Doctor of Nursing Practice                                    Irene Ransom Bradley School of Nursing

Spring 2021

# Goals-of-Care & End-of-Life Quality in Relapsed High-Risk Leukemia: Silent Conversations

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GOALS-OF-CARE & END-OF-LIFE QUALITY IN RELAPSED HIGH-RISK
LEUKEMIA: SILENT CONVERSATIONS


A Scholarly Project Submitted to the Graduate School
in partial Fulfillment of the Requirements for the Degree of
Doctor of Nursing Practice


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May 2021

# GOALS-OF-CARE & END-OF-LIFE QUALITY IN RELAPSED HIGH-RISK LEUKEMIA: SILENT CONVERSATIONS

An Abstract of the Scholarly Project by
Lacy Jo Graham

**BACKGROUND**: The distorted association of "end of life (EOL)" with "goals of care (GOC)" has "silenced" crucial goals discussions in patients with relapsed high-risk leukemia, which raises concerns for the provision of care that is inconsistent with patient's values and preferences (Desharnais et al., 2007; Epstein et al., 2016; Gilligan et al., 2017; Mack et al., 2010; Piggott et al., 2019; Weeks et al., 2012).

**AIM**: The two main goals of this study were to quantify hematologists rate of participation in a GOC pathway initiative during two separate months, then explore their definition and barriers to having/documenting GOC discussions.

**DESIGN**: Mixed-methods, explanatory sequential design (follow-up explanations variant).

**SAMPLE**: Quan: Hematology inpatient admissions during the months of October 2020 and January 2021. Qual: Eighteen leukemia hematologists from one dedicated cancer in the United States.

**RESULTS**: During the two months, an average of 36% of admissions met criteria for GOC pathway initiation, 19% of those had an appropriate initiation order, of which 15.5% had a properly documented and billed GOC discussion. Nine hematologists responded to the SurveyMonkey with two questions. All nine included clinical situation and communication in their definition/components of GOC discussions. Time required and prognostic uncertainty were the two most mentioned barriers.

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**CHAPTER I**

**INTRODUCTION**

The consistent provision of high-quality healthcare by Advanced Practice Providers (APP) has been clearly established and widely recognized in the literature. Initially utilized only in rural, underserved primary care settings, value recognition and good outcomes have prompted mass expansion of scope and specialty role opportunity for these providers, one such specialty being hematology. Collectively, APP's exhibit a strong drive to advocate for, influence, and affect high-quality health care through leadership, evidence-based practice implementation, and quality improvement projects (Sarzynski & Barry, 2019). A southern California dedicated cancer center and research hospital that specializes in hematological malignancies has adopted an inpatient work model that requires the APP to routinely work very closely with and collaborate with many different hematologists. A rotating 14-day inpatient rounding schedule requires each of 35 hematologists to round only 4-6 weeks/year. Eighteen of the 33 hematologists specialize in leukemia, myelodysplastic syndrome, or other blood disorder and rotate through the four leukemia inpatient services. There are often months between inpatient obligations, and for this reason, these physicians rely heavily on APP's to guide them through frequent process and policy changes, quality improvement initiatives, and provide a component of care continuity. The nature of this relationship places the APP in

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a role of leadership with significant opportunity to observe, analyze, and influence the practice habits of physicians.  This role also provides opportunity for the APP to identify and address barriers, in order to establish, hone, and strengthen collaborative multi-disciplinary relationships.

**Clinical Problem/Issue**

In 1997 The Institute of Medicine (IOM) published a report titled *"Approaching Death: Improving Care at the End of life"* that focused on the dying and deaths of adults in America.  A pediatric version, *"When Children Die: Improving Palliative and End-of-Life Care for Children and their Families"* was published in 2003. In 1999 the IOM released *Ensuring Quality Care,* emphasizing that quality care measurement and improvement should not only focus on cancer detection and treatment, but should span the entire disease trajectory, including EOL care (as cited in Odejide, 2016).  By 2013, impressively, many of the goals articulated in the 1997 report had been achieved, including creation of palliative medicine specialty status, increased access to opioids for patients with pain, and the widespread adoption of hospital palliative care teams. And yet, both in research and in the everyday experience of patients, family members, and clinicians, huge gaps remained in the quality of care for the most vulnerable patients. In response, the IOM assembled a diverse panel that, in 2014, issued *Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life*.  The consensus study report organizes findings across five domains: care delivery, clinician-patient communication and advance care planning, professional education, policies and payment systems, and public education and engagement.  It was discovered that although access to specialist palliative care had grown dramatically over the previous 15 to 20

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years, the experience for most patients and families still fell short of what ought to be the standard. The report also notes that patients nearing the EOL ought to receive treatments that match their preferences and goals for care. The last few months of an individual's life is often characterized by frequent hospital admissions, intensive care stays, and burdensome transitions across care settings (Tulsky, 2015). A large proportion of deaths continue to occur in hospitals and promulgate poor quality EOL care and unsustainable costs for the health care system. The 2014 report provides recommendations for creating transformational change in the models of EOL care delivery, clinician-patient communication, and advance care planning (as cited in Meghani & Hinds, 2015).

**Quality End-of-Life Care in Hematology**

The clinical course of hematology-oncology patients differs from patients with solid malignancies as these patients are more likely to be admitted and receive life sustaining measures near EOL. In a survey conducted among hematologist-oncologists, EOL indicators validated for medical oncology patients and considered significant for hematology-oncology patients, included not being admitted to intensive care, not being intubated or receiving cardiopulmonary resuscitation (CPR) within 30 days of death, not receiving chemotherapy within 14 days or a blood transfusion within 7 days of death, and dying outside of an acute care unit (Odejide et al, 2016). The most recent published findings of Korsos et al. (2019) demonstrates that having level of intervention discussions, palliative care consults and physician/patient established goals of treatment may improve EOL quality for patients with hematologic malignancies.

**Low-Quality End-of-Life Care**

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Patients with hematologic malignancies often receive aggressive care at the EOL, leading to lower quality of life. While the use of billed palliative care services among Medicare beneficiaries with hematologic malignancies has steeply increased in recent years, most encounters still occur within days of death in the inpatient setting (Rao, et al, 2019). Aggressive EOL care in patients with advanced-stage cancer is increasing despite growing concerns that this reflects poor-quality care (Wright et al, 2016). Furthermore, studies have found that, regardless of illness, at least 13% of the time, the EOL care provided is inconsistent with the patients' goals-of-care (GOC) and causes psychosocial and financial burden to the family (Khandelwal et al, 2017). Data regarding this phenomenon in hematology specifically, is lacking.

**Goals-of-Care, Palliative Medicine, and End-of-Life Care**

The GOC conversations may be defined as discussions about prognosis and treatment options that clarify patients' values, goals, and priorities. GOC conversations do not routinely occur among patients with advanced cancer, and when they do, it is often late in the course of the illness (Childers, 2017). Ideally, initial, intermediate, and final GOC conversations should occur throughout the illness trajectory (Schulman-Green et al., 2018). EOL discussions should be a component of GOC and should be discussed at various times throughout the illness. Integrated palliative care is correlated with earlier EOL discussion and improved quality of life (Mack et al., 2012). National guidelines (Ferrell et al., 2018) recommend that discussions about EOL care planning happen early for patients with incurable cancer, but, for various reasons, these discussions are still occurring within days of death. Hematologists have specific barriers that interfere with timely EOL discussions, and integration of palliative care specialists may enable earlier

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EOL discussions in patients with hematologic malignancies.  Early EOL discussions are prospectively associated with less aggressive care and greater use of hospice at EOL. GOC conversations should promote informed shared decision making by presenting accurate prognostic information and treatment options to patients and their families and ensure patient/physician concordance of goals is achieved (Mack et al., 2012).  Patients with incurable cancer, and those participating in Phase I trials often have misconceptions regarding the goals of their treatment regimens (Enzinger et al., 2014).  One study found that 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer (Weeks et al., 2012).

**Hematologists are Different**

Historically, hematologists collectively possess certain personality traits, thought processes and practice paradigms that result in very specific barriers to having GOC and EOL discussions.  Several authors have tried to understand the reason why integrating palliative care into hematology is so difficult. Hematologists describe particular issues, such as the difficulty for individual prognostication due to the chemo-sensitivity of hematological malignancies, and the possibility of allogeneic stem cell transplantation that allow ongoing therapeutic goals of curable or long-term survival.  In contrast, acute complications are frequent, unpredictable and change the prognosis rapidly (Prod'homme et al., 2018).  Often the acute complications may contribute to death before the possible involvement of a palliative care team. Furthermore, long relationships that develop between patients and their hematologists and the negative representation of palliative care

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as addressed to dying patients also contributes barriers for referral (Prod'homme et al., 2018).

**Having, Documenting, and Billing for Advance Care Planning**

The barriers to Advance Care Planning in hematologic malignancies exist on many levels, are vast, ongoing, and will require system tools, policies, multidisciplinary collaboration, and APP leadership to address these quality shortcomings. Unfortunately, as with most issues in healthcare, this is a complex problem with another problem uncovered in every solution. Protocols and policies often are met with opposition and slow adoption in a Southern California Cancer research hospital, and despite protocol initiation, significant education, and leadership backing on this issue, compliance remains low. Occurrence of GOC and EOL conversations are lacking, documentation of these conversations remains low, and Intensive Care Unit (ICU) admission in the last 30 days of life remains higher than at similar facilities, despite efforts to address this issue.

**Significance**

*Patient and Family*

Identification of poor prognosis patients, initiating GOC conversations, and ensuring proper documentation of these conversations can reduce misaligned treatment and patient/family suffering. Earlier GOC discussions will better prepare the patients for the day they are "in a different place" in their illness trajectory. Discussing EOL when they are not near the EOL allows time to explore their goals and share them with their family. Discussing health care wishes with a designated speaker reduces the stress on family when making decisions for the patient at the EOL. Physical and psychological

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symptom burden may be reduced with earlier palliative care collaboration, and overall quality at the EOL will improve for patients (Back et al., 2014).

**Advanced Practice Nurse/Advanced Practice Provider (APP)**

The emotional burden is globally present in APPs who work in inpatient hematology, though it varies in etiology and intensity for many reasons. The barriers to EOL discussions that exist in hematologists are different than those existing in APPs. Therefore, APP's often experience emotional distress after witnessing incomplete prognostic conversations and excessive offering of treatment that will yield little to no benefit. APP's see recommendations being made without discussing or considering patient goals and are painfully aware of the suffering the patient will certainly endure. The level of sharing obtained during the more personable conversations between patients and APP's often uncovers the true misconceptions patients have regarding their treatment, prognosis, and chance of meaningful recovery, but hospital culture and their role prevents them from exploring these misconceptions and false hopes. This deeper emotional knowledge presents an ethical struggle and can lead to burnout, anxiety, and depression (Bourdeanu, 2020). The unique opportunity the APP has to influence physician practice and shift paradigms is significant and should be recognized and utilized to generate and disseminate new research and policies pertinent to the practice.

**Specific Aims/Purpose**

While the global issue discussed is large and multifaceted, any quality improvement-research endeavor requires a step-wise approach in which the completion of each stage will likely reveal another issue to be addressed in future research. Application of the "Five Why's" approach (see Figure 1), initially developed by Sakichi

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Toyoda in the 1930's revealed the focus of this scholarly project: protocol utilization and compliance/non-compliance, and why. Prior to designing and completing this study, hospital leadership had placed the researcher on a task force deemed responsible for reducing ICU admissions within 30 days of death in the Southern California Cancer Research facility described above. A hospital based GOC pathway pilot program was created and implemented as a potential solution to the fourth "why," avoidance of GOC discussions. The pathway addresses hematologists evasion of GOC conversations by permitting APP initiation of the pathway process using specific criteria to identify and refer high-risk/poor-prognosis patients. Once the referral is made, a social worker administers a patient and caregiver support screen (Appendix A), which evaluates prognostic understanding. These results are shared with the inpatient team and primary hematologist in a request for a family meeting.

Shortly after the March 2020 GOC pathway implementation the issue of documentation/billing became apparent, and the project objectives were updated. Even when the hematologists were having GOC discussions, they were not documenting them in a standardized place or way, and were not billing for their time, making it difficult for other providers to access and update. The objectives of the hospital based GOC pathway were modified to the following: 1) Augment GOC pathway project by optimizing the primary hematologists' ease of execution and level of comfort during GOC discussions. 2) Establish a documentation process that is easily completed and accessed (without using the search option or "hunting") by other providers during subsequent encounters. 3) Discover actual and potential APP contribution to the GOC pathway pilot project. The Joint Commission National Quality Measures (2018) calls for increased documentation in

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the medical record of GOC.  A metric to be measured, and first purpose of the scholarly project was to evaluate the participation of physicians and APPss in the GOC pathway process through quantification of patients who met the established "poor-prognosis" criteria for pathway initiation, patients with appropriate social work referrals to initiate the pathway, and those with a properly documented GOC discussion in the electronic medical record during that hospital encounter.  A user-friendly Advance Care Planning (ACP) documentation template was created and rolled out one month prior to this inquiry into usage.  The second purpose was to gain insight into the hematologists self-reported definition of a GOC discussion, the most important components, and their perceived barriers.  The goal was to collect and synthesize the candid thoughts, opinions, attitudes, beliefs, practice habits, philosophies, perceptions, and comfort level surrounding GOC discussions and the proper documentation and billing of these conversations.  Five project research questions were constructed to achieve the two purposes.

**Project Questions**

1. How many leukemia inpatients met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021?

2. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had appropriate referral for GOC pathway?

3. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed GOC discussion utilizing the approved template prior to hospital discharge or death?

4. How do the hematologists define "GOC conversation" in one sentence and what do they consider the most important components?

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5. What do the hematologists identify as perceived barriers in having/documenting GOC conversations?

**Figure 1**

*The Five "Whys"*



| Lower EOL quality in patients with hematologic malignancies-WHY? | | | |
|---|---|---|---|
| Hospital/ICU admissions at the EOL | Chemotherapy in the last 14 days of life | No CPR or Intubation in the last 30 days of life | Transfusions at EOL |

| Patients with hematologic malignancies have higher rates of ICU admission in the last 30 days of life- WHY? | | |
|---|---|---|
| Lack of goal concordance Lack of clear goal understanding | Patients often unaware that treatments are palliative and not curative | Unrealistic expectations of experimental treatment by both patients and hematologists |

| Goal disconcordance, EOL care inconsistent with patient values- WHY? | | |
|---|---|---|
| Hematologists avoid GOC discussions for many reasons and there is no standardized documentation process | Assumptions by both patients and hematologists Lack of prognostic understanding | Low rates of Palliative and Supportive Care Medicine in Hematology |

| Hematologists avoid GOC discussions, no system in place to prompt- WHY? | | | |
|---|---|---|---|
| Creation and initiation of GOC Pathway program | Fear of ruining hope, culture | Unaware of documentation template Didn't know they could bill | Time consgtraints, prognostic uncertainty, association with EOL/DNR |

| GOC pathway participation-DESCRIBE/EXPLAIN WHY or WHY NOT? | | |
|---|---|---|
| Consolidated Framework for Implementation Research | Attitude, beliefs, perceived barriers, opinions | Quantify number of patients who 1) meet criteria, 2) have pathway initiated, 3)have properly documented and billed GOC |

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**Definition of Key Terms/Variables**

*Advance Care Planning (ACP):* 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. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences (Sudore et al., 2017).

*Advanced Practice Provider (APP):* Physician Assistants and nurses who have met advanced educational and clinical practice requirements and include Nurse Practitioners (NPs), clinical nurse specialists, nurse anesthetists, and nurse midwives (American Nurses Association, n.d.).

*Aggressive end-of-life care:* ICU admission with or without mechanical ventilation in the last 30 days of life, CPR administration in the last 30 days of life, death in ICU.

*Burnout***: A** state of mental and physical exhaustion caused by one's job (Freudenberger, 1974).

*Continuity of Care***:** Idealized in the patient's experience of a "continuous caring relationship" with an identified health care professional (Guilliford et al., 2006).

*Emotional Distress:* A highly unpleasant emotional reaction which results from another's conduct (Webster, 2020).

*End-of-Life Care:* Care provided to a person with a terminal condition that has become advanced, progressive, and/or incurable in the last 30-90 days of life (COH GOC task force, 2020).

*Epic***:** Electronic Medical Record utilized in Southern California cancer research hospital for inpatient and outpatient documentation.

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*Evidence-Based Practice:* The conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient" is a standard definition of Evidence-based Practice (EBP).  Developed by David Sackett, a pioneer in EBP, this definition describes integrating individual clinical expertise with the best available external clinical evidence from systematic research (Agency for Healthcare Research and Quality, 2020).

*Goal Concordance:* Care that matches patients' preferences, enabled by communication between clinicians and patients or their surrogates (Sanders et al., 2018).

*Goals of Care (GOC):* Derived based upon the patient's expressed preferences, values, needs, concerns and/or desires, may be curative, rehabilitative, life-prolonging, or comfort focused (The Joint Commission, 2018).

*Goals-of-Care Discussion/Conversation:* The clinician-led discussion, professional guidance and support provided to the patient and family intended to result in making decisions that reflect the goals and values of the patient.

*Goals-of-Care Pathway:* Pathway protocol created by the GOC task force to reduce ICU admission in the last 30 days of life that utilizes criteria to identify poor prognosis patients and initiate GOC conversations and earlier palliative referral (COH Goals-of-Care task force, 2020).

*Hematologic Malignancies:* Cancers that affect the blood, bone marrow, and lymph nodes. This classification includes various types of leukemia (acute lymphocytic (ALL), chronic lymphocytic (CLL), acute myeloid (AML), chronic myeloid (CML)), myeloma, and lymphoma (Hodgkin's and non-Hodgkin's (NHL) (Fowler et al., 2011).

***High-Quality Healthcare***: The assessment and provision of effective and safe care, reflected in a culture of excellence, resulting in the attainment of optimal or desired health (Allen-Duck et al., 2017).

***Life-Sustaining Measures***: Interventions aimed to prolong length of life through mechanical and pharmacological means, Cardio-Pulmonary Resuscitation, endotracheal intubation, renal replacement therapy, vasopressor blood pressure support (Zhang et al., 2009).

***Palliative and Supportive Care Medicine (PCM, SCM or PSCM):*** Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment (Hui et al., 2015).

***Poor-Prognosis Patient:*** Relapsed or refractory Acute Myeloid and Acute lymphoblastic leukemia after 1 line of therapy; Lymphoma or Myeloma with disease progression after at least two prior lines of therapy; exclusions: admission for curative intent treatment (i.e. allogeneic hematopoietic stem cell transplant or cellular therapy in a relapsed or refractory patient) (COH GOC task force, 2020).

***Prognostication***: A prediction of future medical outcomes of a treatment or a disease course based on medical knowledge (Sinclair, 2007 as cited in Medscape, 2007)

**Theoretical Framework**

The Consolidated Framework for Implementation Research (CFIR) is a useful tool for guiding rapid-cycle evaluation of the implementation of practice transformation initiatives (Keith et al, 2017). Many research-proven interventions fail to translate into

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meaningful change in the healthcare delivery system.  Some estimates indicate that up to

two-thirds of organizations' efforts to implement change, fail (Burnes, 2004).  Without

adaptation, interventions usually come to a setting as a poor fit, resisted by individuals

who will be affected by the intervention, and requiring an active process to engage

individuals in order to accomplish implementation.  During implementation, it is

important to monitor progress for unanticipated influences (barriers and facilitators) and

progress toward implementation goals (Damschroder et al., 2009).

The CFIR will serve as a roadmap for pathway project evaluation and data

gathered in this study will provide valuable information to fill in existing gaps in

knowledge of the 5 domains of the CFIR.  The CFIR comprises five major domains (the

intervention, inner and outer setting, the individuals involved, and the process by which

implementation is accomplished, see Figure 2), each of which will be examined to

evaluate intervention implementation progress as it pertains to the GOC pathway pilot

project.

**Figure 2**

*Consolidated Framework for Implementation Research 5 Domains*
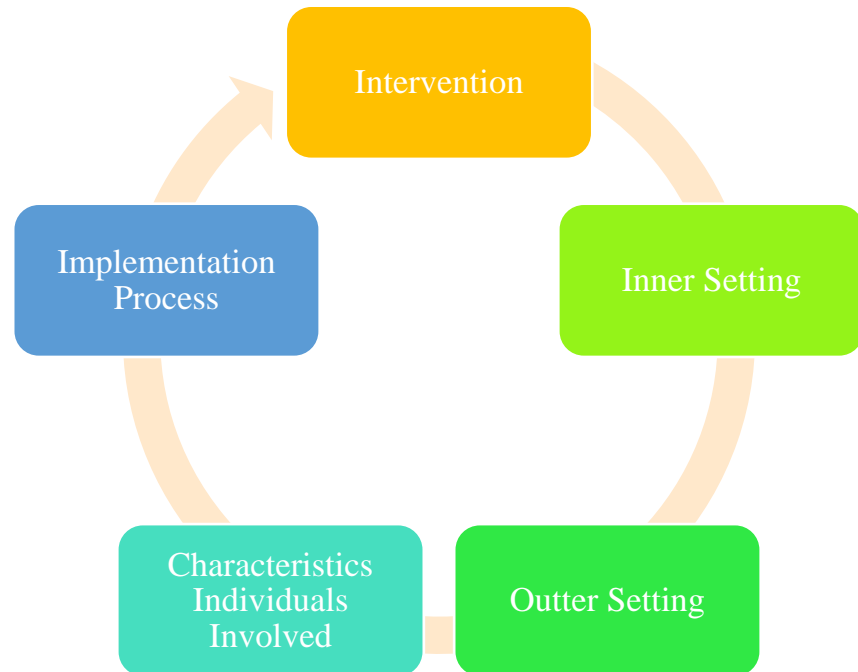


In addition to the CFIR, Rogers (1962) Diffusion of Innovation Theory (see Figure 3) contributed to the theoretical framework of the project goals and design. The researcher recognized the potential ability of APP leadership in diffusion of innovation as a respected opinion leader, change agent, and champion within the institutional social system. The doctorly prepared APP has both the skill and a unique advantage in leading change by exercising his/her role as an innovator and early adopter to positively influence practice change initiatives.

**Figure 3**

*Diffusion of Innovation Model*
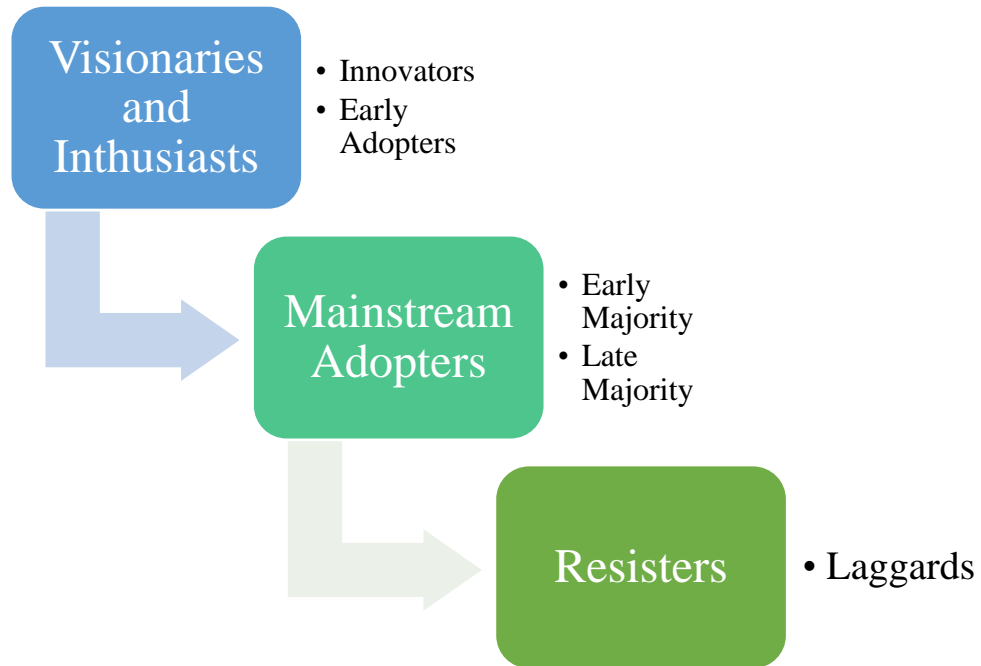


**Logic Model**

A logic model (see Figure 4) assists in brainstorming and planning for the project and project needs. Mapping resources, activities and outputs provides a platform for project initiation to be added to as the project develops. Objectives, including short, medium, and long-term outcome measures (see Figure 5) will guide project evaluation at various stages and tie the activities to the outcomes.

**Figure 4**

*Logic Model*

| Objectives | Resources | Activities | Outputs |
|---|---|---|---|
| Describe the phenomenon of hematologist aversion to GOC discussions | ICU task force | Establish expertise of process. | Quantitative and qualitative data |
| Determine levels of compliance/non-compliance with GOC pathway initiation | Administrative and physician buy-in | Acquire knowledge and data | Meaningful depiction of barriers to GOC pathway |
| Explore hematologists attitudes, beliefs, and opinions regarding GOC conversations and pathway | Multi-disciplinary collaboration | Critical analysis | Personalized interventions based on qualitative findings |
| | Established process | Recognition and planning for future initiatives | |

**Figure 5**

*Outcomes*

**SHORT**

Quantify the number of patients who meet GOC pathway criteria in 2 seperate months.

Quantify appropriate pathway initiation and completion of MD documentation/billing in poor prognosis patients.

Compile the hematologists personal perceived barriers in having/documenting GOC discussions.

Obtain and compile the hematologists personal definition of a GOC discussion.

**MEDIUM**

Analyze qualitative data for patterns and themes specific to this set of Hematologis.

Interpret and organize findings.

Share the findings with hematologists, Nurse Practitioners, and GOC task force.

Publish findings as scholarly project.

**LONG**

Use findings to address specific concerns and create educational interventions for this group of physicians.

Expansion of program to outpatient setting.

Reduction of ICU admissions in the last 30 days of life

Enhance and align hematologist understanding of the GOC pathway and the intended outcomes of the project.

Improve goal-concordant care in high-risk leukemia patients.

# CHAPTER II

# REVIEW OF LITERATURE

## Review Methods

A search of the literature was conducted on Google Scholar. Using the advanced search function produced 129 articles that had been published since 2016, 43 articles since 2019, and 21 articles since 2020, with *all of the words:* aggressive end-of-life care, quality goals-of-care discussion, with *the exact phrase*: quality end-of-life care, *with at least one of the words:* hematology hematologist "hematologic malignancies" "hematologic malignancy" "blood cancer" leukemia lymphoma myeloma, and *without the words:* pediatric. The forty-three articles since 2019 were examined for themes and relevance to the project, then narrowed again to articles *without the words*: Korean Brazil, which was the maximum number of characters allowed in that search criteria box. Further application of exclusion criteria performed through personal review of the 35 remaining articles. Three articles containing "Norway" "Thai" and "Lebanese" were excluded, one feasibility study was excluded, and 19 documents that pertained to oncology as a whole or other disease process, were excluded. The 12 remaining articles were extensively reviewed to extrapolate important topics, data, concepts, and themes. Additional articles utilized were found through reference-mining, the "cited by" and "Related articles" feature, and additional searches of terms and/or combination of terms

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from the original 12 articles in Google Scholar, CINHAL, Summons, PubMed, and : end-of-life; goals-of-care; hematology; hemato-oncology; blood cancer; advanced cancer; aggressive end-of-life care; quality, barriers and facilitators of end-of-life; goals-of-care conversations, discussions; patient-provider communication; prognostication; prognostic understanding; advance care planning; decision-making; process conversation analysis; palliative care; goal-concordance; patient- hematologist discordance; hospice; ICU at EOL; bereaved family member perceptions.  One hundred thirty-one items are cited in this literature review.

**History of Dying**

Prior to the 20th century, the family commonly provided EOL care at home with the assistance of visiting health care professionals.  In the United States, death at home in the care of family has been widely superseded by an institutional, professional, and technological process of dying. This technological process has detached the EOL from the rest of living (Field & Cassel., 1997).  Dr. Cecily Saunders started the modern EOL movement by establishing the first formal hospice program at St. Christopher's in 1967 (Liegner, 1975). In the same period, Dr. Elizabeth Kubler-Ross sought to understand the psyche of the dying patient by describing the psychological stages of dying. She also advocated home, rather than the intensive care unit, as the place of "good death" (Kubler-Ross, 1969).  In 1990, Congress passed the Self-Determination Act, which required healthcare providers to inquire, inform, and assist patients regarding advance directives. (Levin, 1990).

**Advance Directives**

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Unfortunately, despite widespread education and effort, one study in 2010 showed that, only 26.3% of surveyed adults 18 and older had an advance directive. The most frequently reported reason for not having one was lack of awareness (Rao et al., 2014). Another study examined 6,122 Health and Retirement Study (HRS) patients, age 60 and older, who died between 2000 and 2010. In 2017, a systematic review of 150 articles published in the period of 2011-2016 was performed in order to determine the proportion of United States adults with a completed living will, health care power of attorney, or both. Among the 795,909 people in the 150 studies that were analyzed, 36.7 % had completed an advance directive, including 29.3 % with living wills. These proportions were similar across other years reviewed. Similar proportions of patients with chronic illnesses (38.2 %) and healthy adults (32.7 %) had completed advance directives (Yadav et al., 2017). A descriptive study of 50 inpatients with high-risk leukemia defined "complete advance care planning documentation" as in-chart documentation of surrogate decision maker plus either a written advance directive or documented GOC discussions, and found that despite very poor prognosis, only 24% of patients had complete advance care planning documentation in their chart, and only one-third had specific components of advance care planning addressed. This study was the first study to characterize access to palliative care and advance care planning by focusing on this high-risk population of patients with hematologic malignancy and adds to a small but growing body of evidence showing that patients with varied hematologic malignancies are less likely to have access to elements of palliative care and advance care planning than patients with solid tumors (Freeman et al., 2018).

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Kim et al. (2020) explored agreement in EOL treatment wishes in patient-caregiver dyads of patients with hematologic malignancies to find modifiable factors associated with completion of advance treatment directives. The study found significant patient-caregiver discordance in treatment wishes regarding CPR, ventilator support, hemodialysis, and hospice, and noted knowledge about advance directives as the modifiable factor significantly associated with the completion of an advance directive (Kim et al., 2020). A study examining 206 patient/oncologist dyads found a majority of oncologists (76.7%) did not correctly identify GOC that they believed their patients wanted, indicating they did not fully understand their patients' GOC, even at the last meeting prior to death (Douglas et al., 2019). This raises concern that in these cases, patients are less likely to receive care consistent with their preferences (Desharnais et al., 2007; Epstein et al., 2016; Gilligan et al., 2017; Mack et al., 2010; Piggott et al., 2019; Weeks et al., 2012).

**Quality End-of-life Care**

There is a growing amount of substantiated concern regarding the widespread provision of non-beneficial, aggressive interventions and costly over-treatment in the United States at the EOL (Cardona-Morrell et al., 2016; Institute of Medicine, 2015; Lyu et al., 2017; Mohammed at al., 2019). Treating hospital patients who are on an EOL trajectory in the same way as those who have a reversible cause for their illness is not only futile, but also a costly and wasteful form of preventable harm in healthcare (Carter et al., 2017; Farrell et al., 2008; Smith et al., 2013; Zhang et al., 2009). Still, the aggressive treatment for terminal advanced cancer patients at the EOL is a common practice (Mohammed et al., 2019). Health care delivery for people nearing the EOL has

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changed markedly since the Institute of Medicine (IOM) published *Approaching Death: Improving Care at the End of life* (1997), however, both research and the everyday experience of patients, family members, and clinicians suggest that huge gaps remain in the quality of care for the most vulnerable patients. This poor care continues against a backdrop of rising health care costs and a sense that patients who account for the greatest percentage of this expenditure do not benefit from, and may even be harmed by, it's excess.  The report urges a patient-centered and family-oriented approach to EOL care that honors individual preferences as a national priority and emphasizes the needs for improved communication about EOL preferences between clinicians and patients (IOM, 2015).

In 2003, Earl et al. generated the earliest set of EOL quality measures for patients with advanced cancer.  These measures, focused on the potential overuse of intensive care at the EOL and the underuse of hospice services, are now endorsed by national organizations such as American Society of Clinical Oncology (ASCO) and the National Quality Forum (NQF) (ASCO Practice Central, n.d; Earle et al., 2004; Earle et al., 2005; Earl et al., 2008; Grunfeld et al., 2006.; NQF, n.d.).  The eight quality measures are as follows: Hospice >7 days before death; no chemotherapy <14 days before death; no ICU admission in the last 30 days of life; fewer than two hospitalizations in the last 30 days of life; fewer than two Emergency Department visits in the last 30 days of life; no intubation in the last 30 days of life; no CPR in the last 30 days of life; and not dying in an acute care facility.  These measures were later deemed highly acceptable in a large national cohort of hematologic oncologists and no additional hematologic specific measures were added to the list (Oderjide et al., 2016).  The need to evaluate these EOL quality

measures for suitability in hematology was determined after several years of data collection revealed significantly more intensive EOL cancer-directed care (eg. higher rates of ICU admission in the last 30 days of life, lower rates of hospice enrollment, fewer days on hospice, and higher rates of chemotherapy close to death) in patients with hematologic malignances than in those with solid tumor cancers, suggesting suboptimal EOL care for this patient population (Earl et al., 2008; Fletcher et al., 2016; Ho et al., 2011; Howell et al., 2011; Hui et al., 2014; LeBlanc et al., 2015; O'Connor et al., 2014). The number of days spent at home has been suggested as a potential novel, patient-driven indicator of quality EOL (Andersen et al., 2019Groff et al., 2016).  A large population-based analysis of 11,127 patients in Ontario, Canada who died from hematologic malignancies between 2005-2013, found that while over 80% of patients spend greater than 120 of their last 180 days at home, those with acute leukemias spent the fewest at home (Cheung et al., 2019)

The benefits of hospice care at the EOL are well established in patients with solid tumor malignancy and have been shown to improve quality of life for patients and families, as well as improve family perceptions of quality EOL care and minimize, psychological distress, risk for depression and post-traumatic stress for the bereaved (Teno & Curtis, 2016; Wright et al., 2008; Wright et al., 2010) .  Barriers to timely hospice referral and quality EOL care in patients with hematological malignancies include transfusion dependence, the potential for "cure" despite advanced disease, uncertainty regarding prognosis, and concerns about affecting patients' hope, among other things.  Early palliative referral, much like hospice, comes with a stigma in hematology even though it has been well established to be associated with quality EOL

(Hui et al., 2015; LeBlanc et al., 2018; Odejide et al., 2016; Odejide & Steensma, 2020).

In the absence of subspecialty referral, evidence has found linking a high level of primary

palliative care (defined as palliative care delivered by the primary transplant/leukemia

physicians) through GOC discussions and/or advance care planning, with high-quality

EOL care outcomes, often with concurrent disease-directed therapy (Lin et al., 2019).

**Aggressive End-of-life Care**

Adult intensive care unit (ICU) utilization is common near the EOL.  In the

United States, approximately 40% of patients die in the hospital, and nearly 60% of these

deaths occur after admission to the ICU, that is, 1 in 5, or 20% of Americans die while

utilizing ICU care (Angus et al., 2004; Seferian & Afessa, 2006).  A recent population-

based surveillance, epidemiology, and end results-Medicare database set examined

Medicare beneficiaries who died of hematologic malignancies in 2008-2015 and found

that 33% died in an acute hospital setting, and 36.8% had an intensive care unit

admission in the last 30 days of life or died in the ICU (Egan et al., 2020).  There has

been considerable advancement towards patient-centered EOL care in the United States,

but the EOL needs in hematology are unique and make transitions in care settings

challenging.  The labor-intensive level of care needed at the end of the disease trajectory

is often beyond the physical and emotional capability of family members, who are often

unprepared and lack the resources necessary to care for someone in that capacity

(Verhoef et al., 2020).  Even so, patients and families consistently designate home as the

preferred place of death, but instead, more often die in the acute care setting following

escalating intervention (Chino et al., 2019; Howell et al., 2010; Maddocks et al., 1994;

McGrath, 2002).

EOL ICU admissions in patients with cancer may be justified to manage potentially reversible disorders in some patients, however, a significant number of these admissions are potentially inappropriate, as about half of the ICU admissions for patients with cancer result in death (Bosslet et al., 2015; Kress et al., 1999; Thiery et al., 2005; Weir et al., 2014). Despite remarkable treatment advances, many hematological malignancies remain incurable, have unpredictable/uncertain trajectories, and have highly variably outcomes, which can be particularly poor for some karyotypic subtypes. Deterioration is often sudden and unexpected, manifesting as relapse or a devastating failure to respond to one or more lines of intense standard of care chemotherapy regimens (Roman et al., 2016; Smith et al., 2015; Swerdlow et al., 2016). Moreover, patients with hematological malignancies are often treated with multiple new, experimental, and intense antineoplastic regimens with significant or unknown toxicities, and those treatments may continue until the last days of life (Hui et al., 2010; Hui et al., 2013; Sanchez-Cuervo et al., 2020). Clinical trial participation is significantly associated with aggressive EOL care, intensive care unit death, and inferior quality of life near death (Enzinger et al., 2014). Understandably, these patients and their caregivers frequently experience psychological distress (Bishop et al., 2007; Rodin et al., 2013).

Caregivers often indicate dissatisfaction with the care provided to their loved ones at the EOL. Shirai et al (2016) published the first quantitative study evaluating care for myelodysplastic syndrome/leukemia and lymphoma patients during their last hospitalization. They found that 57% of caregivers were not satisfied with the care provided and a "good death" was often not achieved (Shirai et al., 2016). A similar study, also published in 2016, examined family perspectives of older patients with fee-for

service Medicare who died of lung or colorectal cancer, and linked perception of better EOL care to earlier hospice enrollment, avoidance of ICU admissions within 30 days of death, and death occurring outside the hospital (Wright et al., 2016), while another study found that one in 8, or 13% of bereaved family members report that care in the last month of life was not consistent with the decedent's wishes (Khandelwal et al., 2017). McCaughan et al. (2019) examined preferred place of care and death in patients with blood cancers from the perspectives of bereaved relatives and found that, while home is overwhelmingly the preferred place of death, the hospital was sometimes preferred and, on reflection, some relatives identified this as the "right" place for the patient to have died. Factors impacting achievements of home death where disease characteristics, the occurrence and timing of EOL discussions, family networks and resource availability. Early, honest and realistic communication of risk and uncertainty, initiated by hematologist, could prevent over-optimism and facilitate advanced planning among patients and relatives, as well as allow primary care staff adequate time to prepare for the patient's potential death at home.

**Patient-Clinician Communication**

The Institute of Medicine's (IOM) 2015 report on approaching death called for a transformation in how we care for the dying in this country, emphasizing the need for improved communication about EOL preferences between clinicians and patients (IOM, 2015). Improved health care communication has been associated with improvements in many different objective and subjective health outcomes, including blood pressure control, hemoglobin A1C and diabetes, adherence to medication use, and patient satisfaction (Hojat et al., 2011; Slatore et al., 2010; Stein et al., 2005; Stewart, 1995;

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Zachariae et al., 2003; Zolnierek & Dimatteo, 2009). Communication in oncology

practice presents numerous challenges and although studies show that most patients want

their oncologists to discuss EOL plans, these conversations often do not occur (Barakat et

al., 2013; Mack et al., 2010; Wright et al., 2008).  Healthcare providers often do not

discuss GOC with seriously ill hospitalized patients (Anderson et al., 2011; Hofmann et

al., 1997) or they approach them inadequately (Deep et al., 2008; Osborn et al., 2012),

contributing to provision of high intensity care in the final months of life, even when

patients and caregivers prefer treatments focused on comfort and quality of life

(Covinsky et al., 2000; Heyland et al., 2006; Wenger et al., 2000; Yuen et al., 2011).

Mounting evidence suggests that aggressive EOL cancer care is a modifiable

trend, and that earlier discussions between patients and their physicians regarding EOL

preferences could be associated with less aggressive and less costly care near death

(Mack et al., 2012; Roman et al., 2019; Starr et al., 2019; Wright et al., 2008; Wright et

al., 2010; Weeks et al., 1998; Prigerson, 1991).  In 2017, The American Society of

Clinical Oncology (ASCO) released consensus guidelines regarding patient-clinician

communication with recommendations that addressed specific topics, such as discussion

of GOC and prognosis, treatment selection, and EOL care in addition to providing

guidance regarding core communication skills and tasks that apply across the continuum

of cancer care (Gilligan et al., 2017).

Barriers to GOC and EOL discussions in oncology are widely acknowledged and

researched, they include but aren't limited to unrealistic patient expectations, clinician

concern about taking away hope, and unrealistic clinician expectations (Odejide et al.,

2016).  Many patients may not be aware of the dismal prognosis of their cancer, due to

lack of understanding or omission of information by their providers.  In addition, GOC are too often not addressed for patients at high risk of death (El-Jawahri et al., 2017). Patients with metastatic solid tumors typically have a more indolent course of progression compared to patients with hematologic malignancies, and one study found only 4% of patients with hematologic malignancies (vs 23.5% of solid tumor patients) had discussed GOC or code status within the last month before their terminal ICU admission (Heng et al., 2020).

Several researchers agree that hematologists possess certain personality traits and practice paradigms that yield very specific barriers to having GOC and EOL discussions that are not fully understood, and that research on this phenomenon is needed. Prod'homme et al (2018) recently published a qualitative grounded theory study using individual interviews to give rare insight into these hematologist-specific barriers. Hematologists describe particular issues, such as the difficulty for individual prognostication due to the chemo-sensitivity of hematological malignancies, and the possibility of allogeneic stem cell transplantation that allow ongoing therapeutic goals of curable or long-term survival. In contrast, acute complications are frequent, unpredictable and change the prognosis rapidly.  Often the acute complications may contribute to death before the possible involvement of a palliative care team. Furthermore, long relationships develop between patients and their hematologists, and the negative representation of palliative care contributes to lack of referral (Gatta & LeBlanc, 2020).  Prod'homme et al.'s (2018) study uses qualitative grounded theory and individual interviews to identify barriers and explore ten hematologists' thought logic.  The qualitative analysis found barriers to EOL discussions could be grouped into three main categories: the

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hematologist's desire to help patients fight-for-life, the hematologist's own perception of what is good for patients, and the hematologist's difficulty with incertitude (Prod'homme et al., 2018). Additionally, issues with accurate prognostication in the era of exceptional responders, patient prognostic understanding, discordant GOC, and identification of when EOL begins, have been described (Odejide et al., 2014; LeBlanc et al., 2018; Loh et al., 2019).

### *Fight-for-Life*

Prod'homme et al. (2018) recognize that Hematologists' view talking about death as stressful, difficult, and taboo in a recent study. The 2018 study found that physicians often adopt a false positive attitude with their patients in order to avoid the subject of death. They do this by leavings things unsaid, being ambiguous, and omitting certain information. According to them, in the event of recurrence, their responsibility is to reassure their patient with a positive attitude, re-inspire the confidence that was lost when the disease recurred, and provide motivation; this role was not felt to be compatible with conducting an EOL discussion. As long as hematologists have therapeutic options to treat blood-related cancer, they seem unable to open discussions about EOL. Some believe imminent death is proof of professional failure, and fear things such as loss of credibility, jeopardizing patient compliance or patient-physician relationship, and potential negative effect on treatment success and tolerance (Prod'homme et al., 2018).

### *Hematologists own Perceptions of What is Good for Patients*

The willingness of hematologists to consider patient perspectives for the future and talk about EOL is restricted by their desire to maintain patient-physician relationship when a recurrence occurs. In fact, the main factor that contributed to begin an EOL

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discussion was an explicit request coming from the patient. Even then, the hematologists aimed to provide a certain degree of psychological security for the patient, and endorsed probing to see what the patient wants, leaving the door open to conversations, and testing the patient to see whether or not they really wanted to receive an answer. They seek to protect their patients from violent and EOL discussions at the time of recurrence, and often representations of what they feel is best for the patient is defined according to the hematologist's own ideals about health care and EOL (Prod'homme et al., 2018). An example of this issue is often seen at diagnosis of acute myeloid leukemia (AML). Hematologists know that understanding the biology of AML has led to therapeutic interventions potentiating meaningful responses with more acceptable toxicity profiles compared with intensive therapy. Nevertheless, the diagnosis often comes late in life when patients are more likely to have impaired functional status and suffer from other comorbid illnesses. Therefore, the oncologist must be unbiased and fully engaged with the patient, discussing goals of therapy and EOL issues, in a shared decision-making process (Leblanc & Erba, 2019).

### *Difficulty with Incertitude, Hope, and Clinical Trial Participation*

For hematologists, having and EOL discussions and collaborating with palliative care teams is equivalent to affirming that the outcome is inevitably fatal, and therefore incompatible with hope. Certainty of imminent death is the preferred incentive for EOL discussion. Incertitude and hope of remission, however slight, stops any discussion about the threat of death or advance care planning (Prod'homme et al., 2018).

For patients with advanced refractory cancer, experimental therapy, particularly on an early phase clinical trial, is a common therapeutic option (Nurgat et al., 2005).

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Although the principle purpose of clinical trials is to generate knowledge to improve future therapy, many patients incorrectly believe that the primary purpose is to directly benefit participants (Joffe & Weeks, 2002; Peppercorn et al., 2004). Classic Phase I trials are designed with nontherapeutic primary aims of determining toxicity and the optimal dose for subsequent testing and infrequently provide direct benefit (Horstmann et al., 2005; Roberts et al., 2004). Unfortunately, most patients misunderstand the purpose of early phase trials, and enroll anticipating a substantial likelihood of personal benefit, even cure, rather than for altruistic reasons (Daugherty et al., 1995; Meropol et al., 2003; Nurgat et al., 2005; Sulmasy et al., 2010; Truong et al., 2011; Weinfurt et al., 2003; Weinfurt et al., 2008). Nevertheless, several highly successful early-phase trials involving targeted cancer therapies demonstrated that drugs in early development can occasionally provide significant benefit to patient-subjects (Flaherty et al., 2010; Kwak et al., 2010; Topalian et al., 2012).

Many patients with very limited life expectancy are highly motivated to continue disease-directed treatment and pursuing investigational therapy may help them and their loved ones feel they have fought their best fight, thereby finding greater acceptance and peace at the EOL (Agrawal et al., 2006) Conversely, trial participation might distract some patients from coming to terms with death and making EOL plans. National guidelines support balancing hope and desire for more treatment with other EOL GOC, including symptom control, avoiding futile interventions, and supporting the patient's ability to come to terms with and prepare for death (Peppercorn et al., 2011; Steinhauser et al., 2000; Temel et al., 2011; Wright et al., 2008).

*Accurate Prognostication in the Era of Exceptional Responders, Prognostic*

*Understanding, and Discordance in Perceived Chance of Cure*

Understanding one's prognosis is fundamental to making informed treatment decisions.   Novel immunotherapies and genome-targeted treatments, which yield exceptional responses and a small proportion of patients, further complicates hematologists' ability to formulate and communicate prognosis to patients with advanced disease. Existing approaches to improving patient clinician communication in hematology are inadequate to accommodate different levels of skill and aptitude among practicing hematologists (LeBlanc et al., 2018).  One study found that over 90% of hematologists report initiation of prognostic discussions at diagnosis, but only 17.7% readdressed prognosis until death was imminent (Habib et al., 2019).  If, by chance, a hematologist is able to articulate accurate prognostication, often time patients report an inaccurate perception of their prognosis. Prior studies have demonstrated that up to 82% of patients with hematologic malignancies have a different understanding of their prognosis compared with their hematologist (El-Jawahri et al., 2015; El-Jawahri et al., 2019: Lee et al., 2001; Sekeres et al., 2004).  Much of this discordance is skewed toward optimism, meaning that patients tend to have higher expectations for cure, which has significant implications for care received.   The discordance may be related to patient, physician, and/or societal factors, but the optimism motivates patients to opt for more aggressive care (Chen et al., 2017; Chochinov et al., 2000; Derry et al., 2019; Gramling et al., 2016; Henselmans et al., 2017; Loh et al., 2019; Mack et al., 2015; Robinson et al., 2008).

The availability of novel, efficacious treatments is changing the landscape of cancer therapeutics and dramatically improving prognosis in a subset of patients with advanced disease. As hematologists, it is gratifying and exciting to administer therapies such as immune checkpoint inhibitors to patients who previously had a prognosis of less than one year, and occasionally to see their cancer remain quiescent for many years (Wolchok et al., 2017). Unfortunately, many patients do not respond to immunotherapy, have underlying health conditions, or experience toxicities that prohibit administration. The availability of these novel therapies is making the already significant problem of communicating prognosis more complex (Elias, 2019; LeBlanc et al., 2018).

### Identification of When End of Life Begins

The studies raising concerns about the quality of EOL care for patients with blood cancers provide little insight into the associated perceptions and decision-making processes of the hematologic oncologists involved in their care. In addition, little is known about how to define the "EOL phase" for these patients. Participants in four focus groups from the Dana Farber/ Harvard Cancer Center indicated that identifying when the EOL phase of blood cancer begins is challenging (Odejide et al., 2014). Uncertainty regarding prognostication centered on several factors. First, providers for patients with leukemia, lymphoma, and hematopoietic stem cell transplantation specified that possibility of cure for many hematologic malignancies, even in relapse states, makes it difficult to prospectively determine when the EOL phase of disease begins. This was specifically noted as a salient difference between blood cancers and the majority of advanced (Stage IV) solid malignancies, which are incurable. As one participant explained, "For metastatic lung cancer, there is no tail on the survival curve pretty much.

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Whereas with lymphoma although most patients with refractory disease will likely die, we all know there is a tail...through allotransplant" (Odejide et al., 2014 p. e398). Participants agreed that although the median survival for many hematologic malignancies may not differ from advanced solid malignancies, the potential for cure, even when small, impacts their ability to accurately determine when a patient is at the EOL (Odejide et al., 2014). For this reason, interdisciplinary cooperation, timely discussions about specialist palliative referral, and indicators to 'flag' patients in need of specialist or primary palliative care are important, but they are largely missing and further models of early integrated palliative care should be evaluated in prospective studies, and established in daily clinical practice (Oechsle, 2019).

**Summary**

While the research has described several EOL quality indicators, in order to affect change, one must intervene with specific interventions that aggressively address one issue at a time. Administrative and stakeholder input have focused this researchers' effort on reducing ICU admission in the last 30 days of life and EOL healthcare costs, while increasing the quality of EOL care provided in a tertiary inpatient hematological research facility. While researching and synthesizing the available information, the root cause of aggressive EOL care has been identified and described in this literature review, leading to establishment of potential interventions to address existing gaps and shortcomings in common practice, namely, having and documenting earlier GOC and EOL discussions in patients with hematologic malignancies.

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## CHAPTER III

## METHODS/PLAN

### Introduction

Practice problems are often large, polymorphic, system-wide issues with unclear solutions.  For this reason, a mixed-method study that examined the discussion and documentation compliance rates while also exploring perceived barriers in cases of non-compliance provided benefits drawn from the potential strengths of both quantitative and qualitative methods.  Mixed-methods research enabled the researcher to explore diverse perspectives and uncover relationships that exist between the intricate layers of the multi-faceted research questions.  The purposeful mixing of methods in data collection, analysis, and interpretation of evidence fostered data linkage and integration between rates of pathway utilization and perceived barriers, therefore enabling a panoramic view of the research problem.

Benchmark data shows that patients with hematologic malignancies receive more aggressive care at the EOL and have higher rates of ICU admission in the last thirty days of life, which is associated with poor quality EOL care (Wright et al, 2016).  A task force convened to address this issue and created a GOC pathway that could endorse goal concordance.  The rollout of the project was poor, uncommunicated, and did not utilize APP involvement or leadership.  There was an e-mail with a very lengthy document and

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the project came as a surprise both to hematologists and inpatient APP's, who were not educated on the importance or reasoning behind the new pathway.
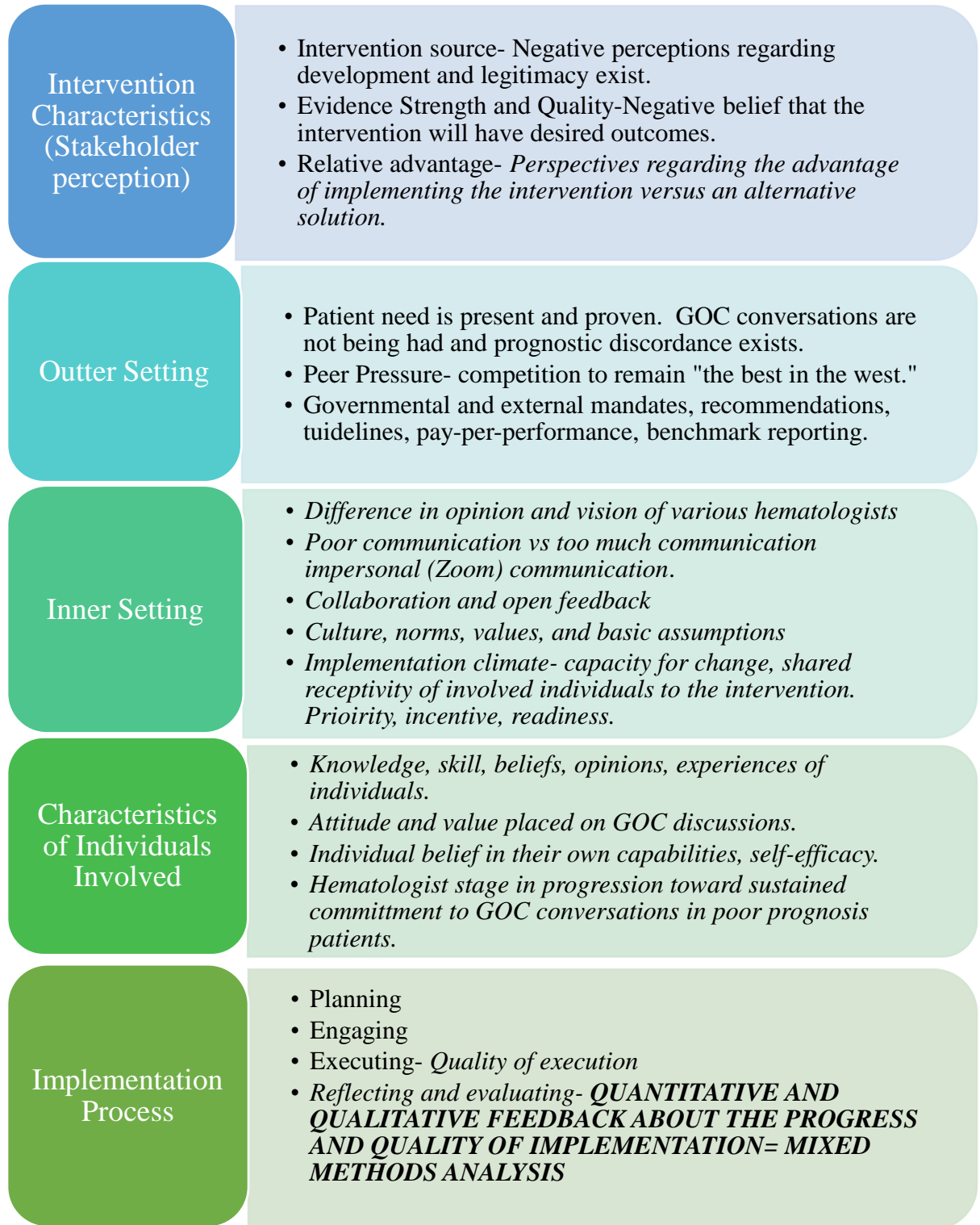
**Project Design**

This study sought to answer five research questions:

1.  How many leukemia inpatients met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021?

2.  How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had appropriate referral for GOC pathway?

3.  How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed GOC discussion utilizing the approved template prior to hospital discharge or death?

4.  How do the hematologists define "GOC conversation" in one sentence and what do they consider the most important components?

5.  What do the hematologists identify as perceived barriers in having/documenting GOC conversations?

It was suspected that compliance with the GOC pathway was low, which indicated the need for evaluation and adaptation. The CFIR will serve as a roadmap for pathway project evaluation and data gathered in this study will provide valuable information to fill in existing gaps in knowledge of the 5 domains of the CFIR. These gaps are italicized in Figure 6.

**Figure 6**

*Consolidated Framework for Implementation Research*

| Intervention Characteristics (Stakeholder perception) | • Intervention source- Negative perceptions regarding development and legitimacy exist.<br>• Evidence Strength and Quality-Negative belief that the intervention will have desired outcomes.<br>• Relative advantage- *Perspectives regarding the advantage of implementing the intervention versus an alternative solution.* |
|---|---|
| Outter Setting | • Patient need is present and proven. GOC conversations are not being had and prognostic discordance exists.<br>• Peer Pressure- competition to remain "the best in the west."<br>• Governmental and external mandates, recommendations, tuidelines, pay-per-performance, benchmark reporting. |
| Inner Setting | • *Difference in opinion and vision of various hematologists*<br>• *Poor communication vs too much communication impersonal (Zoom) communication.*<br>• *Collaboration and open feedback*<br>• *Culture, norms, values, and basic assumptions*<br>• *Implementation climate- capacity for change, shared receptivity of involved individuals to the intervention. Prioirity, incentive, readiness.* |
| Characteristics of Individuals Involved | • *Knowledge, skill, beliefs, opinions, experiences of individuals.*<br>• *Attitude and value placed on GOC discussions.*<br>• *Individual belief in their own capabilities, self-efficacy.*<br>• *Hematologist stage in progression toward sustained committment to GOC conversations in poor prognosis patients.* |
| Implementation Process | • Planning<br>• Engaging<br>• Executing- *Quality of execution*<br>• *Reflecting and evaluating- QUANTITATIVE AND QUALITATIVE FEEDBACK ABOUT THE PROGRESS AND QUALITY OF IMPLEMENTATION= MIXED METHODS ANALYSIS* |

This study used a mixed-methods, explanatory sequential design (follow-up explanations variant) to explore the phenomena of hematologists' aversion towards GOC conversations in the inpatient setting. This study design provided a more comprehensive, in depth understanding of the practice problem and resulted in a framework of evidence to be used in project implementation evaluation. All qualitative data was obtained using an anonymous SurveyMonkey platform to promote participation.

Once the project was approved for exempt status by both the facility's IRB and the academic institution, retrospective chart review by the researcher first quantified the degree of compliance that currently existed in referral of criteria-specified poor-prognosis patients for goals discussions via the GOC pathway, and hematologist compliance in having/documenting/billing for goals discussions in these patients. Percentages from the facility in which the hematologists practice described the issue as it pertains to them more than nation-wide percentages that are published. Compliance was not monitored or manipulated in real-time or influenced by the researcher. However, the researcher remained an established resource if the hematologist chose to reach out and request assistance or guidance. The quantitative data answering research questions 1, 2 and 3 was initially intended to be included in the letter to the hematologists containing the Survey Monkey link requesting qualitative answers to research questions 4 and 5, however, after reviewing the data, it was decided that inclusion of this information may discourage truthful response to the survey questions.

### Sample/Target Population

The study was designed with an identical mixed-method sampling design because the same people were to be used in both strands of the study. The intent of the qualitative

component was to offer detail and elaboration about phenomena that was captured quantitatively. Recruitment for the study consisted of the eighteen hematologists practicing in a southern California dedicated cancer research center, that specializes in hematology, largely leukemia, and other diseases that may be cured with allogeneic hematopoietic stem cell transplant. These eighteen hematologists rotate through four leukemia services on a two-week rotation schedule. Permission was received from both the institution's IRB and the academic entity's IRB. Participation in survey completion was anonymous and voluntary.

The pathway was created to initiate GOC conversations between hematologists and patients with a poor prognosis based on the following criteria:

1) Leukemia/ myelodysplastic syndrome (MDS) with relapsed or refractory disease after one line of treatment.

2) Multiple myeloma or lymphoma with relapsed or refractory disease after two lines of treatment.

3) Excluding those admitted for a potentially curative treatment such as allogeneic stem cell transplant, chimeric antigen receptor T-cell therapy (CAR-T) and autologous transplant.

The study sought to explore leukemia physicians, therefore, only patients identified by the first criteria were initially considered for inclusion in the quantitative data collection. However, in response to an administrative request to the task-force, all inpatient admissions meeting either criteria were included in the quantitative results. The established GOC pathway protocol excluded patients who were admitted for curative

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treatment such as hematopoietic stem cell transplant, and those admitted to receive treatment under some specific IRB protocols with targeted therapies, and CAR-T.

**Inclusion & Exclusion Criteria.**  Only the eighteen hematologists at this facility who specialized in leukemia and rotated through the four leukemia services were included in the qualitative arm of this study.  No lymphoma, myeloma physicians or APPs were asked to participate.

**Ethics and Protection of Human Subjects.**  Prior to data collection, approval was obtained from the Pittsburg State University Irene Bradley School of Nursing Institutional Review Committee and the dedicated cancer center's IRB.  The proposed quantitative research involved retrospective chart review of all patients admitted to the hematology service during the months of October 2020 and January 2021, involved no procedures for which written consent is normally required outside of the research context, and the research presented no more than minimal risk of harm to subjects.

The researcher initially applied for expedited IRB approval by submitting the Expedited Review of Research Involving Human Subjects Criteria Form, The Application for Approval of Investigations Involving Human Subjects, and the Application for Waiver of Informed Consent Form to the Pittsburg State University Office of Graduate and Continuing Studies and the Pittsburg State University Committee for the Protection of Human Research Subjects (CPHRS), after these documents underwent review and were approved by the Pittsburg State University Irene Ransom Bradley School of Nursing.  The request was modified to exempt after receiving exempt approval from the cancer institution's IRB.  Participation in the qualitative SurveyMonkey was voluntary and anonymous, which was explained in a "pre-mail" sent

to the leukemia division three days prior to sending the official study request with IRB approved consent, cover letter, and survey link.  The purpose of the study, voluntary nature of the study, and intended use of the information received was again explained, along with the steps taken to protect respondent anonymity, in the official study request e-mail containing the consent and link to the survey.  The responses were kept anonymous in the survey monkey and the researcher did not share login or password to their account containing the survey results.

**Biases.**  Biases are a potential barrier in any qualitative exploration of human feelings.  Even though anonymity was practically guaranteed, there was still a risk that, consciously or subconsciously, the hematologists would distort their responses to present themselves in the best light or simply because they were unaware of their own behavior and biases.

*Instruments*

The quantitative data was obtained with retrospective chart review by the researcher.  Information was entered into an Excel document consisting of columns: Admit Date, Service, Admitted for, Meets criteria (Y/N), Why?, SW Consult placed (Y/N), Consult date, Location at time of consult, Meeting occurred (Y/N), Proper documentation of GOC meeting under ACP notes using approved template (Y/N), ACP charge present during admission (Y/N) , and an opt-out criteria/ Misc extra information column for notes the researcher considered potentially useful in analyzing and understanding the problems surrounding GOC discussions.   The spreadsheet was later condensed for ease of analysis and the why, consult date, location at time of consult, and opt-out criteria/misc extra information columns were removed.  All information was

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stored on facility locked computer in the approved OneCloud drive for Business under the researcher's institutional account.  The Doctor of Nursing Practice (DNP) student researcher is employed by the facility, has access to the charts and no HIPPA violations took place.  The patient MRN was the only identifier and only identifiable by a current employee with Epic access, however, under the recommendation of the facility's IRB, the MRN was removed from the data collection spreadsheet prior to saving the document each time it was accessed.

The qualitative instrument was a survey (Appendix C), hosted by SurveyMonkey.com and consisted of two exploratory open-ended questions aimed to provoke deep thought and explore the personal opinions and beliefs of the hematologists in an anonymous form.  Content validity was established after review from institutional APP and MD leadership, and scholarly project committee, consisting of two doctorly prepared APP's and a statistician.  The hematologists were informed of the DNP researcher's intent to publicize the de-identified qualitative findings in fulfillment of the DNP scholarly project, and that the information would be used to modify the current protocol at their facility based on what was learned.

### *Procedure and Implementation Plan*

After project approval was obtained from both academic and research facility IRB, retrospective chart review was performed on each patient admitted to the Hematology and Hematology Transplant Readmit services during the months of October 2020 and January 2021.  The charts were personally accessed by the DNP student researcher, who is an employee of the site facility. The history and physical were first examined to determine reason for admission, treatment history, and current disease status.

Patients who were admitted to one of the leukemia services and identified as poor prognosis by the first criteria stated above, underwent further chart review to determine presence of correct social work order to initiate GOC pathway, presence/absence of properly documented GOC conversation, and advanced care planning charge using CPT code 99497 or 99498.  The DNP student researcher worked closely with social worker who tracked the presence or absence of GOC meetings in all inpatients who had the GOC pathway initiated via social work order.  The social worker's data was compared against the researchers data to verify consistency and validity of certain research findings. An Excel spreadsheet (described above) was stored on the secure institutional OneDrive for Business, which is the institutional-wide approved storage cloud that allows the safe construction, storage, sharing, and editing of documents that may contain confidential patient information.  Once all patient charts admitted during the two-month time frame were examined and findings placed in excel, assistance was solicited from a colleague experience in Excel to guide in utilization of Excel features for data extrapolation and analysis.  Additional assistance was provided through program help functions and videos. Figure 7 illustrates the final collection method of extrapolated data.

**Figure 7**

*Raw Data from Chart Review*

| Admit Date | Service | Admitted for | Criteria | SW Cons? | Meeting? | ACP doc? | ACP Charge? |
|---|---|---|---|---|---|---|---|
| ##/##/#### | **Leuk 1,2,3,4** | ……… | Y/N | Y/N | Y/N | Y/N | Y/N |

Though originally intended to be included with the cover letter, the researcher opted out of including the quantitative date in the cover letter that requested survey

completion. It was thought the results may be threatening to the hematologists as they indicated very poor compliance with the pathway and GOC initiative. It was shared that the information obtained would be used to develop strategies to address the well-known aversion to GOC conversations in hematology. The survey was kept open for ten days and reminder e-mails containing the survey link were sent out every 3 days and on the day of survey closing. The service line director offered to "nudge" the hematologists, but the researcher declined their offer to protect the integrity of the responses. Ten days after the initial e-mail, the survey closed. Then, extrapolation and analysis of the qualitative data began with the assistance of a PhD prepared NP, a statistician, a DNP mentor, and other experts.

Consent was assumed with completion of the survey though a very detailed institutional consent form was required by the facility's IRB. It was assumed that each hematologist would be ethical and complete the survey only one time, and do so honestly

During the planning process, the researcher considered the limitations within the sample population concerning generalizability, however, it was the intent of the researcher to limit the findings to this specific population in order to obtain meaningful data that could be used to construct tailored solutions. Also, due to the known phenomenological aversion of hematologists to GOC discussions, there was a concern that there may be a lack of response to the survey.

*Treatment of Data/Outcomes/Evaluation Plan*

**Analysis of Data.** This was an explanatory sequential design research study, and the integration intent was to connect the results and provide a strong explanation for the compliance rate of GOC conversations in hematologists. Descriptive statistics were used

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to analyze and report the quantitative data obtained from chart review and report level of compliance or non-compliance. The inductive qualitative analysis used tags and content analysis to identify themes and categories for each of the open-ended questions of the survey so that an in-depth understanding of the phenomenon could be learned.

**Evaluation Measures.** Outcome and evaluation measures were correlated with the project research questions, objectives established in the logic model (see Figure 4) and goals established in the short, medium and long-term outcomes (see Figure 5). The survey instrument was intended to provoke thoughtful, meaningful responses in a non-threatening and anonymous form. Project quality was based on criteria for doing high-quality mixed methods research, as proposed in many frameworks in Fabregues and Molina-Azorin's (2017) review. The study met the following five criteria:

1. A strong rationale existed for collecting and analyzing both quantitative and qualitative data.

2. The quantitative and qualitative strands were well implemented and adhere to the quality criteria of each tradition.

3. The quantitative and qualitative components of the study were well integrated.

4. The sampling, data collection, and data analysis procedures for both strands were linked to the study intent and the research questions.

5. Inferences were consistent with the study findings and with the study intent.

### *Plan for Sustainability*

In 1987, the United Nations General Assembly issued the report of the world Commission on Environment and Development. The report described sustainability as "meeting our own needs without compromising the ability of future generations to meet

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their own needs, considering social and economic resources in addition to natural resources." Healthcare in its current state in America is not sustainable at this point and change needs to occur. This research project was developed to contribute, in part, to healthcare sustainability by reducing the unwanted and unnecessary use of medical resources that is currently straining our system. By establishing clear goals based on prognostic understanding, patients and providers with goal concordance can make shared decisions that reflect the patient's values, beliefs and desires, especially at the EOL, which is when a person typically uses the most health care resources. Both political and financial components necessitate sustainability of this, and other projects aimed at reducing unwanted and unnecessary EOL healthcare usage.

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**CHAPTER IV**

**FINDINGS**

Patients with hematologic malignancies often receive aggressive care at the EOL, leading to lower quality of life. Aggressive EOL care in patients with advanced-stage cancer is increasing despite growing concerns that this reflects poor-quality care (Wright et al, 2016). Furthermore, studies have found that, regardless of illness, at least 13% of the time, the EOL care provided is inconsistent with the patients' GOC and causes psychosocial and financial burden to the family (Khandelwal et al, 2017).

In April of 2020, a freestanding U.S. academic cancer hospital launched a pilot GOC pathway project ultimately aimed at improving goal concordant care. The pathway identifies "poor prognosis" patients admitted to the hospital based on hematologic disease-specific criteria. The original task force did not include APP leadership or representation during the planning phase, which resulted in an unsuccessful first roll-out. Fortunately, a DNP student leader saw this as an opportunity to prove APP input as a necessity for program success. The project objectives were modified to include "discover actual and potential NP contribution to the GOC pathway pilot project" and, after weeks of multi-disciplinary collaboration, the pathway pilot was re-launched with several revisions that gave ownership to the inpatient APPs.

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The Alliance of Dedicated Cancer Centers (ADCC) represents the ten freestanding U.S. academic cancer hospitals, and this alliance developed a national implementation   initiative to enhance goal-concordant care for patients with cancer.  The initiative recognizes and embraces the vision that all patients with cancer and their families should receive care that aligns with their values and unique priorities.  In September 2020, the ADCC released the Improving Goal Concordant Care (IGCC) Initiative Implementation Planning Guide, which was created to address system gaps in the centers and to establish new expectations for when and how GOC conversations occur.  This placed the DNP student researcher and the GOC pathway project at the center of the institution's plan for a nationwide quality improvement initiative.

When rolling out a practice changing initiative, it is important to monitor progress for unanticipated influences (barriers and facilitators) and progress toward implementation goals (Damschroder et al., 2009).  The implementation of this practice transformation initiative needed to be evaluated.  The CFIR is the theoretical framework that was chosen to serve as a roadmap for pathway project evaluation and the data gathered in this study provided valuable information to fill existing gaps in the knowledge of the 5 domains of the CFIR.

**Purpose**

The first purpose of this scholarly project was to evaluate participation of APPs and physicians in the GOC pathway process and using a quantitative method of study. The second purpose used a qualitative study design to explore hematologists' self-reports regarding their knowledge, opinions and barriers surrounding GOC discussions and the proper billing of these conversations.

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*Project Questions*

1. How many leukemia inpatients met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021?

2. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had appropriate referral for GOC pathway?

3. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed GOC discussion utilizing the approved template prior to hospital discharge or death?

4. How do the hematologists define "GOC conversation" in one sentence and what do they consider the most important components?

5. What do the hematologists identify as perceived barriers in having/documenting GOC conversations?

**Quantitative Sample/Results**

The first 3 project questions were answered with quantitative examination of data that was obtained via chart review of the inpatient admissions for October 2020 and January 2021 (see Table 1). For both months, only patients admitted to the Hematology Transplant Readmit or Hematology service were eligible for inclusion. Admissions to the Bone Marrow Transplant (BMT), breast, colorectal, endocrinology, Emergency Treatment Center (ETC), extended recovery, gastroenterology, gynecologic oncology, integrated care services, internal medicine, interventional radiology, medical oncology, neurosurgery, oncology, orthopedics, otolaryngology head and neck, PED transplant, pediatric transplant readmit, pediatrics, plastic surgery, surgery, surgical oncology, thoracic surgery and urology services were excluded.

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**Table 1**

*Research Questions 1, 2, 3*

| Question Number | Results-October | Results-January |
|---|---|---|
| 1. How many leukemia inpatients met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021? | 63 | 68 |
| 2. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had appropriate referral for GOC pathway? | 19 | 10 |
| 3. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed GOC conversations utilizing the approved template prior to hospital discharge or death? | 19 | 1 |

*October 2020*

The Tableau Dashboard in Epic was used to sort the patients by month of admission and service. For the month of October 2020, each of the 721 total admissions were reviewed, 623 were inpatient admissions and 98 were observation. At the time of the initial access and chart review, 206 patients were admitted as an inpatient to either the Hematology service or the Hem Transplant Readmit service, and 8 patients were admitted to these services under observation during the month of October 2020. Of these 206 admissions, 4 Kaiser admissions, 1 Coronavirus-19 (COVID) admission, and 8 CAR-T admissions were excluded. Of 193 eligible encounters, 63 (33%) patients met criteria for GOC pathway initiation and 130 (67%) did not (Figure 8).

**Figure 8**

*October 2020 Admissions Data*
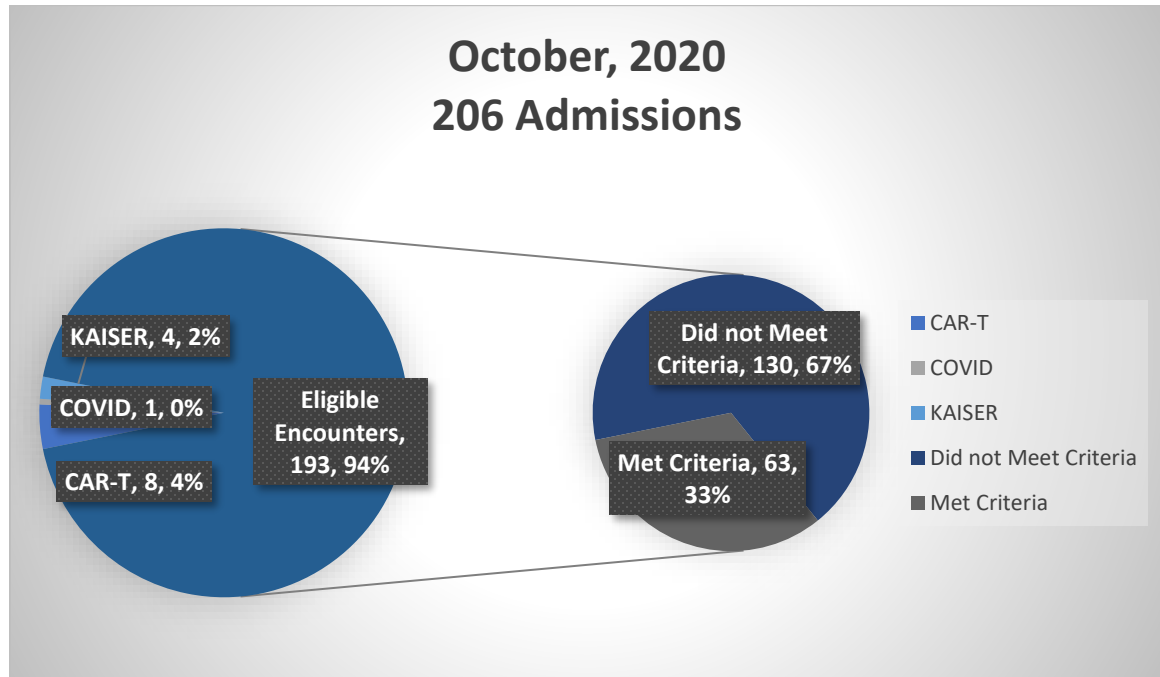


Of the 63 patients who met criteria for initiation of the GOC pathway, 19 had an appropriate social work consult to initiate the pathway and 4 of those had appropriate documentation and billing for a GOC discussion by the physician. Of the 44 patients without appropriate consults placed, 2 eventually had consults upon ICU admission via the ICU pathway and one had a supportive care medicine consult. Forty-one patients who met criteria did not have a social work order or a documented GOC discussion at any point during that admission encounter (Figure 9).

**Figure 9**

*October 2020 Admissions Meeting GOC Pathway Criteria*
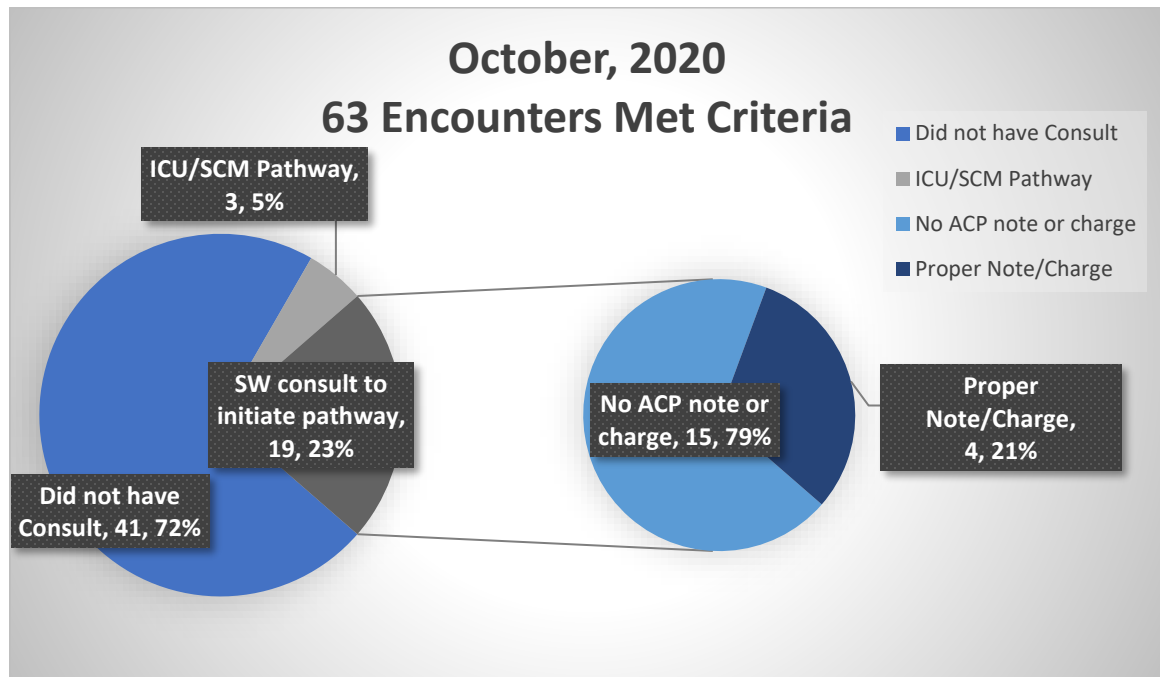


*January 2021*

    In January 2021, 230 patients were admitted as an inpatient to the Hematology service or the Hem Transplant Readmit service. Excluding the 11 CAR-T admissions, 3 Kaiser admissions and 40 COVID admissions, 176 admission encounters were eligible for inclusion in this study. Sixty-eight (39%) patients met the criteria for initiation of the GOC pathway and 108 (61%) did not (Figure 10).

**Figure 10**

*January 2021 Admissions Data*
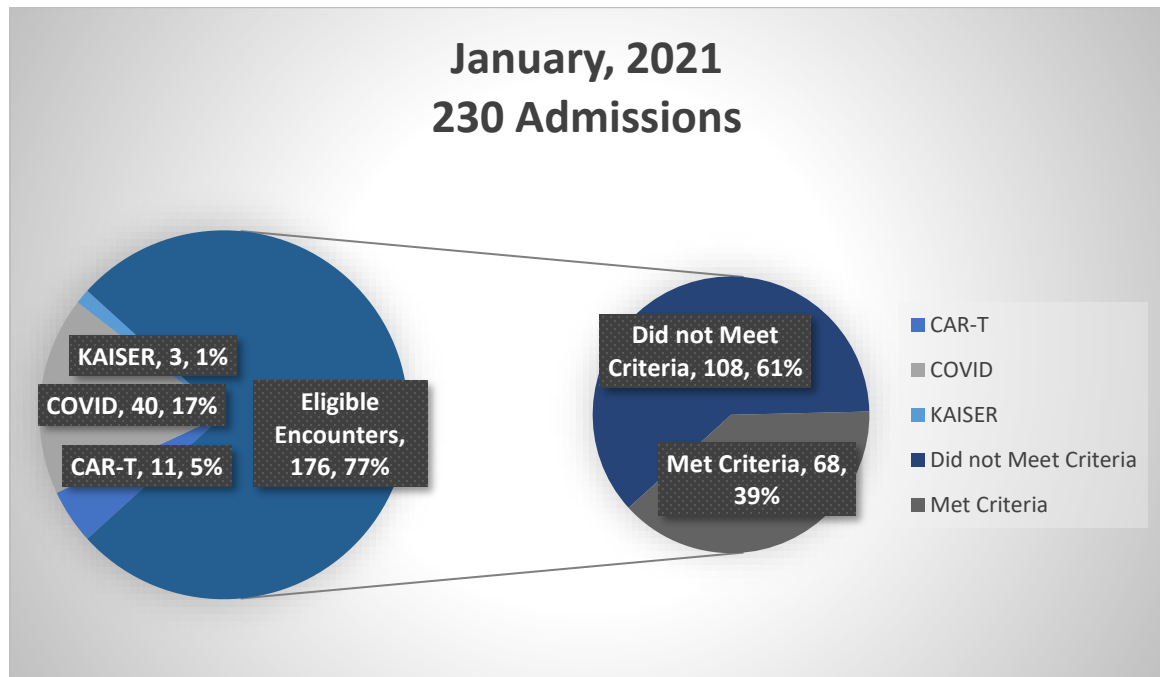


Of the 68 encounters that met criteria for GOC pathway initiation, 10 (15%) had a social work order placed to initiate the pathway. Fifty-three (78%) did not have an order or documented discussion at all, and 5 (7%) had an order placed upon ICU admission via the ICU GOC pathway. Of the 10 encounters with appropriately placed pathway orders, 9 (90%) had no Advance Care Planning documentation and no Advance Care Planning (99497 or 99498) charge during that admission and only 1 (10%) had an appropriately documented and billed GOC discussion by the hematologist (Figure 11).

**Figure 11**

*January 2021 Admissions Meeting GOC Pathway Criteria*
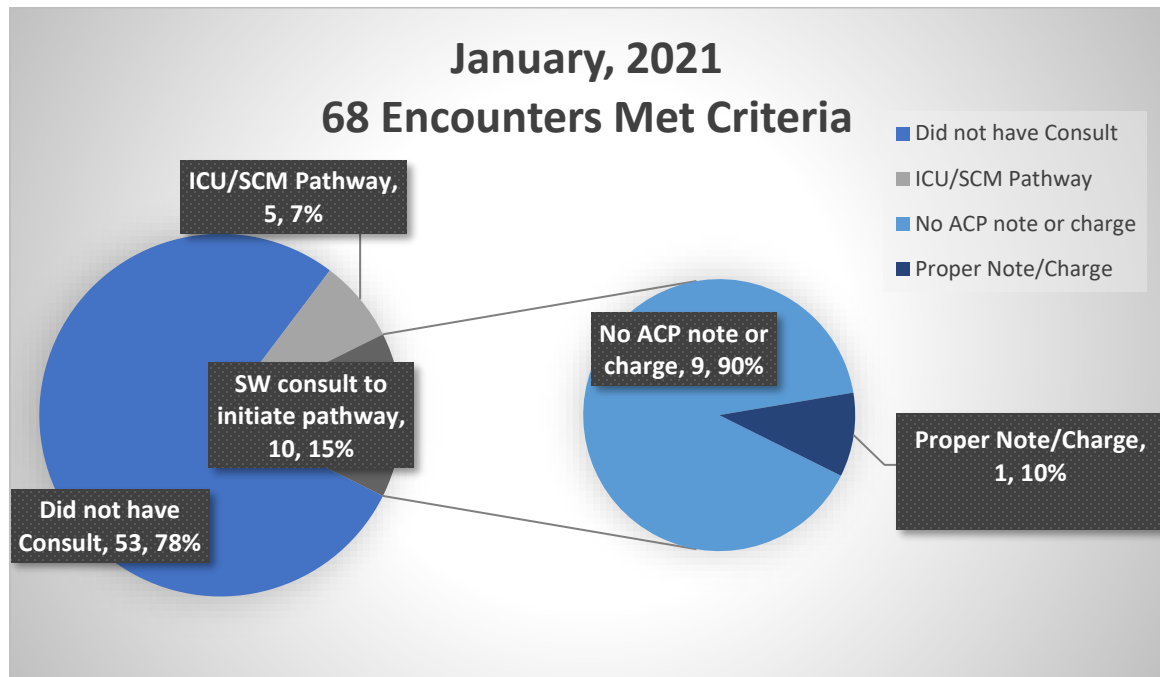


**Qualitative Sample/Results**

Project questions 3 and 4 required a descriptive qualitative inductive design that utilized content and thematic analysis of data that was obtained via an anonymous SurveyMonkey survey with two open ended questions (see Appendix C). The anonymous survey link was sent to all 18 hematologists in the leukemia division and was open for 10 days. Nine hematologists (50%) responded to the survey with 100% completion of both questions. The average time spent completing the survey was five minutes.

Content analysis of each question began with examination of each response and assigning various tags using the tag tool in the SurveyMonkey student package. Thematic analysis of the tags was completed with the assistance of a Doctor of

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Philosophy (PhD) NP and themes were identified. The tags/themes were then independently reviewed by a DNP, a master's prepared supportive care NP, two supportive care physicians and one hematologist. The word cloud feature, which finds common words that are used most often in the responses, was not useful in analyzing the content.

### Question #1

The purpose of the first question was to explore the hematologists' definitions of and key components of GOC conversations in one or two sentences.

Twenty-two tags were created from the 9 answers and assigned appropriately to each response (Figure 12). The number of tags assigned to each question ranged from 5 to 9, the average being 6.3.

**Figure 12**

*Tags Assigned to Question #1 Responses*
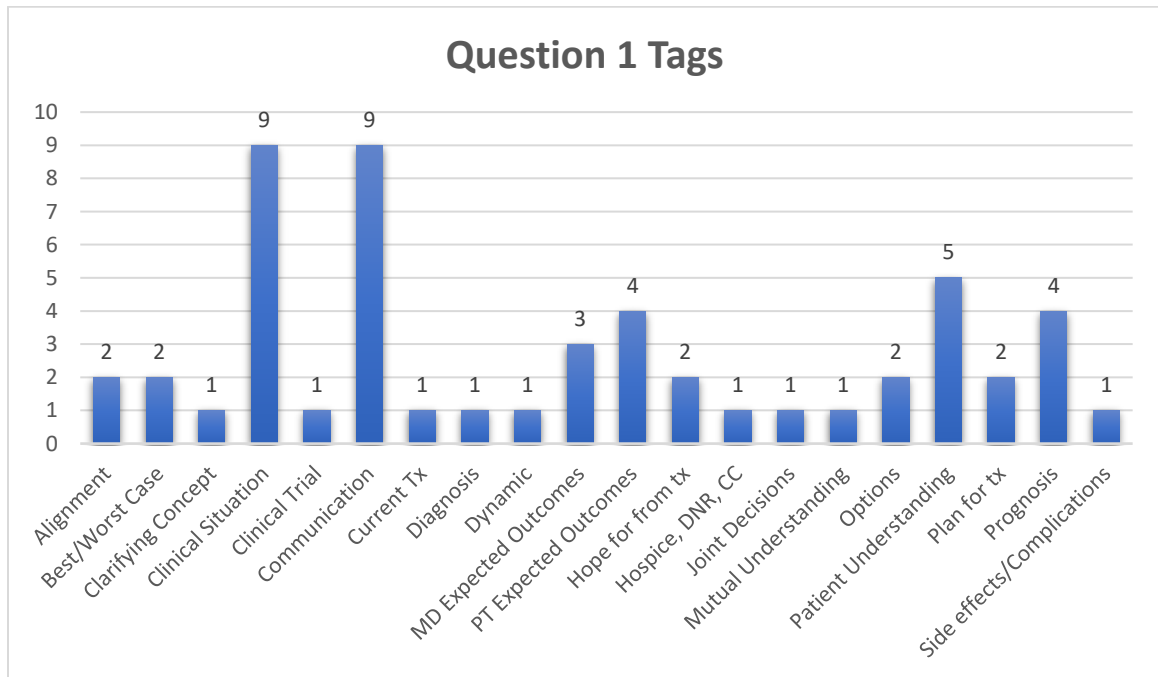
Clinical situation and communication were the two dominating themes and present in 100% of the responses, in some form.  From these, six sub-themes emerged with further thematic analysis, each containing 2-5 of the tagged categories (see Table 2).

**Table 2**

*Clinical Situation and Communication Sub-Themes*

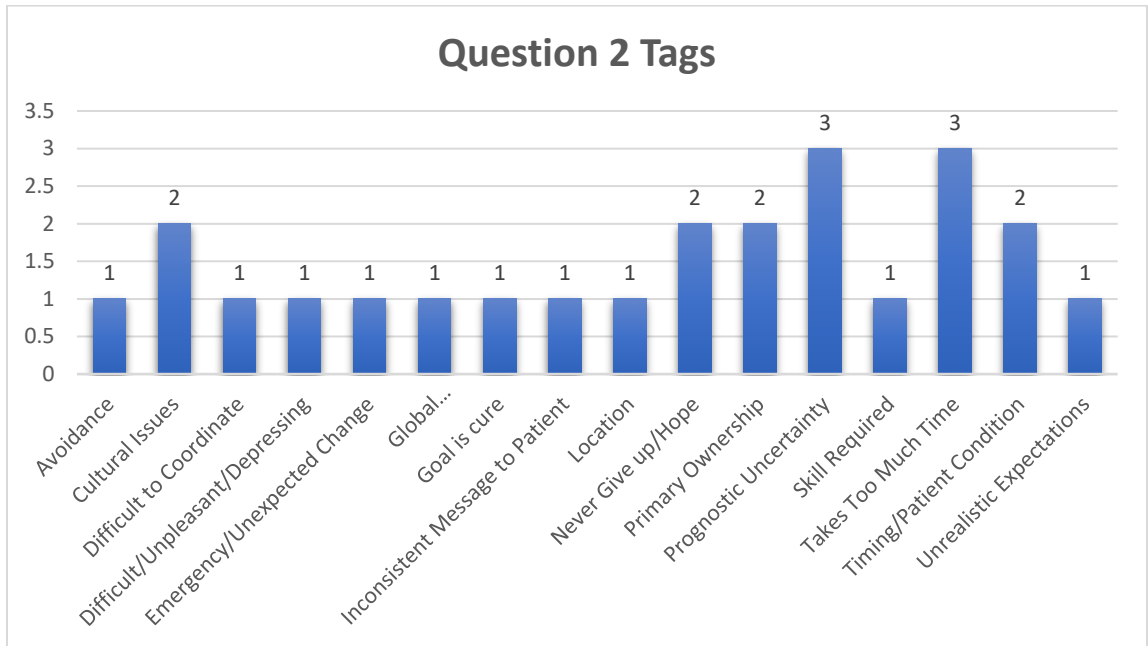| **Sub-Theme** | |
|---|---|
| **Current Condition/Information** | Diagnosis<br>Prognosis<br>Current/previous treatment<br>Treatment Response |
| **Options/Treatment/Strategies** | Plan for tx<br>Hope for tx<br>Clinical trial<br>(end) Hospice, DNR, CC<br>Side effects/Complications |
| **Outcomes** | Expected outcomes-PT<br>Expected outcomes-MD<br>Best/Worst case scenario |
| **Understanding** | Mutual Understanding<br>Patient Understanding |
| **Decision Making** | Joint Decisions<br>Alignment<br>Patient Values/Wishes |
| **Concept** | Clarifying what GOC means to the patient.<br>Dynamic<br>Not hospice, DNR, Comfort Car |

*Question #2*

The purpose of the second question was to gain insight into the hematologists' perceived barriers to having/documenting GOC conversations in the inpatient setting. Barriers may include thoughts surrounding prognostication, culture, effect on hope, comfort level with conversations, time constraints, or pressure to change practice.

Seventeen tags were created and appropriately assigned to each of the nine

responses.  The number of tags for each response ranged from 2 to 5, the average being

2.8 (see Figure 13).  Five themes emerged, each containing 2 to 5 tagged sub-themes (see

Table 3).

**Figure 13**

*Tags Assigned to Question #2 Responses*

**Table 3**

*Themes and Sub-Themes*

| Theme | Sub-Theme |
|---|---|
| **Timing/Location** | Emergency/unexpected change in patient condition<br>Timing/patient condition; goal is cure<br>Location- Clinic setting is best.<br>Difficult to coordinate |
| **Personal/behavioral** | Avoidance<br>Difficult/Depressing/Unpleasant<br>Worried about effect on hope/never give up culture.<br>Ownership by primary hematologist<br>Prognostic uncertainty |
| **Patient** | Unrealistic expectations<br>Never give up attitude*<br>Cultural issues |
| **Discussion** | Skills required.<br>Too much time/don't have time<br>Inconsistent messages to the patient |
| **Concept** | Global misunderstanding of what GOC discussions are<br>Wrong association with EOL/DNR (when typical goal is cure) |

## Outcomes and Objectives

### Short-Term Outcomes

Four short term outcomes that were evaluated were appropriately achieved with

the research questions (see Table 4).

**Table 4**

*Short-Term Outcomes*

| Short-term Outcome | Met | Research Question |
|---|---|---|
| Quantify the number of patients who meet GOC pathway criteria in 2 separate months | Y | 1. How many leukemia inpatients met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021? |

| Quantify appropriate pathway initiation and completion of MD documentation/billing in poor prognosis patients. | Y | 2. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had appropriate referral for GOC pathway? <br> 3. How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed GOC conversations utilizing the approved template prior to hospital discharge or death? |
|---|---|---|
| Obtain and compile the hematologists personal definition of a GOC discussion | Y | 4. How do the hematologists define "GOC conversation" in one sentence? |
| Compile the hematologists personal perceived barriers in having/documenting GOC discussions | Y | 5. What do the hematologists identify as perceived barriers in having/documenting GOC conversations? |

### *Medium-term Outcomes*

Study success was also evaluated against four medium-term outcomes (see Table 5).

**Table 5**

*Medium-Term Outcomes*

| Medium-term Outcome | Met | Method |
|---|---|---|
| Analyze qualitative data for patterns and themes specific to this set of hematologists | Y | Qualitative analysis of SurveyMonkey findings. |
| Interpret and organize findings | Y | Completion of chapters 1-5 of Scholarly project |
| Share the findings with hematologists, APPss, and GOC task force | IP | Some quantitative data has been shared with the task force. All findings will be shared at project completion. |
| Submit findings for publication. | F | The DNP student researcher plans to submit the findings for publication in a peer-reviewed journal upon completion. |

*Y-Outcome met, IP- In progress, F- Future*

In the future, the study will need to be evaluated for success against 5 long-term outcomes (see Table 6).

**Table 6**

*Long-Term Outcomes*

| Long-term Outcome | Plan |
|---|---|
| Use findings to address specific concerns and create educational interventions for this group of physicians. | Plug data into the CFIR, which will be used by the task force to aid in implementation success. |
| Expand the GOC pathway program to the outpatient setting. | DNP researcher will identify an outpatient NP "owner" and invite them to join the task force to create outpatient roll-out plan. |
| Enhance and align hematologist understanding of the GOC pathway and the intended outcomes of the project. | Presentation of results and ongoing NP involvement in the project, serving as a resource and liaison between administration and physicians. |
| Improve Goal Concordant Care in High-risk leukemia patients. | Align with the ADCC's recommendations and participation in the Improving Goal Concordant Care Initiative. |

**Summary**

This study had two explicit purposes, which were appropriately achieved through the chosen methodology. The first purpose, to evaluate participation of APPss and physicians in the GOC pathway process, was achieved through chart review and quantitative analysis of the discovered data. The second purpose, to elicit hematologists' definitions of a GOC discussion and perceived barriers to having/documenting GOC discussions, was achieved through qualitative analysis of anonymous survey data. To provide a broader picture, instead of analyzing the data from two consecutive months, the study utilized data from October 2020 and January 2021. The percentage of eligible

inpatient admissions meeting the specified criteria was similar (33%, 39%) between the two months; however, the number of appropriate referrals (23%, 15%) and documented/billed GOC discussions (21%, 1%) was higher in October than in January. The reasons for the decline are unknown and further research inquiry is needed to explore the trends and causation.

## CHAPTER V

## DISCUSSION

The general purpose of nursing research is to answer relevant questions and solve problems in nursing practice (Polit & Beck, 2021).  Research purposes and specific study goals can range along a descriptive/explanatory continuum, but a fundamental distinction separates the studies that aim to describe phenomena and those that are cause-probing (Polit & Beck, 2021).  This study had two explicit purposes, which were appropriately achieved through this mixed-methods study.

The global, over-reaching purpose of this research was to improve EOL quality in hematology patients by reducing the number of patients who experienced ICU admission in the last 30 days of life.  The focus of this research was to evaluate a program that was created in response to a nation-wide request for a solution to this problem.  The theoretical framework (CFIR) and study purposes were determined by utilizing the 5 "whys" to transform a very large, complex, intimidating problem into a smaller, manageable, less intimidating problem that could be addressed in a single study.  Though the effectiveness of this root cause analysis (RCA) tool has been questioned periodically for assuming the existence of only linear failures (Latino, 2015), the 5 "whys" was easily modified by the researcher (see Figure 1) to acknowledge the divergent causes of each "why," without directly addressing and researching the issues, all of which may be

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appropriate topics for future research.  Addressing the 5th "why" in a single study required a mixed-methods design with two purposes, each lying on opposite ends of the descriptive/explanatory continuum.  Quantifying the number of admitted patients who met GOC pathway criteria and comparing that number to the number of referrals and appropriately documented/billed GOC discussions effectively described the lack of program participation amongst the providers, and qualitative exploration sought to explain and understand why this lack of participation exists.

**Relationship of Outcomes to Research**

*Translating Evidence, Planned Change, and Project Implementation Evaluation*

Using evidence in practice is a complex process that requires more than a practitioner's ability to critically appraise evidence and make rational decisions.  The implementation of evidence-based practice depends on the achievement of significant and planned change involving individuals, teams, and organizations (Rycroft-Malone & Bucknall, 2010).  Many research-proven interventions fail to translate into meaningful change in the healthcare delivery system; some estimates indicate that up to two-thirds of organizations' efforts to implement change fail (Burnes, 2004).

In October 2020, only 6% of patients who met criteria for pathway initiation had a properly documented/billed goals discussion in their electronic medical record at the time of data collection; that number further declined to 1% in January 2021.  In 2017 Keith et al suggested utilization of a structured model to aid in rapid-cycle evaluation of practice transformation initiatives.   In 2009, Damschroder et al. made recommendations for successful program implementation after their study found that success is more likely when monitoring progress for unanticipated influences (barriers and facilitators) and

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progress toward implementation goals.  Logically, one could infer that the inverse is true, and that failure is more likely when the implementation plan does not monitor progress for unanticipated influences (barriers and facilitators) and progress toward implementation goals.   The decline in program participation occurred in the absence of a theoretically based implementation evaluation plan, which inversely supports Damschroeder et al's (2009) findings.

### *The Problem of Aversion*

The phenomenon of hematologist aversion to EOL discussions and poorer EOL quality in hematology is well documented, as is the increased discordance regarding prognosis, treatment goals, and EOL preferences between hematologists and their patients (Earl et al., 2008; Fletcher et al., 2016; Ho et al., 2011; Howell et al., 2011; Hui et al., 2014; LeBlanc et al., 2015; O'Connor et al., 2014).  This study found that up to 90% of inpatient admissions meeting criteria for GOC discussions via GOC pathway lacked documentation/billing of these discussions in their electronic medical record. While this does not prove a pattern of patient/provider misalignment regarding prognosis, treatment, EOL preferences, or goal discordance, it does support an aversion to GOC discussions amongst leukemia hematologists in addition to the heavily researched aversion to EOL discussions. (Howell et al., 2011, Prod'homme et al., 2018, Ojejide et al., 2014).  This research offers a very new and small window of insight into why this suggested pattern of discussion aversion exists despite the growing body of evidence supporting the want, need, and absence of these crucial discussions in patients with hematologic malignancies (Bernacki, 2015).

### *Misconceptions*

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The concept of GOC is historically ambiguous and inconsistent between providers (Brandt et al., 2012).  In 2016, Susan Stanek sought to clarify the concept of GOC using Norris's method of concept clarification to create an operational definition.  She reports three key findings: 1) GOC are the established, agreed on, desired health expectations that are appropriate, documented and communicated. 2) GOC are formulated through the thoughtful interaction between a human being seeking medical care and the healthcare team.  3) Patients, members of the healthcare team and the healthcare system when GOC are established.  There is no mention of EOL or death in her (Stanek, 2016) definition. Perception and stigma remain an issue in the hematology setting.

As shown in much of the previous research on the subject, existence of a stigmatic association of "GOC" with "EOL" (Corbett et al., 2013; Ganguli et al., 2016; Piggott et al., 2019) is evident in this study sample. Some of the hematologists described the conceptual barriers of themselves and their peers surrounding the GOC discussion, while others described their barriers based on their own misconceptions (Table 7).  Many of the same barriers exist for GOC discussions in these hematologists as Prod'homme et al (2018) described as barriers to EOL discussions, which increasingly demonstrates the lack of separation between the two concepts.

**Table 7**

*Misconceptions*

| Type of Barrier | Example |
|---|---|
| Self-Aware | "One barrier to GOC discussions is that both physicians and patients typically associate them with EOL discussions." |
| | "Misunderstanding of the GOC discussions among many people involved- including health care professionals and patient/families." |
| | "The GOC discussion has nothing to do with 'not escalating their medical care' or 'nothing to offer,' or 'you have a poor prognosis and there is no or little hope'." |
| | "The GOC discussions and more specific management items such as code status/comfort care, etc. need to be de-coupled." |
| Unaware | "GOC discussions are sometimes difficult and depressing." |
| | "It is unpleasant to deliver bad news." |
| | "Effect on hope" |
| | "The typical goal is cure in patients with hematologic malignancies." |
| | "Cultural issues, which make talking about death taboo" |

*Prognosis*

It has been shown that hematology patients are more likely to experience ICU admission in the last 30 days of life, which contributes to poor EOL quality, and that earlier and better GOC discussions increase EOL quality and goal concordance between clinicians and their patients (Mack et al., 2012; Roman et al., 2019; Starr et al., 2019; Wright et al., 2008; Wright et al., 2010; Weeks et al., 1998; Prigerston, 1991). Through a survey, Habib et al (2019) found that the majority of hematologists reported discussing prognosis with their patients at diagnosis, yet even though prognosis evolves during the disease course, one in five (20%) reported never readdressing prognosis again with their

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patient, or only doing so near death.  Therefore, nearly four out of five (80%) hematologists do not readdress prognosis throughout the disease trajectory, hence engaging in "silent GOC discussions" that do not contain current, factual prognostic information.  The quantitative lack of documented goals discussions containing prognostic information found in this inquiry may support this finding; however, a prognostic qualitative theme emerged as many of the hematologists define the components of a goals discussion and describe their barriers.  The silent conversations are more likely lack of documentation than lack of existence in this case (Table 8).

**Table 8**

*Prognosis*

| Question | Example |
|---|---|
| **1-Definition and Components** | "A meeting to align patient goals with provider understanding of prognosis." <br><br> "To carry with the patient a conversation to educate them about… prognosis and understand their wishes in regards to what's important to them" <br><br> "Diagnosis, prognosis, options for treatment, clinical trials, back-up plan." <br><br> "A careful discussion…prognosis, clinical situation and what the patient's objectives are given the reality of the situation." |
| **2-Barriers** | "It's hard to assess impact of treatment that may impact prognosis/outcomes of survival" <br><br> "Sometimes lack of all information needed to accurately determine prognosis." <br><br> "Physicians often prognosticate based on unrealistic expectations regarding the likelihood of good outcomes in the face of recurrent disease" |

*Barriers to Goals-of-Care Discussions in Hematology*

Previous research has explored barriers to EOL discussions hematology and GOC discussions in medical oncology.  To date, there is no research focused on GOC discussions in hematology. Piggott et al. (2019) surveyed and reported barriers to GOC discussions from the perspective of medical oncology practitioners and found that participants perceived patient and family member factors as the most important barriers to GOC discussions.  These included family members' difficulties accepting a poor prognosis, lack of family agreement in the GOC, difficulty understanding the limitations of life-sustaining treatments, lack of patients' capacity to make GOC decisions, and language barriers.  Patient and family factors were not identified as a theme in hematologist perceived barriers to GOC discussions.  Both the 2019 study and this study did find lack of time to be a perceived barrier to GOC discussions (Table 9).

**Table 9**

*Lack of Time*

| Question | Example |
|---|---|
| **1-Definition and Components** | N/A |
| **2-Barriers** | "Time constraints, challenge of scheduling."<br><br>"Time constraints…"<br><br>"Usually takes one hour or more."<br><br>"Number of eligible patients might exceed the time capacity that one would want to spend on this." |

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**Observations**

The evolving role of APP as influencers and crucial components in the health care system is increasingly recognized as these professionals continue to expand and display their knowledge (Kilpatrick et al., 2011).  In this study setting, the unique professional relationship between hematology Medical Doctor (MD) and APP creates a captive MD audience for which the APP should utilize to affect evidence-based practice change interventions by influencing, educating, and guiding the physician's practice when a change from the "old ways" is necessary.  In most settings, the value of the APP is recognized by the supervising physician and is respected and appreciated (Trautmann et al., 2015). The evolution of advanced practice into what it is today can be fully attributed to many years of thoughtful motivation and a united vision of practicing to the highest extent of one's knowledge and ability (Hanson & Hamric, 2003).

Initially, this study aimed to further explore and explain hematologist's barriers to having/documenting GOC discussions. The quantitative inquiry was designed to describe physician compliance in GOC pathway completion, however, during data collection, the role of the APP in physician non-compliance became apparent.  While physician barriers must be explored, it became increasingly evident that APP barriers to implementation initiatives must also be explored in future research. To compare the number of poor prognosis patients identified to the number who had properly documented/billed goals discussions would create an unfair disadvantage to the hematologists.  The number of pathway initiations by the APP/GOC meeting requests needed to be compared to the number of documented/billed discussions to more clearly understand the issues at hand. Furthermore, the lack of APP buy-in in the setting of unsuccessful practice-change

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initiatives further supports the power of APP presence and leadership in the successful implementation of initiatives.

**Evaluation of Theoretical Framework**

The CFIR was chosen as a theoretical framework to evaluate the progress of program implementation of the GOC pathway an independent dedicated cancer center in Southern California. The framework was chosen because of the apparent generalizability of the model, which was constructed based on analysis of 19 implementation research models (Damschroder et al., 2009). Since the 2009 publication, the Consolidated Framework for Advancing Implementation Science has been cited in numerous publications, all of which support the successful utilization of the framework for implementing hospital-based practice change. A 2015 study (Breimaier et al.) found the CFIR a valuable and helpful framework for: 1) Assessment of the baseline process and final state of the implementation process and influential factors. 2) The content analysis of qualitative data collected throughout the implementation process. 3) Explaining the main findings. Also, in 2015, the generic implementation framework was published, and was based on the 5 domains of the CFIR (Moullin et al., 2015). In Keith, Crosson et al's (2017) study using the CFIR across 21 primary care practices participating in the comprehensive primary care initiative, results showed that utilizing the CFIR to guide data collection, coding, analysis, and reporting of findings supported a systematic, comprehensive, and timely understanding of barriers and facilitators to practice transformation. Their approach to using the CFIR produced actionable findings for improving implementation effectiveness during the initiative and for identifying improvements to implementation strategies for future practice transformation efforts.

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Throughout this research process, many theoretical frameworks were seen in the literature, but, because of the generalizability and adaptability of the CFIR to almost any setting, it is still thought to be the most appropriate model for this project.

**Evaluation of Logic Model**

The logic model chosen (Figure 3) was appropriate and clearly stated the objectives, resources, activities, and outputs. The objectives were related to the short, medium, and long-term outcomes and were achieved through the activities and outputs. Cited resources plus additional resources obtained throughout the process were also utilized to reach the objectives. The simplicity of the logic model made it the most appropriate for this project as it was easy to read and gave a clear roadmap of the project aims.

**Limitations**

The primary limitation of this study lies within the research topic itself, GOC. There is an overall lack of interest in GOC, which was noted in the mere 50% survey response rate. The novice level of experience possessed by the principal researcher may also be a limitation. The sample size may be considered a limitation as well as the 50% response rate to the survey. Several known limitations were recognized as assumptions early in the research process. It was an assumption that each hematologist would answer the survey only once and do so truthfully. However, the anonymous survey link sent via e-mail was not designed to limit the response to one per person, but instead it was designed to promote easy access and maintain anonymity. The quantitative chart review method presented limitations due to human error and processing since each chart was personally reviewed by the researcher, and criteria for the pathway was determined by the

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researcher's interpretation of the information in the patient's electronic medical record. Also, the study was completed during the COVID-19 pandemic and visitors/family members were not allowed in the facility, therefore, GOC meetings had to take place via Zoom or other remote communication method. The anxiety of learning to live with COVID-19 fears and the changes it brought upon may have caused additional aversion to GOC discussions in hematologists.

### Instrument Limitations

Due to the anonymous survey study design, the responses lacked the advantage of verbal conversation and back-and-forth interaction that takes place with personal interview methods of qualitative discovery. It was impossible to ask for clarification of thoughts or ideas, the interpretation was determined by the health care professionals who examined the data. Prod'homme et al.'s (2018) study used personal interview of ten hematologists to explore the barriers to EOL discussions when potentially fatal hematological malignancies recur, and this study sought to similarly describe barriers to GOC discussions in patients with relapsed high-risk leukemia. The anonymous survey instrument was chosen because it was thought to be the most likely method to successfully collect the candid opinions/thoughts of at least fifteen hematologists, but the low response rate collected the thoughts of only nine hematologists. Also, the instrument demanded interest and effort on the part of the respondent, whereas personal interview could be considered less effort for the hematologist. The hematologists who already possess some level of interest in improving GOC discussions at the facility are likely the ones who took the time to thoughtfully respond to the survey. It is likely that the hematologists who possess the strongest barriers to GOC discussions also possess a

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strong disinterest in of the subject that would deter them from participating in the survey. Also, due to the anonymous survey design, it was an assumption that each hematologist would truthfully respond to the survey questions one time, and that the survey link would not be shared with anyone else who may access and complete the survey. The self-reported nature of the survey also presented an opening for the hematologists to distort their responses or behavior to present themselves in the best light, based on unawareness of self-behavior. The intent was to use open-ended, broad questions that did not lead the respondent in their response; however, the inclusion of examples in question #2 may have led or guided response to the survey and caused data collection biases.

### *Sample Limitations*

The original intended sample size of 20 hematologists was reduced to 18 due to one hematologist retiring and one leaving the practice. Neither physician had been replaced when the survey was opened. The time, or perceived burden of time, required to complete a survey could have played a role in the choice not to complete the survey. This study as well as any study that qualitatively examines hematologists and GOC will likely contain a bias towards those who have examined the existing data, recognize the problem as a problem, see the need for further research of the problem, and have already put forth effort to change and improve the way they practice. The providers who are resistant to change to their practice habits may not see a need to research or contribute to research that studies the topic.

### *Design Limitations*

The original intended sampling method was an identical mixed method sampling design that included the same people in both strands of the study. It was only during

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deep contemplation of the study limitations that the researcher recognized that the quantitative and qualitative data were not obtained using this type of sampling method. The quantitative data was obtained by evaluating all hematology admissions excluding BMT admissions for pathway criteria. Therefore, the quantitative results reported are from all hematology admissions, including the patients who were admitted to the lymphoma and lymphoma/myeloma teams. Only one of the properly documented/billed GOC discussions during October 2020 and January 2021 was authored by a leukemia hematologist, the others were completed by physicians from the lymphoma, myeloma, and supportive care teams. Therefore, the scope of the problem specifically in leukemia hematologists is not accurately described. While this does create a bias in the quantitative data, the effect on the qualitative study purpose is thought to be minimal. The qualitative inquiry is new research and considered to be the most useful component in promoting program success. The study findings will be used to address the hematologists barriers by developing tailored implementation interventions guided by their educational needs. Quantitative data is needed to formally evaluate all programs in the healthcare setting and was therefore necessary to be collected; however, in this case the data was used to more accurately describe a global problem that already exists in healthcare- implementation failure.

**Implications for Future Projects and/or Research**

Throughout the course of this scholarly inquiry, many system issues were uncovered that could benefit from further exploration. The quantitative data shows lack of implementation success within the lymphoma and lymphoma/myeloma teams and future research endeavors should explore the barriers to GOC discussions in lymphoma

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and myeloma specialty hematologists.  Also, the contributory role of the APP to program implementation success or failure should be researched so that implementation endeavors are collaborative and successful.  In this case, the APP's role evolved into one of the most influential factors of program success.  The APP is responsible for properly initiating the GOC pathway with a specific social work order in patients who meet the pathway criteria, yet 75% of the time there was a failure to do so; therefore, the APP barriers need to be researched in the future.  Another area of needed research involves the lack of integration of supportive and palliative care into hematology to determine where in the disease trajectory these services are best utilized and how the APP can promote collaboration within the two specialties.  Patients with hematologic malignancies rarely receive specialist palliative or hospice care and studies prospectively evaluating potential effects of integrated palliative care in these patients are rare (Oechsle, 2018).

**Implications for Practice**

This study was an important first step towards understanding the barriers that hematologists possess surrounding GOC discussions.  As of September 2020, the success of the GOC pathway changed from desired to required when the ADCC implemented the IGCC initiative.  The ADCC is made up of America's leading cancer centers and prioritizes protecting innovation, improving efficiencies, preserving quality-focused health policies, and measuring and setting standards for cancer care; being a part of the alliance's pooled resources offers great benefit to each member institution.  The survival rates are 16% higher than community hospital centers and 8% better than academic centers after five years (ADCC, 2019).  As part of the ADCC, institutions are expected to

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participate in the initiative to improve quality and maintain the integrity of the organization's positive reputation nation-wide.

Quality-focused health policy continues to evolve based on the newest evidence-based facts. But institutional culture and practice change is difficult to achieve. The leaders, innovators, early adopters, and early majority must continue to develop education and programs based on the specific needs of the laggards and late majority. APPs should exercise their influence in the healthcare social system as opinion leaders, change agents, and champions to better diffuse innovation. The doctorly prepared APP possesses the ability to routinely incorporate and utilize theory, such as the diffusion of innovation theory (Rogers, 1962) in planning and implementing practice-changing quality initiatives and evaluating the success of these programs.

**Conclusion**

This study aimed to describe and explore implementation of an institutional GOC pathway program, and hematologists barriers to having/documenting GOC discussions in relapsed high-risk leukemia patients. The study confirmed suspicions that program participation was low and needed evaluated for improvement in implementation. The almost absent number of properly documented GOC discussions warranted exploration of their barriers and offers valuable insight into the hematologist's aversion to GOC discussions. This information will be used for program evaluation with the CFIR, then incorporated into institutional efforts to achieve each of the four core components described in the IGCC initiative implementation planning guide. The initiative was created by the ADCC to address system gaps and establish new expectations for when

and how GOC conversations occur, and the implementation will occur over a three-year

period, between September 2020 and September 2023.

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APPENDIX

**APPENDICES**

## Appendix A: Patient Support Screen

Hello,

Many patients tell us that being in the ICU can feel overwhelming, especially if you're unsure about the next steps in your care and treatment. As part of your care, we meet with you and your family so that you can get up-to-date information about your condition and discuss any questions or concerns you have about your treatment.

With any serious illness, it helps us to know what your values and goals are so that we can honor what's important to you.  The information you share will enable us to know your wishes and best work together as a team.

1. **In case you are ever not able to speak for yourself, who do you want to make medical decisions for you?**
   **Type in name**

2. **How is this person related to you?**

   □   Spouse

   □   Partner

   □   Parent

   □   Child

   □   Sibling

   □   Friend

   □   Other, explain

3. **Which statement is closest to your understanding of your present medical situation?**

   □   Cure is very likely and is in the range of 76% to 100% for me

   □   Cure is likely and is in the range of 51% to 75% for me

   □   Cure is possible but not likely and is in the range of 26% -50% for me

   □   Cure is not at all likely and is in the range of 0-25% for me

      The goal of treatment is to control the disease for as long as possible

   □   Cure is not at all likely and s in the range of 0-25% for me

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The goal of treatment is to focus on comfort, time with family and quality of life

4. **What is most important to you if your medical condition gets worse?**

   □ To live for as long as possible regardless of my medical condition

   □ Continue treatment for a period of time but stop if there is no chance for a meaningful recovery

   □ Continue treatment focused on quality of life and comfort only

5. **Right now, what is the most concerning to you?**

   □ Being able to communicate

   □ Pain

   □ Not getting better

   □ How my family is coping

6. **What abilities are so critical to your life that you can't imagine living without them?**
   **Check all that apply**

   □ Interacting with family and friends in a meaningful way

   □ Performing daily living activities independently

   □ Making my own decisions

   □ Engaging in activities that bring me joy

   □ Nothing is so critical that I cannot imagine living without

7. **Have you shared your health care wishes and goals with your family?**

   □ Yes

   □ No

8. **Has the medical team explained your treatment plan in a way you can understand?**
   □ Yes
   □ No

9. **At this time, do you feel you are getting a consistent message from your doctors about your treatment plan?**

   □   Yes

   □   No

**Appendix B: Cover Letter**

Hello again!

I am very proud to announce that I am pursuing higher education and have chosen to incorporate my role in improving goal concordant care at COH into my scholarly research project.  Chart review of patients admitted to the Hematology/Hem transplant readmit service lines (excluding BMT) for the months of October 2020 and January 2021, indicated that ~30% of our inpatient admissions meet the criteria for consideration of inpatient GOC discussion.

I would like to understand your perceived barriers to having/documenting GOC discussions.  *Please be candid, this is an anonymous survey and participation is entirely voluntary.*  Your answers will be compiled, analyzed, examined for trends, and included in my scholarly project final writing, which I plan to submit for publication once completed.   The findings will also be shared with you as we continue to implement the ADCC's Improving Goal Concordant Care initiative at City of Hope!  Physicians, please click the link below to complete my short survey.  THANK YOU SO MUCH FOR YOUR SUPPORT!

https://www.surveymonkey.com/r/LACYJO-DNP-GOC

Consent is implied by voluntary completion of the survey.  Please see the attached complete informed consent document.

**Appendix C: SurveyMonkey Questionnaire**

1. In one sentence, please give your definition of a GOC conversation.

2. Please describe your perceived barriers to having/documenting GOC conversations. Examples may include thoughts surrounding prognostication, culture, effect on hope, comfort level with conversations, time constraints, or pressure to change the way you practice.

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