), identifying evidence of documented patient priorities in 75.7% of notes (kappa = 0.82, p < .001).

In a retrospective study, Steiner, Morse & Lee (2020) evaluated the performance of an NLP/ML algorithm in identifying the prevalence of EHR documentation of GOCDs for patients with adult congenital heart disease (ACHD) near the EOL. They compared the results of a standardized manual data abstraction process with that of an NLP/ML algorithm that uses mathematical models based on statistical probability of whether documentation is present, guided by single word “tokens” in text. Evidence of GOCDs including patient and family values or wishes; care choices or code status; prognosis in the context of decision-making; or ACP. Notes authored by the primary team (cardiology or cardiothoracic surgery), palliative care, spiritual care, and social work were included in the analyses. Their findings showed a low prevalence of EHR-documented GOCDs (29%) and palliative care consultations (31%) in the last six months of life for decedent patients (n = 62). And the algorithm performed moderately to poorly compared to manual abstraction: In per-note analysis for GOCDs, findings were concordant 50% of the time, with sensitivity of 13% (20/155, 95% CI, 0.08-0.18) and specificity of 93% (124/134, 95% CI, 0.88-0.97). In per-patient analysis for GOCDs, findings were concordant 85% of the time with sensitivity of 70% (16/23, 95% CI 0.51-0.88) and specificity of 95% (37/29, 95% CI, 0.88-1.02).

R. Lee and colleagues (2021) developed, trained, and tested a novel automated approach to identifying GOCD documentation in the EHR using NLP and machine learning (ML). Using a purposive sample of inpatient and outpatient notes from patients with serious illness, they 1) manually reviewed each note for documentation of GOCDs, and 2) developed a program using
NLP and supervised ML to do the same. Of the 3183 notes, 21.2% contained documentation of a GOCD. The mean sensitivity of the NLP/ML program was 82.3% (SD 3.2%), and the mean specificity was 97.4% (SD 0.7%). The authors found the performance of their automated approach was better in the inpatient-only samples of notes, compared to outpatient-only notes.

These studies demonstrate how the science of applying NLP methodologies to the study of documentation of GOCDs and patient care preferences is in its infancy. They also reveal marked progress toward possible new approaches, and their complexities, in measuring GOCDs as a research outcome and quality metric. Pursuit of the holy grail, the elusive research outcome of goal concordant care, may soon be in closer reach as knowledge and utilization of NLP methodologies advance.

Research methods for the study using NLP to identify and characterize documentation of GOC in patients with ovarian cancer will be presented in the following section, chapter 3.
CHAPTER III

RESEARCH METHODS

Chapter 3 provides a description of the methods for the study. The study purpose, research question and aims are presented. Study design, study site, and sample characteristics are explained. Conceptual and operational variables are described and defined. The procedures of the study are described; plans for data management and analysis are presented; and ethical considerations for the study are presented.

Study Purpose, Research Question, and Aims

The purpose of the study is to characterize documentation of goals of care in the EHR for patients diagnosed with ovarian cancer.

The research question addressed by this study is:

Does use of a novel NLP methodology to query structured data and free-text narratives within the EHR uncover documentation of patient values, goals, and preferences that clarify or describe patients’ goals of care? The aims of this study include:

1) Identify concept unique identifiers (CUIs) that reveal patients’ values, goals, and preferences documented in the EHR.

2) Sort, investigate, and describe documentation of goals of care including any differences or variability within documentation or its timing based on select variables such as patient age and race; clinician discipline and specialty (when available); and setting.
This study helps determine which goals of care related CUIs provide the most data, where in the EHR the unstructured goals of care related data are located, identify the authors of the unstructured data including characteristic of discipline, and describe the content, frequency, and timing of the documentation. Differences or variability within documentation based on select variables including patient characteristics are evaluated.

**Description of Study Design**

The proposed research is a secondary analysis of historic data housed in the EHR. It is descriptive and exploratory in nature. The study evaluates both structured and raw free-text notes from the EHR of patients with a diagnosis ovarian cancer who received inpatient and/or outpatient treatment at a large academic health system. These data are analyzed to capture EHR documentation of patient GOC.

Ovarian cancer is the deadliest of all gynecologic cancers typically diagnosed at an advanced stage and is associated with burdensome physical and emotional symptoms (National Cancer Institute, 2021; von Gruenigen et al., 2018). As part of standard and high-value oncologic care, clinical practice guidelines strongly recommend clinicians conduct GOCDs addressing patients’ goals, values, and priorities (Gilligan et al, 2017; Levy et al, 2012). There is a considerable gap in understanding GOCDs in the ovarian cancer population. Evaluation of healthcare provision prior to EOL, including GOCDs, is important in ovarian cancer because concerns about care at EOL are likely to occur earlier in the course of disease (NCI, 2021). Limited published research suggests only a small fraction of patients with ovarian cancer have discussions with their clinicians about their goals and values prior to making treatment decisions; therefore the electronic records of this population should be further explored, characterized, and
analyzed (Frey et al., 2014).

**Study Site**

The primary data source is the information housed in the EHR of the study institution focused on both structured and free-text or unstructured data. The study evaluates multidisciplinary clinical documentation for emergency department, inpatient, and outpatient encounters.

**Sample Characteristics and Size**

Women who are 20 years and older make up 98.7% of new ovarian cancer diagnoses, and the 5-year survival rate for patients with metastatic disease is 30.3% (NCI, 2021). Conversely, 69.7% of patients diagnosed with stage IV ovarian cancer will die within five years of this diagnosis. National guidelines recommend addressing GOC as a standard part of all oncologic care. Since most ovarian cancers are diagnosed in the later stages, the focus of this study is on all patients with a diagnosis of ovarian cancer (Stewart, Ralyea & Lockwood, 2019). People with advanced stage ovarian cancer face EOL decisions sooner than patients with less advanced disease, and for whom knowledge of their goals, priorities, and preferences for EOL care are arguably most urgent. It is for the aforementioned reasons that this study obtained the electronic health records of a sample of adult patients (ages greater than or equal to 18) with a diagnosis of ovarian cancer.

Centers for Medicare and Medicaid Services (2016) first allowed for reimbursement of advance care planning (ACP) activities including GOCDs starting on January 1, 2016. Before this date, clinicians (physicians and non-physician practitioners) were not specifically compensated for time they spent with patients on these important activities. The initiation of
reimbursement for ACP services encouraged clinicians to hold GOCDs and serves as rationale for beginning the retrospective analysis of patient records no earlier than 2016. The study sample is a convenience sample of all available cases from January 1, 2016 to December 31, 2019.

**Conceptual and Operation Definitions of Variables**

**Convenience Sample**

Patients diagnosed with ovarian cancer and who are 18 years and older compose the patient sample of interest.

**Documentation of Goals of Care**

In their organizing framework of ACP outcomes, Sudore and colleagues (2018) identify ACP action outcomes that demonstrate important communication and completion of specific components of ACP. Similarly, Sinuff and colleagues (2015) detail specific forms of documentation in their conceptual framework for improving EOL communication and decision making. And lastly, Sanders, Curtis and Tulsky’s (2018) conceptual model of the relationship between communication and goal-concordant care highlights key communication and documentation elements for GOCDs. These conceptual frameworks provide guidance and point to the essential elements necessary to operationalize this study (Table 1).

Toward the goal of discovering the CUIs that provide the most data describing discussion of goals of care, the presence of any of the following operational elements within free-text clinical notes defines the presence of GOC for this study: 1) Discussion of active medical conditions and possible outcomes, 2) Discussion of values, goals, and preferences in consideration of both current and future care, 3) Sharing of recommendations and decision
making around treatment interventions, 4) Documentation of completion of advance directives or orders for life sustaining treatment, or 5) Referral to subspecialty palliative care services or hospice (Comer, Fettig & Torke, 2020; Lee et al, 2021). The use of the phrase goals of care as discourse within clinical documentation without containing essential elements of the operational definition for GOCD are excluded.

Table 1. Operational Elements that Define Presence of GOC

<table>
<thead>
<tr>
<th>Operational Definition of Goals of Care – requires documentation of any of the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Active medical conditions and possible outcomes</td>
</tr>
<tr>
<td>• Values, goals, and preferences in consideration of both current and future care</td>
</tr>
<tr>
<td>• Sharing of recommendations and decision making around treatment interventions</td>
</tr>
<tr>
<td>• Completion of advance directives or orders for life sustaining treatment</td>
</tr>
<tr>
<td>• Referral to subspeciality palliative care services or hospice</td>
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</tbody>
</table>

*Note. Comer, Fettig & Torke, 2020; Lee et al, 2021.*

**Key Influential Variables**

The organizing framework for ACP outcomes describes how non-modifiable moderator variables such as patient demographics and social support may influence the effectiveness or change the strength of an effect or relationship between two variables (Sudore et al, 2018). Therefore, patient characteristics including age and race were obtained from patient records as they may influence documentation of GOC. Similarly, the presence of patient social support may influence documentation of GOC and is defined as documentation of the involvement of a proxy decision maker in a GOCD and/or documentation of family presence for a GOCD (Table 2). Clinician use of an EHR-based GOCD documentation template to document patient GOC is a system level moderator variable that may influence documentation of GOC. The presence of scanned copies of ADs (including HCPOA, living will, and orders for life sustaining treatment) represent ACP action outcomes and are the tangible by-products of GOCDs.
The clinician unit of analysis can be sub-categorized using non-modifiable moderator demographic variables of interest that may influence documentation of GOC (Sudore et al., 2018). It is anticipated that clinicians across a variety of disciplines may have discussions with patients about their goals of care including therapists, social workers, nurses, chaplains, advanced practitioners, and physicians. The relevant and potentially retrievable clinician characteristic demographic variables include discipline, specialty (when applicable), and level of training (when applicable). For instance, physician training is categorized by post-graduate year, fellow, and attending physician.

Reflected in the conceptual model by Sanders, Curtis and Tulsky (2018), the timing and setting of GOCDs influence communication quality and processes, stressing the importance of longitudinal tracking of certain variables as documentation of GOC is evaluated. The date of diagnosis, date(s) of occurrence(s) of documentation of GOC, date of first palliative care consultation, date of first hospice discussion, and date of patient death (if available) are all important variables that are included for analysis. The setting of the documented encounter may occur in ambulatory clinic, emergency department, or inpatient hospitalization.
Table 2. Operational Definitions of Key Variables

<table>
<thead>
<tr>
<th>Key Influential Variables on Goals of Care Documentation</th>
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</thead>
<tbody>
<tr>
<td><strong>Patient Demographics</strong></td>
<td></td>
</tr>
<tr>
<td>• Race</td>
<td>American Indian American Indian Asian or Pacific Islander Hispanic Hispanic Non-Hispanic Black Non-Hispanic White Other Other</td>
</tr>
<tr>
<td>• Age</td>
<td>Number of years old</td>
</tr>
<tr>
<td><strong>Patient Social Support</strong></td>
<td>Yes/No</td>
</tr>
<tr>
<td>• Documentation of proxy in GOCD</td>
<td>Yes/No</td>
</tr>
<tr>
<td>• Documentation of family presence for GOCD</td>
<td>Yes/No</td>
</tr>
<tr>
<td><strong>Clinician Variables</strong></td>
<td></td>
</tr>
<tr>
<td>• Discipline</td>
<td>Nurse Nurse Physician Physician Advanced Practitioner Advanced Practitioner Chaplain Chaplain Social Worker Social Worker Therapist Therapist</td>
</tr>
<tr>
<td>• Physician Level of Training (if available)</td>
<td>Post-graduate year Post-graduate year Fellow Fellow Attending Attending</td>
</tr>
<tr>
<td>• Specialty (if available)</td>
<td>Nursing Nursing Medicine Medicine Surgery Surgery Oncology Oncology Critical Care Critical Care Palliative Care Palliative Care</td>
</tr>
<tr>
<td><strong>ACP Action Outcomes</strong></td>
<td></td>
</tr>
<tr>
<td>• Advance Directives</td>
<td>HCPOA HCPOA Living Will Living Will Order for life sustaining treatment Order for life sustaining treatment</td>
</tr>
<tr>
<td><strong>Documentation Occurrence of Communication Processes</strong></td>
<td></td>
</tr>
<tr>
<td>• Date</td>
<td>Diagnosis of ovarian cancer Diagnosis of ovarian cancer Documentation of GOC Documentation of GOC Patient death Patient death</td>
</tr>
<tr>
<td>• Institutional Setting</td>
<td>Ambulatory clinic Ambulatory clinic Emergency Department Emergency Department Inpatient hospitalization Inpatient hospitalization</td>
</tr>
</tbody>
</table>

*Note.* HCPOA = health care power of attorney.


**Study Procedures**

Central forms of communication in health care are the narrative sections of clinical documentation. Compared to the structurally coded elements of the EHR including laboratory values and vital signs, narrative notes provide a more nuanced and personalized description of patient history and clinician assessment that give context for clinical decision making (Rosenbloom et al., 2011). Natural language processing (NLP) is a subfield of artificial intelligence studying the ways in which the analysis and synthesis of information expressed in natural language can be automated. NLP is a feasible means of unlocking evidence buried in clinical narratives within the EHR, and increasingly is available and utilized for analysis of large databases (Spasic, Uzuner & Zhou, 2020).

The clinical research database (CRDB) of the study institution was created in 2013 with data available from 2007 to present. CRDB is a large scale, longitudinal clinical repository that is utilized to support clinical research. It is composed of a limited set of clinical data structured to enable an array of data analytics. Through November of 2021, it contained EHR data on more than 2.5 million unique patients, 13 million patient encounters, and 84 million clinical documents. Using a novel NLP clinical engine, the study institution’s health information technology and clinical team mapped concepts from all the narrative notes housed in a clinical data warehouse to the UMLS Metathesaurus, permitting semantic analysis of the unstructured narrative data for systematic analysis (United States National Library of Medicine UMLS Metathesaurus).

Prior to data collection, we ran a query of an established EHR dataset of de-identified data for intensive care unit patients to determine if there were enough data to support this
investigation. Utilizing an existing key term library, a list of keywords and phrases commonly used in GOCDs and/or reflective of the content in these discussions was augmented (Lilley et al., 2018). A CUI search was conducted using the UMLS Methathesaurus browser. Goals of care related terms were matched with associated CUIs (see Appendix A). CUIs identified as containing goals of care related data were then selected for the initial query and provided to the health information technology team. The volume of results of the initial query suggest that ample data are available for evaluation in this study.

**Data Collection**

A request was submitted to the CRDB to identify the available sample cohort of patients diagnosed with ovarian cancer who received healthcare at the study institution starting from January 1, 2016. The sample cohort of patients with ovarian cancer were identified using ICD-10 codes for ovarian cancer.

After submission and approval by the institutional review board (IRB), a data request was submitted to the Informatics & Clinical Research Group (ICRG) to obtain 1) all structured data and raw free-text notes containing relevant GOC related terms as identified by their associated CUIs using NLP methodology, 2) patient race and age, 3) clinician variables including discipline and specialty as permitted by human resources of the study institution.

**Annotation and Validation Process**

The requested data from ICRG was provided in two forms, structured data, and free-text notes. All clinical notes were extracted from the clinical EHR platform as plain text. Clinical note data were then annotated and validated. Annotation involved checking the CUIs for accuracy against the text notes.
Data Management

Access was requested to a research drive folder on the R: drive of the study institution. All data received from ICRG was be stored, secured, and utilized on the protected research drive folder. No EHR data was downloaded to a personal computer.

Plan for Data Analysis

The primary aim of the study was to identify concept unique identifiers (CUIs) that reveal patients’ values, goals, and preferences documented in the EHR. Frequencies of GOC documentation for patients with ovarian cancer will be counted.

A secondary aim of the study is to evaluate documentation of GOC including any differences or variability within documentation or its timing based on select variables. Recognizing that GOCDs and their documentation occur longitudinally starting as early as the date of diagnosis, temporality of specific occurrences will be analyzed including date of diagnosis of ovarian cancer, date(s) of documentation of GOC, and date of patient death. Of particular interest are time after diagnosis to first documentation of GOC, frequency of GOC occurrences prior to death and whether patient age, and/or race, and insurance class correlates with any variability.

Distinct correlations were tabulated between presence of GOC documentation and patient race. Univariate and bivariate statistics for the variables will be conducted, dichotomized by whether patients had presence of documentation of GOC.
Ethical Considerations

This study involves retrospective health record review and risks no harm to deceased patients. The personal health information housed in the EHRs of patients who have undergone treatment for ovarian cancer within an academic health system were evaluated. Patient and clinician anonymity and confidentiality were protected through use of a limited data set provided for data analysis. This study sought approval from the Institutional Review Board of Loyola University Chicago and was assigned a status of exempt (LU 215846).

Further detailed description of the research methods, training and augmentation of rules-based NLP algorithm, and analysis of data will be presented in the following section, chapter 4.
CHAPTER IV
DATA PROCESSING AND ANALYSIS

This chapter describes the results of this study which investigated a novel NLP methodology to query structured and unstructured data within the EHR to uncover documentation of patient values, goals, and preferences that clarify or describe patients’ goals of care. This chapter describes the identification of GOC-related concept unique identifiers (CUIs), the processing of clinical documentation using CUIs, and a clinical natural language processing (cNLP) engine to identify elements of documentation of GOC for patients with ovarian cancer, and the analyses undertaken to characterize the documentation.

Obtaining the Sample

The electronic health records of patients with a diagnosis of ovarian cancer who received care and treatment at the study institution comprised the patient sample for this study. The desired patient population was first selected through ICD-10 diagnosis codes, used by health care providers to document diagnoses in patient health care records (Centers for Medicare and Medicaid Services [CMS], 2022). A search of CMS code descriptions resulted in the following ICD-10 codes for ovarian cancer diagnoses:

- C561 Malignant neoplasm of right ovary
- C562 Malignant neoplasm of left ovary
- C563 Malignant neoplasm of bilateral ovaries
- C569 Malignant neoplasm of unspecified ovary

These ICD-10 codes for ovarian cancer were used to search the study institution’s clinical research database for all patients with documented diagnoses of ovarian cancer treated during the
study period. The patient sample was conveniently identified from January 1, 2016, through December 31, 2019. All clinical notes for the patient sample documented in the EHR during the three-year study period were loaded into the cNLP engine for processing and analysis.

**Aim 1: Building and Refining the Rules-Based NLP Algorithm**

The first study aim intended to identify concept unique identifiers (CUIs) that reveal patients’ values, goals, and preferences documented in the EHR. Utilizing the previously outlined operational definition of goals of care (GOC), combined with a published NLP key term library and concepts identified by searching the United Medical Language System Metathesaurus browser, a comprehensive list of GOC-related concepts and associated CUIs was generated, see Appendix A (Lilley et al., 2018; NLM). The list of GOC-related CUIs was provided to the Informatics & Clinical Research Group (ICRG). The ICRG built the initial rules-based clinical natural language processing (cNLP) algorithm to identify evidence of GOC documentation in individual clinical notes from the sample of patient notes obtained from the EHR. GOC-related CUIs are used as the primary data organizer and means of semantic analysis of the unstructured data, the clinical notes. The sample of patient notes were then processed through the cNLP producing raw results. See Appendix B for a map demonstrating the stepwise process of building the rules-based algorithm.

The initial raw results included 21,407 total notes. At least one GOC-related CUI was identified in 1,690 CUI-positive notes. Raw results also included note type descriptions and total number of note types representing CUI positive notes, resulting in 397 unique note types, and the most frequently occurring CUIs from CUI-positive notes, see Table 3. During pragmatic review of the note types in the sample, numerous note types were identified as unrelated or non-
contributory to clinical documentation of GOC. Rather, these note types described diagnostic and therapeutic procedures, lab values, and radiology reports. The note types lacking face validity for possible documentation of GOC were therefore removed from the overall sample of notes. After note removal, 15,059 total notes remained in the sample – including 1,624 CUI-positive notes and 34 distinct note types. Examples of the note types that were removed are described as follows:

- Glucose-Fingerstick
- WH Breast Tomosynthesis Screening Bilateral
- Rad Insertion of G Tube Percutaneous
- Porta Catheter Insertion
- CT Chest/Abdomen/Pelvis with Contrast
- Lipid Profile
- Surgical Pathology
- CT Abdomen & Pelvis with Contrast
- EKG-12-Lead – All Loyola Locations
- Complete Metabolic Panel
- APTT

Table 3. Raw Results Following Initial cNLP Processing and Remaining Note Sample After Reduction

<table>
<thead>
<tr>
<th></th>
<th>Raw Results</th>
<th>Results after note removal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notes in sample</td>
<td>21,407</td>
<td>15,059</td>
</tr>
<tr>
<td>CUI positive notes</td>
<td>1,690</td>
<td>1,624</td>
</tr>
<tr>
<td>CUI positive note types</td>
<td>397</td>
<td>34</td>
</tr>
<tr>
<td>Patients in sample</td>
<td>___</td>
<td>628</td>
</tr>
<tr>
<td>Patients with CUI positive note(s)</td>
<td>___</td>
<td>224</td>
</tr>
</tbody>
</table>

Note Validation

A concept mapper tool was then used to validate GOC-related CUIs identified in a subset
of the sample of patient notes. The subset of patient notes reviewed for validation was
determined by randomly selecting notes from note type categories with the highest frequency of
CUI-positive notes:

- Palliative Care Note
- DC Summary
- ANC Admission
- ANC Progress
- History & Physical
- Progress Note

The sample of notes identified as having at least one CUI representing documentation of GOC
by the initial cNLP rule, “CUI-positive dataset,” was loaded into the concept mapper tool. The
tool permitted visualization of the complete text of each narrative note from the EHR coupled
with all the representative CUIs mapped to the note by the cNLP engine. For each of the notes in
the CUI-positive dataset, the documentation was systematically reviewed, evidence of
documentation of GOC within the narrative was identified, concepts within the text of the note
were mapped to the associated CUI, and then all CUIs reflective of GOC evidence were labeled
as important (true positive). Where there were CUIs identified by cNLP as evidence of GOC
that were not supported by the context of the narrative note, these CUIs were labeled as noise
(false positive). Saturation was reached after close examination and review of 372 notes.

To demonstrate the process of note validation, text from a clinical note is presented here
followed by the resultant cNLP validation using the concept mapper tool. The exemplar text
containing no patient identifying information comes from a Palliative Medicine Progress Note:

Gyn/Onc has discussed poor prognosis throughout weekend. Today pt continues to
deteriorate – MICU called, also discussed poor prognosis. Pt is now comfort care,
DNR/DNI, no further HD. Continue levothyroxine as withdrawal from this can be
unpleasant. Comfort care order set initiated.
After reviewing text from the clinical note, the concept mapping tool was used to manually validate GOC-related CUIs as important (true positive), represented by a red circled exclamation mark, see Figure 6. CUIs mapped to other unrelated concepts were not tagged.

Figure 6. cNLP CUI Results for a Palliative Medicine Progress Note After Manual Validation

<table>
<thead>
<tr>
<th>C0030231^palliative care^1</th>
</tr>
</thead>
<tbody>
<tr>
<td>C0030625^passive cutaneous anaphylaxis^1</td>
</tr>
<tr>
<td>C0030705^patients^1</td>
</tr>
<tr>
<td>C0033229^prochlorperazine^1</td>
</tr>
<tr>
<td>C0033325^forecast of outcome^1</td>
</tr>
<tr>
<td>C0034330^pyrrolidonecarboxylic acid^1</td>
</tr>
<tr>
<td>C0038492^student^1</td>
</tr>
<tr>
<td>C0038854^suppository^1</td>
</tr>
<tr>
<td>C0040165^levothyroxine^1</td>
</tr>
<tr>
<td>C0040223^time^1</td>
</tr>
<tr>
<td>C0078944^patient-controlled analgesia^1</td>
</tr>
<tr>
<td>C0086409^hispanics^1</td>
</tr>
<tr>
<td>C0150521^comfort measures^1</td>
</tr>
<tr>
<td>C0199168^medical service^1</td>
</tr>
<tr>
<td>C0278252^prognosis bad^1</td>
</tr>
</tbody>
</table>

**Important GOC-Related CUIs Identified by cNLP**

A priori, a list of GOC-related CUIs was prepared as a first step in building cNLP algorithm rules (see Appendix A). After the first running of cNLP on the full sample of notes, and after the initial round of validation, a subset of the CUIs identified a priori was confirmed as important in identifying documentation of GOC. Additionally, more than one hundred new CUIs were marked as important through validation and a posteriori shown to uncover evidence of GOC documentation. Many CUIs reflective of GOC documentation were anticipated a priori and identified by the cNLP engine, while many unanticipated CUIs identified by cNLP were mapped to the data and discovered through the validation process. The algorithm rules were
augmented by adding the 15 most frequently occurring newly identified CUIs, specifically those CUIs with six or more important occurrences appearing in the sample of notes, see Table 4.

Table 4. Important GOC-Related CUIs Used to Augment cNLP Algorithm Rules

<table>
<thead>
<tr>
<th>A priori GOC-related CUIs</th>
<th>A posteriori most frequently occurring GOC-related CUIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>DNR C0582114</td>
<td>Discussion Communication C2584313</td>
</tr>
<tr>
<td>DNR status C2911025</td>
<td>Coding C0009219</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation C0007203</td>
<td>Goals finding point in time patient narrative C2979882</td>
</tr>
<tr>
<td>Comfort measures C0150521</td>
<td>Family Collection C2700055</td>
</tr>
<tr>
<td>Goals of care C2930505</td>
<td>In care finding C0580931</td>
</tr>
<tr>
<td>Treatment options C0683525</td>
<td>Discussion procedure C0557061</td>
</tr>
<tr>
<td>Neoadjuvant therapy C0600558</td>
<td>Care activity C1947933</td>
</tr>
<tr>
<td>Hospice care C0085555</td>
<td>Home hospice C3275086</td>
</tr>
<tr>
<td>Palliative Care C0030231</td>
<td>Meetings C0556656</td>
</tr>
<tr>
<td>Prognosis bad C0278250</td>
<td>Comfort C1331418</td>
</tr>
<tr>
<td></td>
<td>Forecast of outcome C0033325</td>
</tr>
<tr>
<td></td>
<td>Disease progression C0242656</td>
</tr>
<tr>
<td></td>
<td>Comprehension C0162340</td>
</tr>
<tr>
<td></td>
<td>Consultation C0009818</td>
</tr>
<tr>
<td></td>
<td>Therapeutic procedure C0087111</td>
</tr>
<tr>
<td></td>
<td>Decision C0679006</td>
</tr>
<tr>
<td></td>
<td>Home health encounter C1553498</td>
</tr>
<tr>
<td></td>
<td>Subjective finding point in time patient narrative C2979880</td>
</tr>
<tr>
<td></td>
<td>Possible C0332149</td>
</tr>
<tr>
<td></td>
<td>Choose action C1707391</td>
</tr>
<tr>
<td></td>
<td>Agreement C0680240</td>
</tr>
<tr>
<td></td>
<td>Perceived quality of life C0518214</td>
</tr>
<tr>
<td></td>
<td>Discussed with patient C1273395</td>
</tr>
</tbody>
</table>

Identification of CUI Permutations

Following augmentation of the algorithm rules, cNLP was run again on the entire sample of notes. The results demonstrated far more GOC-positive notes than anticipated, many more than would hold face validity. After the first effort of cNLP processing, 1,142 notes resulted as GOC-positive. Surprisingly, the first round of validation and subsequent rules augmentation resulted in almost ten times the number of GOC-positive notes – 11,104 notes, after cNLP
processing. Given the concern over the dramatic increase in number of GOC-positive notes and concern these notes were falsely identified as positive, a deeper qualitative analysis was pursued based upon field observations during prior validation efforts. The primary concern stemmed from the observation that the dramatic increase in number of GOC-positive notes were falsely resulting positive owing to an individual CUI.

To address the concern of an individual CUI appearing in isolation within a narrative note that falsely identifies the note as GOC-positive, a second round of note validation was performed to test these assumptions. A single GOC-related CUI when mapped back to the appropriate section of the narrative note may not reflect evidence of documentation of GOC. However, when two or more important GOC-related CUIs appear together within the same note, this permutation of CUIs may meaningfully reflect documentation of GOC. With this supposition, another round of validation was undertaken to uncover potentially important GOC-related CUI permutations occurring within CUI positive notes – CUIs representative of GOC documentation that when used in specific combinations with other CUIs meaningfully represent evidence of GOC. The ICRG prepared another dataset from the 372 previously validated notes. This dataset included only the notes in which at least three GOC-related CUIs were identified as important.

Using the top 65 most frequently occurring CUIs marked “important” from initial validation, a smaller dataset of notes was created in which at least three GOC-related CUIs were identified in each note. The goal was to identify potential clusters of CUIs that only when present in notes together represent evidence of GOC. For the notes in this smaller dataset, the author went back through each note using the concept mapping tool. The identified GOC-related CUIs were then copied into a spreadsheet. Using a search function, GOC-related CUI clusters
were readily highlighted and recognized in other notes. The CUI permutations uncovered by this effort were used to further refine the rule-based algorithm with the addition of subrules.

**Rule Refinement**

After rules augmentation, ICRG re-processed the original set of the 372 rule-predicted GOC-positive notes through cNLP. By comparison after the first round of rules augmentation and refinement, 350 notes were found to be true-positive for GOC documentation. And after the second rounds of rules augmentation, 314 notes resulted as true-positive for GOC documentation. This reduction in true-positive notes, and thereby a reduction in the number of retained false-positive notes represents the desired improvement in the rules.

To identify true and false negative rule-based cNLP note evaluations, a third round of validation was pursued after the second round of rules augmentation. After rule augmentation, 58 rule-predicted GOC-negative notes were manually reviewed using the concept mapper and evaluated for documentation of GOC. This evaluation revealed 11 false-negative occurrences in which the refined rules falsely identified the note as negative for GOC documentation. Based on this evaluation, the algorithm rules were further refined into the final rules, see Appendix C.

**Field Note Observations**

Throughout note validation processing and analysis, the author compiled field notes of observations. Certain note types were not utilized to document GOC, however were falsely identified as CUI positive by the initial cNLP rule. When this occurred, review of the narrative text commonly revealed use of language in a templated note that triggered the cNLP to falsely identify it as CUI positive. The cNLP rule was therefore further augmented to exclude the following note types:
Patient Instruction
ANC Discharge

Missed Terms and Common Acronyms

During review of narrative notes, the author found GOC-related terms and common acronyms for important terms within the narrative note for which the cNLP engine failed to map to an associated CUI. In these instances, the author reported the examples to the ICRG. The ICRG then wrote specific rules augmenting the algorithm so these important GOC-related terms would trigger as CUI positive in subsequent cNLP processing. Examples of GOC-related terms for which the rule was refined include:

- Advance directive
- Comfort care
- Do not intubate
- Do not resuscitate
- DPOA
- DNR/DNI
- Durable power of attorney
- Healthcare power of attorney
- HCPOA
- Palliative
- Palliative Medicine
- Power of attorney
- POA

Non-Ovarian Cancer Diagnoses Identified Within Sample of Patients

When reviewing the narrative notes for CUI validation, text describing the patient as having a diagnosis other than a primary ovarian cancer were found, albeit infrequently. The discovery of these errors in identification of the sample are due to several possible causes: 1) Use of a diagnosis code for ovarian cancer during the initial phase of diagnosis, which was subsequently determined to be a different primary cancer, and 2) The primary cancer was
something other than ovarian but had metastasized to the ovary. The occurrence of these coding errors was identified slightly over ten percent of the time; 40 out of 372 notes. While a small portion of the sample included in the study may not have had pathology-identified ovarian cancers, these patients were documented to have other serious and life-limiting, aggressive forms of cancer including metastatic colorectal, gastric, breast, and endometrial cancers often involving the ovaries or the tissues in and around the peritoneum and pelvis. A decision was made to accept the sampling error and include the GOC-related information obtained from these patients’ records during the process of rule refinement since the information gleaned from these notes provide valuable information about GOC documentation that could be helpful to the study.

**Patient Values and Priorities Rarely Missed**

During manual review, the author found rare instances in which cNLP failed to capture the documentation of patients’ priorities or values, especially when the patient narrative was not identified by quotation marks. For example, one note documented a patient’s concern about the adverse effect of alopecia (hair loss) impacting her treatment decision to avoid a chemotherapeutic agent intended to best control the cancer. The documentation in the note demonstrated shared decision-making including discussion of trade-offs between patient and provider, informed by the patient’s priorities and values, to avoid this agent and exclude it as part of the anti-cancer therapy. Based on the study’s operational definition of GOC, this example demonstrates evidence of documentation of GOC, however it was not identified by cNLP processing. There were more frequently occurring examples in which cNLP did capture such priorities and values, particularly when the clinician note author used quotation marks to identify the patient voice. When quotation marks identified a patient statement, cNLP processing
identified this with a CUI descriptor, C2979880 subjective finding point in time patient narrative, capturing the voice of the patient. These rare misses serve as examples of errors that can occur when utilizing NLP. After repeated efforts to refine and improve the rules-based algorithm, field observations identified rare occurrences of false-negative lack of capture by the cNLP engine. These rare misses were accepted by the author.

**cNLP Engine Performance**

A confusion matrix is commonly used to describe the performance of NLP engines using specified rules-based algorithms. During the initial phase of rules validation for this study, 372 notes predicted by the rules to be GOC-positive were manually annotated. This effort revealed 350 notes as true positive for evidence of GOC and 22 false positive for evidence of GOC. Subsequently, 58 notes predicted by the rules to be GOC-negative were manually annotated. The latter effort revealed 47 true negative notes and eleven false negative notes. In Table 5, the confusion matrix demonstrates the cNLP performance and identification of GOC-positive notes, comparing predicted classification by the rules and actual classification by manual annotation, described as true positive (TP), true negative (TN), false negative (FN), and false positive (FP).

**Table 5. Confusion Matrix for cNLP Engine Identification of GOC Documentation**

<table>
<thead>
<tr>
<th></th>
<th>Actually Positive</th>
<th>Actually Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predicted Positive</strong></td>
<td>350 (94% TPs)</td>
<td>22 (6% FPs)</td>
</tr>
<tr>
<td><strong>Predicted Negative</strong></td>
<td>11 (19% FNs)</td>
<td>47 (81% TNs)</td>
</tr>
</tbody>
</table>
The initial rules predicted 372 notes as positive for documentation of GOC elements, and through manual annotation only 22 of those notes were evaluated as false predictions. After refinement of the rules, in a sample of 58 notes predicted as negative for documentation of GOC elements, 47 notes were correctly evaluated as negative, while 11 notes were found to be positive. The confusion matrix demonstrates good accuracy for predicting actual documentation of GOC elements, and good discrimination for predicting when documentation of GOC elements are not present in notes. These confusion matrix results supported further refinement of the rules to improve precision and cNLP engine performance.

**Aim 2: Pairing Structured Data with cNLP Output**

The second study aim sought to sort, investigate, and describe documentation of GOC including any differences or variability within documentation or its timing based on select variables. Once the algorithm rules were refined and finalized, the ICRG processed the entire sample of notes through the cNLP engine. After rules-based processing, the ICRG divided all clinical notes in the sample into two datasets, GOC-positive and GOC-negative. The ICRG prepared spreadsheets for both datasets in which structured data of interest were paired with every note. To answer the study aims, the variables of interest included patient age, race, and insurance class; clinician author discipline and specialty (when available); setting; and timing of diagnosis, GOC-positive note(s), and death (when available). Accessibility of the desired structured data was limited by availability of data through the EHR, and by human resource policies of the study institution.

Over the course of the three-year study period, it is acknowledged that patients get older in years and their age increases. Similarly, it is acknowledged that patients’ insurance may
change because of their employer-based health insurance and eligibility for Medicare or Medicaid. Therefore, for the purpose of data analysis, a decision was made to use values for patient age and insurance class at the time of the patient’s diagnosis. For each note, the associated structured data included: date, author specialty, note type, and encounter type. For each patient, the associated structured data included: age at time of diagnosis, race and ethnicity, insurance class at time of diagnosis, date of diagnosis, date(s) of GOC-positive note(s), and date of death (if available).

**Data Screening and Sorting**

*Author Specialty*

Author specialty was accessed and obtained through the job descriptions assigned by the study institution’s EHR. Clinical note authors were represented by 92 distinct human resource-defined job descriptions, many of which redundantly represented the same discipline. There were 40 physician specialties and sub-specialties distinctly identified by a specific job description, while other author disciplines were not distinguished by specialty. To both accurately represent the discipline of the clinician authors and simplify the analysis, 92 job descriptions including redundancies were collapsed into 13 author discipline categories: Advanced Practice Registered Nurse, Chaplain, Dietician, Genetic Counselor, Nurse, Occupational Therapist, Other, Pharmacist, Physical Therapist, Physician, Speech Language Pathologist, and Student. The student category represents prelicensure medical, nursing, and psychology students.
Note Type

Note type description was obtained directly from the study institution’s EHR. Evidence of GOC documentation was found in 32 different note types. Some degree of redundancy was discovered during data screening; therefore several note types were collapsed into a single, representative note type category. For example, notes labeled NSG Case Manager, NSG Staff, and Nursing Note were collapsed into the note category – Nursing Note. The collapsing of note types resulted in a total of 22 different note types in which evidence of GOC was documented.

Encounter Type

Encounter type defines the location (or status) of the patient when the healthcare services were provided and when clinical notes were filed. This description was obtained directly from the study institution’s EHR, describing 19 separate location status types. These specific encounter types were collapsed into three categories: Outpatient, Inpatient, and Emergency. For example, encounter types labeled Outpatient Surgical, Radiation Oncology, Ambulatory Surgical Center, and Cancer Center, among others, were collapsed into the encounter type – Outpatient.

Age

Patient age at the time of ovarian cancer diagnosis was obtained from the EHR of the study institution.

Race and Ethnicity

Descriptions of patient race and ethnicity were obtained from the EHR of the study institution. Patient race types were divided into six sub-types: Asian, Black/African American, Hispanic, Other, Preference not indicated, and White. Based on the lack of variability in the majority White sample, patient race was collapsed into two categories: Non-White and White,
for the purposes of statistical analyses. Patient ethnicity types were divided into four sub-types: Hispanic, Non-Hispanic or Latina, Prefers not to answer, and Unknown. Patient ethnicity was thereby categorized into two sub-types, Hispanic and Non-Hispanic or Latina, for the purposes of some statistical analyses.

Insurance Class

Insurance class represents the type of healthcare insurance patients carried at the time of their ovarian cancer diagnosis. For those patients who did not have health insurance at the time of diagnosis, their payor source was included in the category of insurance class. Insurance class was obtained directly from the study institution’s EHR. There were 17 insurance classes identified for the sample of patients. The insurance class types were collapsed into four categories: Private insurance, Medicare, Medicaid, and Uninsured. For example, insurance types labeled Assistance, Medicaid, Managed Medicaid, MMAI, and Institutional were collapsed into the insurance class category – Medicaid. Missing data for insurance class was identified for 2 GOC-positive patients and 3 GOC-negative patients.

Date of Diagnosis

The date of diagnosis with ovarian cancer was a desired variable to indicate the time after which documentation of elements of GOC are expected to occur. The date of diagnosis was obtained through billing data, specifically the date when ICD-10 code for ovarian cancer was first utilized.

Date(s) of GOC-Positive Note(s)

An unanticipated finding was noted during data screening. There were patients for whom a GOC-positive note occurred before the date of ovarian cancer diagnosis. In the dataset
provided by the ICRG, this was represented by negative values (difference between date of first GOC-positive note and date of diagnosis). Upon further analysis, the ICRG found ICD-10 codes reflecting ovarian mass filed prior to the diagnosis date. To the author, these observations reflect the typical differential diagnostic phase patients experience before their ovarian cancer is biopsy confirmed. This phase may take days or even weeks for the healthcare team to move from a presumed diagnosis of ovarian cancer to confirmation of ovarian cancer. In the cases where a GOC-positive note was found prior to the date of diagnosis, this very likely occurred in the setting of a presumed malignancy. For these patients, a decision was made to transform the data such that date of diagnosis and date of first GOC-positive note occur on the same day – date of first GOC-positive note was therefore transformed from a negative value to zero.

**Date of Death**

During data screening, considerable missing data for date of death was noted. Date of death was available for 106 (27%) patients in the GOC-positive patient sample. For the patients with a documented date of death, it was assumed date of death was retrievable in the EHR because of in hospital death. Given date of death was not retrievable for most of the patient sample, there was not enough data to analyze temporality of GOC-positive note prior to death for the entire GOC-positive patient sample. Instead, data analysis was performed using the smaller sample of GOC-positive patients for whom date of date was available.

**Characterization of Findings**

Clinical notes for patients with ovarian cancer, identified by representative billing codes, were analyzed by a cNLP engine using the established CUI-defined rules to uncover elements of documentation of GOC within the narrative, unstructured data. Data analysis of cNLP outputs
was descriptive in nature. Frequencies and percentages were computed to describe patient sample characteristics, clinician author discipline, patient location, and note type. The second study aim intended to describe documentation of GOC including any differences or variability within documentation or its timing based on select variables. Statistics were computed to identify differences between GOC-positive and GOC-negative patient samples and associations between sample characteristics and documentation of elements of GOC. Data were analyzed using IBM SPSS Statistics (Version 29).

A total of 14,151 clinical notes, representing 627 unique patients, were analyzed resulting in 4,038 GOC-positive notes and 10,113 GOC-negative notes. GOC-positive notes represented 28.5% of notes, while GOC-negative notes represented the remaining 71.5% of notes. There were 422 unique patients, representing 67.3% of patients, identified as having GOC-positive notes; and 205 patients, representing 32.7% of patients, for whom zero GOC-positive notes were identified, see Table 6.

Table 6. Clinical Notes Associated with Unique Patients Analyzed by cNLP Engine

<table>
<thead>
<tr>
<th></th>
<th>Total n</th>
<th>GOC – positive n</th>
<th>%</th>
<th>GOC – negative n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notes</td>
<td>14151</td>
<td>4038</td>
<td>28.5</td>
<td>10113</td>
<td>71.5</td>
</tr>
<tr>
<td>Patients</td>
<td>627</td>
<td>422</td>
<td>67.3</td>
<td>205</td>
<td>32.7</td>
</tr>
</tbody>
</table>

The average (mean) age of patients for whom GOC-positive note(s) were identified was 60.8 years; patient ages ranged between 16 and 97 years, with a standard deviation of 14.5. The average (mean) age of patients for whom zero GOC-positive note(s) were identified was 60.2 years; patient ages ranged between 17 and 91 years, with a standard deviation of 15.5. The overwhelming majority of patients in each sample were White – GOC-positive sample (76.8%)
and GOC-negative sample (78.0%); and Non-Hispanic or Latina – GOC-positive sample (86.5%) and GOC-negative sample (89.3%). Insurance class for GOC-positive patients was represented by private insurance (46.4%), Medicare (44.1%), Medicaid (8.8%), and 0.2% were uninsured. Similarly, insurance class for GOC-negative patients was represented by private insurance (44.4%), Medicare (43.9%), Medicaid (10.2%), and there were no uninsured patients (Table 7).

While the overall patient sample lacks racial and ethnic diversity and is predominately White, the sample characteristics between GOC-positive and GOC-negative patients are comparable across the variables of interest including age, race, ethnicity, and insurance class. The GOC-positive group is slightly more Black/African American and Hispanic/Latina; and contains more patients who are covered by private insurance (46.4% versus 44.4%). The GOC-negative group contains slightly more patients whose payor source is Medicaid (10.2% versus 8.8%).
Table 7. Patient Characteristics and Frequency of GOC Positive Documentation and GOC Negative Documentation

<table>
<thead>
<tr>
<th>Sample Characteristics</th>
<th>GOC – positive n</th>
<th>GOC – negative n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unique patients</strong></td>
<td>422</td>
<td>205</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>Black/African American</td>
<td>37</td>
<td>14</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>45</td>
<td>14</td>
</tr>
<tr>
<td>Preference not indicated</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>White</td>
<td>324</td>
<td>160</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>52</td>
<td>18</td>
</tr>
<tr>
<td>Non-Hispanic or Latina</td>
<td>365</td>
<td>183</td>
</tr>
<tr>
<td>Prefers not to answer</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Insurance class</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance</td>
<td>196</td>
<td>91</td>
</tr>
<tr>
<td>Medicare</td>
<td>186</td>
<td>90</td>
</tr>
<tr>
<td>Medicaid</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

**GOC Documentation**

In the GOC-positive patient sample, the minimum and maximum number of GOC-positive notes per patient was one and 129, respectively. The average (mean) number of GOC-positive notes identified was 9.6 notes per patient and the standard deviation from the mean was 15.6.

**Clinician Authors**

As shown in Table 8, GOC-positive notes were authored by 11 distinct disciplines. Additionally, GOC-positive notes were authored by students from a variety of disciplines. Physicians most frequently authored GOC-positive notes (47.3%), followed by nurses (23.9%), and physical therapists (4.6%).
Table 8. Sample Characteristics Representing Clinician Authors and Frequency of GOC Positive Documentation

<table>
<thead>
<tr>
<th>Clinician author discipline</th>
<th>GOC – positive notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td><strong>Physician (MD/DO)</strong></td>
<td>1909</td>
</tr>
<tr>
<td><strong>Nurse (RN)</strong></td>
<td>967</td>
</tr>
<tr>
<td><strong>Physical Therapist (PT)</strong></td>
<td>187</td>
</tr>
<tr>
<td><strong>Student</strong></td>
<td>121</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>113</td>
</tr>
<tr>
<td><strong>Occupational Therapist (OT)</strong></td>
<td>90</td>
</tr>
<tr>
<td><strong>Social Worker</strong></td>
<td>70</td>
</tr>
<tr>
<td><strong>Advanced Practice Registered Nurse (APRN)</strong></td>
<td>65</td>
</tr>
<tr>
<td><strong>Dietician</strong></td>
<td>64</td>
</tr>
<tr>
<td><strong>Chaplain</strong></td>
<td>39</td>
</tr>
<tr>
<td><strong>Speech Language Pathologist (SLP)</strong></td>
<td>14</td>
</tr>
<tr>
<td><strong>Genetic Counselor</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>Pharmacist</strong></td>
<td>1</td>
</tr>
</tbody>
</table>

The author specialty category for physicians identified Obstetrics and Gynecology physicians most frequently authored GOC-positive notes, followed by Internal Medicine physicians, and Hematology/Oncology physicians.

**Patient Location**

GOC-positive notes were most frequently identified for hospitalized patients (73.3%), followed by ambulatory patients (26.0%). For patients in the Emergency Department GOC-positive notes were found least often (0.7%), see Table 9.

Table 9. Location Status of Patient at Time of GOC-Positive Note

<table>
<thead>
<tr>
<th>GOC – positive notes by patient location</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital (Inpatient)</td>
<td>2959</td>
<td>73.3</td>
</tr>
<tr>
<td>Ambulatory (Outpatient)</td>
<td>1050</td>
<td>26.0</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>29</td>
<td>0.7</td>
</tr>
</tbody>
</table>
**Note Type**

Of the GOC-positive notes, the most frequent note types identified as containing documentation of elements of GOC were Progress Notes (31.0%) and Plan of Care Notes (25.1%), see Table 10. Only 1.2% of the GOC-positive notes were authored by a Palliative Care Specialist, and less than 1% were authored by a Hospice Clinician.

Table 10. Frequency of Note Types Containing Elements of GOC Documentation

<table>
<thead>
<tr>
<th>GOC-positive notes by note type</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progress Note</td>
<td>1252</td>
<td>31.0</td>
</tr>
<tr>
<td>Plan of Care Note</td>
<td>1012</td>
<td>25.1</td>
</tr>
<tr>
<td>History &amp; Physical</td>
<td>391</td>
<td>9.7</td>
</tr>
<tr>
<td>Consult Note</td>
<td>299</td>
<td>7.4</td>
</tr>
<tr>
<td>Letter</td>
<td>298</td>
<td>7.4</td>
</tr>
<tr>
<td>Nursing Note</td>
<td>220</td>
<td>5.4</td>
</tr>
<tr>
<td>Admission Note</td>
<td>185</td>
<td>4.6</td>
</tr>
<tr>
<td>Emergency Department Note</td>
<td>112</td>
<td>2.8</td>
</tr>
<tr>
<td>Discharge Summary</td>
<td>111</td>
<td>2.7</td>
</tr>
<tr>
<td>Psychiatry Note</td>
<td>52</td>
<td>1.3</td>
</tr>
<tr>
<td>Palliative Care Note</td>
<td>49</td>
<td>1.2</td>
</tr>
<tr>
<td>Anesthesia Note</td>
<td>21</td>
<td>0.5</td>
</tr>
<tr>
<td>Hospice Note</td>
<td>14</td>
<td>0.3</td>
</tr>
<tr>
<td>Radiology Note</td>
<td>11</td>
<td>0.3</td>
</tr>
<tr>
<td>Pastoral Care</td>
<td>5</td>
<td>0.1</td>
</tr>
<tr>
<td>Bedside Procedure</td>
<td>2</td>
<td>0.0</td>
</tr>
<tr>
<td>Co-management Hospitalist</td>
<td>2</td>
<td>0.0</td>
</tr>
<tr>
<td>Operative Brief Note</td>
<td>1</td>
<td>0.0</td>
</tr>
<tr>
<td>Pharmacy Note</td>
<td>1</td>
<td>0.0</td>
</tr>
</tbody>
</table>

**GOC Documentation in Relation to Date of Death**

Date of death was available for 106 (27%) patients in the GOC-positive patient sample. In this subset of 106 patients, 73.6% did not have a GOC-positive note filed in the last month of life, while 26.4% of patients had a GOC-positive note filed within the last month of life, see Table 11.
Table 11. Patients With and Without a GOC-Positive Note Within 30 Days of Death

<table>
<thead>
<tr>
<th>GOC-positive note within 30 days of death</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>78</td>
<td>73.6</td>
</tr>
<tr>
<td>Yes</td>
<td>28</td>
<td>26.4</td>
</tr>
</tbody>
</table>

Analyses to Identify Differences Between Groups Based on Characteristics of the Sample

Statistical analyses were undertaken to examine differences in age, race (White and Non-White), ethnicity (Non-Hispanic, Hispanic/Latina, Prefers not to answer, and Unknown), or insurance class (Insurance, Medicare, Medicaid, Uninsured) between the GOC-positive patient sample and the GOC-negative sample.

Age: GOC-Positive Versus GOC-Negative

An independent samples t-test was conducted to compare the two groups, GOC-positive patient sample and GOC-negative patient sample, based on age. There was no significant difference in scores for GOC-positive patients (Mean = 60.75, Standard Deviation = 14.46) and GOC-negative patients (Mean = 60.21, Standard Deviation = 15.46; t (625) = .42, p = .67, two-tailed). The magnitude of the differences in the means (mean difference = .53, 95% CI [-1.942, 3.006]) was small (Cohen’s d = 0.4).

Race, Ethnicity, and Insurance Class: GOC-Positive Versus GOC-Negative

Chi-Square tests for independence were conducted to compare the two groups, GOC-positive patients and GOC-negative patients, based on the characteristics of race, ethnicity, and insurance class. There were no significant associations demonstrated between the groups based on race, ethnicity, or insurance class. See Table 12.
Table 12. Chi-Square Results Between Race, Ethnicity and Insurance Class, and GOC-Positive and GOC-Negative Patients

<table>
<thead>
<tr>
<th></th>
<th>Pearson Chi-Square value</th>
<th>df</th>
<th>Asymptotic significance (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>.07&lt;sup&gt;a&lt;/sup&gt;</td>
<td>1</td>
<td>.80</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>2.49</td>
<td>3</td>
<td>.48</td>
</tr>
<tr>
<td>Insurance class</td>
<td>.93</td>
<td>3</td>
<td>.82</td>
</tr>
<tr>
<td>n of cases</td>
<td>627</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. a = continuity correction computed for 2 x 2 table.

Analyses to Identify Relationships Between Number of GOC-Positive Notes per Patient and Characteristics of the Sample

The relationship between the total number of GOC-positive notes identified per patient and age, race, ethnicity, and insurance class were investigated.

Age: Number of GOC-Positive Notes Identified per Patient

Pearson correlation did not identify a relationship between patient age and the total number of GOC-positive notes identified per patient, r = .013, n = 422, p = .786.

Race, Ethnicity, and Insurance Class: Number of GOC-Positive Notes Identified per Patient

One-way Analysis of Variance (ANOVA) did not identify relationships between the total number of GOC-positive notes identified per patient and ethnicity or insurance class. However, ANOVA demonstrated a statistically significant relationship between the total number of GOC-positive notes identified per patient and race (White: Mean 8.3, Standard Deviation 12.7; and Non-White: 13.43, 22.185; p < .003). A significant positive association is demonstrated between Non-White race and mean number of GOC-positive notes, see Table 13. The analysis demonstrates significantly more GOC-positive notes identified for Non-White patients compared to Whites.
Table 13. One-Way ANOVA Results Between Characteristics of Race, Ethnicity, Insurance Class and Mean Number of GOC-Positive Notes per Individual Patient

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>2108.077</td>
<td>1</td>
<td>2108.077</td>
<td>8.836</td>
<td>.003</td>
</tr>
<tr>
<td>Within groups</td>
<td>100205.430</td>
<td>420</td>
<td>238.584</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>6.358</td>
<td>1</td>
<td>6.358</td>
<td>.026</td>
<td>.872</td>
</tr>
<tr>
<td>Within groups</td>
<td>102212.764</td>
<td>416</td>
<td>245.704</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance class</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>612.032</td>
<td>2</td>
<td>306.016</td>
<td>1.256</td>
<td>.286</td>
</tr>
<tr>
<td>Within groups</td>
<td>101344.217</td>
<td>416</td>
<td>243.616</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Analyses to Identify Relationships Between the Mean Number of Days from Diagnosis of Ovarian Cancer to the First GOC-Positive Note and Characteristics of the Sample

The relationship between the mean number of days from diagnosis of ovarian cancer to the first GOC-positive note and age, race, ethnicity, and insurance class were investigated.

*Age: Days to the First GOC-Positive Note*

Pearson correlation did not identify a relationship between patient age and mean number of days to the first GOC-positive note, $r = .068$, $n = 422$, $p = .161$.

*Race, Ethnicity, and Insurance Class: Days to the First GOC-Positive Note*

One-way ANOVA did not identify relationships between race, ethnicity or insurance class, and mean number of days between diagnosis of ovarian cancer and the first GOC-positive note. See Table 14.
Table 14. One-Way ANOVA Results Between Characteristics of Race, Ethnicity, Insurance Class and Mean Number of Days to the First GOC-Positive Note

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>48.963</td>
<td>1</td>
<td>48.963</td>
<td>.002</td>
<td>.966</td>
</tr>
<tr>
<td>Within groups</td>
<td>11057726.015</td>
<td>420</td>
<td>26327.919</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>51993.653</td>
<td>1</td>
<td>51993.653</td>
<td>1.967</td>
<td>.162</td>
</tr>
<tr>
<td>Within groups</td>
<td>10996575.792</td>
<td>416</td>
<td>26434.076</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Insurance class</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between groups</td>
<td>29169.339</td>
<td>2</td>
<td>14584.669</td>
<td>.550</td>
<td>.577</td>
</tr>
<tr>
<td>Within groups</td>
<td>11021646.212</td>
<td>416</td>
<td>26494.342</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Discussion of results and further analysis of study findings will be presented in the following section, Chapter V.
CHAPTER V

DISCUSSION OF RESULTS

This chapter offers a review and discussion of the study findings organized by the research question and aims. Discussion will focus on the efficacy of the novel NLP methodology in uncovering elements of documentation of goals of care for patients with ovarian cancer and will evaluate and analyze the novel documentation findings based on patient, clinician, and healthcare setting characteristics. Study strengths and limitations, implications for nursing, and conclusions will be offered.

Aim 1: CUIs Uncover GOC Documentation

This study identified CUIs that uncover elements of GOC documented within unstructured narrative EHR notes for patients with ovarian cancer. The process for identifying the most important CUIs and CUI permutations reflective of GOC elements was an iterative, months-long endeavor, requiring teamwork and close partnership between the clinician researcher and informatics experts. Occurrences of cNLP CUI-mapping failure were found during manual annotation and rule validation efforts. When these occurrences were discovered, rules were augmented by 1) deleting note types from analysis that demonstrated false identification of GOC-related CUIs; and 2) adding missed phrases and acronyms to the rules to improve cNLP precision. The result of the collaboration is the final rule for identifying elements of GOC, seen in Appendix C. The confusion matrix describing the predictive and discriminatory accuracy of the rules supports the quality of the cNLP engine performance. When the cNLP
engine analyzed clinical notes for the patient sample using the algorithm rules, elements of GOC documentation were identified.

Analogous studies have used NLP methods to identify documentation of discussions of patient values and priorities. In a retrospective analysis of unstructured EHR free-text notes, clinician documentation of patient priorities was reliably identified by an automated NLP model in older adult patients with multiple chronic conditions (Razjouyan et al., 2021). A mixed-methods study evaluated the performance of three NLP modeling approaches including bag-of-words, rule-based, and a hybrid approach for identifying GOC discussions in the EHR for hospitalized patients with serious illness (Uyeda et al., 2022). They found that NLP is a promising methodology for identifying GOC discussions, though the infrequency of GOC discussions in clinical practice and their documentation can limit NLP performance. These studies show NLP methodologies as feasible and precise means of finding documentation of GOC in the EHR.

This retrospective study identified elements of GOC documentation from the EHRs of patients with ovarian cancer with efficiency and precision as was previously done by investigators at our institution using the same technology, UMLS Metathesaurus, and CUI-organized ontology mapping (Oosterhouse et al., 2021). The methodologies employed to build algorithm rules are sound, feasible, and reproducible. And while the rules developed for this project are uniquely suited to this institution and this sample, they serve as a resource for investigators to augment, refine, and validate for wider use in other institutions and with other sample populations. As the science of NLP matures, it will be important to conduct comparison studies to improve performance and utility of the methodology.
Sample Characteristics

The overall patient sample lacks diversity based on race and ethnicity. The sample is overwhelmingly Non-Hispanic and White. Interestingly, the characteristics for both GOC-positive and GOC-negative samples of patients are comparable across nearly all categories except for size. The GOC-positive sample is approximately twice as large, representing 422 unique patients (67.3%) compared to 205 patients in the GOC-negative sample (32.7%). Composition of the samples based on age, race, ethnicity, and insurance class are nearly identical, with only slightly more patients identifying as Hispanic in the GOC-positive sample and slightly more patients with Medicaid health insurance in the GOC-negative sample.

GOC Documentation

Over the course of this 3-year retrospective review, the records of 627 unique patients were analyzed by cNLP for elements of GOC documentation and 67.3% of patients were found to have elements of this documentation in clinical EHR notes. This also means that for 32.7% of these patients there was not a single element of GOC documentation uncovered in clinical notes. For the slightly more than one-third of patients for whom GOC elements were not found, these patients do not have documented evidence of receipt of standard, guideline-supported cancer care. Both American Society of Clinical Oncology and National Comprehensive Cancer Network have strong recommendations for clinicians to address goals, values and priorities with patients and families (Gilligan et al., 2017; Dans et al., 2021). While the protective nature of clinicians who worry about disrupting hope, inflicting undue harm, and increasing fear and anxiety in their patient can serve as barriers to conducting GOC discussions, these concerns are directly refuted by patients themselves (Chandar et al., 2016; Robinson, 2017). In a qualitative study, through semi-structured interviews following the completion of a GOC discussion, patients with
gynecologic malignancies (50% with ovarian cancer) generally felt the conversations were useful, provided space to express their values, and did not compromise the patient-clinician relationship (Zanolli et al., 2022).

The study findings are consistent with those from a retrospective chart review evaluating patients with gynecologic malignancies, published a year prior to the time range of this study (Zakhour et al., 2015). Their review found that 71% of patients had a documented EOL discussion. A more recent published pilot intervention study to promote timely GOC conversations between gynecologic cancer patients and their providers collected baseline data including documentation of a GOC discussion (Davidson et al., 2022). Prior to the intervention, GOC discussions were documented for only 30.2% of patients; post intervention the documentation rate improved to include 88.7% of patients.

Some variability in rates of documentation of GOC is explained at least in part by how each study defines GOC. In this study, a broad operational definition was utilized to identify documented elements of GOC. The Zakhour study was similar in defining EOL care discussions as documented conversations that included any reference to code or resuscitation status, hospice or palliative care, shifting treatment focus to symptom-based care, GOC at end of life, or AD completion. In contrast, the Davidson (2022) intervention study defined GOC discussion more holistically, using an EHR note template including all the following: patient’s understanding of curability of cancer and prognosis, important GOC, discussion of code status, and/or hospice.

**Total Number of GOC-Positive Notes per Patient**

The GOC-positive sample, for whom elements of GOC were identified, has considerable variability in number of GOC-positive notes per patient. The number of GOC-positive notes ranges from one singular note to 129 notes per individual patient, with a mean of 9.6 notes per
patient; standard deviation of 15.6. Deeper qualitative, manual review of outlier notes may provide explanation for this variability. At least in part it may be explained by the broad operational definition of GOC used in crafting the algorithm rules to identify GOC-positive notes. Another contributing factor may be a consequence of the “copy and paste” phenomenon common with EHR documentation practice patterns such that historical documentation from prior notes is duplicated in subsequent notes, potentially artificially increasing the per patient GOC-positive note tally (Hammond et al., 2003).

**Clinician Authors**

A novel finding of this study is the great diversity of clinician authors of GOC-positive patient notes. There were 11 distinct author disciplines identified by presence of elements of GOC in their clinical documentation. The disciplines with the most frequent authorship of GOC-positive notes were physician (47.3%) and nurse (23.9%). Physical therapists (4.6%), students (3.0%), and occupational therapists (2.2%) were next in line. These findings demonstrate that each of the 11 disciplines engage in various aspects of serious illness communication and reveal a level of understanding and acknowledgement of how patients’ GOC impact their engagement with various disciplines, and the decisions they make about their care. The diversity of clinician authors highlights opportunities to think more broadly about how to better address system barriers to improving and increasing GOC discussions, and moreover to the inclusion of interdisciplinary perspectives on GOC in both EHR documentation and in the patient’s healthcare plan. The variety of disciplines contributing to the documentation of patient GOC points to the team nature of cancer care, as well as the importance each team member plays in assuring the care they deliver is concordant with patient-defined goals and priorities. The notion that healthcare trainees from nursing, medicine, and psychology outpaced other professionals’
documentation of GOC elements can be viewed as a positive indicator – that rising nurses and physicians and psychologists are incorporating patient GOC into their documentation reflects progress toward the possibility of delivery on the promise of goal-concordant care.

**Patient Location**

Only 26% of GOC-positive notes were filed when patients were in an outpatient setting. More than 73% of GOC-positive notes were filed when patients were hospitalized. These results are consistent with findings by Zakhour and colleagues (2015). Through retrospective chart review of 136 decedent women with gynecologic malignancy, 71% had a documented EOL conversation – 19% of these conversations were in the outpatient setting and 81% in the inpatient setting. Additionally, EOL conversations occurring in the outpatient setting were associated with lower rates of health care utilization, receipt of chemotherapy in the last two weeks of life, and in-hospital death. By the very nature of their in-hospital location, patients with ovarian cancer who are hospitalized require higher intensity healthcare, are generally sicker, and are at higher risk for dying compared to patients seen in the outpatient setting. They are also at higher risk for losing capacity to articulate their care preferences, values, and priorities – their GOC. The lower percentage of outpatient GOC documentation compared to inpatient GOC documentation represents a lost opportunity to engage patients in earlier GOC discussions, potentially compromising patient autonomy.

**Note Type**

GOC-positive documentation was identified in 19 distinct EHR note types. The note types that most frequently contained GOC-elements were Progress Notes (31%) and Plan of Care Notes (25.1%). These findings may direct clinicians, investigators, and rules refinement for future NLP research in the uncovering of GOC documentation.
Only a small fraction of GOC-positive notes were classified as Palliative Care or Hospice. The small number of GOC-positive hospice notes is an expected finding, especially since the provision of hospice care and its documentation generally occurs outside hospitals, clinics, and emergency departments – rather 98.2% of hospice care is in the home setting (National Hospice and Palliative Care Organization, 2020). Related to palliative care, the limited number of GOC-positive palliative care notes may reflect one of two scenarios: A lack of availability or access to palliative care services, and/or limited consultation and utilization of available palliative care services for this patient sample.

Missed Opportunities. There is inconsistent data on referral to specialty palliative care services in patients with ovarian cancer. Referral of patients with ovarian cancer for inpatient palliative consultation improved from 2.7% to 10.4% over a six-year period out of a sample of over 100,000 patients for nonelective hospitalization (Uppal et al., 2016). Patterns of palliative care referral and integration for 258 patients with platinum resistant ovarian cancer were retrospectively studied – most patients (71%) were referred to palliative care, with 43% of referrals occurring within three months of death. In a retrospective chart review of 204 patients with gynecologic malignancy, 52.5% received specialty palliative care consultation prior to death; 88.8% were inpatient and 11.2% were outpatient consultations (Schneiter et al., 2019). The identification of only 49 palliative care notes (1.2%) in a sample of 14,151 notes representing 627 patients is reflective of extremely poor access and/or utilization of palliative care services in this study’s institution, particularly in comparison to the previously cited retrospective evaluations. Palliative care consultation has been associated with better EOL outcomes among gynecologic oncology patients including increased hospice enrollment and advance care planning documentation (Schneiter et al., 2019). These data can also be viewed as
many, many missed opportunities to receive benefit from the additional layer of support provided to patients and families when palliative care services are institutionally prioritized and when palliative care clinicians are engaged in the care of patients with ovarian cancer diagnoses.

**GOC Documentation in Relation to Date of Death**

Among the 106 patients for whom date of death was available in the EHR, 73.6% had documentation of GOC elements more than 30 days before dying, while 26.4% did not. The importance of the timing of GOC discussion in proximity to death relates to markers of the quality of EOL care. Patients with gynecologic malignancy who have early EOL conversations (defined as more than 30 days before death) were shown to have lower rates of health care utilization, lower likelihood of receiving chemotherapy in the last two weeks of life, and were less likely to die in the hospital (Zakhour et al., 2015). The Zakhour findings mimicked a similar retrospective study of decedents from ovarian cancer for whom timing of EOL conversations demonstrated similar associations with quality of EOL care (Lopez-Acevedo et al., 2013). While 100% of these patients had identified GOC-positive notes, 26.4% of patients had a note filed within their last month of life, an indicator of lesser quality of EOL care. These data suggest that opportunities were missed to improve the EOL experience of more than a quarter of the patients with a GOC-positive note.

**Aim 2: Differences and Variability in GOC Documentation**

Statistical analyses were undertaken to examine differences in patient age, race, ethnicity, or insurance class between patients with and without documentation of elements of GOC (GOC-positive versus GOC-negative samples). Additionally, analyses were performed to examine the relationship between patient age, race, ethnicity, or insurance class, and total number of GOC-positive notes identified per patient, and between the mean number of days from diagnosis of
ovarian cancer to the first GOC-positive note and characteristics of the sample. There were no statistically significant differences identified between patients with or without documentation of GOC elements based on these characteristic variables. There were no statistically significant differences revealed between the mean number of days from diagnosis of ovarian cancer to the first GOC-positive note and the characteristic variables of interest.

There were no relationships identified between patient age, ethnicity, or insurance class and number of GOC-positive notes that met statistical significance. However, a positive and statistically significant relationship between mean number of GOC-positive notes identified per patient and Non-White race was demonstrated (p < .003). The positive relationship between mean number of GOC-positive notes and Non-White race demonstrates variation of GOC documentation based on the characteristic of race. Non-White patients were found to have significantly greater number of GOC-positive notes compared to Whites.

**Disparities in Ovarian Cancer**

To understand the aforementioned significant finding, it is worthwhile to review the data describing disparities in healthcare and health outcomes for patients with ovarian cancer. With a sample of 7,756 decedent Medicare beneficiaries with ovarian cancer, national trends and racial disparities in EOL care were evaluated (Mullins et al., 2021). Despite the clinical climate moving toward less aggressive EOL care for women with ovarian cancer – a quality indicator – they found the use of aggressive EOL interventions persists, and care is most aggressive for Non-White women. Non-White women were also less likely to use hospice compared to Whites.

In an earlier and similar study, the Texas Cancer Registry-Medicare database was used to evaluate EOL care for patients with ovarian cancer (Taylor et al., 2017). From the records of 2,344 decedent patients, it was found that being a minority was associated with receiving
intensive and invasive EOL care. Hispanic and Black patients were less likely to enroll and die in hospice (Black odds ratio [OR], 0.66; 95% CI, 0.50 to 0.88; p = .004; Hispanic; OR, 0.76; 95% CI, 0.61 to 0.94; p = .01); Hispanic patients were more likely to be admitted to ICU (OR, 1.37; 95% CI, 1.05 to 1.78; p = .02); and Black patients were more likely to have more than one ER visit (OR, 2.20; 95% CI, 1.53 to 3.16; p < .001) and receive a death-delaying procedure (OR, 2.13; 95% CI, 1.49 to 3.04; p < .001) in their last month of life.

Disparities in Cancer and Serious Illness

In a retrospective and cross-sectional study, the records from a national database of 21,335 decedent adults with metastatic cancer who died in hospital were analyzed for disparities in care (Deeb et al., 2021). Racial and ethnic minority patients and those with Medicare and Medicaid coverage were more likely to receive low-value and high-cost aggressive medical interventions at EOL. In a separate retrospective cohort study, the EHRs of hospitalized patients with serious illness were evaluated by NLP for GOC discussions (Uyeda et al., 2023). GOC discussions were found more frequently for older patients and those with higher disease burden, and less frequently among racially or ethnically minoritized patients.

Family members of patients who died in an ICU have also contributed to understanding the breadth of health disparities on EOL care. As part of a cluster-randomized trial of a palliative care intervention, family members of decedents completed self-report surveys evaluating quality of dying (Lee et al., 2016). Family members returned 1290 surveys for 2859 decedents. Patient and family minority race and ethnicity were both associated with lower ratings of quality of dying (Nonminority family survey score 7.1 ± 3.0 (mean ± SD); Minority 6.1 ± 3.6; p = .001). The studies which identify disparities in delivery of EOL care including GOC documentation in
patients with serious illness stress the importance and even suggest that disparity may be identified in this study evaluating documentation of GOC.

Owing to the pervasive nature of socio-economic status (SES) on health, SES is an important factor in relation to the uncovering of potential disparities in healthcare access and care provision (Krieger, 1994). Limited by available data for retrospective analysis, use of insurance class, specifically Medicaid as an indicator of SES, has been studied and validated in EHR-based research (Casey et al., 2018). For these reasons, examining a possible relationship between insurance class, a proxy for SES, and documentation of elements of GOC is important in identifying potential differences. This study did not identify a relationship between GOC documentation and characteristic of Medicaid insurance coverage.

In semi-structured interviews, 74 clinicians from a national sample, representing primary care, geriatrics, and palliative care, and including physicians, nurses and social workers, expressed having difficulty discussing ACP and reported avoiding ACP with certain racial and ethnic groups (Ashana et al., 2021). One representative quote about a minoritized population, “What you are taught about African American families is that you don’t talk to them about their goals of care,” is an example of clinician bias contributing to variability in care and disparities (p. 341). Given this language came directly from the mouth of a clinician, expressing avoidance to engaging in ACP discussions with minoritized patients, the finding of a positive relationship between mean number of GOC-positive notes and Non-White race from this study is curious.

Understanding a Curious Finding

Deeper analysis is needed to understand the positive relationship that was identified in this study between mean number of GOC-positive notes and Non-White race. While it is beyond the aims of this study, a future qualitative project examining the records of Non-White patients
with high numbers of notes identified as GOC-positive would help to understand and explain the finding. Clarification of clinical context and the emergence of themes may provide a rationale for the positive relationship between Non-White race and number of GOC-positive notes observed in this study.

Prior cited studies have demonstrated the GOC of Non-White patients are more likely than Whites to favor intensive and aggressive care at EOL, and less likely to include comfort-focused care plans and hospice services. It is therefore hypothesized that the statistically significant increased mean number of GOC-positive notes among Non-White patients in the study might be explained by repeated clinician documentation in which concern is expressed about existing GOC, and repeated clinician documentation reflecting GOC discussion in which a change in GOC is recommended. The phrase “goals of care” has been described as an ill-defined “buzz phrase” that clinicians use to 1) intimate that a patient is not doing well clinically, 2) suggest that code status needs to be addressed, and 3) that employing life prolonging interventions is medically futile and needs to be reconsidered (Klement & Marks, 2020). The implication when the “buzz phrase” is employed is that the current GOC for aggressive intervention and maximum life prolongation are not feasible and should be readdressed. These phenomena described by Klement and Marks may help explain the curious finding that clinician authors conveyed through frequent documentation – expressing concern over the discrepancy between patients’ existing and aggressive GOC, and clinicians’ opinions about limited medical feasibility and appropriateness of patients’ GOC, particularly related to code status and life support. More GOC documentation for Non-White patients may demonstrate evidence of discordance between the health care team’s recommendations and the preferences expressed by the patient/family.
Study Strengths

This study accomplished two endeavors. First, the study developed and validated a novel cNLP methodology using CUIs as the primary data organizer. Second, it used CUIs to identify documentation of GOC elements for patients with ovarian cancer amidst the vast amount of unstructured data contained in the EHR.

The study offers a means for efficient and meaningful evaluation of a massive amount of unstructured clinical data that is virtually inaccessible without harnessing technology in the form of a novel cNLP engine. This study exemplifies how technology such as NLP enables large-scale retrospective record review – making it a pragmatic, accessible, and feasible means of engaging in nursing research; making what was previously inaccessible both accessible and measurable – akin to finding a needle in a haystack.

From a GOC-related key term library, the study builds a rules-based algorithm using CUIs and CUI permutations to identify GOC elements in the EHR. The rules that were developed and refined through repeated validation can be used and augmented for future study.

There has been limited study of GOC documentation in patients with ovarian cancer. This study adds to the science by describing the great variety of clinician disciplines who participate in GOC documentation, and by offering information about where to find such documentation. By including aims to investigate possible disparities in care, this study also highlights the need for future analyses to better understand care gaps and develop solutions to assure equitable care and outcomes for all patients regardless of age, race, or social status.

Study Limitations

There are limitations of this study. While NLP has enormous potential to answer important research questions, EHR-based research depends solely on the presence, accuracy, and
quality of clinician documentation. NLP can efficiently identify elements of GOC documentation as long as clinicians are producing the documentation. If clinicians fail to document their GOC communications with patients, then NLP will also fail to identify GOC documentation.

Unstructured data extracted from clinical notes uncovers data and information that almost exclusively represents the clinician voice. The voice of the patient and those close to the patient, when present, are only present through interpretation by clinicians. When the desired data include knowledge of patient values, goals, priorities, worries, fears, illness understanding, and processes of decision making, the possibility for misrepresentation of patient data can introduce error and limit the validity of findings.

This study used a generous operational definition of GOC, permitting positive evaluation of GOC when just a single element is documented. This definition gave credit to clinicians for GOC documentation when they documented something as granular as a recommendation for palliative care consultation. However, even if the GOC element is as finite as a recommendation, it provides valuable narrative information to other clinicians about how the note author is thinking about a patient’s care and what information the patient has received. The GOC elements are pieces of a story; where even the pieces in isolation are informative. These important pieces of a patient’s story – their expressed values and care preferences, their hopes and worries – are the very documentation that when uncovered, can provide useful roadmaps with sign-posts for clinicians to achieve the holy grail, the provision of goal-concordant care.

Lastly, this was a retrospective review using a convenient, predominantly White sample that lacked diversity. Institutional and clinician EHR documentation differences, and cancer type of the study population, limit generalizability of the NLP methods and findings. The study offers
a detailed description of the iterative, rule-building process that can be reproduced and tailored for other institutions, as well as for other cancers and diseases.

**Implications and Future Directions**

Computational methods including NLP and machine learning offer avenues to capture patient-centered information through a low-burden approach, presenting increased “means for precision palliative care” (Durieux, Tarbi & Lindvall, p. 1168, 2022). For patients with serious illness, their time and attention are precious resources. It is an ethical obligation of clinician researchers to honor this. By harnessing the extensive data housed in EHRs and using novel methods to leverage the content of naturally-occurring clinical conversations, tools such as NLP help to uncover and understand complex and historically difficult to measure concepts such as GOC and goal-concordant care.

**Nursing Research**

Application of the processes and outcomes of this study can be utilized by nurse scientists to refine and validate the algorithm rules to identify elements of GOC for their institutions and EHRs – to study a more diverse population of patients with ovarian cancer, and additionally to broaden or augment the rules for use in other advanced cancers and serious illnesses. Nurse informaticists might utilize similar methods to evaluate the quality of documentation and communication in their institutions. Considerable overlap in the language of GOC documentation from this study is expected to translate across institutions and beyond ovarian cancer to other serious illnesses. Future investigators are sure to discover uniquenesses based on disease type; clinician specialist training, communication styles, and patterns; also based on region, institutional setting, and EHR features. This research will help to further build, grow, and refine key term and CUI libraries to improve the precision of GOC identification through NLP.
Harnessing NLP as Measurement Tool for Intervention Study Outcomes

A validation and feasibility study evaluated use of deep learning NLP to measure the outcome of documented GOC discussions in a pragmatic randomized clinical trial of a communication intervention, comparing its performance to NLP-screened human abstraction and conventional manual abstraction (Lee et al., 2023). Deep-learning NLP and NLP-screened human abstraction were described as having favorable characteristics for measuring an EHR outcome at scale. The study suggests that NLP may facilitate measurement of previously inaccessible outcomes in clinical trials. Lee and colleagues offer a use case for NLP methodologies as feasible means for evaluation of nursing research outcomes in future studies of serious illness communication interventions and in studies evaluating for patient receipt of goal-aligned healthcare interventions.

Another study examined the performance of NLP in capturing ACP documentation in clinical notes for a large sample size of oncology patients participating in a pragmatic clinical trial (Lindvall et al., 2022). NLP demonstrated favorable performance in identification of all four defined domains for ACP documentation, and in a fraction of the time, compared to manual chart review of EHRs. Similarly, this validation study shows promise for future nursing research in the measurement of ACP documentation, the trial outcome of interest, in large EHR datasets. A future follow-up study might then evaluate the same large EHR dataset for receipt of goal-concordant care. The design for this future study would be longitudinal, utilizing repeated NLP measurements to identify GOC within ACP documentation, enabling evaluation for delivery care concordant with patients’ expressed goals.

Patient Reported Electronic Health Information

A quality improvement project demonstrated the feasibility and uptake of patients with
cancer, followed in a supportive care clinic, self-reporting symptoms electronically in the form of the Edmonton Symptom Assessment System (ESAS) both before and after their clinic visits (Hui et al., 2023). Self-reported symptoms were recorded in real-time in the EHR and helped to inform the clinical team of patient needs and distress level. An important area for future nursing research is the development and validation of a similar electronic tool for patients and families to self-report their values and priorities, in addition to any prior advance directives. Patient-reported goals of care elements could be easily imported to the EHR through a patient-facing portal, identified by NLP engines, and utilized in real-time to support clinician-patient communication around their goals of care.

Valuable contributions to nursing science include answering various research questions such as: Is electronic reporting of patient/family values and priorities acceptable and feasible? How closely matched are patient-reported GOC to the documentation of clinicians? Does the clinical team utilize patient and family-reported GOC elements in shared decision-making and recommendations about care planning? Does use of patient and family-reported GOC influence their relationships with the clinical team? Do patients feel heard and understood?

**NLP Identification of Target Population Followed by Clinical Nudging**

NLP and machine learning (ML) are being used to identify at-risk patient populations for the targeting of communication interventions. NLP and ML enable rapid and real-time identification of seriously ill patients, permitting electronic notifications and clinical nudges to promote GOC discussions and documentation by the clinicians involved in caring for high-risk patients.

Oncology patients were identified by a machine leaning algorithm at high risk for 6-month mortality (Manz et al., 2023). In this randomized clinical trial, the patient mortality data
was then used to behaviorally nudge oncology clinicians to have serious illness conversations (SICs) with their high-risk patients. Manz and colleagues showed how a machine learning-based intervention and nudges to clinicians led to an increase in SICs and a reduction in systemic cancer therapy given in the last two weeks of life.

In a cohort study, a machine learning mortality prediction algorithm was used to identify patients at high risk for 30-day mortality (Chi et al., 2023). By notifying physicians through a communication “nudge” of the high mortality risk, patients were five times more likely to have EHR-documented GOC discussions than matched controls.

There are seemingly infinite applications of this research methodology – using NLP to identify a target study population followed by a clinical nudge to evaluate an intervention. NLP might even be used to identify marginalized and underserved groups, or patients at high risk for losing capacity as a natural consequence of their progressive illness; then a timely clinical nudge is directed to the patient and/or their family to encourage communication with the clinical team about their GOC. Registered nurses and advance practice nurses working in all care settings, as well as other interdisciplinary team members, are prime candidates for receipt of such clinical nudges to further study their engagement and influence on serious illness communication and discussion and documentation of GOC.

Nursing Practice

Translating and applying research findings revealed by computational methods like NLP into clinical practice has great power to improve clinical care and nursing practice.

NLP Output Utilization to Enhance Efficiency and Care

Information obtained through NLP can be harnessed and organized to support nurses in all practice settings to provide precision nursing. For example, at the beginning of the day, an
oncology infusion nurse working in a cancer treatment center accesses their daily schedule including all the patients planned for infusion and hydration. They access the NLP engine and within seconds a report is generated, organized by patient with information gleaned from the EHR including relevant GOC elements as well as identification of important missing elements. This report arms the nurse with background information about their patients and directs their nursing care plans accordingly. For historically underserved patients, a report that specifically identifies important missing elements may serve as a trigger to direct nursing interventions that address these gaps.

Similarly, a clinical nurse specialist (CNS) working in an academic hospital’s oncology unit might utilize a NLP engine to routinely generate a report describing the unit’s performance on specific quality metrics – for instance, documentation of a surrogate decision maker (SDM) for each patient housed on the unit. During a particular week, if the report reveals lower than acceptable measures for this SDM documentation, they might schedule lunch-and-learn sessions focused on improving performance on this measure. The same NLP engine can be utilized to evaluate results of the quality improvement efforts.

For nurses working in emergency departments (ED) and intensive care units (ICU), they are often the first clinicians meeting and receiving patients who may be in extremis and lack capacity to participate in healthcare decision making. Specifically for patients with cancer diagnoses, the initial moments of assessment and care can be frenetic as the healthcare team is working to stabilize, clinically evaluate, and develop a care plan that is ideally inclusive of the patient’s GOC. An immediately available and accessible NLP-generated tool reporting patient GOC could be immensely beneficial and valuable to support necessary in-the-moment care, planning, and decision-making. In these situations, NLP GOC reports ought not be used as
medical orders or advance directives, rather they should be used as curated data, a jumping-off-point to support and enhance in-the-moment discussions, decision-making, and the provision of care.

If the science of NLP continues to advance at the rapid pace it has in recent years, it is conceivable to imagine a time when patients are documenting their priorities and goals, identifying proxy decision maker(s), and requesting referrals for supportive care through the use of patient portals or by using clinic-based kiosks or tablet computers. Consider use of nudges to clinicians, based upon NLP analyses of patient-documented GOC elements. For example, if a patient indicates their priority is to X, an electronic nudge to the Oncology APRN at the appropriate time can inform them of this priority, and thus encourage a conversation around this priority, and through shared decision-making augment the patient’s care plan accordingly.

**NLP Predicts Survival, Targeting Provision of Scarce Resources**

In a retrospective prognostic study, initial oncologist consultation documents were analyzed using traditional NLP and neural language models to predict 6-month, 36-month and 60-month survival for patients regardless of cancer type (Nunez et al., 2023). The ability to predict survival with such specificity may enable oncology clinicians to better target patients for specific communication and ACP interventions. Armed with knowledge of expected prognoses may also provide non-physician clinicians the encouragement to more fully engage in, and conduct GOC conversations.

Having data to support prognostication may offer guidance to clinical staff (oncologists, nurses, social workers, and others) for when to consider and advocate for referral to the embedded palliative care clinic. Given the scarce resource of specialist palliative care in cancer
centers and in community settings, harnessing the prognostic abilities of NLP can more directly target patients who would most benefit from the support offered by palliative care specialists.

**Nursing Education**

A scoping review demonstrated how NLP has been increasingly used in palliative care research for its versatility and accuracy (Sarmet et al., 2023). Given the myriad potential use cases for NLP in both future nursing research and nursing practice, inclusion of NLP and other computational tools ought to be included in nursing curriculum at all levels, from baccalaureate to doctoral level programs. Exposure to the work of nurse researchers and informatics specialists throughout nursing education in the form of elective coursework, experiential opportunities, and through research assistantships using NLP will support nurses in acquiring the knowledge, skill, and confidence to become leaders in this field of expertise. If supported through education, the advancement of NLP methodologies will serve to create pipelines for nursing informatics roles in clinical care, research, and industry.

NLP may be harnessed to improve nursing education in serious illness communication, and communication more broadly. An exploratory pilot study investigated the feasibility of measuring palliative care communication in telehealth visits; evaluated the quality of recordings for automated transcription aided by NLP; and qualitatively described the visit content (Tarbi et al., 2023). This pilot offers preliminary evidence and potential for augmented use in communication training and evaluation for nursing students. Transcribed recordings of simulated patient-nursing student encounters can be analyzed by NLP for important GOC-related keywords. The NLP generated outputs could offer valuable feedback and/or evaluation for content and quality of the student’s communication.
NLP is being used in surgical residency programs to help analyze and synthesize performance information, facilitating the incorporation of a variety of assessments for use by program directors to focus attention on residents who might benefit from additional support and better tailor development of educational interventions (Abbott et al., 2021). Nursing education might also benefit from a similar type of NLP use, to improve both education and evaluation of nursing students. Given the rapid analysis and evaluation offered by NLP engines, use in educational realms, particularly around evaluation of performance, might allow for a much more rapid response with supportive educational interventions when learners are found to be struggling or underperforming.

**Conclusions**

This study sought to characterize documentation of GOC in the EHR for patients diagnosed with ovarian cancer using a novel NLP methodology. This undertaking required identification and iterative refinement of GOC-related CUIs and CUI permutations used to build algorithm rules that guided NLP analyses. The algorithm rules were repeatedly refined to maximize NLP performance. Free-text narrative clinical notes were evaluated using NLP and elements of GOC were successfully identified, satisfying the first study aim.

A total of 14,151 clinical notes, representing 627 unique patients, were evaluated by NLP. Elements of GOC documentation were identified for 67.3% of the overwhelmingly Non-Hispanic, White patient sample. Notably, eleven distinct disciplines were identified as clinician authors of GOC-positive notes, highlighting the interdisciplinary nature of serious illness communications. Only 1.2% of GOC-positive notes were authored by a palliative care specialist, representing missed opportunities for offering the extra layer of support that palliative care provides patients and families. GOC-positive notes were most frequently identified for
hospitalized patients (73.3%), and 26.4% of patients for whom death date was available had GOC-positive notes filed in the last month of life – both findings reveal missed opportunities to improve the quality of patients’ EOL experience. While the study investigated for possible relationships between the documentation of GOC and variables of age, race, ethnicity, and insurance class, only one statistically significant relationship was identified. Statistical analysis with ANOVA demonstrated a positive association between the total number of GOC-positive notes identified per patient and Non-White race (p < .003). An in-depth analysis of the clinical notes of outlier Non-White patients (with high numbers GOC-positive notes) is necessary to understand this relationship. Characterization of documentation of GOC for this population including investigation for possible disparities were successful, satisfying the second study aim.

The results of this study demonstrate the impressive reach of NLP to uncover important clinical data related to GOC for patients with ovarian cancer that is otherwise practically impossible to retrieve from the EHR related to the time-consuming nature and the attention-to-detail required with manual chart abstraction. Additionally, the data outputs from NLP can be efficiently sorted and paired with demographic information for further evaluation and large-scale statistical analyses. Use of NLP shows promise for future study, interventions, and clinical practice to improve care and nudge closer to delivering on the promise of providing care that is value and goal-directed, goal concordant care for patients dealing with ovarian cancer.
APPENDIX A

GOALS OF CARE RELATED TERMS AND ASSOCIATED CUIS
Advance care planning (ACP) C0600371
  Unsuitable for ACP C4074946
  Coordination of ACP C3863893
  Education about ACP C4075894
  Discussion about ACP C4075855
  Discussion about ACP declined C4075135
  Discussion about ACP with caregiver C4075255
  ACP discussion ACP documented C4535883
  Discussion about ACP with family member C4075853
  ACP E&M services C3869417
  ACP discussion documented in the medical record (COA) C2368539
  Coordination of ACP initial 30 minutes C3863891
  ACP declined C4075883
  ACP request by patient C4074974
  ACP by physician, first 30 minutes C5416607
  ACP by other qualified health care professional, first 30 minutes C5416606
  ACP by other qualified health care professional, each additional 30 minutes C5416609
  ACP including the explanation and discussion of ADs such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional C3869416
  ACP discussed and documented in the medical record, patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan (DEM) (GER, Pall Cr) C1971427
  ACP by physician or other qualified health care professional, first 30 minutes C3865479
  ACP by physician or other qualified health care professional, each additional 30 minutes C5416608
  Counseling and discussion regarding ADs or EOL care planning and decisions, with patient and/or surrogate C1509087
  ACP including the explanation and discussion of ADs such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate C3865288
  ACP including the explanation and discussion of ADs such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes C3865287

Advance Directives C0001683
  EMS advance directives C3261365

Code status C0742531
  Code status Do not intubate C0742532
  Code status Do not resuscitate C0742533
  Code status Do not resuscitate per family C0742543
  DNR C0582114
  DNR orders C0079252
  DNR order C4700051
DNR status C2911025
DNR on file C2133666
DNR on file rescinded C2133971
Active DNR on file C2133667
Inactive DNR on file C2133668
Family/guardian request DNR (but no documentation) C3842142
State EMS DNR or medical order form C3842144
Code status Full code C0742535
No Chest compression C0746912
Cardiac chest compression C5441466
Doctor’s orders: chest compression not permitted C2148539
Cardiopulmonary resuscitation C0007203
Chest compressions C4032596

Comfort measures C0150521
Provide pain relief/comfort measures C0514894
Patients who are receiving Comfort care only C4542760
Comfort care only C4068771
Comfort care only status C4076040
Comfort care management C1272375
Palliative care C0030231
Spiritual support C0150355

Dying
Death anxiety C0522179
Fear of dying process C4061521
Preferences relating to death and dying C0582076
Shares feelings about dying C0517299
Wishes about care if dying C3897167

End of life (EOL)
EOL care planning C4076454
Counseling for EOL issues C4545274
EOL care plan C4544318
EOL education, guidance and counseling C1828345
EOL surveillance C1827517
EOL issues C2362520
Device EOL C3665940
EOL treatment management C1880499
Terminal patient care C0039548
EOL care planning C4076454
Palliative EOL care C2032843
Has EOL care plan C4075859
Difficulty reaching EOL decisions C4540896
Discussion about EOL care planning C4075896
Assistance offered to patient in planning for end of life issues C3693672
Counseling provided on symptom mgt, EOL decisions, and palliation C3248296
Patient counseling for EOL issues C2051444
Counseling on EOL and palliative care C3251120
Oncology: primary focus of visit; supervising, coordinating or managing care of patient
with terminal cancer or for whom other medical illness prevents further cancer treatment;
includes symptom management, EOL care planning, management of palliative therapies
C1617338

Family discussion
Facilitate family discussion C4711346
Discussion with family about decision C1320365
Discussion about care plan with family C1320364
Discussion about cardiopulmonary resuscitation with family member C4075871
Discussion about advance care planning with family member C4075853

Goals of care C2930505
Facilitate patient’s articulation of goals of care C0511333
Assess/intervent advanced dx, goals of care prioritize comfort C2921527
Documentation of advanced disease diagnosis, goals of care prioritize comfort (Pall Cr)
C2368536
Assess/intervent advanced dx, goals of care do not prioritize comfort (Pall Cr)C2368537
Partial matches:
- Care goals documented C2598385
- Goals, preferences, and priorities for care experience C4263487

Goals of treatment
Treatment goals C0679840
Relationship of treatment regimen to goals C4716564
Define treatment goals C0677092
Communicate individual patient treatment goals with all staff members C4712560

Goals for treatment
Treatment goals C0679840
Goals, preferences, and priorities for medical treatment C3869633

Goals, options, limitations, and risks of therapy C2012312
Discuss therapy/treatment options C0550365
Treatment options C0683525
Discussion about options C0557066
Discharge care options C2599743
Clear about which benefits and risks matter most C4727306
Medical treatment options C4716358
Purpose of different treatment options C4716424
General options include radiation C2010745
General options include surgery C22010748
Chooses among treatment options C4717411
General options include chemotherapy C2010739
Information provided about options of care C1822097
Salvage therapy C0085405
Neoadjuvant therapy C0600558
Adjuvant therapy C0677850
Surgical treatment options C1820875
Available treatment options C4716300

Hospice
Hospice care C0085555
Hospice prior to death
Referral to hospice C0584064
Hospice programs C0086422
Hospice care education C1272405

Ongoing discussion
Group discussion C0237576
Facilitate family discussion C4711346
Discussion about preferences C0557065
Discussion about treatment C0557063
Discussion about options C0557066

Palliative Care C0030231
Encounter due to palliative care C0700049
Specialist palliative care C1273400
Referral to palliative care service C0584096
Consultation for palliative care C4076282
Encounter for palliative care C0375892
Request consultation by palliative care C3862501
Counseling on EOL and palliative care C3251120
General options include palliative care C2010743
Terminal patient care C0039548
Neoplasm palliative treatment C0920718
Cancer palliative treatment C0920416

Preferences
Preferences relating to death and dying C0582076
Goals, preferences, and priorities upon death C4263488
Discussion about preferences C0557065
Natural death C0277610
Goals & or preferences in order of priority C4265489
Place of death C0421611
Comfortable death status C1319165
Preferred place of death C1273399
Goals, preferences, and priorities under certain health conditions C4263489
Goals, preferences, and priorities for care experience C4265450
Goals, preferences, and priorities for medical treatment C3870126
Provide information about patient’s condition in accordance with patient preferences C0514867

Priorities, health C0018736
Goals, preferences, and priorities under certain health conditions C4263489

Prognosis
Prognosis bad C0278250
Guarded prognosis C0278253
Prognosis counseling C0587875
Uncertainty of Prognosis C4061505
Prognosis uncertain C0420835
Hopeless prognosis C4554370
Prognosis context C1444707
Aware of prognosis C2732818
Unaware of prognosis C3697017
Informing patient of prognosis C0588448
Caregiver aware of prognosis C3532771
Caregiver unaware of prognosis C3875504
Relative aware of prognosis C3532786
Informing relative of prognosis C0730371
Fear of prognosis C0548855
Disease prognosis C4716643
Informing next of kin of prognosis C0730373
Prognosis/outlook C0420834
Cancer prognosis C1516221
Visit for pastoral care for new diagnosis or prognosis C2130223
Facilitate expression of fears about prognosis or success of treatments C4710225
Provide factual information concerning diagnosis, treatment, and prognosis C0514769
Prognostic features used for tumor prognosis C5204352
Prognostic marker C1514475
Health education goals: disease process/prognosis and therapeutic regimen understood C3694128
Participate in health care team discussion concerning the patient’s condition, prognosis, and plan of care so all can speak with uniformity C47712753

Serious Illness
Serious injury/illness/impairment C5419420
Terminal illness C0679247
Critical illness C0010340
Catastrophic illness C0007397
Severity of illness C0521117
Progressive illness C4061418
Insight into illness C3176579
Values clarification C0150401
  Assist patient in values clarification C4712279
  Use values clarification techniques to help individual clarify beliefs and values, as appropriate C0516410
APPENDIX B

PROCESS MAP
ICD-10 codes used to obtain sample

A priori GOC-related CUIs used to build initial rules-based algorithm

NLP processing #1

cNLP outputs analyzed & sorted
New posteriori GOC-related CUIs identified

Concept mapper used to validate 372 notes predicted to be positive for GOC documentation

Raw results sorted followed by removal of irrelevant note types from sample of notes

Algorithm rules augmented
Added 15 most frequently identified GOC-related CUIs

NLP processing #2

cNLP output results in 10 times more GOC-positive notes
Concern for large increase in false positives

Algorithm rules augmented
Added GOC-related CUI permutations using subrules

Important GOC-related CUI permutations identified through data sorting

Further qualitative analysis of cNLP output
Concept mapper used to evaluate for GOC-related CUI permutations

NLP processing #3

cNLP output results in reduction of true GOC-positive notes
Algorithm refinement is demonstrated

Note data paired with patient & author-related data

Final NLP processing of entire sample of notes

Algorithm rules augmented and finalized
APPENDIX C

FINAL RULE FOR ELEMENTS OF GOALS OF CARE DOCUMENTATION
IRB 215846 Goals of Care Documentation – Rule Definition

Required elements for identifying Goals of Care Documentation (GOCD) within a section of clinical narrative are detailed here.

**CUI combinations**
Combinations of CUIs that when occurring together within the same note are likely to represent evidence of GOCD but unlikely to do so independently (positive)

independently these CUIs do not represent evidence of GOCD (negative)

*Implementation for CUI combinations in CNIE rules are facilitated through the use of subrules*

**CNIE Subrules Definitions**

*Any NLP result which contains both CUIs from a row is considered ‘positive’*

**Subrule 1 – therapeutic procedure C0087111**

<table>
<thead>
<tr>
<th>C0087111 therapeutic procedure</th>
<th>C2700055 family collection</th>
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<tbody>
<tr>
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<td>C1276305 curative intent</td>
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**Subrule 2 – family collection C2700055**

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<td>C2584313 discussion communication</td>
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| Subrule 8 – subjective finding point in time patient narrative C2979880 |
Subrule 9 – treatment options C0683525

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Subrule 10 – disease progression C0242656

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Subrule 11 – discussed with patient C1273395

| C1273395 discussed with patient | C033325 forecast of outcome |

Subrule 12 – agreement C0680240

| C0680240 agreement | C0087130 uncertainty | C0679006 decision |

Subrule 13 – adverse effects C0879626

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<td>C0879626 adverse effects</td>
<td>C0600558 neoadjuvant therapy</td>
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**These CUIs stand alone as positive evidence of GOC documentation (positive CUIs):**

**Subrule 14**

*Any occurrence of one of the following CUIs is considered ‘positive’*

C2979882 goals finding point in time patient narrative
A full evaluation for GOCD is set up based on a positive result from any of the 14 subrules. A composite rule referencing the 14 subrules using ‘OR’ logic provides this ability.

Other Criteria - Excluded Note Types

These note types are to be excluded from the rule:
“ANC Discharge”
“Patient Instruction Notes”
“Death Note”
REFERENCE LIST


VITA

Dr. Hillarie Joehl is a Nurse Practitioner specialized in Palliative Care. She earned a Bachelor of Arts in Music from Northwestern University, a Bachelor of Science in Nursing from The Johns Hopkins University, a Master of Science from University of California San Francisco, and a Doctor of Philosophy from Marcella Niehoff School of Nursing, Loyola University Chicago. She is board certified as both Acute Care Nurse Practitioner and Advance Certified Hospice and Palliative Care Nurse. She has held positions in Palliative Medicine since 2009 and is currently providing both inpatient consultation and outpatient consultation within a cancer treatment center. Dr. Joehl serves as mentor for the Coleman Fellows Palliative Medicine Training Program in Chicago; faculty for the Palliative Medicine Fellowship Program at Resurrection Medical Center in Chicago; as well as VitalTalk faculty, offering monthly trainings primarily to medical residents and early career nurse practitioners to advance their serious illness communication skills.

Dr. Joehl enjoys mentoring trainees interested in palliative care and advancing serious illness communication. Her dissertation research evaluates both structured and unstructured data from the electronic health record using natural language processing to describe goals of care documentation for patients with serious illness. Her scholarly interests include interprofessional education of healthcare trainees in palliative care and serious illness communication with the goals of improving the care of patients and families dealing with serious illness, as well as the professional wellbeing and satisfaction of healthcare workers.