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QUALITY IMPROVEMENT

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

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Authors' disclosures of conflicts of interest are found at the end of this article.

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Abstract

Background: Advanced practice providers (APPs) affect high-quality health care through leadership, evidence-based practice implementation, and quality improvement projects. When planning solutions to clinical problems, leadership must solicit APP input to promote success. Hematology patients are more likely to receive poor-quality end-of-life (EOL) care than those with solid tumors. Regardless of disease, aggressive EOL care is increasing despite evidence that it is often inconsistent with patients' goals of care (GOC). Data regarding this phenomenon in hematology specifically is lacking. The distorted association of "end of life" with "goals of care" has "silenced" crucial goals discussions in patients with relapsed or refractory high-risk leukemia, which raises concerns for the provision of care that is inconsistent with patients' values and preferences. Hematologists may possess certain traits and distinct barriers leading to what one might call an aversion to GOC discussions in the inpatient setting. **Aims:** (1) Quantify hematologists' rate of participation in a GOC pathway initiative during two separate months. (2) Explore the hematologists' definition of and barriers to having GOC discussions. **Design:** This is a mixed-methods, explanatory sequential design (follow-up explanations variant). **Sample:** Quantitative: Hematology inpatient admissions during two nonconsecutive months in 2021. Qualitative: Eighteen leukemia hematologists from one dedicated cancer center. **Results:** During the 2 months, an average of 36% of admissions met the criteria for GOC pathway initiation, 19% of those had an appropriate initiation order, and < 1% had a properly documented and billed GOC discussion. Nine hematologists responded to a SurveyMonkey poll with two questions. All nine included clinical situation and communication in their definition of GOC discussions. Time limitations and prognostic uncertainty were the two most reported barriers. **Discussion:** The findings demonstrate that the apprehension of hematologists to have GOC conversations is similarly seen in the

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APPs' reluctance to initiate a pathway intended to lead to GOC conversations. The percentage of eligible inpatient admissions meeting the specified criteria was similar between the 2 months; however, the number of appropriate referrals and documented or billed GOC discussions was higher in the earlier month, demonstrating temporal decline. Further research inquiry is needed to explore causation of this phenomenon.

The consistent provision of high-quality health care by advanced practice providers (APP) has been clearly established and increasingly recognized in 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, APPs 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). In many health-care settings, including the inpatient hematology setting, attending physicians benefit from the APPs' motivation to guide them through frequent process modifications, policy changes, and quality improvement initiatives. The nature of the relationship between APPs and their attendings places the APP in a leadership role with significant opportunity to observe, analyze, and influence the practice habits of physicians.

BACKGROUND

Aggressive end-of-life (EOL) care in patients with advanced-stage cancer is increasing despite growing concerns that this reflects poor-quality care (Wright et al., 2016; Earle et al., 2008; Hui et al., 2015; Odejide et al., 2016). Furthermore, studies have found that, at least 13% of the time and regardless of illness, the EOL care provided is inconsistent with the patient's goals of care (GOC) and causes psychosocial and financial burden to the family (Khandelwal et al., 2017). Patients with incurable cancer and those participating in phase I trials often have misconceptions regarding prognosis of their disease and the goals of their treatment regimens (Enzinger et al., 2014; Meropol et al., 2003; Nurgat et al., 2005). 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). Data regarding this phenomenon in hematology specifically, is lacking (Egan et al., 2020).

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 (Hui et al., 2014). There is evidence 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 (Korsos et al., 2019; Heng et al., 2020). Collectively, hematologists may possess specific barriers and misconceptions surrounding GOC and EOL discussions; they feel less comfortable with death and dying than solid tumor oncologists and are more likely to interpret their patients' decline as a failure on their own part (Hui et al., 2015; Hui et al., 2016). Some previously described issues include concerns about taking away patients' hope, the difficulty for individual prognostication, the possibility of cure with allogeneic stem cell transplantation, and frequent potential for acute complications that are unpredictable and change the prognosis rapidly (Odejide et al., 2014; Prod'homme et al., 2018).

Identification of poor prognosis patients, initiating GOC conversations, and ensuring proper documentation of these conversations can reduce misaligned treatment and patient/family suffering. Discussing GOC when not near the EOL allows high-risk leukemia patients the time to explore their goals and share them with their family (Back et al., 2014).

The emotional burden that accumulates within the multidisciplinary team members who care for inpatients with high-risk leukemia is universally present. Nurses and APPs often experience moral distress after witnessing informal or incomplete conversations in which a patient agrees to a palliative or experimental treatment without knowing that the treatment will not cure their disease (Lazzarin et al., 2012; Mack et al.,

2015). Prognostication and treatment recommendations are made by a hematologist, which may leave the APP feeling silenced, unable to advocate for patients when they see recommendations being made without accurate prognostic disclosure or exploration of patient goals (Lazzarin et al., 2012). Discussions regarding disease trajectory, prognosis, and survival are challenging for both patients and physicians (Kitta et al., 2021). Advanced practice providers are at risk for emotional exhaustion as they are highly aware of the suffering that patients and families may endure because of false hope (Bourdeanu et al., 2020). The level of sharing exchanged during private conversations between patients and APPs can uncover the true misconceptions patients have regarding their treatment, prognosis, chance of cure, and chance of meaningful recovery (Lazzarian et al., 2012). This can lead to burnout, anxiety, and depression (Bourdeanu et al., 2020).

PURPOSE

The Alliance of Dedicated Cancer Centers (ADCC) developed a national initiative to enhance goal-concordant care for patients with cancer that addresses system gaps and establishes new expectations for when and how GOC conversations occur. The Improving Goal Concordant Care (IGCC) 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 response, physician and social work leadership in a dedicated cancer center formed a task force to address this issue and created a GOC pathway intended to identify high-risk hematology patients and initiate a pathway that could improve patient/hematologist communication and goal concordance. The rollout of the project was poor, uncommunicated, and did not recognize the potential of APP leadership. An inpatient APP with interest in the subject joined the committee, and after weeks of multidisciplinary collaboration, the pathway pilot was relaunched with several revisions that gave ownership to the APP in identifying poor prognosis patients and appropriately initiating the pathway with a social work order. The patients are then seen and administered a support screen, which evaluates prognostic understanding and explores the patient's priorities and preferences for both current and EOL situations. The results are then shared with the primary hematologist by a social worker, who is responsible for the coordination of family meetings to discuss GOC.

Consistency among providers is crucial but can be challenging with a rotating inpatient rounding system; inconsistent information may lead to false hope and misconceptions regarding treatment goals and prognosis. To promote consistency, a user-friendly template was created, and the hematologists were educated on appropriate documentation/billing of advanced care planning (ACP) discussions so that they can be found easily in the chart.

The first purpose of this study was to evaluate the participation of physicians and APPs in the GOC pathway process through quantification of: (1) Patients who met the established poor prognosis criteria (Table 1) for pathway initiation; (2) patients with appropriate social work referrals to initiate the pathway, and (3) patients with a properly documented GOC discussion in the electronic medical record during that hospital encounter. The second purpose was to gain insight into hematologists' self-reported definition of, components of, and barriers to inpatient GOC discussion. The goal was to collect and synthesize the candid thoughts, opinions, attitudes, beliefs, practice habits, philosophies, perceptions, and comfort level surrounding GOC discussions.

METHODS

This study used a mixed-methods, explanatory sequential design (follow-up explanations variant) to explore the phenomenon of hematologists' aversion toward GOC conversations in the

Table 1. Poor Prognosis Criteria

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

1. Leukemia/myelodysplastic syndromes 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, and autologous transplant.

inpatient setting. All quantitative data were obtained via chart review by the researcher alone. All qualitative data were obtained using an anonymous SurveyMonkey poll to promote participation. Rogers' (1962) Diffusion of Innovation Theory contributed to the study's theoretical framework, goals, and design, which sought to demonstrate the APP role in the diffusion of innovation as a respected opinion leader, change agent, and champion within the institutional social system. The APP has both the skill and a unique advantage in leading change by exercising their role as an innovator and early adopter to positively influence practice change initiatives.

SAMPLE

All hematology inpatient admissions, regardless of diagnosis, were included in the quantitative results. However, only the eighteen hematologists who treated leukemia, myelodysplastic syndromes, and other diseases potentially cured by allogeneic stem cell transplant were included in the request for a qualitative SurveyMonkey response for this study. A survey of lymphoma/myeloma physicians may occur in the future. Permission was received from both the institution's Institutional Review Board (IRB) and the academic entity's IRB. Participation in survey completion was anonymous and voluntary.

IMPLEMENTATION

After project approval was obtained from both academic and research facility IRB, a retrospective chart review was performed on each patient admitted to the Hematology and Hematology Transplant Readmit services during 2 nonconsecutive months in 2020 and 2021. The social worker's data was compared against the researcher's data to verify the consistency and validity of certain research findings.

A request for survey completion was then sent to all 18 hematologists rotating through the leukemia inpatient services. The survey was kept open for 10 days, and reminders were sent out every 3 days and on the day of survey closing. Extrapolation and analysis of the qualitative data was done with the guidance and assistance of a PhD-prepared nurse practitioner, a statistician, a Doctor of Nursing Practice-prepared mentor, and other experts.

RESULTS

This project's aims were to quantify the number of inpatients with leukemia who met the established GOC pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021; quantify the number of inpatients with poor prognosis leukemia admitted in October 2020 and January 2021 who had an appropriate referral for a GOC pathway; quantify the number of inpatients with poor prognosis leukemia admitted in October 2020 and January 2021 who had a properly documented and billed GOC discussion utilizing the approved template prior to hospital discharge or death; describe how hematologists define a "GOC conversation" in one sentence and what they consider the most important components; and describe what hematologists identify as perceived barriers in having or documenting GOC conversations.

Quantitative Sample Results

In October 2020, each of the 721 total admissions were reviewed, and of 193 eligible encounters, 63 met the criteria for GOC pathway initiation, 19 (30%) had an appropriate social work consult placed by the APP to initiate the pathway, and only four (6%) had appropriate MD documentation and billing for a GOC discussion. In January 2021, 176 of 230 admissions were eligible for inclusion, 68 patients met the criteria for initiation of the GOC pathway, 10 (15%) had a social work order placed by the APP to initiate the pathway, and only one had an appropriately documented and billed GOC discussion by the hematologist (Table 2).

Qualitative Sample Results

A descriptive qualitative inductive design provoked content and thematic analysis of data that were obtained via an anonymous SurveyMonkey poll with two open-ended questions. Nine hematologists (50%) responded to the survey.

Question 1 explored the hematologists' definitions of and key components of a GOC conversation. Twenty-two tags were created from the nine answers and assigned appropriately to each response. Clinical situation and communication were the two dominating themes and present in 100% of the responses, in some form. From these, six subthemes emerged with further thematic

Table 2. Results of Research Questions 1, 2, and 3

Question	October 2020	January 2021
How many leukemia inpatients met the established goals-of-care pathway criteria for poor prognosis upon admission during the months of October 2020 and January 2021?	63	68
How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had an appropriate referral for the goals-of-care pathway?	19 (23%)	10 (15%)
How many poor prognosis leukemia inpatients admitted in October 2020 and January 2021 had a properly documented and billed goals-of-care conversation utilizing the approved template prior to hospital discharge or death?	4 (6%)	1 (1%)

analysis, each containing two to five of the tagged categories (see Table 3).

The purpose of Question 2 was to gain insight into hematologists' perceived barriers to having or documenting GOC conversations in the inpatient setting. Seventeen tags were created and appropriately assigned to each of the nine responses. Five themes emerged, each containing two to five tagged subthemes (see Table 4).

DISCUSSION

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).

This study found that during the early implementation process, up to 99% of inpatient admissions meeting criteria for GOC discussions via the GOC pathway lacked documentation or billing of these discussions in their electronic medical record. While this does not prove a pattern of patient

Table 3. Hematologist Clinical Situation and Communication Subthemes of a Goals-of-Care Conversation

Subtheme	
Current condition/ information	• Diagnosis • Prognosis • Current/previous treatment • Treatment response
Options/treatment/ strategies	• Plan for treatment • Hope for treatment • Clinical trial • Hospice, Do-Not-Resuscitate Comfort Care • Side effects/complications
Outcomes	• Expected outcomes: PT • Expected outcomes: MD • Best/worst case scenario
Understanding	• Mutual understanding • Patient understanding
Decision-making	• Joint decisions • Alignment • Patient values/wishes
Concept	• Clarifying what goals of care means to the patient • Dynamic • Not hospice, Do-Not-Resuscitate Comfort Care

Note. PT = physical therapy.

Table 4. Hematologists' Perceived Barriers to Having or Documenting Goals-of-Care Conversations: Themes and Subthemes

Theme	Subtheme
Timing/ location	• Emergency/unexpected change in patient condition • Timing/patient condition; goal is cure • Location: Clinic setting is best • Difficult to coordinate
Personal/ behavioral	• Avoidance • Difficult/depressing/unpleasant • Worried about effect on hope/ "Never give up" culture • Ownership by primary hematologist • Prognostic uncertainty
Patient	• Unrealistic expectations • "Never give up" attitude • Cultural issues
Discussion	• Skills required • Too much time/don't have time • Inconsistent messages to the patient
Concept	• Global misunderstanding of what goals-of-care discussions are • Wrong association with end of life/Do-Not-Resuscitate (when typical goal is cure)

or provider misalignment regarding prognosis, treatment, EOL preferences, or goal discordance, it does support an aversion to GOC discussions among leukemia hematologists in addition to the heavily researched aversion to EOL discussions (Howell et al., 2011; Prod'homme et al., 2018; Odejide et al., 2014). This research offers a 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 et al., 2015).

Consistent with much of the previous research, 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 5). Many of the same barriers exist for GOC discussions in these hematologists as Prod'homme and colleagues (2018) described as barriers to EOL discussions, which increasingly demonstrates the lack of separation between the two concepts.

Prognosis was notably the most cited component of a goals discussion. Ironically, previous research reported that while the majority of hematologists surveyed reported discussing prognosis with their patients at diagnosis, only one out of five (20%) readdress prognosis throughout the disease trajectory (Habib et al., 2019), hence engaging in "silent GOC discussions" (Table 6). Kitta and colleagues (2021) similarly note the "silent" transition from curative to palliative treatment with their qualitative findings surrounding patients' perceptions of EOL discussions with medical oncologists.

Previous research (Piggott et al., 2019) indicated lack of time as a barrier to EOL discussions in hematology and GOC discussions in medical oncology. This research, focusing on GOC in hematology, also indicates lack of time as a key barrier (Table 6).

The evolving role of APPs 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., 2012). In this study setting, the professional collaboration between the hematology MD and APP creates a unique opportunity for the APP to affect implementation of evidence-based practice change interventions by influencing and guiding the physician to incorporate new tasks into their practice habits. During data collection, the role of the APP in contributing to physicians' level of participation in this initiative became apparent, with appropriate referrals only being made about 20% of the time. It became increasingly evident that future research should explore the barriers APPs have surrounding the topic of GOC discussions in the hematology inpatient setting. The low level of APP buy-in in the setting of a minimally successful practice-change initiative further supports the power of APP leadership in achieving successful implementation

Table 5. Hematologist Misconceptions Regarding Goals-of-Care Discussions

Type of barrier	Example
Self-aware	"One barrier to goals-of-care discussions is that both physicians and patients typically associate them with end-of-life discussions."
	"Misunderstanding of the goals-of-care discussions among many people involved, including health-care professionals and patients or families."
	"The goals-of-care 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 goals-of-care 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."

Table 6. Hematologists' Self-Reported Definition of, Components of, and Barriers to Inpatient GOC Discussion

Question	Example
Definition and components	"A meeting to align patient goals with provider understanding of prognosis."
	"To carry with the patient a conversation to educate them about…prognosis and understand their wishes in regard to what is important to them."
	"Diagnosis, prognosis, options for treatment, clinical trials, backup plan."
	"A careful discussion…prognosis, clinical situation, and what the patient's objectives are given the reality of the situation."
Barriers	"It's hard to assess impact of treatment that may impact prognosis or outcomes of survival."
	"Sometimes, lack of all information needed to accurately determine prognosis."
	"Physicians often prognosticate based on unrealistic expectations regarding the likelihood of good outcomes in the face of recurrent disease."
	"Time constraints, challenge of scheduling."
	"Time constraints…"
	"Usually takes 1 hour or more."
	"Number of eligible patients might exceed the time capacity that one would want to spend on this."

initiatives. Establishing a process like the GOC pathway described in this paper is one way to empower APPs to initiate GOC discussions earlier in high-risk patients, emphasizing the distinction between GOC and EOL discussions, and eventually separating the two concepts for both patients and providers.

Disclosure

The authors have no conflicts of interest to disclose.

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