

ORGANIZATIONAL AND IMPLEMENTATION FACTORS THAT INFLUENCE THE
IMPLEMENTATION OF GOALS OF CARE PROGRAMS WITHIN CANCER CENTERS

by

KRISTEN LANDRUM

(Under the Direction of Zhuo Chen)

ABSTRACT

Patients with advanced cancers prefer shared decision making that includes conversations about their prognosis, values, preferences, and goals for life and care. Patients who are engaged in these goals of care (GOC) discussions by their oncology providers have better outcomes, less healthcare utilization, and lower costs of care. Unfortunately, only a small percentage of advanced cancer patients are engaged in GOC conversations.

This mixed-methods evaluation studied the implementation experience of a collaborative intervention to enhance GOC discussions across 10 large, academic cancer hospitals. This research combined analysis of process measures with survey responses from implementation leaders, to describe the organizational and implementation factors that contributed to operational integration and improvement. The results and recommendations should assist other cancer providers in adopting GOC programs and thus improve care for patients with advanced cancer.

INDEX WORDS: Cancer, operational improvement, shared decision making, goals of care, goal concordant care, end of life care, healthcare utilization

ORGANIZATIONAL AND IMPLEMENTATION FACTORS THAT INFLUENCE THE
IMPLEMENTATION OF GOALS OF CARE PROGRAMS WITHIN CANCER CENTERS

by

KRISTEN LANDRUM

B.A., Colgate University, 1995

M.P.H., George Washington University, 1997

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial
Fulfillment of the Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

ATHENS, GEORGIA

2024

© 2024

Kristen Landrum

All Rights Reserved

ORGANIZATIONAL AND IMPLEMENTATION FACTORS THAT INFLUENCE THE
IMPLEMENTATION OF GOALS OF CARE PROGRAMS WITHIN CANCER CENTERS

by

KRISTEN LANDRUM

Major Professor:	Zhuo Chen
Committee:	Jessica Cathey Smith
	Finly Zachariah

Electronic Version Approved:

Ron Walcott
Vice Provost for Graduate Education and Dean of the Graduate School
The University of Georgia
December 2024

ACKNOWLEDGEMENTS

So many people helped get me here. I could never acknowledge all of them, but I will thank a few. First, I would like to express my gratitude to Drs. Chen, Smith and Zachariah for their guidance and contributions throughout this process. Second, a huge shoutout to my 2020 cohort (“The Quarantined Cohort”). I never imagined that I could form bonds that tightly with people I hadn’t even seen in person. Our GroupMe chat was constant for three years and continues to be a resource to this day.

This research was only possible because of the dedication and commitment of the members of the Improving Goal Concordant Care (IGCC) Implementation Workgroup. It has been such a privilege to be part of this journey, and an honor to contribute to work that is making care better for people with cancer. I continue to be proud of the unwavering support of the leaders of the Alliance of Dedicated Cancer Centers.

Finally, sincere thanks to my family. What a gift it is to know that you always have a team ready and available to support you. Starting the DrPH program the same day my son started as a UGA undergrad was a life twist I could not have imagined. That first year was a hard one, for so many reasons, but I knew we would get through it together. You only beat me to graduation by one semester! You are my best, Grant, and I am so very proud of you. And, speaking of wonderful twists in my life... Strider, what an amazing year this has been. You are my person. I can’t wait for the rest of our married lives.

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	iv
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER	
1 Introduction and Background	1
Cancer Incidence, Mortality and Cost	1
Patient Experience of Cancer	3
The Role of Communication.....	4
Describing and Addressing the Problem	6
Research Aims	7
2 Review of the Literature	9
Definition of Goals of Care.....	9
Impact of EOL Discussions on Utilization	10
Impact and Use of GOCC	12
Research Evaluating GOC Interventions	15
Measuring GOC Interventions	18
Components of GOC Interventions	19
Enablers and Barriers of GOC Implementation.....	20
Applying Implementation Science.....	22

3	Methods	25
	Study Design.....	25
	Study Setting.....	25
	Study Participants	26
	Quality Improvement Intervention	26
	Data Sources	29
	Data Collection	33
	Data Handling.....	34
	Data Analysis	34
	Limitations	37
4	Results.....	40
	Participant Characteristics	40
	General Descriptive Statistics.....	40
	Aim 1 Results.....	43
	Aim 2 Results.....	52
	Aim 3 Results.....	58
	Mixed Methods Results	64
5	Discussion.....	69
	Implications for Public Health and Health Care	69
	Interpretation of Implementation Success	71
	Interpretation of Major Enablers and Barriers	77
	Key Recommendations	82

Future Research and Directions	85
Summary	88
REFERENCES	89
APPENDICES	
A Appendix A	119
B Appendix B	137
C Appendix C	140
D Appendix D	141

LIST OF TABLES

	Page
Table 1: Overall Costs of Cancer Care, and Patient Out-of-Pocket Costs, by Phase of Care	2
Table 2: Summary of Utilization Findings with GOC Discussions.....	11
Table 3: Summary of Utilization Findings with Earlier EOL Discussions	12
Table 4: Summary Table of Clinical Trials and Prospective Cohort Studies	17
Table 5: Factors that Act as Enablers or Barrers to GOC Implementation	21
Table 6: IGCC Measure Definitions	30
Table 7: GOC Implementation Survey Description.....	32
Table 8: IGCC Evaluation Research Questions.....	35
Table 9: Center-Specific Implementation Summary	42
Table 10: Correlation Across Survey Items and Process Measures	43
Table 11: IGCC Aggregate Communication Skills Training Rate	44
Table 12: Change in IGCC GOC Documentation Rate	45
Table 13: Change in Center-Specific GOC Documentation Rate	46
Table 14: Description and Mean Score of Domain Categories	48
Table 15: Implementation Experience Item Scores	50
Table 16: Outcome Item Scores.....	51
Table 17: Key Findings, Interpretation and Recommendations	65

LIST OF FIGURES

	Page
Figure 1: GOC Intervention Logic Model	7
Figure 2: IGCC Participant Cancer Centers.....	26
Figure 3: IGCC Annual Implementation Milestones.....	28
Figure 4: Center-Specific Communication Skills Training Rates	44
Figure 5: Communication Skills Training Rates and GOC Documentation Rates.....	47
Figure 6: Implementation Enablers and Barriers at IGCC Sites.....	58
Figure 7: Strength of Domain Category Correlations with Implementation Items	60
Figure 8: Strength of Implementation Item Correlations with Outcome Items	62
Figure 9: Strength of Domain Category Correlations with Process Measures	64

CHAPTER 1

INTRODUCTION AND BACKGROUND

Cancer Incidence, Mortality, and Cost

The American Cancer Society predicts that more than 2 million new cancer cases will be diagnosed in the United States in 2024 (excluding basal and squamous cell skin cancers and noninvasive cancers); equivalent to nearly 5,500 new diagnoses per day (Siegel et al., 2024). Advances in public health, combined with dramatic innovation in cancer detection and treatment, have contributed to decreasing mortality rates in the US over the past decades. Still, approximately 612,000 deaths from cancer are expected in the US in 2024 – about 1,680 deaths per day – placing cancer as the leading cause of death in the US for people younger than 85 years of age, and the second leading cause of death overall (Siegel et al., 2024). Moreover, health disparities persist in cancer incidence and mortality. For instance, Black women have 40% higher breast cancer mortality rates, and American Indian and Alaska Native men and women have the overall highest cancer incidence and mortality rates, compared to other racial and ethnic groups in the US (Siegel et al., 2024).

Innovations in cancer treatment have been accompanied by staggering increases in costs. The overall cost of cancer treatment in the US was \$183 billion in 2015, and conservative projections indicate that these costs will increase 34% to \$246 billion by 2030 (Mariotto et al., 2020). Unfortunately, patients and their families feel the impact of the high costs of cancer (Smith et al., 2022). In the US, patient economic burden associated with cancer care was more than \$21 billion

in 2019, including patient out-of-pocket costs of \$16 billion and patient time costs of nearly \$5 billion (Yarbroff et al., 2021).

Table 1

*Overall Costs of Cancer Care, and Patient Out-of-Pocket Costs, by Phase of Care**

	Phase 1: Initial (12 months following diagnosis)	Phase 2: Continuing (months between)	Phase 3: End-of-Life (12 months before death)
Overall cost, United States (Mariotto et al., 2020)	\$41.8K	\$5.3K	\$105.5K
Patient out-of-pocket payments for medical services and prescription drugs (Yarbroff et al., 2021)	Medical care: \$2,200 Prescription: \$243	Medical care: \$466 Prescription: \$127	Medical care: \$3,823 Prescription: \$448

*Average annualized; among patients 65 and older with Medicare

As noted by Mariotto et al., cancer cost data has gradually evolved from a ‘U-shaped’ curve – with high costs in the first year following diagnosis, matched by high costs in the last year of life for those who die from cancer – into a ‘J-shaped’ curve, with costs in the end-of-life (EOL) phase being markedly higher. These high costs reflect increasing treatment intensity toward the EOL, especially for those diagnosed with advanced cancers (Mariotto et al., 2020). Table 1 illustrates the disproportionately high costs in the EOL phase, from both societal and patient perspectives.

The financial impact of cancer on patients and their families has been termed ‘financial toxicity’ (Zafar et al., 2013). Beyond the patient out-of-pocket costs depicted in Table 1, financial toxicities can include income impacts on patients and caregivers as well as associated psychological burden and negative coping behaviors (e.g., skipping or reducing cancer-directed therapies; reducing spending food or other medications) (Abrams et al., 2021; Zheng, 2020; Tucker-Seeley et al., 2019; Kent et al., 2013). Research indicates that half of cancer patients and

survivors experience financial toxicity (Smith et al., 2022; Han et al., 2020; Altice et al., 2016). Patients who have lower income, inadequate health insurance, and who are racial and ethnic minorities are more likely to experience cancer-related financial toxicity (Pazone et al., 2022; Politi et al., 2021; Wheeler et al., 2018; Chino et al., 2017).

Overall, the contributors to high societal and patient costs of cancer care are complex and beyond the scope of this dissertation. For more than a decade, however, professional societies have recognized that oncology providers have a responsibility to acknowledge treatment costs, to discuss costs with patients as part of shared decision making, and to help patients navigate the financial impacts of their cancer diagnosis and treatment (Meropol et al., 2009). This responsibility has been built into oncology alternate payment models, such as the Center for Medicare & Medicaid Innovation (CMMI) Oncology Care Model (OCM), active between 2016 and 2022, and the Enhancing Oncology Model (EOM), active between 2023 and 2028 (Centers for Medicare & Medicaid Services, 2023).

Patient Experience of Cancer

Beyond financial toxicity, navigating cancer diagnosis and treatment can have substantial physical and psychosocial impacts on individuals and their caregivers. Treatments often extend over months or years, including multiple modalities such as surgery, radiation, and chemotherapy or other systemic therapies, each with associated side effects and toxicities (Lee, Jiménez-Fonseca, Galán-Moral et al., 2023). Substantial research demonstrates that cancer and its treatments can lead to significant impairments in quality of life and difficulty in coping (Lee, Jiménez-Fonseca, Galán-Moral et al., 2023; Kim et al., 2017; Ness et al., 2013; Carlson et al., 2012; Gao et al., 2010; Wilson et al., 2007; Zabora et al., 2001). Anxiety, depression, and fear of disease progression are common among patients with cancer (Bergerot et al., 2022).

These cancer impacts can be even more profound in patients with advanced cancer, who often experience higher symptom burden and psychosocial impairment (Ng & Ozdemir, 2023; Bergerot et al., 2020; Breitbart et al., 2018; Gao et al., 2010). Advanced cancer patients face greater existential challenges associated with their diagnoses, such as uncertainty about the future and distress (Breitbart et al., 2018). Unfortunately, patients find it difficult to talk to their providers about their symptoms, worries and needs, and they may not raise issues in clinical conversations (Back, 2020).

The Role of Communication

Correspondingly, a growing body of research demonstrates the importance of physician communication skills in achieving optimal patient and health system outcomes. Cancer patients and their families need supportive, effective communication from their providers to help meet their informational, physical, emotional, and psychosocial needs during their cancer journey (Rai et al., 2019; Moore et al., 2018; Gilligan et al., 2017; Chawla et al., 2016). Most people with cancer prefer a patient-centered or shared decision-making approach (Back, 2020; Taramin et al., 2010). They rely on open and effective communication, including dialogue about diagnosis, prognosis, treatment options, side effects and financial toxicities (Moore et al., 2018; Gilligan et al., 2017).

Regrettably, people with cancer have unmet communication needs, report suboptimal communication, and report disparities in the quality of communication (Rai et al., 2019; Moore et al., 2018; White-Means et al., 2017; Chawla et al., 2016, Tariman et al., 2010). Studies suggest that poor provider communication can generate anxiety, depression and uncertainty among people with cancer, reduce their coping skills, and lead to dissatisfaction about care (Walshe et al., 2017; Donovan-Kicken et al., 2011; Hagerty et al., 2005).

These issues are exacerbated for patients with advanced cancers. Most advanced cancer patients report that they prefer active involvement in their care, including open and sensitive discussion about their diagnosis, quality of life and treatment choices (Back, 2020; Collins et al., 2018; Wright et al., 2008; Hagerty et al., 2005). The process of shared decision-making between clinicians and patients about patients' prognosis, preferences, values and life goals, intended to inform treatment and care planning, are called goals of care (GOC) discussions. This type of shared decision-making is crucial for patients with advanced cancers and other serious illnesses, as these individuals generally prefer care focused on comfort, including less intensive healthcare utilization and dying at home (Pinto et al., 2024; Xia et al., 2023; California Healthcare Foundation, 2019; Wright et al., 2016; Coalition of Compassionate Care of California, 2015). Patients who do not participate in meaningful GOC discussions tend to receive more intensive, more costly care near the end of life (Starr et al., 2019; Zhang et al., 2009). On the other hand, research suggests that advanced cancer patients who have GOC discussions have better outcomes, better family outcomes, and less intensive end-of-life care (Manz, Rocque & Patel, 2023; Starr et al., 2019; Cheung et al., 2015; Wright et al., 2008; Zhang et al., 2009).

Professional guidelines dictate that the primary oncologist is responsible for addressing GOC issues (Ferrell et al., 2017); however, this rarely happens in standard clinical practice (Epstein et al., 2022; Mack, Cronin, Keating et al., 2012; Mack, Cronin, Taback et al., 2012). A 2016 study found patient goals documented in the electronic health record (EHR) in only 4% of outpatient medical oncology visits with patients with metastatic pancreas or lung cancers (Raskin et al., 2016). When GOC conversations do occur, it is often during a hospitalization and/or very close to the end of life (Knutzen et al., 2021; Mack et al., 2012). There are myriad contributing factors to this gap in care, including national shortages of specialist palliative care providers;

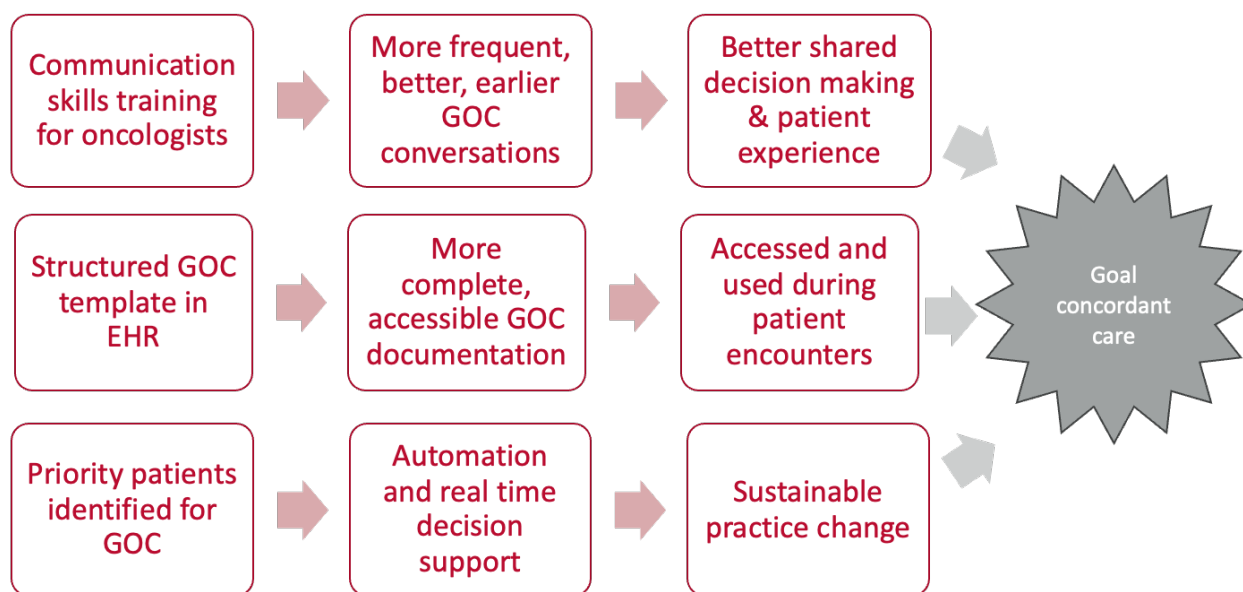
lack of training and awareness among oncologists; oncologists' discomfort and lack of self-efficacy; clinician time constraints; lack of financial and infrastructural support from health systems; and misaligned payment incentives (Manz, Rocque & Patel, 2023; Schulman-Green et al., 2018).

Describing and Addressing the Problem

This gap in care can be summarized with the following problem statements:

1. Health systems do not provide the training, practice infrastructure, or support necessary for reliable, effective and efficient patient engagement regarding goals of care.
2. Oncologists do not routinely communicate with their advanced cancer patients about patients' priorities, values, and goals of care.

In response to this problem, the Alliance of Dedicated Cancer Centers (ADCC) launched the Improving Goal Concordant Care (IGCC) initiative, an operational improvement collaborative among 10 freestanding, academic cancer centers across the country: City of Hope Cancer Center (Duarte, CA); Fox Chase Cancer Center (Philadelphia, PA); Fred Hutchinson Cancer Center (Seattle, WA); Dana-Farber Cancer Institute (Boston, MA); Moffitt Cancer Center (Tampa, FL); MD Anderson Cancer Center (Houston, TX); Memorial Sloan Kettering Cancer Center (New York, NY); Roswell Park Cancer Institute (Buffalo, NY); The James Comprehensive Cancer Center (Columbus, OH); and USC Norris Comprehensive Cancer Center (Los Angeles, CA). Between September 2021 and December 2023, each of the 10 cancer centers attempted to implement a multi-component intervention designed to enhance goals of care conversations with advanced cancer patients (Loggers et al., 2023; McNiff et al., 2021), as reflected in the logic model (Figure 1). IGCC is more fully described in Chapter 3.

Figure 1*GOC Intervention Logic Model*

Presently, the IGCC collaborative is complete, including collection of the evaluation measures. Analysis of the IGCC process measures alone, however, provides only a narrow snapshot into the IGCC implementation experience across the 10 complex cancer systems. The lessons learned from IGCC can be greatly enriched with context from the local implementation champions at each center. This research describes a mixed methods evaluation to identify and describe enablers and barriers to implementation success across the collaborating sites. The dissemination of these findings can help other cancer centers to more effectively and efficiently implement similar interventions, increasing their likelihood of success.

Research Aims

The aims of this study are to:

1. Describe the implementation experience of the IGCC participating cancer centers.

2. Describe enablers and barriers to IGCC implementation across 10 cancer centers using the Promoting Action on Research Implementation in Health Services (i-PARIHS) framework (Harvey & Kitston, 2018).
3. Assess which organizational contextual and facilitation factors are most closely associated with successful implementation.
4. Summarize lessons learned to inform implementation, sustainability, scale and spread of future goals of care projects.

CHAPTER 2

REVIEW OF THE LITERATURE

Two major areas of the literature are relevant for this research. The first seeks to summarize the evidence regarding the impact of communication on the outcomes of people with advanced cancer, including a scoping literature review regarding GOC in cancer. The second describes the contributions of implementation science methods and frameworks to the research.

Definition of Goals of Care

In this research, I am using the definition of GOC proposed by Secunda et al.: “GOC are operationally defined as the *overarching aims* of medical care for a patient that are informed by *patients’ underlying values and priorities*, established within the existing *clinical context*, and used to *guide decisions* about the use of or limitation on specific *medical interventions*” (Secunda et al., 2020, page 1561). Goals of care communication (GOCC) is also referred to as serious illness communication (SIC) (Jacobsen et al., 2022). There are three major themes of the GOCC concept: 1) GOCC can promote and protect patient autonomy and patient-centered care, 2) GOCC can help patients avoid unwanted care, and 3) GOCC can confer psychological and emotional support to patients and their families who are facing complex, difficult decisions (Secunda et al., 2020, page 1563). GOC are dynamic and change over time.

The process of advance care planning (ACP), including the use of advance directives (AD), is related to but distinct from GOCC. ACP is a process for informing future medical care, and ADs formalize those decisions into written documents. Despite buy-in to the concept of ACP over the past 25 years, high-quality research has failed to demonstrate that ACP improves end-

of-life care. As noted by Morrison et al., “Despite the intrinsic logic of ACP, the evidence suggests it does not have the desired effect. Many clinicians may be disappointed that promoting conversations with patients well in advance of needed medical decisions has not improved subsequent care as hoped. New research focused on training clinicians and preparing patients and families to engage in high-quality discussions when actual (not hypothetical) medical decisions must be made is needed to achieve the outcomes that ACP has not” (Morrison et al., 2021, page 1576).

These real-time discussions seeking to align specific clinical decisions with patient values and priorities are GOCC (Secunda et al., 2022). The expectation is that these GOCC involve a trusted clinician who has detailed knowledge of a patient’s medical condition and the ability to create a safe environment for the discussion. During one or more conversations, the clinician engages the patient (and caregivers, if desired) in organized, open and empathetic communication about 1) current and desired level of patient knowledge about their cancer and prognosis; 2) patient preferences; 3) patient goals, values, and priorities; and 4) medical recommendations for care (Jacobsen et al., 2022). GOCC may be repeated at key points throughout the cancer trajectory (e.g., disease progression; changes in treatment regimen).

Impact of EOL Discussions on Utilization

GOCC have fundamental importance as integral aspects of shared decision-making and high-quality cancer care. GOCC also represent a lever for increasing cancer care value, described as the intersection of cost and quality (Raghavan & Legnini, 2016). Given the high costs of cancer treatment and the associated patient financial toxicity described in Chapter 1, research regarding impacts on utilization and cost is meaningful. Most published research explores the impact of communication related to EOL care and costs and utilization of services near the EOL.

Of note, ‘EOL discussions’ and ‘GOC discussions’ are not synonymous; while GOCC may include EOL discussions, GOCC should occur as early as possible in the care trajectory of people with serious illness. This terminology distinction, however, is recent and still solidifying in the literature (Secunda et al., 2022).

A 2019 systematic review by Starr et al. evaluated the associations among EOL discussions, health care utilization, site of death and cost in advanced cancer patients. Based on 20 studies published between 2012 and 2019, the authors found EOL discussions to be associated with less intensive care at EOL, less acute care at EOL, less chemotherapy near death, less emergency department use, shorter length of hospital stay, greater likelihood of death outside the hospital, and higher hospice use. Overall, EOL discussions were associated with significantly lower healthcare costs in the last 30 days of life. Table 2 summarizes key findings.

Table 2

Summary of Utilization Findings with GOC Discussions (adapted from Starr et al., 2019)

Utilization Metric	Key Findings
Intensive care at EOL	Lower use with EOL discussions; odds ratios ranging 0.26 to 0.68
Acute care at EOL	Lower use with EOL discussions; odds ratios ranging 0.43 to 0.69
Chemotherapy near death	Lower use with EOL discussions; odds ratios ranging 0.41 to 0.57
Hospice enrollment	Higher use with EOL discussions; odds ratios ranging 1.79 to 6.88
Healthcare costs in the last 30 days of life	Median \$1,048 with EOL discussion vs. median \$23,482 without; $p < 0.001$

A critical finding of this systematic review was that earlier EOL discussions are associated with less utilization, compared with conversations occurring closer to death. The

authors identified six studies (Marcia et al., 2018; Lopez-Avevedo et al., 2013; Zakhour et al., 2015; Ahluwalia et al., 2015; Zaros et al., 2013; Mack, Cronin, Keating et al., 2012) that included discussion timing in the analysis. Collectively, these studies suggest that earlier conversations (30+ days or more before death) are associated with lower likelihood of receiving any aggressive care in the last 30 days or life, less acute care in the last 30 days of life, less ICU use in the last 30 days of life, and higher hospice enrollment, as described in Table 3.

Importantly, these earlier discussions are consistent with the concept of GOCC.

Table 3

Summary of Utilization Findings with Earlier EOL Discussions (adapted from Starr et al., 2019)*

Utilization Metric	Key Finding
Acute care in the last 30 days of life	Lower use with EOL discussions; odds ratios ranging 0.03 to 0.67
ICU admission in last 30 days or life	Lower use with EOL discussions; odds ratios ranging 0.19 to 0.33
Hospice enrollment	Higher with EOL discussions; odds ratios 2.8, 95% CI 2.06 to 3.75, $p < 0.001$
Any aggressive care in the last 30 days of life	Lower use with EOL discussions; odds ratios ranging 0.10 to 0.34

*Sources: Marcia et al., 2018; Lopez-Avevedo et al., 2013; Zakhour et al., 2015; Ahluwalia et al., 2015; Zaros et al., 2013; Mack, Cronin, Keating et al., 2012

Impact and Use of GOCC

While impact on utilization may be relatively straightforward to assess, utilization does not reflect the most important outcome of GOCC. An evolving body of literature indicates that earlier palliative care, including GOCC, is associated with enhanced satisfaction, quality of life, symptom control, psychosocial well-being and acceptance among patients with advanced cancer, as well as decreased caregiver burden (El-Jawahri et al., 2017; Ferrell et al., 2017; Temel et al.,

2017; Mack et al., 2010; Wright et al., 2008). Timely communication enables patients and their caregivers to participate more actively in treatment decisions, to prioritize their care based on their own preferences, and to receive specialized palliative care services if desired (Mayland et al., 2021; Clayton et al., 2007). Patients with advanced cancer who do not participate in meaningful GOCC can misunderstand basic aspects of their clinical situation, such as their prognosis and intent of treatment; for instance, patients may assume treatment is for cure, even if it is for palliation (Weeks et al., 2012). Without a structured discussion, there is persistent discordance between patients and their providers with respect to GOC, and dissatisfaction among patients and caregivers (Douglas et al., 2019).

Research suggests that advanced cancer patients are hesitant to broach these types of issues with their providers (Walczack et al., 2015; Brandes et al., 2014; Frosch et al., 2012). Unfortunately, clinicians fail to initiate these discussions, as well; they do not adequately communicate with their seriously ill patients about their prognosis, and do not sufficiently elicit their values, preferences, or goals of care (Ng & Ozdemir, 2023; Bernacki et al., 2014; Liu et al., 2014; Walczak et al., 2013; Mack, Cronin, Taback, et al., 2012). Provider factors contributing to inadequate GOCC include lack of confidence in their communication abilities (Granek et al., 2017; Almack et al., 2012) and worry about patient distress or loss of hope (Zhi et al., 2015; Granek et al., 2013; Baile et al., 2002). Oncologists report that addressing a patient's end of life is the most stressful and uncomfortable part of oncology care (Baile et al., 2002). Nearly all clinicians believe that GOCC are important; but, fewer than a third of clinicians report having received serious illness communications training (Fulmer et al., 2018).

Recognizing this professional gap, the American Society of Clinical Oncology (ASCO) developed a clinical practice guideline addressing patient-clinician communication (Gilligan et

al., 2017). The publication reinforces to cancer providers that strong health care communication skills can be learned, and that good interpersonal skills alone are insufficient. The authors note that “Challenging conversations in oncology are in many ways akin to complex interventional procedures or operations in that they require careful planning and execution, using well-developed strategies to facilitate optimal communication” (Gilligan et al., 2017, page 3618). The guideline recognizes that there are emerging communications skills training programs that can improve provider communication skills and patient experience.

Subsequent systematic reviews have catalogued the impact or effectiveness of communications skills training in oncology settings (Fischer et al., 2019; Moore et al., 2018). Harnischfeger et al. published the most recent and relevant review in 2022, seeking to identify and summarize studies with interventions aimed at improving communication of end-of-life issues among cancer providers. Among the 22 communication interventions reviewed, including 13 randomized controlled trials, the authors found the most frequently addressed training topic was breaking bad news, followed by dealing with patients’ emotions. Three interventions specifically targeting GOCC were identified (Annadurai et al., 2021; Bickell et al., 2020; Malhotra et al., 2020). All but one study reviewed reported significant positive effects of the intervention on at least one measured outcome (Harnischfeger et al., 2022).

In summary, professional oncology guidelines establish the expectation that oncologists should engage their advanced cancer patients in GOCC, while training interventions exist which are effective in improving communications skills. Since myriad other factors contribute to achieving GOCC in real-world cancer care, it is useful to explore research implementing GOCC interventions in practice.

Research Evaluating GOC Interventions

According to the previously described systematic review by Secunda et al. (2020), the first publication using the term ‘goals of care’ was published in 1987. Related manuscripts increased rapidly since then, with nearly 90% of publications they identified published within the last decade of their search window (2009 to 2018) (Secunda et al., 2020). Amidst this growth, I sought to understand what this literature reveals about interventions to improve GOCC overall, and specifically within the oncology setting.

In 2018, Myers et al. conducted a systematic review to outline and summarize evidence regarding healthcare provider tools or practices for ACP or GOCC. The authors’ literature search was not specific to cancer or oncology. While 36 papers describing 34 studies were identified in the search, the authors noted that the predominance were related to ACP instead of GOCC. These researchers concluded that the literature at the time lacked agreement on components of GOC discussions, expected outcomes, or patient outcome evidence. They recommended “exploring the elements of GOC discussions that could be amenable to standardization” (Myers et al., 2018, page 1129).

A 2021 systematic review by Cripe et al. examined the evidence that GOCC are associated with higher-value care. Again, the search was not specific to cancer or oncology. The authors identified 32 articles published through July 2019. Ten articles reported results from eight intervention studies, 17 articles described participants' perspectives, and five articles were retrospective. The authors found results suggesting relationships between GOCC and indicators of high-value care (i.e., utilization and cost) in non-randomized intervention studies and retrospective studies, but limited evidence in randomized intervention studies. Like Myers et al.,

Cripe and colleagues reported challenges differentiating between ACP and GOCC in the literature, and an overall lack of consensus regarding what GOCC entails (Cripe et al., 2021).

For purposes of my research, I sought a more complete examination of GOC intervention implementation experience within cancer settings. I also wanted to catalogue the various measures applied and impacts studied in the literature, versus Cripe et al. (2021) focusing on value. For this reason, in July 2024, I conducted a scoping review of the literature search to identify intervention studies (including quality improvement interventions) related to GOCC among adult cancer patients conducted within the US or Canada. The PubMed search of publications between January 2010 and July 2024 revealed 27 relevant papers. Appendix A includes the search parameters and terms used for the scoping review, and an abstracted description of each study. Table 4 provides a high-level summary of the measures and findings of the clinical trials and prospective cohort studies identified in the scoping review.

Collectively, these studies provide mixed results from multi-dimensional interventions to improve GOCC. Most studies measuring the frequency of GOCC and documentation in the electronic health record (EHR) reported improvement. Emerging data are promising for clinician ‘nudges’ to engage in GOCC, along with those to prepare patients for GOCC. Measures of patient outcomes indicated reduced anxiety and depression and improved patient satisfaction, but results were mixed. There were also mixed findings about the impact on EOL health care utilization, with less utilization shown in some studies and no impact in others. One study suggested that after training, GOCC can be held efficiently and without negatively impacting productivity (Pintova et al., 2020a, Pintova et al., 2020b).

Table 4

*Summary Table of Clinical Trials and Prospective Cohort Studies, Literature Scoping Review,
GOC Interventions in Adult Cancer Patients*

Measure Area	Findings Measured; Improved	Findings Measured; Not Improved
Frequency of GOCC	Takavorian et al., 2024 Manz, Zhang, Chen et al., 2023 Annadurai et al., 2021 Manz et al., 2020 Paladino et al., 2019 Patel et al., 2018	Bickell et al., 2020
Timing of GOCC	Paladino et al., 2019	
Communications skills	Bickell et al., 2020	Annadurai et al., 2021
Advance directives	Manz et al., 2020	Apostal et al., 2015
Nudges	Bernecki et al., 2019 (provider) Takavorian et al., 2024 (provider + patient) Manz, Zhang, Chen et al., 2023 (provider)	Apostal et al., 2015 (provider) Takavorian et al., 2024 (provider only) Takavorian et al., 2024 (patient only)
Utilization	Patel et al., 2024 (total daily spend; systemic therapy; outpatient care) Manz, Zhang, Chen et al., 2023 (systemic therapy) Patel et al., 2018 (hospice, ED visit, hospitalizations, costs) Apostal et al., 2015 (critical care; hospice)	Patel et al., 2024 (acute care, long term care, hospice) Manz, Zhang, Chen et al., 2023 (hospice enrollment, hospice length, inpatient death, EOL ICU use) Bickell et al., 2020 (hospitalizations, ICU use, chemotherapy) Paladino et al., 2020 (aggressive indicators)
Patient outcomes	Bernecki et al., 2019 (anxiety; depression)	Bernecki et al., 2019 (peacefulness) Schenker et al., 2022 (quality of life; symptom burden, mood)
Survival		Bernecki et al., 2019

Reported results were generally positive among the QI evaluation studies reviewed, although definitions and rigor varied. QI evaluations were predominantly for multi-component interventions implemented in the outpatient oncology setting. GOC documentation increased in all relevant studies (Seevaratnam et al., 2024; Reddy et al., 2023; Aneka et al., 2022; Davidson et al., 2022; Conduit et al., 2021; Karim et al., 2018). The studies focusing on timing of GOC documentation found promotion of earlier GOCC to be successful (Davidson et al., 2022; Epstein et al., 2022) and found earlier documentation to be positively associated with other EOL measures (Epstein et al., 2022). Generally, interventions to improve GOCC also increased palliative care consults when both were measured (Karim et al., 2018; Hanson et al., 2017). Those analyzing change in one or more measures of care utilization found predominantly decreased utilization, including QI interventions in the ambulatory setting (Davidson et al., 2022; Epstein et al., 2022) and in the inpatient setting (Hui et al., 2023; Leung et al., 2023). One study (Reddy et al., 2023) included an assessment of patient symptom scores and performance status, and reported improvement on both. Across QI studies, use of criteria to identify high risk patients and use of triggers seemed positive (Seevaratnam et al., 2024; Hui et al., 2023; Davidson et al., 2022; Karim et al., 2018).

Measuring GOC interventions

The inconsistency of measures used throughout these studies raises concern about the ability to efficiently evaluate the impact of GOC interventions, whether in the context of a designed experiment, a QI project, and/or a monitoring and feedback intervention component. As depicted in the logic model, Figure 1 in Chapter 1, the intended outcome of GOCC is goal-concordant care for patients with cancer. Receiving goal concordant care has long been

recognized as an indicator of high-quality cancer care – and promoted for quality measurement – but remains a stubborn challenge measurement.

In recognition, Sanders et al. published a model for measuring goal concordant care, including the following proposed domains of measurement (Sanders et al., 2018):

- Patient or surrogate-reported outcomes
 - Report that current care is goal-concordant
 - Trust or confidence that future care will reflect goals and values
- Patient-specific care indicators
 - EOL care reflects previously expressed preferences
- Population level care indicators
 - Utilization, including hospice
 - Location of death
- Surrogate-reported EOL outcomes
 - Belief that EOL care reflected patient's goals and values

The authors posit that communication between clinicians and patients enables goal concordance; thus, measurement should focus on communication and its impact. They propose that 'implementation-ready' measures are 1) the timing and setting of serious illness communication, 2) patient experience of communication and care, and 3) caregiver bereavement surveys including perceived goal concordance of care (Sanders et al., 2018, page 7).

Components of GOC interventions

The literature identified in the scoping review revealed several major components most often tested in GOC interventions. These are:

- Formal communications skills training, to improve GOCC skills and self-efficacy, using best practices of adult learning (e.g., role play; ongoing coaching)
- Checklists or guides to provide real-time GOCC prompts for clinicians
- EHR documentation templates or forms that help guide the conversation, promote complete documentation, and aid in subsequent access/retrieval
- A process to identify patients who most need GOCC (high-risk or priority patients)
- Triggering or nudging functions for oncology providers to engage in GOCC with prioritized patients
- Triggers for referral to specialty palliative care consults for prioritized patients
- Monitoring and feedback for clinicians

There is less evidence published regarding patient-direct education to prepare them to engage in GOCC, or nudges to prompt patients to raise these issues; however, several studies support integration of direct patient engagement into GOCC interventions (Takavorian et al., 2024; Anaka et al., 2022; Bernecki et al., 2019; Paladino et al., 2019).

Enablers and Barriers to GOC Implementation

I conducted a final exploration of the GOC literature identified in the scoping review to catalogue enablers and barriers to implementation, which were described in six studies using qualitative methods. A summary of the identified enablers and barriers, with associated references, is in Table 5. In grouping these into common areas, I identified the following themes: 1) organizational cultural factors; 2) clinician cultural factors; 3) patient and family factors; 4) implementation factors; 5) and use of a multicomponent intervention. Factors associated with this final theme are consistent with components of GOC interventions identified above.

Table 5*Factors that Act as Enablers or Barriers to GOC Intervention Implementation*

Factor	Supporting References
Theme: Organizational Culture Factors	
Leadership engagement / buy in	Kumar et al., 2023 Andersson et al., 2022
Leadership reinforcement	Kumar et al., 2023 Paladino et al., 2022
Institutional QI climate; comfort with use of data to drive improvement	Paladino et al., 2022
Integration into strategic plan; institutional goals	Kumar et al., 2023
Institutional commitment of financial resources	Kumar et al., 2023 Paladino et al., 2022
Institutional workflow and time support for GOCC	Schulman-Green et al., 2018
Theme: Clinician Team Culture Factors	
Knowledge and beliefs re: GOCC	Paladino et al., 2023
Attitude and self-efficacy re: GOCC	Paladino et al., 2023 Andersson et al., 2022 Paladino et al., 2022 Parikh et al., 2022
Clinician perception of impact (on patient and clinician outcomes)	Paladino et al., 2023 Schulman-Green et al., 2018
Clarity of roles and responsibilities for GOCC	Paladino et al., 2023
Theme: Patient and Family Factors	
Patient health literacy	Schulman-Green et al., 2018
Patient functional status	Schulman-Green et al., 2018
Family understanding and acceptance	Schulman-Green et al., 2018
Theme: Implementation Factors	
Internal marketing; change management	Kumar et al., 2023 Andersson et al., 2022
Implementation facilitation skill	Paladino et al., 2022
Role of local champion/ facilitator, including time and support	Kumar et al., 2023 Andersson et al., 2022 Paladino et al., 2022
Intrinsically motivated champions	Paladino et al., 2022
Time allocation for implementation and training	Kumar et al., 2023 Andersson et al., 2022
Incentives for training and documentation	Kumar et al., 2023 Paladino et al., 2022
Theme: Multicomponent Implementation	
Communication skills training	Kumar et al., 2023 Paladino et al., 2022
Communication and adaptation coaching	Paladino et al., 2022
EHR and data infrastructure	Kumar et al., 2023 Paladino et al., 2022
Identification of priority patients	Kumar et al., 2023

	Andersson et al., 2022
Process automation; triggering	Kumar et al., 2023 Paladino et al., 2022 Parikh et al, 2022
Use of reporting / metrics; comparison with peers	Kumar et al., 2023 Paladino et al., 2022 Parikh et al, 2022

Similarly, in an opinion piece on how cancer practices and hospitals can promote GOCC, Manz and colleagues (2023) recently proposed that successful interventions are characterized by customized implementations with financial support, provider training, defined workflows, and team engagement. They recommend a process to measure implementation impact that is aligned with external (e.g., policy, payer) and institutional priorities; integrates feedback and peer comparison for clinicians; and evaluates subpopulations to understand disparities in care. Importantly, these experts note that the similarities in approaches in many of the published interventions to enhance GOCC suggest that differences in their effectiveness may be due to intervention characteristics, implementation approaches, and local context (Manz, Rocque, & Patel, 2023; emphasis added).

Indeed, integrating any change into oncology practice should be done with sensitivity to the complexity of these systems, employing rigorous approaches that maximize likelihood of a successful intervention implementation. The application of implementation science methodologies and frameworks can promote sound planning, implementation and evaluation of interventions in healthcare settings.

Applying Implementation Science

Healthcare organizations are complex adaptive systems, characterized by numerous interconnected elements that can respond to stimuli in different and unpredictable ways (Institute of Medicine, 2001). Cancer care is especially complex, given the multimodality and

multidisciplinary nature of oncology treatment. Efforts to implement operational improvements within these complex systems are challenging; they require an understanding that organizational features are as important to success as are individual (e.g., provider-level) responses (Li et al., 2018).

Implementation science is a multidisciplinary field that bridges the gap between research findings and their integration into routine clinical practice and policy. It seeks to understand and improve the uptake, adoption, and sustainability of evidence-based interventions to enhance care delivery and patient outcomes. Central to implementation science is the study of factors influencing successful implementation, including organizational structures, provider behaviors, patient preferences, and contextual factors such as policy environments and socioeconomic conditions (Damschroder et al., 2009).

Implementation scientists aim to develop strategies that optimize the translation of research into practice by systematically identifying barriers and facilitators to implementation. This can entail strategies tailored to specific contexts and stakeholders, e.g., adapting interventions to local settings, training healthcare providers in new practices, and fostering collaborations across stakeholders (Eccles & Mittman, 2006). Collectively, these approaches can promote and speed the translation of evidence into everyday clinical practice (Li et al., 2018).

Implementation Science Framework

Implementation science approaches generally integrate the structure of an organizational or conceptual framework. One of the first implementation science frameworks to explicitly integrate the multi-dimensional, complex nature of implementation and the central importance of context was the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Harvey & Kitson, 2016). PARIHS was first published in 1998 (Kitson et al., 1998),

followed by a complete description of the framework's development and refinements in 2008 (Kitson et al., 2008). PARIHS defines successful implementation (SI) of evidence into practice was a function of the quality and type of evidence (E), the characteristics of the setting or context (C) and the way in which the evidence was introduced or facilitated (F) into practice (Kitson et al., 2008).

PARIHS was widely used in studies in the decade following its publication (Bergström et al., 2020); with research application, users noted limitations in the framework's inclusion of dimensions such as the intended targets for implementation and the broader external context (Harvey & Kitson, 2016). In 2016, the PARIHS developers proposed a second-generation framework, Integrated Promoting Action on Research Implementation in Health Services (i-PARIHS), including the new construct of 'recipient' and revisions to the constructs of evidence, context, and facilitation. Specifically, i-PARIHS prompts consideration of the “facilitation of an innovation with the intended recipients of implementation in their (local, organizational, and health system) contexts” (Harvey & Kitson, 2016, page 2). In practice, when applying i-PARIHS to implementation or evaluation, the four constructs of influence are: 1) the innovation being implemented, 2) the recipients of the implementation effort, 3) the organizational context in which the implementation is carried out, and 4) the facilitation of the implementation.

CHAPTER 3

METHODS

Study Design

This mixed-methods evaluation study includes development, implementation and analysis of a survey of healthcare providers at 10 cancer centers (GOC Implementation Survey), as well as secondary, retrospective analysis of data collected during a quality improvement collaborative. University of Georgia's Human Subjects Office reviewed this study and assigned a determination of Not Human Research ([PROJECT00009477](#)).

Study Setting

Study sites included 10 cancer centers across the US, illustrated in Figure 2. All 10 sites are freestanding, academic medical centers that are unique in the US in that they are licensed hospitals treating only cancer patients in inpatient and outpatient hospital settings. This shared distinction as cancer-only hospitals is the force that led to the creation of the Alliance of Dedicated Cancer Centers (ADCC); these 10 cancer hospitals are the only members.

All participating cancer centers have developed networks of affiliated provider sites that extend their reach beyond the 'main campus;' however, most centers focused their IGCC implementation only on main campus and, consequently, the evaluation assess implementation at the main site.

Figure 2*IGCC Participant Cancer Centers***Study Participants**

The inclusion criterion for collection of quantitative evaluation measures was participation in the IGCC. Inclusion criteria for the GOC Implementation Survey were persons whose roles were IGCC Implementation Workgroup (IWG) leads during the initiative. I selected these recipients due to their detailed knowledge of implementation at their sites. Each center maintained two IWG clinician leads: one representing oncology, and one representing palliative/supportive care.

Quality Improvement Intervention

The conceptual development, core intervention components and evaluation plan for the IGCC have been previously described in introductory publications (Loggers et al., 2023; McNiff et al., 2021). Briefly, the 10 cancer centers members of the ADCC agreed to plan a collaborative project in 2019, focused on enhancing goal concordant care amongst advanced cancer patients. The Chief Executive Officers (CEOs) or Presidents from each cancer center solidified this

commitment with a published commentary in the professional literature (McNiff et al., 2021).

ADCC provided coordinated facilitation and infrastructure for planning and implementation of the IGCC; hereafter referred to as the ‘coordinating team’.

While engaging in planning for IGCC, members of the coordinating team led a process to catalogue structural aspects of relevance at each cancer center (e.g., availability of palliative care specialists and resources; existing infrastructure and training investments in GOCC). Then, committees of oncology, palliative care, and quality experts from each cancer center convened in facilitated group processes to articulate the vision, core components, aims and measures for IGCC. Informed by published literature at the time, and the expertise of the group, the multi-component intervention that all IGCC participants agreed to implement included 1) communication skills training for oncology providers, 2) EHR optimizations to capture and use GOC documentation, and 3) center-specific definition of priority populations to receive GOC discussions. All also agreed to participate in measurement and evaluation.

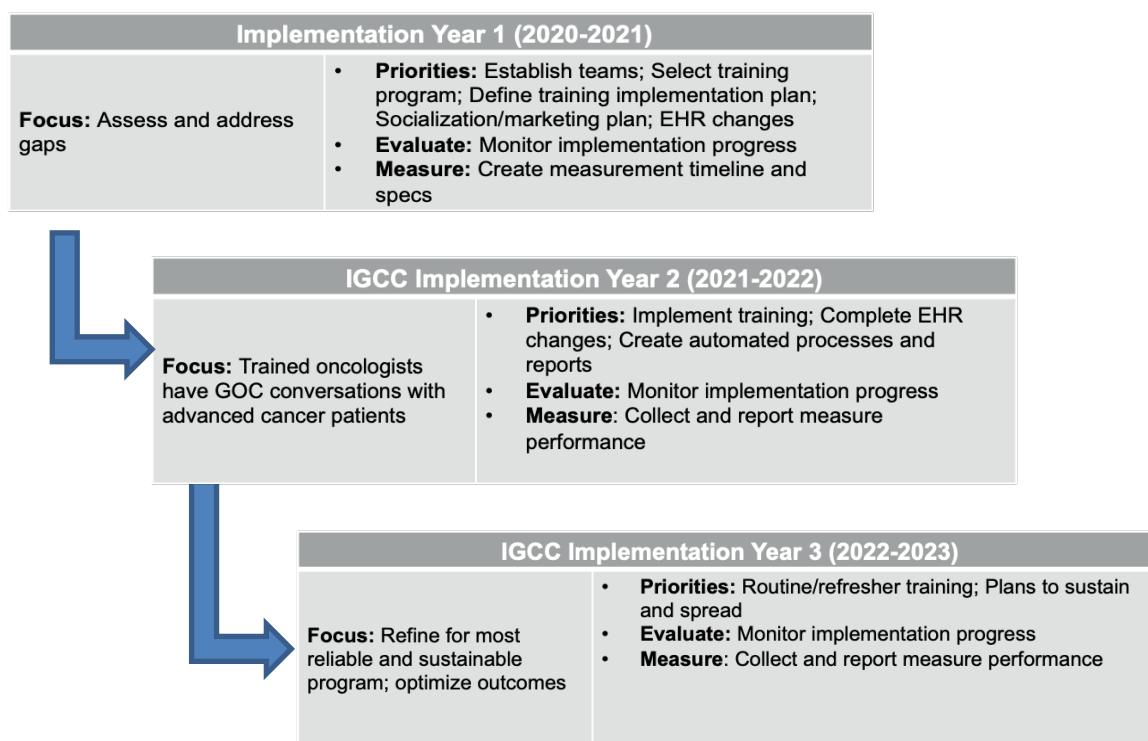
As each center was at a different level of starting maturity (that is, some had not invested in enhancing GOCC in any way, while others had training programs or initial EHR templates in place), each site planned a tailored implementation. The coordinating team provided a detailed ‘IGCC Implementation Guide’ to support the development of a customized, written implementation plan at each center.

Between September 2021 and December 2023, each of the 10 cancer centers attempted to implement their tailored, multi-component intervention designed to enhance GOCC. A high-level outline of the annual implementation milestones and priorities is in Figure 3. Collaborative work during this time was overseen by the IGCC IWG, made up of the core project team from each site (at minimum, the oncology physician lead and the palliative/supportive care physician

lead from each cancer center; most sites also had a project manager and/or quality specialist engaged in the IWG). The IWG met monthly, or more frequently, throughout the Collaborative.

Figure 3

IGCC Annual Implementation Milestones for Participating Cancer Centers



Throughout the implementation period, the coordinating team communicated with the ADCC Board of Directors; conducted IGCC project planning; facilitated IWG meetings; convened and managed bi-directional information exchange with a collaborative Patient Family Advisory Committee; planned and managed topic-focused sessions, including with guest expert thought leaders; provided and managed the infrastructure for resource sharing and report/data submission; and conducted analyses and prepared comparative and trended reports. Further, the coordinating team served as a resource or ‘connector’ when sites experienced challenges or considered new approaches, by connecting individuals across cancer centers who had similar

experiences. At the same time, the IWG members (especially the physician leaders) served as their local implementation champions. These individuals spearheaded resource requests, led change management with their peers, ensured submission of evaluation information and measures, and provided day-to-day oversight to promote institutional momentum and progress. In addition, all played leadership roles in the implementation of their training programs (often serving as master trainers), and most developed and shepherded institutional HIT requests (including for EHR modifications, reports and trigger functions).

Data Sources

Data sources for this mixed-methods evaluation research include process measures collected during IGCC implementation, as well as the GOC Implementation Survey, developed for this study.

Process Measures

The complete set of IGCC evaluation measures has been described (Loggers et al., 2023). Two main process measures informed the evaluation; each had a performance target established prior to the launch of the initiative.

- The percent of eligible providers who received communication skills training (referred to as ‘communication skills training rate’ hereafter)
 - Target: At least 65% of oncology providers will have received communication skills training
- The percent of deceased patients with a GOC discussion documented in the EHR before death (referred to as ‘GOC documentation rate’ hereafter)
 - Target: At least 70% of selected, advanced patients will have received at least one goals of care conversation with documentation in the EHR

Table 6*IGCC Communication Skills Training & GOC Documentation Measure Definitions*

Measure Title	Denominator	Numerator	Performance Target
Percent of eligible oncologists and APPs who complete communication skills training Short title: communication skills training rate	Number of hematologic oncologists, medical oncologists, general oncologists and APPs who provide patient care at any location, under the license of the Center and in scope for the IGCC Initiative, in the reporting period. (‘General’ oncologist is a descriptive term used here to indicate oncologists who see multiple tumor types, e.g., are not sub-specialists)	Number who complete training in GOC communication skills training	At least 65% of oncology providers will have received goals of care communication skills training
Percent of deceased patients with at least one goals of care discussion documented in the EHR before death Short title: GOC documentation rate	Number of patients meeting the deceased patient population definition in the reporting period Deceased Patient Population Definition - Diagnosis of cancer AND - Died during inpatient stay at reporting center within the 3-month period AND had at least 1 visit (inpatient and/or ambulatory) at the reporting center in the previous 6 months, OR - Died during the 3-month period AND had at least 2 visits (inpatient and/or ambulatory) at reporting center within previous 6 months	Number of deceased patients with at least one goals of care discussion documented in the EHR before death Defined as documentation in patient goals field + one or more of the following: - Intent of the current treatment - Physician's estimated prognosis - Prognosis disclosed to patient - Patient goals - Recommendations	At least 70% of selected, advanced cancer patients will have received at least one goals of care conversation with documentation in the EHR (including documentation that the patient declined)

Each measure has specific numerator and denominator definitions, which were used by the cancer centers for reporting (Table 6). We employed a deceased patient population for the EHR documentation measure for measurement feasibility and denominator consistency.

Survey: Close-Ended

I selected i-PARIHS (Harvey & Kitston, 2018) as the most relevant implementation science framework for this research; see Chapter 2 for a review of the i-PARIHS model. All i-PARIHS constructs (1. the innovation being implemented; 2. the recipients of the implementation effort; 3. the organizational context in which the implementation is carried out; and 4. the facilitation of the implementation) influenced the IGCC implementation and were considered in survey development. The survey's major Domain Categories (Table 7) are derived from the organizational context and facilitation i-PARIHS constructs. As a collaborative initiative, IGCC's implementation included external, collaborative facilitation in the form of the coordinating team (bringing process improvement expertise and collaborative structure), as well as the facilitation leadership or oversight at each center by the IWG champions.

I developed the GOC Implementation Survey questions in part by drafting an item pool drawn from the literature described in Table 5 in Chapter 2. These qualitative studies describe factors that have previously been identified as enablers or barriers to implementing interventions to enhance GOC discussions. Except for binary branching items, I used a standard five-point Likert scale for survey responses (Strongly Agree to Strongly Disagree). Three main types of items were included in the GOC Implementation Survey: those that assessed respondent perceptions of implementation enablers present at their center (grouped into I-PARIHS-informed Domain Categories); those that assessed respondent perceptions of implementation success at their site (Implementation Experience items); and those that assessed respondent perceptions of

the impact of their GOC program on their site (Outcome items). Table 7 summarizes the mapping of all items to i-PARIHS domains and core components of the IGCC intervention.

Table 7

GOC Implementation Survey Description

Domain Categories	Items (N)	Example Items
Resources	6	My center committed the financial resources that we needed for an operational improvement initiative of this scale.
Culture	5	In general, oncology providers are accepting of care delivery improvements that are implemented at my center.
Leadership	6	Leaders at my center helped reduce or remove barriers to our GOC program implementation.
Strategic integration	4	During our GOC implementation, my center's strategic plan or goals reflected key aspects of our program.
Adaptability	2	At my center, we adjusted our training program during our GOC program implementation, due to feedback from attendees.
Incentives	3	At my center, leaders aligned oncology provider incentives with the objectives of our GOC program.
Reporting and benchmarking	3	At my center, we created actionable, meaningful reports from our EHR or other HIT systems that supported our GOC program implementation.
Champion role	7	As a champion at my center, I found the work of leading our GOC program implementation to be rewarding.
Implementation Experience	Items (N)	Example Items
Training	2	Overall, my center succeeded in implementing our communication skills training program to oncology providers.
EHR documentation	4	Overall, my center's EHR GOC build has improved providers' ability to document goals of care discussions.
Priority population	3	At my center, we applied our priority population definitions to prospectively identify patients for GOC discussions.
Overall	3	Overall, my center was able to integrate GOC conversations into our clinical and operational workflows.
Outcomes	Items (N)	Example Items
GOC program outcomes	6	Overall, the GOC program at my center has improved patient care.

Although not captured as a Domain Category, I included several survey items regarding alignment of the GOC program with other institutional priorities. These assessed whether the

GOC program was 1) connected to billing practices (most notably, to the use of ACP billing codes); 2) aligned with payer programs; 3) used as an exemplar for external accreditors or certifiers (e.g., The Joint Commission); or 4) was explicitly linked to other cancer center operational priorities (e.g., reducing ICU length of stay, reducing readmissions).

Two highly-engaged, project manager members of the IWG at two different sites – but who are not the target respondents – pilot-tested the draft survey. The pilot testers completed the full draft survey and provided structured feedback regarding interpretability and clarity of the draft survey. Pilot testing resulted in modifications to three survey questions.

Survey: Open-Ended

Survey items included six open-ended questions, assessing unexpected findings or challenges in implementing GOC programs, the most significant barriers, and the factors most important to success. Respondents were invited to provide free-text narrative responses.

Data Collection

Process Measures

Between the fourth quarter of 2021 and the third quarter of 2023, participants at the IGCC cancer centers collected and reported quarterly data for the IGCC measure set, including the two process measures used in this analysis: 1) communication skills training rate; 2) GOC documentation rate. Data were submitted via REDCap; only aggregated data were submitted.

Survey

For the GOC Implementation Survey, I purposively sampled the 10 oncology and 10 palliative/supportive care clinician champions who served as IWG members from each cancer center. I used a standardized recruitment email, with an explanation of the project's purpose and details of the data collection method. A consent letter (including details about voluntary

participation in the study, participants' rights, the risks of participation, limits to confidentiality, and procedures for reporting complaints and/or adverse events to investigators and to the IRB) was attached. These individuals had the option to decline to participate in the survey. The survey was administered using Qualtrics survey software (Qualtrics, Provo, UT).

Data Handling/Record Keeping

In this evaluation study, the most important risk is reputational risk for the survey respondent and cancer centers participating in IGCC. Participating sites were not equally successful in the implementation of their GOC programs, and a collaborative-level analysis will reveal this inconsistency. For this reason, ensuring confidentiality was important for this research. IWG members were informed that all data will be de-identified before publication. The survey was administered using Qualtrics and associated identified survey data files stored on secure network drives within the firewall protected UGA network. Survey responses were labeled with study IDs that are linked by a separate list that includes respondents'/cancer centers' names.

Data Analysis

As previously indicated, the aims of this study are to:

1. Describe the implementation experience of the IGCC participating cancer centers
2. Describe enablers and barriers to IGCC implementation across 10 cancer centers using the i-PARIHS framework
3. Assess which organizational contextual and facilitation factors are most closely associated with successful implementation
4. Summarize lessons learned to inform implementation, sustainability, scale and spread of future goals of care projects

I developed research questions associated with Aims 1 through 3, as described in Table 8.

Table 8

IGCC Evaluation Research Questions

Research Question	Data Source(s)	Analytic Approach
Aim 1. Describe the implementation experience of the IGCC participants		
Did IGCC sites achieve training targets during the course of implementation?	IGCC process measures	Count/frequency summary statistics
Did training rates differ across sites?		Chi square test
Did IGCC sites achieve significant improvement in GOC documentation during the course of implementation?	IGCC process measures	T tests using first and final quarter data
Did sites with higher training rates have higher GOC documentation rates?	IGCC process measures	Pearsons correlation between reported training rates and reported goals plus documentation rates
What was the site champion perception of the IGCC implementation experience?	GOC Implementation Survey	Count/frequency summary statistics
Aim 2. Describe enablers and barriers to IGCC implementation		
Which factors were most often identified by respondents?	GOC Implementation Survey	Count/frequency summary statistics
		Qualitative, thematic and content analysis
Aim 3. Assess which organizational contextual and facilitation factors are most closely associated with successful implementation		
Which domain categories are most strongly associated with implementation experience?	GOC Implementation Survey	Spearman's r correlation
Which implementation experience categories are most strongly associated with outcome scores?	GOC Implementation Survey	Spearman's r correlation
Which domain categories are most strongly associated with training rates?	GOC Implementation Survey + IGCC process measure	Spearman's r correlation
Which domain categories are most strongly associated with EHR documentation rates?	GOC Implementation Survey + IGCC process measure	Spearman's r correlation

Quantitative Analysis

I used R 4.2.1/RStudio for all analyses. For the communication skills training rate and GOC documentation rate process measure results, I generated descriptive statistics of responses (mean, range). I calculated chi squared tests to assess training differences across sites. T tests were used to explore change in GOC documentation from the first and last data submissions (null hypothesis: no change in documentation), and Pearson's correlation to examine associations between communication skills training rates and GOC documentation rates.

For the quantitative survey results, I analyzed the frequency of missing response data. Since each center had two survey respondents, I used Krippendorff's alpha to understand agreement across respondents for domain category items reported in the survey. For each center, response values from the two respondents were averaged. I generated descriptive statistics for each survey item (mean, median, min, max) across all 20 responses. To explore correlations among the Domain Categories, Implementation Experience items, and Outcome items, I used Spearman's r, which is appropriate for non-parametric tests, given the Likert scale response categories.

Finally, I computed Spearman's r correlations between the Implementation Experience survey items related to training and GOC documentation in the EHR with the corresponding process measure results collected during the evaluation, and between the survey Domain Categories and these process measure results. For all correlations, strengths were assigned as follows: Very strong = >0.90 ; Strong = $0.70 - 0.89$; Moderate = $0.40 - 0.69$; Weak = $0.20 - 0.39$; Very weak = <0.20 .

Qualitative Analysis

I compiled text responses to six open-ended survey questions and removed all individual or organizational identifiers in the text. My qualitative data analysis was guided deductively by the IGCC core components and i-PARIHS framework domains included in the questions, as well as inductively through emerging themes. After thoroughly reading all text responses, I conducted initial coding by highlighting key words, phrases, or concepts that were recurring within the data. I then clustered the codes, grouping similar codes together based on their meaning and create broader themes that encompass these related codes. Positive factors (i.e., enablers) and negative factors (i.e., barriers) were grouped separately, and frequency of each factor documented. Finally, I reviewed the themes to ensure they accurately capture the major ideas within the narratives.

Integration of Quantitative and Qualitative Data

Following completion of the quantitative and qualitative data analysis, I used a mixed-methods approach to integrate and compare the findings, organized according to relevant i-PARIHS framework constructs. Ultimately, quantitative findings from IGCC process measures, quantitative findings from close-ended survey items, and qualitative findings from open-ended survey items were integrated into a joint table display format (Guetterman et al., 2015) for presentation.

Limitations

Several methodologic limitations are important to consider. Most notably, we were unable to use an experimental or quasi-experimental study design when implementing IGCC. Evaluation activities occurred throughout implementation, but we do not have robust pre-implementation data. As explored in Chapter 2, the desired outcome of ‘goal concordant care’ is

very difficult to measure; thus, proxy measures are often used, as was the case in IGCC. The process measures were submitted by each site at the aggregate (numerator/denominator) level, which prevents more detailed analyses (e.g., comparing individual physician GOC documentation rates before and after training). Submitted process measure data also were not validated. To enhance data accuracy and comparability, we developed detailed measure definitions; conducted trainings with staff submitting data at each site; and created data submission forms with instructions and prompts. Sites were given the opportunity to correct submissions, e.g., if irregularities were noted.

The use of the deceased patient denominator for GOC reporting also limits our ability to understand the impact of GOCC, as the IGCC promotes earlier discussions that are not necessarily end-of-life focused. The IGCC did not specify the patient population that would most benefit from GOCC; this was left to each participating center. Certain sites implemented with a goal of broad patient engagement (e.g., cancer is a serious illness and most patients should have a documented GOCC). Others implemented specific and more narrow definitions for ‘priority populations’ based on complex clinical factors including stage, progression, performance status, and treatment history. The deceased patient denominator was chosen to minimize site reporting burden and to increase comparability of data submitted across sites.

Further, the numerator of the GOC documentation process measure assesses the completion of GOC documentation, and not the quality of that documentation. Participating cancer centers created EHR reports that looked only for the presence or absence of documentation. These sites were expected to provide their care team members with training regarding GOC documentation, and to evaluate the quality of documentation, but that was not centralized by the IGCC coordinating team.

The survey data may be impacted by common survey biases, including selection bias and response bias. Selection bias was mitigated by recruiting all leads to complete the survey; sampling was not used. I addressed non-response bias by attention to outreach, reminders and survey length. I attempted to reduce response bias with careful question design, use of a conceptual framework to guide domains/items, pilot testing, and reinforcing that no identified data will be shared.

For this research, the small survey sample size (with only 20 surveys administered) imposes limitations on my ability to conduct certain analyses, e.g., a regression analysis to indicate which domain category most strongly predicts outcome scores.

The assumptions pertinent to these methods are:

- Participating sites' training records accurately and completely captured communication skills training provided to oncologists and APPs during the three-year study period.
- GOC documentation in the EHR reflects an open, engaged conversation with patients (as much as the patient wishes to discuss GOC), and is not just a 'box checking' documentation exercise.
- GOC information reflects patient wishes, preferences and goals at the time of documentation in the EHR.
- Respondents were knowledgeable in all areas assessed in the survey, and truthful in their responses.

CHAPTER 4

RESULTS

Participant Characteristics

Cancer Centers

IGCC participating cancer hospitals (n=10) range in size (from 20 to 746 inpatient beds), inpatient volume (from a low of 561 to a high of 29,943 adult oncology admissions in 2023), and approximate new patients initiating treatment (from a low of 1,600 to a high of more than 20,000 per year). As specialty hospitals, people with cancer diagnoses make up the vast majority of the inpatient and outpatient volume across the centers. All centers are located in metropolitan areas; though, as tertiary referral centers, patient catchment areas can be diffuse. The majority (6/10) have Epic as their electronic health record; two have Cerner and two have Allscripts. All site-level results are blinded to cancer center name, presented by numbers 1-10, in random order.

Survey Respondents

Twenty members of the IGCC IWG who served as implementation champions at their cancer centers were invited to complete the GOC Implementation Survey. All 20 responded, for a 100% response rate. Participants included 19 physicians and one clinical PhD, seven women and 13 men.

General Descriptive Statistics

Process Measures: Communication Skills Training & GOC Documentation

During the three-year study period, nine of the 10 participating sites implemented communication skills training for oncologists and oncology APPs. Among those nine centers, a

total of 2,421 providers (medical oncologists, hematologic oncologists, general oncologists, and APPs) were eligible to receive training during the study period. The number of eligible providers per center ranged from 61 to 730, with a mean of 269. Provider Ns are removed from all center-level data presented below to preserve anonymity.

Similarly, nine of 10 centers implemented a structured GOC documentation note or template in their EHR. The site that did not implement the GOC template went live with their GOC template in November 2023, which was technically during the three-year study period, but too late to allow for inclusion in measurement. The center that did not implement training (Site 10) was not the same as the center that did not implement the GOC template (Site 9). One center (Site 8) was unable to report on GOC rates for all decedents due to data limitations; see Table 9.

This analysis focused on the first period of GOC documentation data submission (fourth quarter 2021, “2021-Q4”) and the final period of GOC documentation data submission (fourth quarter 2021, “2023-Q4”). Sites reported for all eligible decedents in that quarter (see Table 6 for definitions), and the subset of those decedents that died as inpatients during that quarter. The total number of decedents reported in 2023-Q4 was 3,336, and number of inpatient decedents reported was 705. The total number of decedents reported per center in 2023-Q4 ranged from 154 to 1,336 (mean=645) and the number of inpatient decedents ranged from 7 to 245 (mean=100). Decedent Ns are removed from all center-level data presented below to preserve anonymity.

Table 9*Center-Specific Communication Skills Training and GOC Documentation Implementation**Summary*

Center	Training implemented?	GOC template implemented and total decedent reported?	GOC template implemented and inpatient decedent reported?
1	Yes	Yes	Yes
2	Yes	Yes	Yes
3	Yes	Yes	Yes
4	Yes	Yes	Yes
5	Yes	Yes	Yes
6	Yes	Yes	Yes
7	Yes	Yes	Yes
8*	Yes	Site was not able to report GOC for all decedents; not included in all decedent analyses	Yes
9*	Yes	Not implemented within measurement period; not included in GOC analyses	Not implemented within measurement period; not included in GOC analyses
10*	Not implemented; removed from all training analyses	Yes	Yes

*Due to these exclusions, analyses of training rates include 9 centers; analyses of GOC documentation among all decedents include 8 centers; analyses of GOC documentation among inpatient decedents include 9 centers; and analyses combining training and GOC documentation include 7 centers.

Survey Data

There were no missing close-ended survey responses. Two responders from each center responded to each item. Agreement across the two respondents was moderate (ranging from 0.3 to 0.7 across centers for all combined questions, $n=77$), as expected given the individualized nature of many items (e.g., regarding respondents' experience serving as champions).

Agreement Between Process Measure and Survey Results

There was a moderate (0.50) correlation between the Implementation Experience survey items related to training implementation success and the communication skills training rate process measure submitted, and a strong (0.79) correlation between the Implementation

Experience survey items related to EHR changes for GOC documentation and the GOC documentation rate process measure.

Table 10

Correlation Between Training and EHR Documentation Results Across Survey Items and Process Measures

Implementation Survey Items (mean score across items)	IGCC Process Measure (submitted 2024-Q4; N=9 centers for each analysis)	Correlation Value
-Overall, my center succeeded in implementing our communication skills training program to oncology providers. -Overall, our communication skills training program improved oncology providers' ability to have goals of care conversations.	Percent of eligible oncologists and APPs who complete communication skills training	0.50
-At my center, we created useful, acceptable GOC documentation in our EHR. -At my center, oncology providers were accepting of the GOC documentation built into our EHR.	Percent of deceased patients with at least one goals of care discussion documented in the EHR before death	0.79

Aim 1 Results: Describe the implementation experience of the IGCC participants

Results for this aim reflect findings from the two main IGCC process measures (Communication skills training and GOC documentation in the EHR) and from the champion responses on the GOC Implementation Survey.

Communication Skills Training

The target rate for communication skills training established prior to IGCC launch was 65%. For all eligible providers across the nine centers that implemented training, 73% received communication skills training. Training rates exceeded the target for medical oncologists and APPs, who were also the greatest proportion of eligible providers, and did not meet target among general oncologists and hematologic oncologists.

Table 11
*IGCC Aggregate Communication Skills Training Rate, by Provider Type**

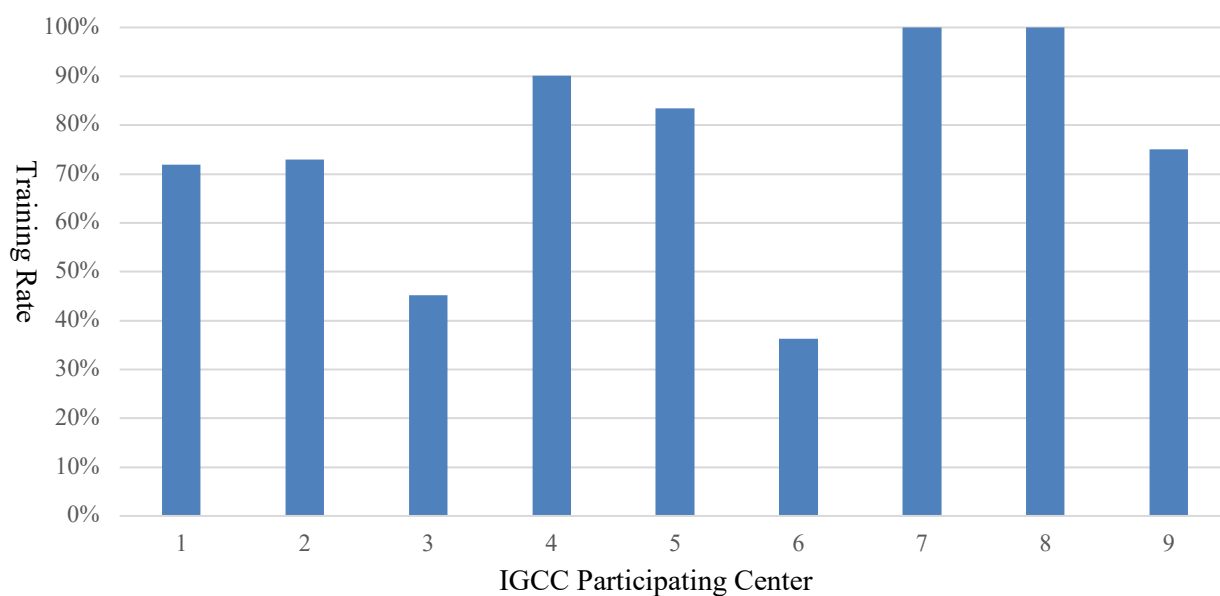
Provider Type	N Eligible	N Trained	Training Rate
Advanced practice providers	1314	989	75.3%
General oncologists	84	40	47.6%
Hematologic oncologists	342	211	61.7%
Medical oncologists	681	525	77.1%
Total	2421	1762	73.0%

*among 9 centers implementing training

Across the nine sites, center-level training rates ranged from 36% to 100% during the study period, as shown in Figure 4.

Figure 4

Center-Specific Communication Skills Training Rates



GOC Documentation

By the final measurement quarter (2023-Q4), the aggregate GOC documentation rate (measured as completion of the ‘patient goals’ field plus one additional field, see Table 6) was 39% among all decedents and 56% among inpatient decedents. This failed to meet the target

of 70% established prior to IGCC launch. Table 12 shows that the IGCC sites combined achieved significant improvement in their GOC documentation rates from the first to final measurement period, for both all decedents (11% to 39%, $p<0.0001$) and inpatient decedents (15% to 56%, $p<0.0001$).

Table 12

Change in Aggregate IGCC GOC Documentation Rate from First to Last Measurement Quarter*

Population	2021-Q4 Rate	2023-Q4 Rate	p-value
All decedents	10.60%	38.60%	<0.0001
Inpatient decedents	15.10%	55.50%	<0.0001

*Patient goals field + at least one additional GOC field

Five of eight centers (63%) showed significant improvement across the measurement periods for GOC documentation among all decedents, and six of nine (67%) among inpatient decedents. The 2023-Q4 documentation rate varied from a low of 4% among inpatient decedents to a high of 89% among inpatient decedents. Across time periods and most sites, GOC documentation was higher among those who died while admitted at the reporting center than those who died elsewhere (Table 13).

Table 13*Change in Center-Specific GOC Documentation Rate from First to Last Measurement Quarter*

Center [^]	Population	2021-Q4 Rate	2023-Q4 Rate
1	All decedents	33.9%	34.8%
1	Inpatient decedents	37.3%	49.7%*
2	All decedents	0.0%	41.5%*
2	Inpatient decedents	0.0%	66.0%*
3	All decedents	3.0%	5.7%*
3	Inpatient decedents	2.9%	4.4%
4	All decedents	7.8%	29.6%*
4	Inpatient decedents	6.7%	32.3%*
5	All decedents	2.6%	60.5%*
5	Inpatient decedents	4.1%	83.7%*
6	All decedents	29.4%	33.1%
6	Inpatient decedents	37.7%	57.6%*
7	All decedents	19.1%	31.7%*
7	Inpatient decedents	30.4%	20.8%
8†	All decedents	N/A	N/A
8	Inpatient decedents	0.0%	67.9%*
10	All decedents	35.3%	33.5%
10	Inpatient decedents	54.3%	41.6%

[^] Center 9 did not implement structured EHR template and is not included

†Site did not report all decedents, only those who died as inpatients

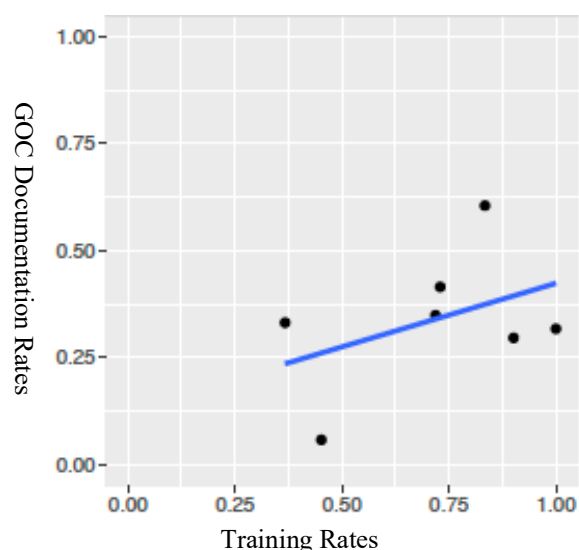
*Statistically significant change

Communication Skills Training x GOC Documentation

Seven centers were included in the analysis of the correlation between communication skills training rates and GOC documentation rates (see Table 9 for description of exclusions). Correlation between training rates and GOC documentation rates were moderate, at 0.42, as illustrated in Figure 5. Site 10, excluded from this correlation due to lack training implementation, started with and maintained comparatively high levels of GOC documentation, as shown above in Table 13.

Figure 5

Center-Specific Communication Skills Training Rates and GOC Documentation Rates



Champion Perceptions of Implementation Experience, Success, and Program Outcomes

Champion responses to the GOC Implementation Survey category are reported by Domain Categories (each including multiple items, see Table 14), individual Implementation Experience items, and individual Outcome items.

Domain Categories assessed respondents' agreement about their experience of enablers of implementation at their sites. Descriptive statistics for each survey item within the Disease Categories are in Appendix B. Among the Disease Categories, those with agreement (mean score of 2.0 or above, with '1' response indicating Strong Agreement and '2' response indicating Agreement) are: Resources, Leadership, Reporting/Benchmarking, and Champion Role. Table 14 includes a description of each Domain Category and mean scores for all items in the category.

Table 14*Description and Mean Score* of Domain Categories; Source: GOC Implementation Survey*

Category	Description	Mean, (N items)
Resources	Overall financial support; overall human resources; funding for training; support for trainers; resources for EHR changes	2.0 (6)
Leadership	Leaders offered vocal support; leaders made decisions and removed barriers; leaders modeled support by getting trained; new champions identified during implementation	2.0 (6)
Reporting and Benchmarking	Created actionable, meaningful reports; reports shared with oncology providers and executive leadership	1.7 (3)
Champion Role	GOC work rewarding and personally important to site champions; recognition and impact of champion role; desire to continue as champion	1.8 (7)
Strategic Integration	GOC integrated into strategic plan or organizational goals; presented to Board of Directors; presented to Patient Family Advisory Committee	2.2 (4)
Culture	QI culture; provider perceptions and attitudes about GOC communication; public communication about GOC culture	2.4 (5)
Adaptability	Training adjusted due to feedback and/or logistics	2.6 (2)
Incentives	Incentives offered for training; protected time for training; oncology provider incentives aligned with GOC program objectives	2.8 (3)

*1=Strongly Agree; 5=Strongly Disagree

During the implementation, all sites sought to align their GOC programs with other institutional priorities or programs. The majority (60%, n=12) connected their GOC program to billing practices (e.g., ACP billing), and 67% of those found that this alignment had a positive impact on their GOC program implementation. Sixty percent also explicitly linked their GOC program to other cancer center operational priorities (e.g., reducing ICU length of stay or

readmission rates) and 58% found that alignment to have a positive impact. The majority (55%, n=11) reported that use of the GOC program as an exemplar for external accreditors or certifiers (e.g., The Joint Commission) had a positive impact on their GOC program implementation. Half (10) reported aligning their GOC program and payer programs, and 40% reported that this alignment had a positive impact. Appendix C contains additional details about these items.

The Implementation Experience survey results reveal champions' perceptions of their site implementation. On average, respondents were positive about their implementation of IGCC core components, with agreement: that their center succeeded in implementing training (mean=1.8; note that this high score despite disagreement from the one center that did not implement training); about their ability to deploy useful and acceptable GOC documentation in their EHRs (mean=1.7); and that their site created definitions for meaningful and actionable priority patient populations for GOC discussions (mean=2.0).

Further, respondents generally perceived that these interventions were meeting initial goals, reporting that: training improved providers' ability to have GOC conversations (mean=1.8), EHR templates facilitated provider ability to have GOC discussions with patients (mean=1.8) and increased access to and retrieval of GOC documentation when needed (mean=1.7), and that priority population definitions were used to prospectively identify populations for GOC discussions (mean=1.8). Respondents perceived implementation success in change management with their provider colleagues, and that oncology providers understood the vision for the GOC program (mean=1.8).

Table 15*Implementation Experience Item Scores, Grouped by IGCC Component; Source: GOC**Implementation Survey*

Survey Implementation Experience Items	Mean Score*	Median Score	Min Score	Max Score
Training-Related				
Overall, my center succeeded in implementing our communication skills training program to oncology providers.	1.8	1.3	1	4.5
Overall, our communication skills training program improved oncology providers' ability to have goals of care conversations.	1.8	1.5	1	3.5
EHR GOC Documentation-Related				
At my center, we created useful, acceptable GOC documentation in our EHR.	1.7	1.5	1	3.5
At my center, oncology providers were accepting of the GOC documentation built into our EHR.	2.5	2.3	1.5	4
Overall, my center's EHR GOC build has increased access to and retrieval of a patient's documented goals of care when needed.	1.7	1.5	1	4
Overall, my center's EHR GOC build has improved providers' ability to document goals of care discussions.	1.8	1.5	1	4
Priority Definition-Related				
At my center, we created definitions for clinically meaningful and actionable priority patient populations for GOC discussions.	2.0	1.5	1	4
At my center, we applied our priority population definitions to prospectively identify patients for GOC discussions.	1.8	1.3	1	4
Overall Implementation				
At my center, we applied our definitions to trigger oncology providers to have GOC discussions.	2.2	1.3	1	5
Overall, my center was able to integrate GOC conversations into our clinical and operational workflows.	2.5	2.0	1	5
At my center, we were able to make a compelling case to oncology providers about the need for our GOC program.	1.8	1.5	1	4
Overall, oncology providers at my center understand the vision for our GOC program.	1.8	1.5	1	3.5

*1=Strongly Agree; 5=Strongly Disagree

Respondents reported the least agreement on items related to creating an acceptable and sustainable workflow. This included providers' acceptance of the GOC documentation built in the EHR (mean=2.5), and triggering providers to have GOC discussions with priority patients (mean=2.2). Ultimately, the lowest score of the Implementation Experience items was a mean of 2.5 about the overall integration of GOC conversations into clinical and operational workflows.

Finally, respondents' perceptions of the impact of their site GOC program implementation varied, as reflected in the Outcome Item scores (Table 16). There was strongest overall agreement that oncology providers place a high value on GOC discussions (mean=1.8; with scores ranging only from 1 to 2.5). All other items had scores ranging across the agreement/disagreement scale. There was least agreement that the GOC programs changed the culture of the cancer center (mean=2.5).

Table 16

Outcome Item Scores; Source: GOC Implementation Survey

Survey Outcome Items	Mean Score*	Median Score	Min Score	Max Score
Overall, oncology providers at my center have embraced the vision for our GOC program.	2.1	1.8	1	4
At my center, most oncology providers place a high value on goals of care discussions for our patients.	1.8	1.5	1	2.5
The changes implemented in my center as part of our GOC program have now become standard operations/standard of care.	2.0	1.8	1	4.5
The changes implemented in my center as part of our GOC program are likely to continue, despite future pressures and competing demands.	1.8	1.5	1	4
Overall, our GOC program changed the culture of our cancer center.	2.5	2.3	1	5
Overall, the GOC program at my center has improved patient care.	2.1	2.0	1	4.5

*1=Strongly Agree; 5=Strongly Disagree

Aim 2 Results: Describe enablers and barriers to IGCC implementation

The open-ended survey questions revealed multiple themes about the implementation experience at each of the participating cancer centers. The main themes offered by respondents are summarized below, with illustrative quotations.

- **Time.** Respondents frequently cited the barrier of providers' lack of time, and competing demands for their time. Relevant challenges mentioned included protected time for providers' communication skills training; the time needed to document about GOC in the EHR; and the time needed to have a GOC discussion in a patient visit.
 - "In theory, all clinicians were amenable to earlier GOC conversations with their patients and felt that they had learned the skills in the communication workshops. However, in busy clinics and inpatient settings, clinicians were busy and did not make GOC a priority."
 - "The time commitment for [the training program] was very challenging for busy providers. This was especially so for our general oncologists in the community areas."
 - "There is no protected time reserved in templates to have these discussions, mostly templates are overbooked ..."
- **Leadership support.** The importance of vocal, sustained support from cancer center executives was commonly mentioned by respondents. The contributions of leadership support included articulating the vision, integrating program goals into strategic plans, making resources and incentives available, communicating the benefits of GOC conversations and documenting GOC in the EHR, and the value of communication skills training. Some respondents at centers that experienced a leadership change during the

three-year implementation period found new leadership to be supportive, while others encountered resistance that slowed or de-railed their improvement efforts. Beyond the ‘c-suite’, respondents described the benefits of building additional champions among department heads or other clinical leaders.

- [A factor most critical to our success was] “vocal and consistent encouragement by leadership of the importance of training/GOC conversations as well as implications for patient care and outcomes.”
- “Strong support from the senior leadership including the cancer center’s CEO and President.”
- “Champion support was helpful at encouraging change...engaging champions who provided peer encouragement for the training.”
- Vision and culture. Respondents observed both the challenge and importance of effectively communicating the vision for their GOC program. They articulated the culture change that was required for implementation of centers’ GOC programs.
 - [A factor most critical to our success was] “communicating the goals and vision of the program and the impacts it will have on our patient experience and outcomes.”
 - “GOC documentation was a new process and required education and culture change...”
 - “One of the biggest challenges was helping providers understand this wasn't about end-of-life conversations... it was about communication, understanding and ensuring patients were informed and participated in their care at all stages of their cancer journey.”

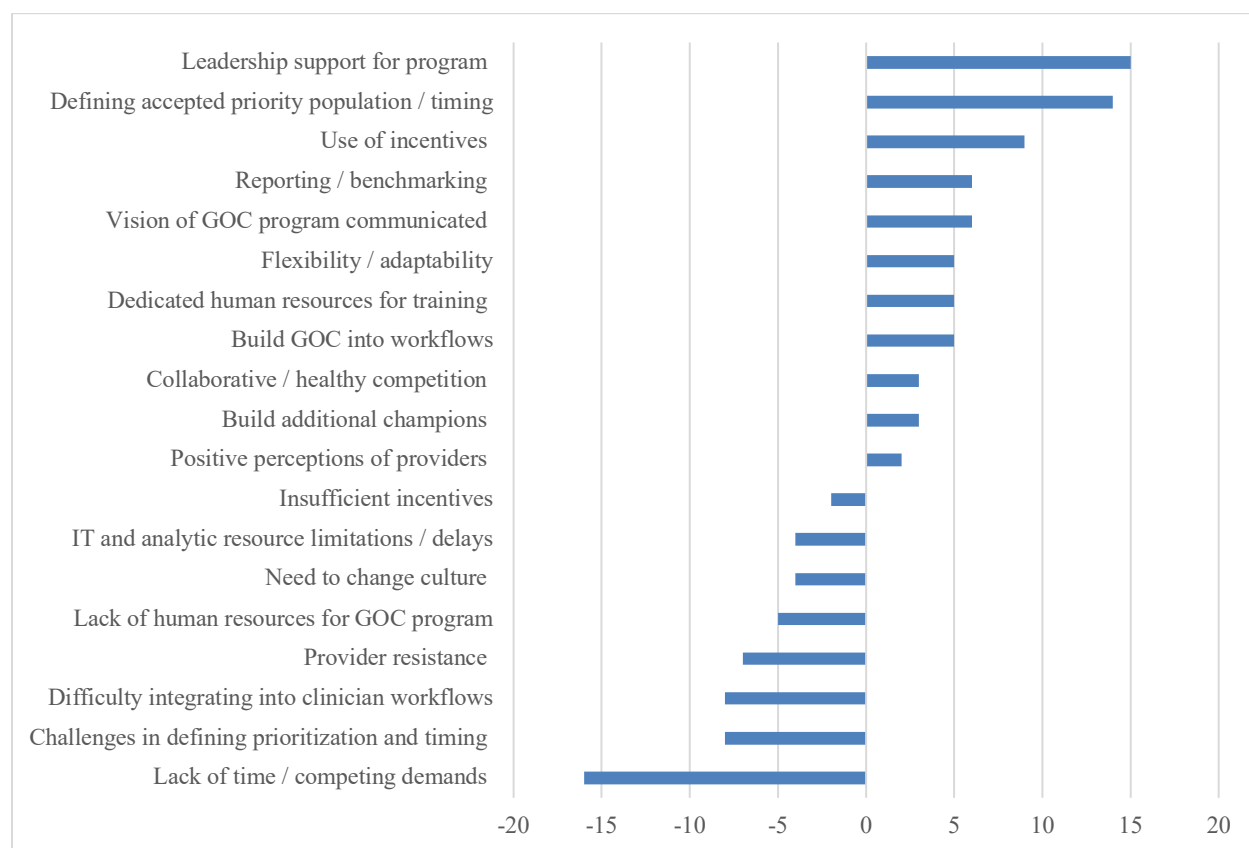
- Human resources. The most common staffing-related factor raised by respondents was administrative and project management time. Lack of IT and analytic resources was also referred to as a barrier, as these were needed to achieve changes to EHRs and related analyses and reports. Further, respondents mentioned the need for experienced trainers with financial support to conduct communication skills trainings.
 - [A major contributor to implementation success was] “having the quality group prioritize this project so they would help with reports, having the informatics group prioritize this project so they would create the templates, having the oncology leadership prioritize the project so that they would be willing to push for culture change within their physicians.”
 - “Changes occur slowly and dependent on IT availability and resource allocation for this project.”
 - “... a dedicated Program Manager who was able to coordinate the outreach and training” [was a key factor in their implementation success].
- Clinician workflows. Respondents shared the critical importance of integrating GOCC into providers’ workflows. This included creating efficient EHR documentation approaches and automation of processes. While triggers or nudges for providers were often raised as important contributors, some also noted that they need to be carefully designed to avoid having them be ignored by providers. Barriers raised included difficult or redundant EHR documentation requirements, and resistance of providers to use structured fields instead of free text (e.g., in progress notes) for nuanced GOCC.
 - “An easy-to-use, quick template with common language learned in our communication workshop was a contributor to use.”

- “Our most important finding is that we needed to develop a system within the EHR to identify the priority patient population and to nudge clinicians to initiate and document GOC discussions.”
- “GOC conversations can be wide ranging in content - from exploring values without any discussion about treatment preferences, to a very focused discussion about whether or not a patient wants the next cancer-directed treatment, to discussing transition to comfort care or hospice. It was challenging to create 1 structured note that could capture this whole range of discussions, but the process of trying to create a note helped our organization better understand and approach GOC conversations throughout the patient's cancer journey.”
- “Lack of nudges to remind clinicians to document a note was the biggest impediment to adoption.”
- “... the transplant and immunotherapy teams agreed that all patients facing these therapies should have a goals of care conversation as part of the intake process.”
- Provider perceptions. Respondents reflected on experiencing resistance from providers, including regarding the perceived benefits of training and of documenting GOCC. On the other hand, some reported positive perceptions of providers regarding the benefits of communication skills training.
 - “Providers initially were skeptical of benefit [of training] and saw this as ‘another thing to do’ ...”
 - [A major challenge was] “convincing trainees that [training] would benefit them and cut down the time of having GOC conversations.”

- Flexibility / adaptability. Several respondents indicated the importance of adapting their goals of care program, especially the training program and priority population definitions, based on experience and feedback from providers.
 - “Flexibility, modifying the course/cases to be more engaging and applicable to the providers we were training.”
 - “Use of a self-assessment for learners to state particular areas for focus of the training provided high value of training for time invested.”
 - “... analyzing what criteria have worked well and assessing what tweaks would be helpful to further refine priority populations.”
- Incentives. Most respondents mentioned financial incentives for training and/or GOC documentation in the EHR to be an integral aspect of implementation success. Protected time was also viewed by some as an incentive. The ability to provide incentives for GOC programs was described as closely tied to leadership support.
 - “Participation exponentially increased once it was incentivized.”
- Prioritization and timing. Respondents perceived that the most difficult intervention components to achieve were defining priority patients for GOC conversations and specifying expected timing of these discussions. They noted the need to carefully balance the benefits of these definitions for reliable and sustainable implementation with the need to maintain space for providers to use their clinical judgement.
 - “The priority population was initially challenging to describe and define in a simple and feasible manner that would make operationalizing it pragmatic and not overwhelming.”

- “Challenges ... were not overcome in determining specific hematological factors for determining priority populations due to the complexity of disease progression.”
- “Implementing priority populations...through an incentivized target created concern about supplanting clinician judgement instead of being a tool to augment clinical decision making.”
- Comparing and sharing. Respondents expressed the importance of providing reporting and benchmarking among providers, teams or departments within their centers. Additionally, they noted the utility of engaging in a collaborative for this initiative, for the best practice sharing and ‘healthy competition’ across the cancer centers.
 - [A major contributor to success in GOC documentation was] “inter-departmental competition and regular scorecard reporting.”
 - “Reporting data back to the clinicians seems to work well and provide additional motivation for early goals of care conversations.”
 - “Despite [our] hurdles, we’ve observed steady progress through regular feedback mechanisms and consistent reporting of usage data.”
 - “Also reminding our faculty that their colleagues at the other elite NCI centers were also undergoing or had completed this training.”
 - “Regular discussions and support from other [IGCC participating cancer centers] have been invaluable to our progress.”

Figure 6 presents the relative frequency of the main themes emerging from the qualitative analysis when described as an enabler (displayed as a positive number) or as a barrier (displayed as a negative number).

Figure 6*Implementation Enablers and Barriers at IGCC Sites**

*By theme frequency among open ended survey items; barriers presented as negative numbers and enablers as positive numbers

Aim 3 Results: Assess which organizational contextual and facilitation factors are most closely associated with successful implementation

Organizational Characteristics and Implementation Experience Scores

The first findings for this aim reveal the organizational characteristics that were most closely associated with positive implementation experiences at the IGCC centers. The strength of correlations across Domain Category and Implementation Experience item scores are summarized in Figure 7, and numerical results are in Appendix D, Table D1. Overall, there were

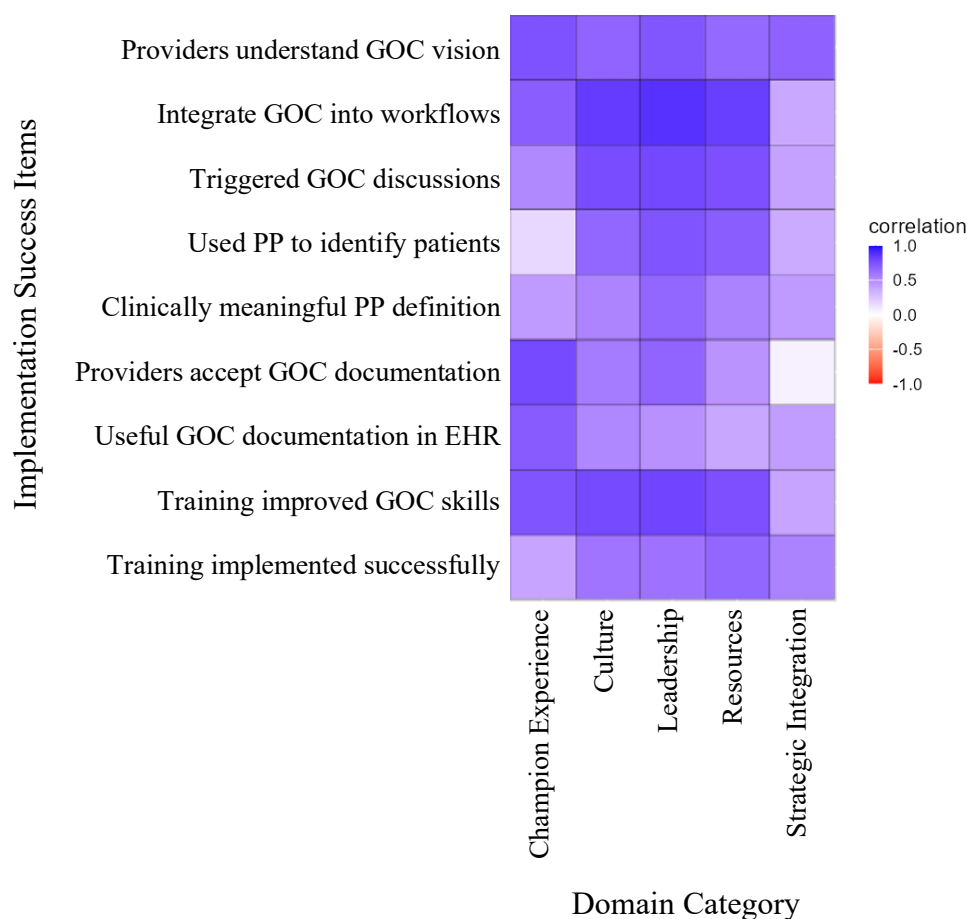
no very strong correlations, 17 strong correlations, 23 moderate correlations, five weak correlations, and two very weak correlations across the Domain Category scores and Implementation Experience item scores.

Leadership, Resources, and Champion Role had the strongest associations with the Implementation Experience items, followed by Culture (Leadership: correlations ranging 0.47 - 0.88, with five strongly correlated items; Resources: correlations ranging .038 - 0.83, with four strongly correlated items; Champion Role: correlations ranging 0.17 - 0.78, with five strongly correlated items; Culture: correlations ranging 0.52 - 0.84, with three strongly correlated items). Strategic Integration had no strong correlations with Implementation Items, indicating less importance for positive implementation experiences.

Figure 7

Strength of Domain Category Correlations with Implementation Items; Source: GOC

Implementation Survey



Implementation Experience Scores and Outcome Scores

The next findings in this aim describe respondents' perceptions of successful implementation of IGCC components along with achieving desired outcomes changes (Figure 8 provides a visual summary, and numerical results are in Appendix D, Table D2). Correlation strength varied among Implementation Experience items and Outcome items (two very strong,

11 strong, 36 moderate, three weak, two very weak). Considering the Implementation Experience items related to the three IGCC core components:

- The training-related implementation success items generally had moderate association with the positive Outcome items, except for a very strong correlation between training improving providers' GOC conversation skills and providers embracing the vision of the center's GOC program.
- The two EHR GOC documentation-related implementation success items also had the strongest correlation with the outcome of providers embracing the vision of the center's GOC program, while correlations with the outcome of providers valuing GOC discussions were weak; all others were moderate.
- The two priority population implementation success items were moderately correlated with the positive outcome items.

Providers' understanding the GOC program vision had the strongest correlations with the desired Outcome items, followed by the two workflow-related Implementation Experience items (integrating into workflows and triggering GOC discussions). Providers understanding the GOC program vision was very strongly correlated with one outcome (GOC program changes likely to continue), strongly correlated with four outcomes (providers embracing the vision of the GOC program; GOC program changes becoming standard practice; the GOC program changing the center's culture; and the GOC program improving patient care), but weakly correlated with providers valuing GOC discussions.

Triggering GOC conversations was strongly correlated with the GOC program changes becoming standard practice, and moderately correlated with all other positive outcomes.

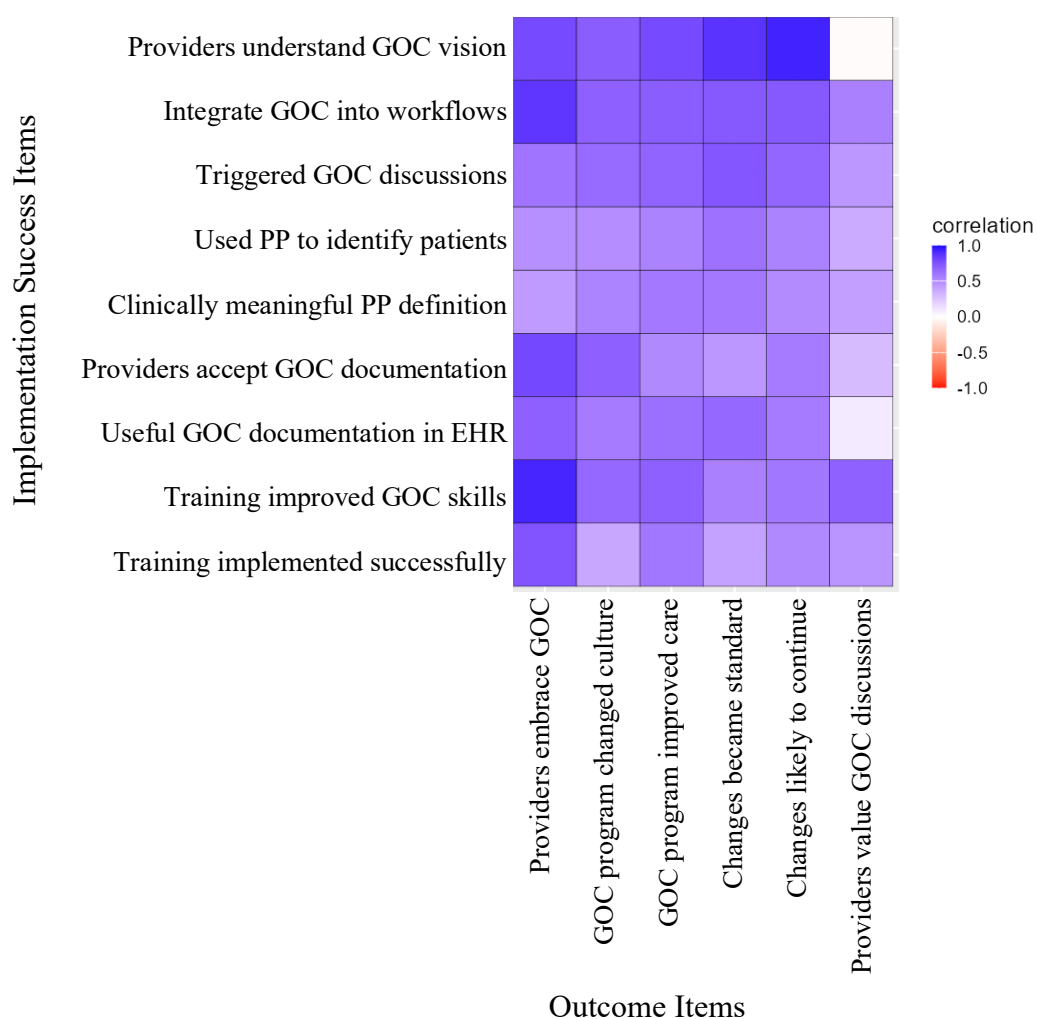
Integrating GOC into workflows was strongly correlated with four positive outcomes (providers

embracing the vision of the GOC program; GOC program changes becoming standard practice; GOC program changes likely to continue; the GOC program improving patient care) and moderately with the GOC program changing the center's culture and providers valuing GOC discussions.

Figure 8

Strength of Implementation Item Correlations with Outcome Items; Source: GOC

Implementation Survey



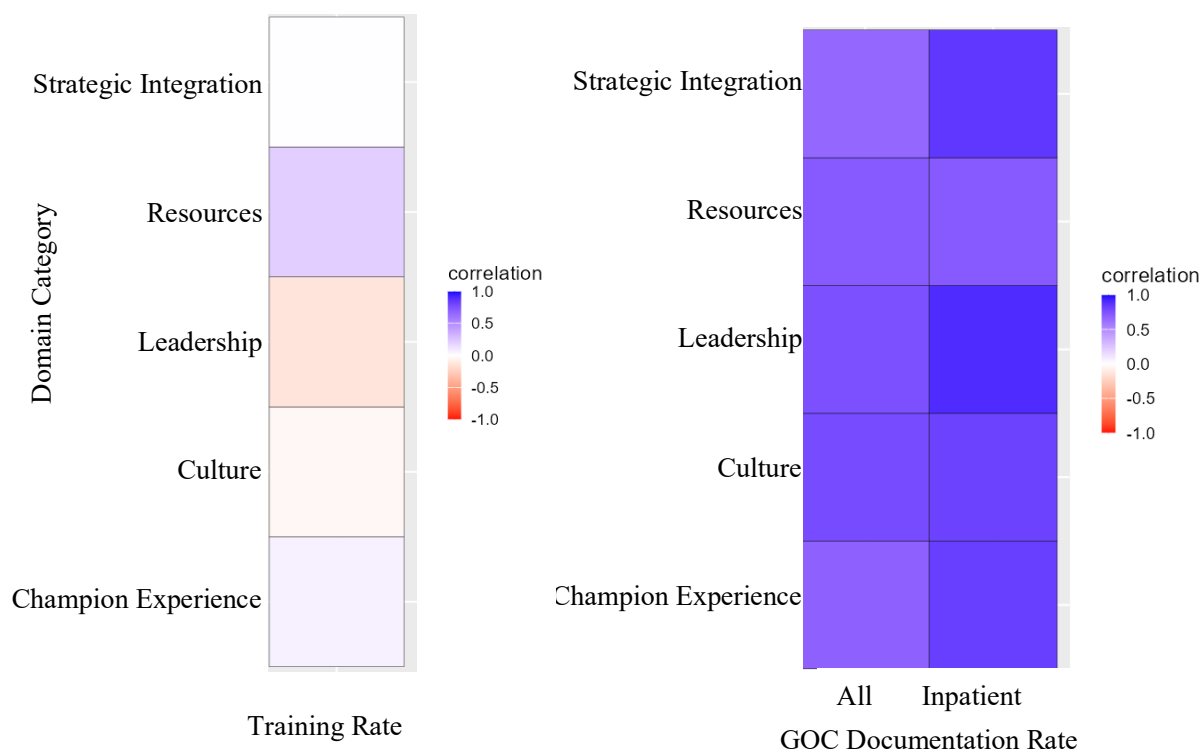
Organizational Characteristics and Process Measure Scores

Finally, the survey Implementation Experience items were replaced with data reported from the IGCC process measures. The analysis to explore the Domain Category correlations with the communication skills training rate process measure revealed little to no association, with weak or very weak correlations (Figure 9). On the other hand, the Domain Category correlations with GOC documentation rate in the final quarter of reporting (2024-Q4) showed strong relationships. Scores from each of the Domain Categories (Champion Role, Culture, Leadership, Resources, and Strategic integration) were strongly associated with the measure rates for GOC documentation. These strong associations persisted for GOC documentation measured among all decedents and for GOC documentation measured among those who died while admitted as inpatients.

Figure 9

Strength of Domain Category Correlations with Communication Skills Training and GOC

Documentation Rates; Source: GOC Implementation Survey and IGCC Process Measures



Mixed Methods Results

As a final step in compiling results, I merged key findings from across the data sources in this study and organized them according to i-PARIHS framework construct in Table 17.

Implications and recommendations for future implementations resulting from this collation are explored in detail in the following chapter.

Table 17*Key Findings, Interpretation and Recommendations for Future Implementations*

i-PARIHS Construct	Quantitative Data	Qualitative Data	Recommendations
Organizational Factors	<u>Survey, Summary</u> The Leadership and Resources domain categories had among the strongest associations with implementation success items. Champions generally felt that they had leadership support and the resources needed for their implementation. Champions from only one site disagreed with having leadership support. They did not perceive that there was adequate protected time for training or adequate oncology provider incentives aligned with GOC program objectives Most did not agree that their GOC program goals were integrated into centers strategic plan or discussed with Board -level leadership. They did not agree that messaging related to the GOC program was integrated into public/patient-facing communications.	<u>Open-Ended Items, Summary</u> Champions reinforced the importance of vocal, sustained support from cancer center executives, including articulating the vision, integrating program goals into strategic plans, making resources and incentives available. The human resources available were often considered insufficient, especially administrative, project management, IT and analytic resources. Champions considered financial incentives for training and/or GOC documentation in the EHR is an integral aspect of implementation success. Protected time was also viewed by some as an incentive. The ability to provide incentives for GOC programs was described as closely tied to leadership support.	Institutions must understand and be ready to provide the leadership support and resources necessary. Success will require broad organizational alignment to ‘change how we do business.’ This includes integration into strategic plans and goals, provider metrics and incentives.

i-PARIHS Construct	Quantitative Data	Qualitative Data	Recommendations
Recipient Factors	<u>Survey, Summary</u> Providers' understanding the GOC program vision had one of the strongest correlations with the desired Outcome items. Champions felt that they were able to make a compelling case to oncology providers about the need for our GOC program, and that the vision was understood. They agreed that providers generally were accepting of care delivery improvements, and that they had a positive attitude about communication skills training. They perceived that oncology providers place a high value on GOC discussions.	<u>Open-Ended Items, Summary</u> Champions reported that providers' lack of time, and competing demands for their time, is a major barrier. They noted that provider culture change is required for GOC implementation. All faced some degree of resistance from providers, including regarding the perceived benefits of training and of documenting GOCC. They perceived that vision of the GOC program must be effectively communicated.	The competing demands for provider time must be accounted for and addressed in the implementation – not just adding another responsibility. Provider resistance is to be expected, especially beyond the early adopters. Provider understanding of the GOC program vision is critical and should be part of a change management plan.
Facilitation and Implementation Factors	<u>Process Measures, Summary</u> 9/10 sites implemented training for oncologists and APPs. 1762 of 2,421 eligible providers were trained, for a 73% rate across 9 sites. Training rates ranged 48% - 77% across oncology provider types.	<u>Open-Ended Items, Summary</u> Champions indicated that integrating GOCC into providers' workflows is of critical importance, including creating efficient EHR documentation approaches and automation of processes.	The entire workflow should be mapped before implementing interventions. Testing and refinement of the workflow should be part of the implementation plan. Although difficult, defining priority populations for

i-PARIHS Construct	Quantitative Data	Qualitative Data	Recommendations
	Center-level training rates ranged 36% to 100%. 10/10 sites changed their EHRs to capture the agreed upon GOC fields; 1 was too late to be included in measurement. By the final measurement, the aggregate GOC documentation rate among 9 centers was 39% for all decedents and 56% for inpatient decedents. Aggregate GOC documentation rates significantly improved from the first to final measurement quarter. Training rates were only moderately correlated with GOC EHR documentation rates. <u>Survey, Summary</u> Generally, Implementation Success scores of the three IGCC core components (training, EHR GOC documentation, priority population definition) were only moderately correlated to positive Outcome items. The Champion Role was one of the domain categories with the strongest	The most difficult intervention components to achieve were defining priority patients for GOC conversations and specifying expected timing of these discussions. Champions responded that an overall contributor to success was tapping into ‘healthy competition’, by providing reports with comparison among providers, teams or departments within the centers, and by comparison across the cancer centers.	GOCC and timing expectations are critical to integration. Consider feasible automation during development. Offering a communication skills training program is insufficient to achieve training penetration among providers. Creating a GOC EHR template is insufficient to achieve GOC documentation. Plan for marketing, and carrot and stick influencers (e.g., use of incentives and/or mandates). Stakeholder-specific reports, with benchmarking, should be created, refined, and used. Site champions will be critical to implementation success. Champions should be carefully selected and provided sufficient, dedicated time to perform the role.

i-PARIHS Construct	Quantitative Data	Qualitative Data	Recommendations
	associations with positive Implementation Experience. Workflow-related Implementation Experience items (integrating into workflows and triggering GOC discussions) were among the strongest correlations with the desired Outcome items. Champions did not feel they had successfully integrated GOC conversations into clinical and operational workflows. Overall, the site champions found their GOC work rewarding and personally important, felt that their work as champion was recognized, and desired to continue to serve as a champion in this work.		Additional research into real-world implementation of GOC programs is needed to refine interventional components to maximize desired outcomes for patients/caregivers, providers and the healthcare system. Programs should be implemented with a rigorous evaluation plan.

CHAPTER 5

DISCUSSION

This mixed-methods evaluation study describes the IGCC implementation experience across 10 cancer hospitals, including the organizational and implementation factors that contributed to operational integration and improvement in GOC discussions. This is the largest known multi-site study to date of an intervention to enhance GOCC among patients with advanced cancer. This study contributes to the literature by integrating empirical data from evaluation process measures with quantitative and qualitative survey items from implementation champions at each of the cancer centers.

Implications for Public Health and Healthcare

Despite advances in detection and treatment, the incidence, prevalence and mortality of cancer continue to be major public health issues in the United States. This year, we will face the unfortunate milestone of more than 2 million new cancer diagnoses in the US (Siegel et al., 2024). Cancer treatment is one of the most substantial contributors to healthcare expenditures in the country, and the US spends more on cancer care than any other country (Li et al., 2020). The cancer costs borne by society – and by patients and their families – are disproportionately attributable to those with advanced cancers nearing the end of their lives (Yarbroff et al., 2021; Mariotto et al., 2020).

Patients with advanced cancer want to be engaged in shared decision-making about their care (Back, 2020; Collins et al., 2018; Wright et al., 2008; Hagerty et al., 2005), and professional guidelines reinforce the oncologists' responsibility in engaging patients in effective shared

decision-making communication and practices (Ferrell et al., 2017; Gilligan et al., 2017). GOCC are a crucial aspect of this shared decision-making spectrum; in the absence of these discussions, people with cancer tend to receive cancer treatments that are inconsistent with their wishes and more costly (Starr et al., 2019; Zhang et al., 2009). Conversations with patients with advanced cancer about their prognosis-informed goals empowers the care team with essential information to deliver patient-centered care. These GOCC can align care with what matters most to patients, improve their quality of life, psychologic outcomes, and satisfaction, and empower them to be actively involved in decisions as their cancer changes (Mayland et al., 2021; Bernacki et al., 2019; Wright et al., 2010; Wright et al., 2008; Clayton et al., 2007). For clinicians, education aimed at improving comfort with these conversations can enhance their relationships with their patients and colleagues, improve job satisfaction, and reduce anxiety associated with having difficult conversations (Harnischfenger et al., 2022). For health systems, providing the infrastructure to promote earlier conversations about goals and values can improve satisfaction and decrease costs (Starr et al., 2019; Patel et al., 2018). Together, at a system level for cancer care delivery, longitudinal GOC discussions conducted by oncology teams align with all aspects of the quadruple aim (Bodenheimer & Sinsky, 2014).

Yet, GOCC rarely occur in routine oncology practice (Epstein et al., 2022; Mack, Cronin, Keating et al., 2012; Mack, Cronin, Taback et al., 2012). Like many challenges in care delivery, the reason for this enduring gap is captured by the well-known saying, “Every system is perfectly designed to get the results it gets,” which was informed by (and is often attributed to) the pioneering engineer W. Edwards Deming and coined by Dr. Paul Batalden of the Institute of Healthcare Improvement (Proctor, 2008). Changing clinical care is not accomplished by changing an individual’s actions; rather, it is accomplished by adjusting the healthcare system in

which individuals operate. This concept is central to the field of implementation science, which has evolved as a dedicated discipline to drive the uptake, adoption, and sustainability of evidence-based interventions to enhance care delivery (Damschroder et al., 2009).

Implementation scientists seek to systematically identify barriers and facilitators to achieving desired system change. The i-PARIHS framework used in this research guides consideration of the organizational context in which the implementation is carried out and the facilitation of the implementation (Harvey & Kitson, 2016).

Thus, this structured exploration of the enablers and barriers to the IGCC implementation is intended to enrich the lessons that can be drawn from measure analysis alone. My research provides a nuanced understanding of the enablers and barriers that influenced the IGCC process measure results across the 10 complex cancer systems. Most importantly, description and dissemination of these findings can help other cancer centers to more effectively and efficiently implement similar, real-world interventions. When you consider that there are 1,500 clinical institutions across the country (American Society of Clinical Oncology, 2024) where care is provided to more than 600,000 people who die from cancer each year (Siegel et al., 2024), the importance of these findings becomes clear.

Interpretation of Implementation Success

This research provides insight into the potential for a real-world, collaborative initiative to promote change across 10 institutions. This evaluation revealed notable progress in some areas and room for ongoing development in others.

Communication Skills Training

Nine of the 10 centers implemented communication skills training programs for oncology physicians and oncology APPs. Seven of the nine sites surpassed the IGCC training target of

65%, while the other two had rates well under half of eligible providers. This analysis revealed that 1,762 of 2,241 eligible providers were trained. Of those trained, 776 were physician oncologists. According to ASCO, there were 15,959 practicing oncologists in the US in 2023 (American Society of Clinical Oncology, 2024); thus, the IGCC collaborative resulted in communication skills training for 5% of practicing oncologists in the country at the time of the final data submission. When surveyed following the implementation period, the site champions from the nine centers strongly agreed that their site had succeeded in implementing the training, and perceived that training improved their providers' ability to engage in GOCC.

It is important to note that training rates differed across provider types. In aggregate, the centers had most training success with subspecialist medical oncologists and oncology APPs, with more than three-quarters of each provider type receiving training. These two provider types also represent the vast majority (86%) of eligible providers across the centers. The other two provider groups, 'general oncologists' and hematologic oncologists, have smaller proportional representation among eligible providers but garnered more discussion during the IGCC conceptual planning phase. Most of the IGCC participating centers employ general oncologists, who treat a range of cancer diagnoses, usually at satellite locations of the cancer center (as compared to subspecialist medical oncologists or hematologic oncologists, whose practice is subspecialized by cancer types such as thoracic, gastrointestinal or lymphoma). During IGCC planning, leaders were concerned about the ability to engage the general oncologists in communication skills training, given their heavy clinical loads and (in some instances) schedules involving days spent at distant practice locations. Ultimately, the study revealed that centers were only able to achieve an aggregate 48% training rate among general oncologists.

For hematologic oncologists, the leaders planning IGCC were concerned about known differences in hematologic practice patterns and norms. A portion of hematologic malignancies are acute, and these diseases can have a more unpredictable course of illness and complications (Salins et al., 2020). Compared to other cancers, patients with hematologic malignancies are more likely to be admitted to the hospital and receive life-sustaining treatment near the end of life (Hui et al., 2014) and less likely to receive care from specialist palliative or hospice services (Prod'homme et al., 2018). Hematologic oncologists have been shown to be less comfortable with death and dying than medical oncologists, more concerned about taking away patient hope, and less comfortable with prognostication (Prod'homme et al., 2018; Hui et al., 2015; Odejide et al., 2014); ultimately, less likely to engage their patients in GOC discussions (Graham et al., 2023). For these reasons, IGCC leaders anticipated that hematologic oncologists would be more resistant than medical oncologists to receiving communication skill training and documenting GOC discussions. Still, they determined that inclusion of hematologic oncologists in training and measurement was important to achieve meaningful operational improvements stemming from IGCC. This research found that overall communication skills training rates were 62%, lagging that of medical oncologists but nearing the IGCC target rate.

GOC Documentation in the EHR

Before launch of the collaborative, the IGCC participating sites agreed upon a standard set of documentation areas to capture a complete GOC note in the EHR, but did not specify the exact field name language to be used or the functionality for data capture (e.g., through a dedicated template or tab vs a ‘smart phrase’). This flexibility reflected the fact that centers had different electronic systems, documentation expectations/policies, relevant fields already existing at the start of IGCC, and comfort with patient access to GOC documentation reflected through

patient portals. By the completion of the IGCC implementation period, all sites succeeded in modifying their EHRs to capture GOC discussions in structured fields (even though one center's 'go-live' date was too late for inclusion in the evaluation measurement). This success deserves recognition, as navigating the institutional or health system process for EHR modifications is complex and often underestimated, but critical to achieving operational improvements in healthcare (Carr et al., 2023).

Five of eight centers (63%) showed significant improvement across the measurement periods for GOC documentation among all decedents, and six of nine (67%) among inpatient decedents. The site champions reported overall agreement that they succeeded in deploying useful and acceptable GOC documentation in their EHRs. Moreover, the site champions perceived that their EHR builds met initial goals, in facilitating provider ability to have GOC discussions with patients and increasing access to and retrieval of GOC documentation when needed.

It is assumed that the IGCC measurement of GOC documentation in structured EHR fields underestimates actual GOC discussions, since some of these occur and are documented only in text-based progress notes. Using structured fields for GOC documentation can be perceived by providers as too restrictive to describe complex discussions, overly time-consuming, and/or divergent from standard documentation workflows; as much as 80% of clinical information in EHRs is text-based (Lindvall et al., 2022). Early research has shown that GOCC can be identified from text-based documentation using natural language processing and machine learning (Lee et al., 2023; Lindvall et al., 2022; Lee et al., 2021). While these approaches may offer future alternatives, a key driver of the IGCC requirement for structured GOC documentation was the ability to easily access and retrieve relevant documentation in

subsequent visits or admissions. Presently, this requires use of structured fields; however, there is promise for clinician-facing EHR tools that use natural language processing and machine learning applications to locate prior, narrative GOC documentation and synthesize it into meaningful, actionable summaries at the point of care (Lee et al., 2021).

Finally, the difference between the IGCC GOC documentation rates among all decedents and among inpatient decedents warrants comment. Across the measurement time periods and most of the IGCC sites, GOC documentation was higher among those who died while admitted at the reporting cancer center than those who died elsewhere. This research did not evaluate the cause of this difference, and it is probable there are multiple contributing factors. One likely contributor can be drawn from the literature; research has shown that GOC discussions too often occur during an inpatient hospital admission and very close to death (Knutzen et al., 2021; Mack et al., 2012). Advocates for goal concordant care promote ‘earlier and better’ GOC discussions (Manz, Rocque, & Patel, 2023), well in advance of death and in settings that foster open communication. Higher GOC rates among those who die as inpatients within the reporting center may indicate that these discussions are happening too late and during a time of crisis for the patient and their caregivers. Unfortunately, more nuanced study of the place and timing of GOC conversations was beyond the scope of the IGCC evaluation.

Relationship Between Training and GOC Documentation

Results of this study showed only moderate correlation between communication skills training rates and GOC documentation rates – although both increased during the study period, the sites with the highest training rates were not necessarily the sites with the highest GOC documentation rates. Foundationally, communication skills training focuses on building the quality and efficiency of the GOCC, and not on documentation. Still, the IGCC sites agreed to

integrate education about completing GOC documentation in the EHR as part of their training curriculum (either integrated into the communication skills training program or following completion). While myriad factors can impact GOC documentation rates, these findings may indicate 1) the need for ongoing refinements of the IGCC centers' training programs; 2) the need for additional post-training support for providers, reinforcing documentation; and/or 3) the need for EHR build and workflow refinements.

Priority Population Definition

Of the core components, the IGCC sites had most difficulty creating and automating the priority population definitions needed to designate patients who would most benefit from GOCC. While this study did not dive deeply into the contributing factors, qualitative results suggest that challenges included provider discomfort with prognostication and concerns about these definitions replacing clinical judgement; these findings are consistent with previous studies (such as Paladino et al., 2022; Parikh et al., 2022). Further, IGCC sites found automating complex priority population definitions to be challenging, as they required the existence and use of structured fields in the EHR or other HIT systems, or the development of an advanced alternative such as the use of machine learning models (Manz et al., 2020). While implementing this IGCC core component proved difficult, ongoing development of actionable definitions of priority populations and timing for GOC is crucial for reliable integration of these discussions into the standard workflow. Overall, this continues to be a work in progress for the IGCC sites.

Impact on Outcomes

As discussed in Chapter 2, measurement difficulties challenge the assessment of interventions to improve GOC documentation and goal concordant care. In this study, the GOC Implementation Survey was a tool to assess champion perception of GOC program outcomes at

their center. All champion respondents agreed or strongly agreed that providers at their centers place a high value on GOC discussions. Otherwise, champions were less positive about impact on outcomes, and their responses varied considerably across the 10 sites (e.g., on items related to sustainability). Most notably, champions were uncertain about the GOC program changing the culture of the cancer center or improving patient care. After three years of devoted effort, these are somewhat sobering findings and serve as reminders that practice transformation is difficult and time-consuming. The IGCC participating centers have opportunities to continue to refine their GOC programs based on the lessons learned from this collaborative and its evaluation, and to study the patient, provider and system impacts. The major enablers and barriers identified in this research will remain relevant to the ongoing development and sustainability of these programs across the IGCC centers.

Interpretation of Major Enablers and Barriers of Implementation

Successful implementation of the GOC program at each center was heavily reliant on the enduring support of the cancer center leaders. This finding reinforces previous qualitative studies of GOC implementation success (Kumar et al., 2023; Andersson et al., 2022; Paladino et al., 2022) and is a commonly cited factor in implementation science (Li et al., 2018). The willingness of the CEOs at all 10 cancer centers to co-author a commentary article early in the initiative (McNiff et al., 2022) resulted a public commitment to implement GOC programs at their own centers, under the collaborative IGCC umbrella. By the end of the collaborative, the site champions noted the importance of leaders' vocal reinforcement of the GOC program, and their willingness to 'walk the walk' by attending communication skills training early and supporting the experience.

The IGCC implementation provided a case study regarding the impact of leadership investment. Early in the IGCC intervention period, Cancer Center 10 experienced changes in several executive positions. Unfortunately, that site became the outlier that did not implement communication skills training. Survey and qualitative responses from site champions reveal that the new leadership did not prioritize the previously planned GOC interventions at that site. Center champions continued to participate in IGCC activities and to advocate as possible within their site. This center had invested early in creating a GOC documentation template in the EHR and had among the highest rates of GOC documentation by the first IGCC measurement (35% of all decedents and 54% of inpatient decedents, compared to 11% and 15% for the IGCC aggregates, respectively). Without further leadership support, GOC documentation decreased by the final measure (33% of all decedents and 42% of inpatient decedents), resulting lower than the IGCC aggregate rates (39% and 56%, respectively).

Several other key enabler or barrier factors revealed from the IGCC evaluation were tightly related to leadership support. One was the availability of resources, including staffing resources, as has been shown in other studies (Kumar et al., 2023, Paladino et al., 2022). To implement their GOC programs, the centers had to cover the direct costs for vendors to conduct the communication skills training (either with trainers onsite or via a train-the-trainer model), or, in the case of one center, the costs for professional development experts to create a new training program that met the IGCC requirements. Some of the IGCC sites also had distinct expenditures associated with the EHR modifications. Even with leadership support, approval of these charges led to substantial implementation delays in some instances.

IGCC champions provided mixed responses regarding the adequacy of staff resources to contribute to their GOC program implementation. The IGCC evaluation reinforces other

published studies that described the need for expert trainers to conduct communication skills training and HIT staff resources to modify EHRs (Kumar et al., 2023; Paladino et al., 2023). This research also identified the importance of dedicated project/program managers and administrative staff to contribute to day-to-day implementation of the centers' GOC programs. Center champions found that a large operational endeavor was required to achieve even the minimum expectations of IGCC participant implementations, and this could not be done by relying on staff to take on unplanned work or make progress 'in their free time.' Moreover, once centers started to work toward creating sustainable workflows, they encountered the need for expert staff who could create informatics solutions, including sophisticated reporting, system automation, and use of natural language processing or artificial intelligence (e.g., to identify high risk, priority patient populations).

Additional factors closely aligned with leadership support were protecting time and use of incentives. Provider lack of time has previously been described as a major barrier in implementing GOC programs (Kumar et al., 2023; Andersson et al., 2022; Piggott et al., 2019) and was predicted to be a challenge prior to IGCC launch. Despite various approaches attempted by the cancer centers during the implementation period, provider time endured as one of the most significant barriers identified by the IGCC champions. Most sites rejected mandating the communication skills training, due to concerns of adding to the burden of provider trainings already required by regulation and/or due to cultural norms. To encourage participation in training, which required several hours of dedicated time, some sites allowed those hours to count toward the targets set for clinical or administrative time. Other centers offered a financial incentive for completing training. Encouraging the completion of GOC discussions (and the associated documentation) was more difficult. IGCC sites that attempted to incentivize GOC

documentation using a quality measure found definition of the denominator – usually the priority patient population – to be difficult to actualize. An added complication is that the incentive structures for physicians and APPs are different at the IGCC sites, so distinct solutions are required for both. Regardless, the champions considered incentives to be central to implementation success.

Further, this research highlighted the difficulty in adjusting patient visit schedules to provide adequate time to have GOC discussions – a challenge reflecting the intersection of time barriers and workflow barriers. Indeed, this research revealed workflow integration as one of the most difficult aspects of implementation. Among the Implementation Experience survey items, the lowest aggregate score from champions was for overall integration of GOC conversations into clinical and operational workflows. The IGCC champions were uncertain about their success in achieving provider acceptance of the GOC documentation and the ability to trigger providers to have GOC discussions.

The IGCC sites generally prioritized launching training programs and building EHR documentation capability, and then focused on efforts to anticipate or address overall workflow barriers. While it might have seemed overwhelming to the IGCC champions to engage more proactively in workflow planning, this may have ultimately streamlined a sustainable implementation. As a multi-site operational improvement initiative, the IGCC evaluation provides valuable insights in this area. Among the QI studies in the literature, only a few (Seevaratnam et al. 2024; Kumar et al., 2023; Hanson et al., 2017) attempted to operationally integrate a multi-component intervention similar to IGCC, and these were limited to single systems. The research studies reviewed in Chapter 2 are critical in building the evidence base for workflow integration (e.g., the Manz, Zhang, Chen et al., 2023 clinical trial testing triggers for

GOC conversations) but these do not represent truly real-world implementation. Workflows in these cancer center environments are complex, with highly inter-connected systems of people, infrastructure and processes. Interventions to improve care create disruptions to the system (Clarkson et al., 2018) that need to be anticipated and addressed. IGCC sites that approached implementation with a quality improvement mentality may have been too discretely focused to account for system complexity.

The IGCC collaborative provides an especially interesting opportunity to understand the role of the champion. The value of a dedicated champion is a common theme in quality improvement and implementation science, but the champions' experience and impact have not been well explored in the GOC literature. The IGCC champions – oncology and palliative care leaders from each organization – devoted countless hours to leading their site implementation and participating in the collaborative. When surveyed, the champions reported finding it difficult to balance their workload and time needed for the GOC program implementation. It is reassuring that the survey also revealed strong agreement from the champions that serving in that role was important to them personally, and that they found the work of leading their GOC program implementation to be rewarding. Most agreed that their work as a champion was recognized within their center. After three years, these leaders remain engaged and committed, as indicated by the strong agreement that they would like their champion role to continue as their center seeks to sustain or grow the GOC program. The majority agreed that the GOC champion experience will have a lasting impact on their career path.

This research also explored whether these findings regarding the champion role were associated with the implementation success at these sites, as the i-PARIHS framework tells us that the constructs of influence in an implementation includes both the organizational context

and the facilitation. These champions' facilitation efforts were in fact important: the Champion Role Domain Category scores were found to have some of the strongest associations with positive Implementation Experience items. In my lived experience throughout the IGCC collaborative, the commitment displayed by the IGCC champions is best described as passionate. Although observational and subjective, I believe that the champions' passion has been a major enabler of implementation success across the centers.

Key Recommendations for Cancer Centers Planning GOC Programs

The main driving force for this evaluation study was a desire to produce recommendations to help other cancer centers to more effectively and efficiently implement GOC programs. The results of this study, summarized above and described in Table 17, informs a set of recommendations for future efforts to implement interventions to improve goal concordant care for advanced cancer patients.

1. *Practice transformation requires a business plan, not an improvement plan.* Much of healthcare has embraced the quality improvement philosophy, and small pilot studies are commonplace. Unfortunately, those seeking practice transformation are unlikely to achieve it through organic scaling of a successful pilot. The IGCC centers would have been better positioned for sustainable success with more structured, consistent planning prior to implementation. In addition to standard business planning activities and content, specific recommendations include:

a. *Map out a full, integrated workflow that is enabled by technology.* Apply lessons from health system engineering / safety science, which recognize that complex systems need to be engineered to make it easy for people to do the 'right thing' (Donaldson, 2008). The GOC workflow should include identification of

patients who should have GOCC; timing of these discussions; triggering functions for the discussions; decision aids that can guide oncology team members in having the discussion; technology for direct patient engagement; EHR documentation that is acceptable to oncology team members; and GOC documentation that is accessible and retrievable. Engage diverse stakeholders in this mapping process, including process improvement and informatics experts (if available).

- b. Fully define the human resources required*, including project managers, administrative support, HIT, and informatics. It is not realistic to assume that staff can simply add to existing workloads.
- c. Project the costs and the return on investment (ROI)*. ROI calculations should be specific to the cancer center/institution; select those that are meaningful to leadership. For instance, some institutions may be motivated by a research-informed ROI of \$1,500 reduction in spending in the last month of life (Kumar et al., 2023) and others by significant decrease in ICU mortality and length of stay (Hui et al., 2023).

- 2. Seek enthusiasm, not just buy-in, of key leaders*. It is commonly suggested that those seeking to gain support for organizational change in healthcare should focus on buy-in (for example, James, 2020). Implementing a GOC program entails both workflow and cultural changes, requiring commitments from leaders and champions that exceed buy-in. An institution that is lacking strong enthusiasm and deep personal commitment from senior leader(s) and champions who will oversee implementation is unlikely to be successful.

3. ***Make the commitment to the program visible.*** Goals, objectives and measures related to the GOC program should be integrated into the cancer center's strategic plan and/or annual goal planning. Progress and metrics should be shared with the Board and/or other executive leaders. Messaging related to the GOC program should be incorporated into public facing descriptions of organizational priorities.
4. ***Include an incentive plan.*** Healthcare organizations design provider incentive plans to encourage desired behaviors or practices. Including GOC program components – like completion of communication skills training and achieving targets for GOC discussion documentation – into provider incentives is an important signal of institutional commitment and an important step for changing the standard of care.
5. ***Plan for change management and framing.*** Implementing a GOC program requires culture change, especially for providers. Program planners should carefully consider how and when providers will be informed, educated, engaged, and expected to act. Further, sites can prepare messaging that is most likely to overcome provider resistance. This may be a compiling data and/or preparing a compelling story about the impact on patients and their caregivers. This may also be framing the GOC program approach differently; for instance, IGCC sites were intrigued by framing goals of care as an aspect of precision medicine (e.g., your care is tailored based on your diagnosis, genomics, and wishes/values).
6. ***Use a team approach.*** Even physicians who are receptive to training and engaging patients in GOC discussions will face major barriers from time limitations. APPs can also lead GOCC; however, emerging evidence indicates that other clinical team members, including nurses and social workers (Graham et al., 2023; Volandes et al., 2023; Wasp et

al., 2022; Schenker et al., 2022) and even lay navigators (Patel et al., 2018; Rocque et al., 2017), may have instrumental roles in engaging patients in these discussions. Each institution should consider a team approach that is most appropriate based on their staffing models. Team roles and responsibilities for GOCC should be clear (e.g., limiting discussions regarding prognosis to providers), and their workflows defined (e.g., patient identification; EHR documentation expectations). Patients and their caregivers should always be considered part of the team. Plan for how to directly prime and integrate patients and their caregivers into the process, such as gathering validated GOC survey responses through patient portals.

7. ***Cultivate dashboards and healthy competition.*** The design of a GOC program should include reporting, through automated dashboards, of metrics targeted at various key stakeholders. For instance, reports for front-line clinicians should include benchmarking comparisons with their peers at the individual or group level. Reports for executive leadership should track progress toward established goals, including metrics that demonstrate ROI. Organizations should benchmark externally as much as possible, based on published data or collaborative participation. Over time, cancer programs should evolve measures of GOC (for instance, the timing and quality of the documentation), and goal concordant care.

Future Research and Directions

As described throughout this dissertation, the evidence-base supporting GOC in oncology has been building over the past decade (for instance, Cripe et al., 2021; Secunda et al., 2020; Myers et al., 2018). Still, our understanding of the interventions and impacts of GOCC in advanced cancer patients remains limited in key areas. First, more research is needed to

understand the most pressing and actionable gaps in communication skills among oncologists and other care team members, as well as creative approaches to deliver training in the most impactful, acceptable and accessible ways possible. For instance, Ariadne Labs, the developer of the Serious Illness Care Program, is testing the use of avatars to promote role-play-based learning (Ariadne, 2024). Relatedly, more evidence is needed regarding cancer team members who can participate in GOCC for advanced cancer patients. The oncologist is generally considered the ‘quarterback’ responsible for managing a patient’s journey, but many team members contribute to high-quality cancer care. For GOCC, a team-based approach is likely more cost-effective than a provider-driven approach and may lead to better outcomes for patients. Studies applying implementation science methods can add learnings regarding various team models, impact on patient and provider outcomes, and pragmatic lessons about team dynamics/teamwork, especially team communication and coordination.

Additional research into GOC interventions that directly engage the patient and caregivers is needed. Despite decades of focus on shared decision making, the standard healthcare model is of providers as the active purveyors of information and patients as the passive recipients. GOC presents an important opportunity to change this dynamic, if patients are informed and empowered to initiate GOCC even if their providers do not. Initial research findings testing direct patient engagement into GOCC interventions are promising (Takavorian et al., 2024; Manz, Zhang, Chen et al., 2023; Anaka et al., 2022; Bernecki et al., 2019; Paladino et al., 2019), but best practices have not fully emerged.

Further, the testing of new technologies to promote GOC should be prioritized. There is strong promise for machine learning and natural language processing solutions to contribute to the interventional and workflow barriers that arise from difficulty in accessing needed data for

GOC programs. These technologies could be impactful at multiple key points: for high-risk patient identification; development of triggering functionality; identification of GOC documentation from free text and integration into clinician-facing tools; measurement of the presence and quality of GOCC; and measurement of goal concordant care (Manz, Zhang, Chen et al., 2023; Lee et al., 2023; Vu et al., 2023; Manz et al., 2020; Lindvall et al., 2022; Lee et al., 2021; Poort et al., 2020).

Finally, there are important policy drivers to promote GOC and enhance goal concordant care. Policy interventions could impact societal perceptions and target misconceptions. For example, the National Academy of Sciences, Engineering and Medicine (NASEM) engaged experts in a 2024 workshop entitled, *Changing Public Perceptions to Build Awareness, Knowledge, and Uptake of Palliative Care: An Evidence-based Approach*. This effort explored social marketing solutions to address the public's lack of familiarity with palliative care and misconceptions that palliative care is for people who are dying (NASEM, 2024). Similar efforts that are devoted specifically to social marketing related to GOCC are needed. The shift in medicine – and especially oncology – toward precision medicine may present an opportunity. The public has become accustomed to the use of terms such as personalized medicine, precision medicine, and targeted care. Future social marketing efforts could build awareness that personalized medicine includes GOC, e.g., care based on patient preferences and values is as important as care based on genomics.

Payment policy could be a driving force in GOCC. As previously discussed, people with serious illness generally express preference for care that is less aggressive and more comfort focused (Pinto et al., 2024; Xia et al., 2023; California Healthcare Foundation, 2019; Coalition of Compassionate Care of California, 2015). These preferences result in care that is less costly. As

long as this social norm remains true, GOCC is a lever to lower healthcare costs without any rationing or other steps to limit access that are unacceptable in US society. Alternate payment models in oncology could incentivize GOCC specifically. Most notably, the CMS Enhancing Oncology Model (EOM) already includes components intended to promote shared decision making and reduce costs of care near the end of life (Centers for Medicare & Medicaid Services, 2023). Adding specific requirements and measures focused on GOCC would require only modest program changes for EOM. For oncology providers, the additional payments that are included in the EOM model, which are meant to help providers build infrastructure and modify systems, can be directed to sustainable GOCC integration.

Summary

GOC discussions are essential to shared decision-making for people with advanced cancer. GOCC are associated with better outcomes for patients, caregivers, providers and the healthcare system. This mixed-methods evaluation studied the implementation experience of a collaborative intervention to enhance GOC discussions across 10 cancer hospitals. This research adds to the literature by describing the organizational and implementation factors that contributed to operational integration and improvement in GOCC. Dissemination of these lessons should help other cancer centers to more effectively and efficiently implement GOC programs and thus improve care for patients with advanced cancer.

REFERENCES

- Abrams, H. R., Durbin, S., Huang, C. X., Johnson, S. F., Nayak, R. K., Zahner, G. J., & Peppercorn, J. (2021). Financial toxicity in cancer care: Origins, impact, and solutions. *Translational Behavioral Medicine, 11*(11), 2043–2054.
<https://doi.org/10.1093/tbm/ibab091>
- Adaji, E., Johnson, M., George, M. C., & Nortjé, N. (2024). Enhancing oncologists' comfort with serious illness conversations: The impact of serious illness conversation guide (SICG) training. *Journal Of Cancer Education: The Official Journal of The American Association for Cancer Education, 10.1007/s13187-024-02441-w*. Advance online publication.
<https://doi.org/10.1007/s13187-024-02441-w>
- Ahluwalia, S. C., Tisnado, D. M., Walling, A. M., Dy, S. M., Asch, S. M., Ettner, S. L., Kim, B., Pantoja, P., Schreibeis-Baum, H. C., & Lorenz, K. A. (2015). Association of early patient-physician care planning discussions and end-of-life care intensity in advanced cancer. *Journal of Palliative Medicine, 18*(10), 834–841
- Almack, K., Cox, K., Moghaddam, N., Pollock, K., & Seymour, J. (2012). After you: Conversations between patients and healthcare professionals in planning for end of life care. *BMC Palliative Care, 11*, 15. <https://doi.org/10.1186/1472-684X-11-15>
- Altice, C. K., Banegas, M. P., Tucker-Seeley, R. D., & Yabroff, K. R. (2016). Financial hardships experienced by cancer survivors: A systematic review. *Journal of the National Cancer Institute, 109*(2), djw205. <https://doi.org/10.1093/jnci/djw205>

American Society of Clinical Oncology (2024). 2023 Snapshot: State of the oncology workforce in America. *JCO Oncology Practice*, OP2400262. Advance online publication.

<https://doi.org/10.1200/OP.24.00262>

Anaka, M., Lee, M., Lim, E., Ghosh, S., Cheung, W. Y., & Spratlin, J. (2022). Changing rates of goals of care designations in patients with advanced pancreatic cancer during a multifactorial advanced care planning initiative: A real-world evidence study. *JCO*

Oncology Practice, 18(6), e869–e876. <https://doi.org/10.1200/OP.21.00649>

Andersson, S., & Sandgren, A. (2022). Organizational readiness to implement the serious illness care program in hospital settings in Sweden. *BMC Health Services Research*, 22(1), 539.

<https://doi.org/10.1186/s12913-022-07923-5>

Annadurai, V., Smith, C. B., Bickell, N., Berns, S. H., Kelley, A. S., Lindenberger, E., Morrison, L. J., Yuen, J. K., Egorova, N., Franco, R., Back, A. L., & Gelfman, L. P. (2021). Impact of a novel goals-of-care communication skills coaching intervention for practicing oncologists. *Journal of Palliative Medicine*, 24(6), 838–845.

<https://doi.org/10.1089/jpm.2020.0207>

Apostol, C. C., Waldfogel, J. M., Pfoh, E. R., List, D., Billing, L. S., Nesbit, S. A., & Dy, S. M. (2015). Association of goals of care meetings for hospitalized cancer patients at risk for critical care with patient outcomes. *Palliative Medicine*, 29(4), 386–390.

<https://doi.org/10.1177/0269216314560800>

Ariadne Labs. (2024, October 1) Serious Illness Care Program.

<https://www.ariadnelabs.org/serious-illness-care/serious-illness-care-program/>

- Back A. L. (2020). Patient-clinician communication issues in palliative care for patients with advanced cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 38(9), 866–876. <https://doi.org/10.1200/JCO.19.00128>
- Baile, W. F., Lenzi, R., Parker, P. A., Buckman, R., & Cohen, L. (2002). Oncologists' attitudes toward and practices in giving bad news: An exploratory study. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 20(8), 2189–2196. <https://doi.org/10.1200/JCO.2002.08.004>
- Bergerot, C. D., Philip, E. J., Bergerot, P. G., Siddiq, N., Tinianov, S., & Lustberg, M. (2022). Fear of cancer recurrence or progression: What is it and what can we do about it?. *American Society of Clinical Oncology Educational Book. American Society of Clinical Oncology. Annual Meeting*, 42, 1–10. https://doi.org/10.1200/EDBK_100031
- Bergerot, C. D., Philip, E. J., Bergerot, P. G., & Pal, S. K. (2020). Distress and quality of life among patients with advanced genitourinary cancers. *European Urology Focus*, 6(6), 1150–1154. <https://doi.org/10.1016/j.euf.2019.10.014>
- Bergström, A., Ehrenberg, A., Eldh, A. C., Graham, I. D., Gustafsson, K., Harvey, G., Hunter, S., Kitson, A., Rycroft-Malone, J., & Wallin, L. (2020). The use of the PARIHS framework in implementation research and practice-a citation analysis of the literature. *Implementation Science: IS*, 15(1), 68. <https://doi.org/10.1186/s13012-020-01003-0>
- Bernacki, R. E., Block, S. D., & American College of Physicians High Value Care Task Force (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*, 174(12), 1994–2003. <https://doi.org/10.1001/jamainternmed.2014.5271>

- Bernacki, R., Paladino, J., Neville, B. A., Hutchings, M., Kavanagh, J., Geerse, O. P., Lakin, J., Sanders, J. J., Miller, K., Lipsitz, S., Gawande, A. A., & Block, S. D. (2019). Effect of the serious illness care program in outpatient oncology: A cluster randomized clinical trial. *JAMA Internal Medicine*, 179(6), 751–759.
<https://doi.org/10.1001/jamainternmed.2019.0077>
- Bickell, N. A., Back, A. L., Adelson, K., Gonsky, J. P., Egorova, N., Pintova, S., Lin, J. J., Kozuch, P., Bagiella, E., & Smith, C. B. (2020). Effects of a communication intervention randomized controlled trial to enable goals-of-care discussions. *JCO Oncology Practice*, 16(9), e1015–e1028. <https://doi.org/10.1200/OP.20.00040>
- Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *Annals of Family Medicine*, 12(6), 573–576.
<https://doi.org/10.1370/afm.1713>
- Brandes, K., Butow, P. N., Tattersall, M. H., Clayton, J. M., Davidson, P. M., Young, J., Epstein, R. M., & Walczak, A. (2014). Advanced cancer patients' and caregivers' use of a Question Prompt List. *Patient Education and Counseling*, 97(1), 30–37.
<https://doi.org/10.1016/j.pec.2014.06.010>
- Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M., Nelson, C. J., & Brescia, R. (2000). Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*, 284(22), 2907–2911.
<https://doi.org/10.1001/jama.284.22.2907>
- California Healthcare Foundation. (2019). Help wanted: Californians' views and experiences of serious illness and end-of-life care. <https://www.chcf.org/publication/help-wanted-californians-views-serious-illness/#related-links-and-downloads>.

- Carlson, L. E., Groff, S. L., Maciejewski, O., & Bultz, B. D. (2010). Screening for distress in lung and breast cancer outpatients: A randomized controlled trial. *Journal of clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 28(33), 4884–4891. <https://doi.org/10.1200/JCO.2009.27.3698>
- Carr, L. H., Christ, L., & Ferro, D. F. (2023). The electronic health record as a quality improvement tool: Exceptional potential with special considerations. *Clinics in Perinatology*, 50(2), 473–488. <https://doi.org/10.1016/j.clp.2023.01.008>
- Centers for Medicare & Medicaid Services. (2023, June 27). Update: Enhancing Oncology Model factsheet. <https://www.cms.gov/newsroom/fact-sheets/update-enhancing-oncology-model-factsheet>
- Chawla, N., Blanch-Hartigan, D., Virgo, K. S., Ekwueme, D. U., Han, X., Forsythe, L., Rodriguez, J., McNeel, T. S., & Yabroff, K. R. (2016). Quality of patient-provider communication among cancer survivors: Findings from a nationally representative sample. *Journal of Oncology Practice*, 12(12), e964–e973. <https://doi.org/10.1200/JOP.2015.006999>
- Cheung, M. C., Earle, C. C., Rangrej, J., Ho, T. H., Liu, N., Barbera, L., Saskin, R., Porter, J., Seung, S. J., & Mittmann, N. (2015). Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer*, 121(18), 3307–3315. <https://doi.org/10.1002/cncr.29485>
- Chino, F., Peppercorn, J. M., Rushing, C., Kamal, A. H., Altomare, I., Samsa, G., & Zafar, S. Y. (2017). Out-of-pocket costs, financial distress, and underinsurance in cancer care. *JAMA Oncology*, 3(11), 1582–1584. <https://doi.org/10.1001/jamaoncol.2017.2148>

- Clarkson, J., Dean, J., Ward, J., Komashie, A., & Bashford, T. (2018). A systems approach to healthcare: From thinking to -practice. *Future Healthcare Journal*, 5(3), 151–155.
<https://doi.org/10.7861/futurehosp.5-3-151>
- Clayton, J. M., Hancock, K. M., Butow, P. N., Tattersall, M. H., Currow, D. C., Australian and new Zealand Expert Advisory Group, Adler, J., Aranda, S., Auret, K., Boyle, F., Britton, A., Chye, R., Clark, K., Davidson, P., Davis, J. M., Girgis, A., Graham, S., Hardy, J., Introna, K., Kearsley, J., ... Thoracic Society of Australia and New Zealand (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia*, 186(S12), S77–S105. <https://doi.org/10.5694/j.1326-5377.2007.tb01100.x>
- Coalition of Compassionate Care of California. (2015). Dying in California: A status report in end of life care. <https://www.chcf.org/wp-content/uploads/2017/12/PDF-DyingCalifStatusReport.pdf>.
- Collins, A., McLachlan, S. A., & Philip, J. (2018). Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliative Medicine*, 32(1), 133–142. <https://doi.org/10.1177/0269216317735247>
- Conduit, C., Thompson, M., Thomas, R., Nott, L., & Wuttke, M. (2021). Implementing 'Goals of Care' discussion and palliative care referral for patients with advanced lung cancer: An outpatient-based pilot project. *Internal Medicine Journal*, 51(4), 540–547.
<https://doi.org/10.1111/imj.14817>
- Cripe, L. D., Vater, L. B., Lilly, J. A., Larimer, A., Hoffmann, M. L., & Frankel, R. M. (2022). Goals of care communication and higher-value care for patients with advanced-stage

- cancer: A systematic review of the evidence. *Patient Education and Counseling*, 105(5), 1138–1151. <https://doi.org/10.1016/j.pec.2021.08.016>
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science : IS*, 4, 50. <https://doi.org/10.1186/1748-5908-4-50>
- Davidson, B. A., Puechl, A. M., Watson, C. H., Lim, S., Gatta, L., Monuszko, K., Drury, K., Ryan, E. S., Rice, S., Truong, T., Ma, J., Power, S., Jordan, W., Kurtovic, K., & Havrilesky, L. J. (2022). Promoting timely goals of care conversations between gynecologic cancer patients at high-risk of death and their providers. *Gynecologic Oncology*, 164(2), 288–294. <https://doi.org/10.1016/j.ygyno.2021.12.009>
- Donaldson M.S. (2008). An overview of to err is human: Re-emphasizing the message of patient safety. In: Hughes R.G., (Ed), *Patient safety and quality: An evidence-based handbook for nurses* (chapter 3). Agency for Healthcare Research and Quality. <https://www.ncbi.nlm.nih.gov/books/NBK2673/>
- Donovan-Kicken, E., & Caughlin, J. P. (2011). Breast cancer patients' topic avoidance and psychological distress: The mediating role of coping. *Journal of Health Psychology*, 16(4), 596–606. <https://doi.org/10.1177/1359105310383605>
- Douglas, S. L., Daly, B. J., Meropol, N. J., & Lipson, A. R. (2019). Patient-physician discordance in goals of care for patients with advanced cancer. *Current Oncology* (Toronto, Ont.), 26(6), 370–379. <https://doi.org/10.3747/co.26.5431>
- Eccles, M. P., & Mittman, B. S. (2006). Welcome to implementation science. *Implementation Science*, 1, 1. <https://doi.org/10.1186/1748-5908-1-1>

- El-Jawahri, A., Traeger, L., Greer, J. A., VanDusen, H., Fishman, S. R., LeBlanc, T. W., Pirl, W. F., Jackson, V. A., Telles, J., Rhodes, A., Li, Z., Spitzer, T. R., McAfee, S., Chen, Y. A., & Temel, J. S. (2017). Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: Results of a randomized clinical trial. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 35(32), 3714–3721. <https://doi.org/10.1200/JCO.2017.73.2800>
- Epstein, A. S., Riley, M., Nelson, J. E., Bernal, C., Martin, S., & Xiao, H. (2022). Goals of care documentation by medical oncologists and oncology patient end-of-life care outcomes. *Cancer*, 128(18), 3400–3407. <https://doi.org/10.1002/cncr.34400>
- Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., Firn, J. I., Paice, J. A., Peppercorn, J. M., Phillips, T., Stovall, E. L., Zimmermann, C., & Smith, T. J. (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical practice guideline update. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 35(1), 96–112. <https://doi.org/10.1200/JCO.2016.70.1474>
- Fischer, F., Helmer, S., Rogge, A., Arraras, J. I., Buchholz, A., Hannawa, A., Horneber, M., Kiss, A., Rose, M., Söllner, W., Stein, B., Weis, J., Schofield, P., & Witt, C. M. (2019). Outcomes and outcome measures used in evaluation of communication training in oncology - a systematic literature review, an expert workshop, and recommendations for future research. *BMC Cancer*, 19(1), 808. <https://doi.org/10.1186/s12885-019-6022-5>
- Fries, J. F., Koop, C. E., Beadle, C. E., Cooper, P. P., England, M. J., Greaves, R. F., Sokolov, J. J., & Wright, D. (1993). Reducing health care costs by reducing the need and demand for

- medical services. The Health Project Consortium. *The New England Journal of Medicine*, 329(5), 321–325. <https://doi.org/10.1056/NEJM199307293290506>
- Fromme, E. K., Benjamin, E., & Mitchell, S. (2022). Serious Illness Care Programme-contextual factors and implementation strategies: A qualitative study. *BMJ Supportive & Palliative Care*, bmjspcare-2021-003401
- Frosch, D. L., May, S. G., Rendle, K. A., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Affairs (Project Hope)*, 31(5), 1030–1038. <https://doi.org/10.1377/hlthaff.2011.0576>
- Fulmer, T., Escobedo, M., Berman, A., Koren, M. J., Hernández, S., & Hult, A. (2018). Physicians' views on advance care planning and end-of-life care conversations. *Journal of the American Geriatrics Society*, 66(6), 1201–1205. <https://doi.org/10.1111/jgs.15374>
- Gao, W., Bennett, M. I., Stark, D., Murray, S., & Higginson, I. J. (2010). Psychological distress in cancer from survivorship to end of life care: prevalence, associated factors and clinical implications. *European Journal of Cancer (Oxford, England : 1990)*, 46(11), 2036–2044. <https://doi.org/10.1016/j.ejca.2010.03.033>
- Gilligan, T., Coyle, N., Frankel, R. M., Berry, D. L., Bohlke, K., Epstein, R. M., Finlay, E., Jackson, V. A., Lathan, C. S., Loprinzi, C. L., Nguyen, L. H., Seigel, C., & Baile, W. F. (2017). Patient-clinician communication: American Society of Clinical Oncology consensus guideline. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 35(31), 3618–3632. <https://doi.org/10.1200/JCO.2017.75.2311>

- Graham, L. J., Hite, A., Harris, J., & Belcher, G. (2023). Silent conversations: Goals of care and end-of-life quality in relapsed high-risk leukemia. *Journal of the Advanced Practitioner in Oncology*, 14(5), 380–387. <https://doi.org/10.6004/jadpro.2023.14.5.3>
- Granek, L., Krzyzanowska, M. K., Tozer, R., & Mazzotta, P. (2013). Oncologists' strategies and barriers to effective communication about the end of life. *Journal of Oncology Practice*, 9(4), e129–e135. <https://doi.org/10.1200/JOP.2012.000800>
- Granek, L., Nakash, O., Cohen, M., Ben-David, M., & Ariad, S. (2017). Oncologists' communication about end of life: The relationship among secondary traumatic stress, compassion satisfaction, and approach and avoidance communication. *Psycho-oncology*, 26(11), 1980–1986. <https://doi.org/10.1002/pon.4289>
- Greer, J. A., Moy, B., El-Jawahri, A., Jackson, V. A., Kamdar, M., Jacobsen, J., Lindvall, C., Shin, J. A., Rinaldi, S., Carlson, H. A., Sousa, A., Gallagher, E. R., Li, Z., Moran, S., Ruddy, M., Anand, M. V., Carp, J. E., & Temel, J. S. (2022). Randomized trial of a palliative care intervention to improve end-of-life care discussions in patients with metastatic breast cancer. *Journal of the National Comprehensive Cancer Network : JNCCN*, 20(2), 136–143. <https://doi.org/10.6004/jnccn.2021.7040>
- Grossman, S. R., Gustin, J., Nelson, J., Rajasekhara, S., Reddy, A., Tulskey, J. A., Zachariah, F., & Landrum, K. M. (2023). ADCC's improving goal concordant care initiative: Implementing primary palliative care principles. *Journal of Pain and Symptom Management*, 66(2), e283–e297. <https://doi.org/10.1016/j.jpainsymman.2023.05.008>
- Guetterman, T. C., Feters, M. D., & Creswell, J. W. (2015). Integrating quantitative and qualitative results in health science mixed methods research through joint displays. *Annals of Family Medicine*, 13(6), 554–561. <https://doi.org/10.1370/afm.1865>

Hagerty, R. G., Butow, P. N., Ellis, P. M., Dimitry, S., & Tattersall, M. H. (2005).

Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology : Official Journal of the European Society for Medical Oncology*, 16(7), 1005–1053. <https://doi.org/10.1093/annonc/mdi211>

Han, X., Zhao, J., Zheng, Z., de Moor, J. S., Virgo, K. S., & Yabroff, K. R. (2020). Medical financial hardship intensity and financial sacrifice associated with cancer in the United States. *Cancer Epidemiology, Biomarkers & Prevention: a Publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*, 29(2), 308–317. <https://doi.org/10.1158/1055-9965.EPI-19-0460>

Hanson, L. C., Collichio, F., Bernard, S. A., Wood, W. A., Milowsky, M., Burgess, E., Creedle, C. J., Cheek, S., Chang, L., Chera, B., Fox, A., & Lin, F. C. (2017). Integrating palliative and oncology care for patients with advanced cancer: A quality improvement intervention. *Journal of Palliative Medicine*, 20(12), 1366–1371. <https://doi.org/10.1089/jpm.2017.0100>

Harnischfeger, N., Rath, H. M., Oechsle, K., & Bergelt, C. (2022). Addressing palliative care and end-of-life issues in patients with advanced cancer: a systematic review of communication interventions for physicians not specialised in palliative care. *BMJ Open*, 12(6), e059652. <https://doi.org/10.1136/bmjopen-2021-059652>

Harvey, G., & Kitson, A. (2016). PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice. *Implementation Science: IS*, 11, 33. <https://doi.org/10.1186/s13012-016-0398-2>

Heng, J., Sedhom, R., & Smith, T. J. (2020). Lack of advance care planning before terminal oncology intensive care unit admissions. *Journal of Palliative Medicine*, 23(1), 5–6. <https://doi.org/10.1089/jpm.2019.0391>

Hui, D., Bansal, S., Park, M., Reddy, A., Cortes, J., Fossella, F., & Bruera, E. (2015).

Differences in attitudes and beliefs toward end-of-life care between hematologic and solid tumor oncology specialists. *Annals of Oncology : Official Journal of the European Society for Medical Oncology*, 26(7), 1440–1446. <https://doi.org/10.1093/annonc/mdv028>

Hui, D., Didwaniya, N., Vidal, M., Shin, S. H., Chisholm, G., Roquemore, J., & Bruera, E.

(2014). Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer*, 120(10), 1572–1578.

<https://doi.org/10.1002/cncr.28614>

Hui, D., Nortje, N., George, M., Wilson, K., Urbauer, D. L., Lenz, C. A., Wallace, S. K.,

Andersen, C. R., Mendoza, T., Haque, S., Ahmed, S., Delgado-Guay, M., Dalal, S., Rathi,

N., Reddy, A., McQuade, J., Flowers, C., Pisters, P., Aloia, T., & Bruera, E. (2023). Impact

of an interdisciplinary goals-of-care program among medical inpatients at a comprehensive cancer center during the COVID-19 pandemic: A propensity score analysis. *Journal of*

Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 41(3),

579–589. <https://doi.org/10.1200/JCO.22.00849>

Institute of Medicine Committee on Quality of Health Care in America. (2001). *Crossing the*

quality chasm: A new health system for the 21st century. Washington (DC): National

Academies Press (US). Appendix B, Redesigning health care with insights from the

science of complex adaptive systems. Available from:

<https://www.ncbi.nlm.nih.gov/books/NBK222267/>

Jacobsen, J., Bernacki, R., & Paladino, J. (2022). Shifting to serious illness

communication. *JAMA*, 327(4), 321–322. <https://doi.org/10.1001/jama.2021.23695>

James, T. A., (2020). Gaining leadership buy-in for organizational change in health care.

Harvard Medical School: Trends in medicine.

<https://postgraduateeducation.hms.harvard.edu/trends-medicine/gaining-leadership-buy-organizational-change-health-care>.

Karim, S., Harle, I., O'Donnell, J., Li, S., & Booth, C. M. (2018). Documenting goals of care among patients With advanced cancer: Results of a quality improvement initiative. *Journal of Oncology Practice*, 14(9), e557–e565. <https://doi.org/10.1200/JOP.18.0003>

Kent, E. E., Forsythe, L. P., Yabroff, K. R., Weaver, K. E., de Moor, J. S., Rodriguez, J. L., & Rowland, J. H. (2013). Are survivors who report cancer-related financial problems more likely to forgo or delay medical care?. *Cancer*, 119(20), 3710–3717. <https://doi.org/10.1002/cncr.28262>

Kim, G. M., Kim, S. J., Song, S. K., Kim, H. R., Kang, B. D., Noh, S. H., Chung, H. C., Kim, K. R., & Rha, S. Y. (2017). Prevalence and prognostic implications of psychological distress in patients with gastric cancer. *BMC Cancer*, 17(1), 283. <https://doi.org/10.1186/s12885-017-3260-2>

Kitson, A. L., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. *Implementation Science : IS*, 3, 1. <https://doi.org/10.1186/1748-5908-3-1>

Kitson, A., Harvey, G., & McCormack, B. (1998). Enabling the implementation of evidence based practice: a conceptual framework. *Quality in Health Care : QHC*, 7(3), 149–158. <https://doi.org/10.1136/qshc.7.3.149>

- Knutzen, K. E., Sacks, O. A., Brody-Bizar, O. C., Murray, G. F., Jain, R. H., Holdcroft, L. A., Alam, S. S., Liu, M. A., Pollak, K. I., Tulskey, J. A., & Barnato, A. E. (2021). Actual and missed opportunities for end-of-life care discussions with oncology patients: A qualitative study. *JAMA Network Open*, 4(6), e2113193.
<https://doi.org/10.1001/jamanetworkopen.2021.13193>
- Kumar, P., Wixon-Genack, J., Kavanagh, J., Sanders, J. J., Paladino, J., & O'Connor, N. R. (2020). Serious illness conversations with outpatient oncology clinicians: Understanding the patient experience. *JCO Oncology Practice*, 16(12), e1507–e1515.
<https://doi.org/10.1200/JOP.19.00765>
- Lee, E. M., Jiménez-Fonseca, P., Galán-Moral, R., Coca-Membribes, S., Fernández-Montes, A., Sorribes, E., García-Torralba, E., Puntí-Brun, L., Gil-Raga, M., Cano-Cano, J., & Calderon, C. (2023). Toxicities and quality of life during cancer treatment in advanced solid tumors. *Current Oncology (Toronto, Ont.)*, 30(10), 9205–9216.
<https://doi.org/10.3390/curroncol30100665>
- Lee, R. Y., Brumback, L. C., Lober, W. B., Sibley, J., Nielsen, E. L., Treece, P. D., Kross, E. K., Loggers, E. T., Fausto, J. A., Lindvall, C., Engelberg, R. A., & Curtis, J. R. (2021). Identifying goals of care conversations in the electronic health record using natural language processing and machine learning. *Journal of Pain and Symptom Management*, 61(1), 136–142.e2. <https://doi.org/10.1016/j.jpainsymman.2020.08.024>
- Lee, R. Y., Kross, E. K., Torrence, J., Li, K. S., Sibley, J., Cohen, T., Lober, W. B., Engelberg, R. A., & Curtis, J. R. (2023). Assessment of natural language processing of electronic health records to measure goals-of-care discussions as a clinical trial outcome. *JAMA Network Open*, 6(3), e231204. <https://doi.org/10.1001/jamanetworkopen.2023.1204>

- Leung, C., Andersen, C. R., Wilson, K., Nortje, N., George, M., Flowers, C., Bruera, E., & Hui, D. (2023). The impact of a multidisciplinary goals-of-care program on unplanned readmission rates at a comprehensive cancer center. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, 32(1), 66. <https://doi.org/10.1007/s00520-023-08265-6>
- Li, M., Lakdawalla, D. N., & Goldman, D. P. (2020). Association between spending and outcomes for patients with cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 38(4), 323–331. <https://doi.org/10.1200/JCO.19.01451>
- Li, S. A., Jeffs, L., Barwick, M., & Stevens, B. (2018). Organizational contextual features that influence the implementation of evidence-based practices across healthcare settings: a systematic integrative review. *Systematic Reviews*, 7(1), 72. <https://doi.org/10.1186/s13643-018-0734-5>
- Lindvall, C., Deng, C. Y., Moseley, E., Agaronnik, N., El-Jawahri, A., Paasche-Orlow, M. K., Lakin, J. R., Volandes, A., & Tulskey, T. A. I. J. A. (2022). Natural language processing to identify advance care planning documentation in a multisite pragmatic clinical trial. *Journal of Pain and Symptom Management*, 63(1), e29–e36. <https://doi.org/10.1016/j.jpainsymman.2021.06.025>
- Liu, P. H., Landrum, M. B., Weeks, J. C., Huskamp, H. A., Kahn, K. L., He, Y., Mack, J. W., & Keating, N. L. (2014). Physicians' propensity to discuss prognosis is associated with patients' awareness of prognosis for metastatic cancers. *Journal of Palliative Medicine*, 17(6), 673–682. <https://doi.org/10.1089/jpm.2013.0460>

Loggers, E. T., Case, A. A., Chwistek, M., Dale, W., Delgado Guay, M. O., Edge, S. B., Lopez-Acevedo, M., Havrilesky, L. J., Broadwater, G., Kamal, A. H., Abernethy, A. P., Berchuck, A., Alvarez Secord, A., Tulskey, J. A., Valea, F., & Lee, P. S. (2013). Timing of end-of-life care discussion with performance on end-of-life quality indicators in ovarian cancer. *Gynecologic Oncology*, 130(1), 156–161.

<https://doi.org/10.1016/j.ygyno.2013.04.010>

Lopez-Acevedo, M., Havrilesky, L. J., Broadwater, G., Kamal, A. H., Abernethy, A. P., Berchuck, A., Alvarez Secord, A., Tulskey, J. A., Valea, F., & Lee, P. S. (2013). Timing of end-of-life care discussion with performance on end-of-life quality indicators in ovarian cancer. *Gynecologic Oncology*, 130(1), 156–161.

<https://doi.org/10.1016/j.ygyno.2013.04.010>

Mack, J. W., Cronin, A., Keating, N. L., Taback, N., Huskamp, H. A., Malin, J. L., Earle, C. C., & Weeks, J. C. (2012). Associations between end-of-life discussion characteristics and care received near death: a prospective cohort study. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 30(35), 4387–4395.

Mack, J. W., Cronin, A., Taback, N., Huskamp, H. A., Keating, N. L., Malin, J. L., Earle, C. C., & Weeks, J. C. (2012). End-of-life care discussions among patients with advanced cancer: a cohort study. *Annals of Internal Medicine*, 156(3), 204–210.

<https://doi.org/10.7326/0003-4819-156-3-201202070-00008>

Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology : Official Journal*

of the American Society of Clinical Oncology, 28(7), 1203–1208.

<https://doi.org/10.1200/JCO.2009.25.4672>

Maguire P. (1999). Improving communication with cancer patients. *European Journal of Cancer* (Oxford, England : 1990), 35(10), 1415–1422. [https://doi.org/10.1016/s0959-8049\(99\)00178-1](https://doi.org/10.1016/s0959-8049(99)00178-1)

Malhotra, C., Rajasekaran, T., Kanesvaran, R., Yee, A., Bundoc, F. G., Singh, R., Tulsy, J. A., & Pollak, K. I. (2020). Pilot trial of a combined oncologist-patient-caregiver communication intervention in Singapore. *JCO Oncology Practice*, 16(2), e190–e200. <https://doi.org/10.1200/JOP.19.00412>

Manz, C. R., Zhang, Y., Chen, K., Long, Q., Small, D. S., Evans, C. N., Chivers, C., Regli, S. H., Hanson, C. W., Bekelman, J. E., Braun, J., Rareshide, C. A. L., O'Connor, N., Kumar, P., Schuchter, L. M., Shulman, L. N., Patel, M. S., & Parikh, R. B. (2023). Long-term effect of machine learning-triggered behavioral nudges on serious illness conversations and end-of-life outcomes among patients with cancer: A randomized clinical trial. *JAMA Oncology*, 9(3), 414–418. <https://doi.org/10.1001/jamaoncol.2022.6303>

Manz, C. R., Rocque, G. B., & Patel, M. I. (2023). Leveraging goals of care interventions to deliver personalized care near the end of life. *JAMA Oncology*, 9(8), 1029–1030. <https://doi.org/10.1001/jamaoncol.2023.1981>

Manz, C. R., Parikh, R. B., Small, D. S., Evans, C. N., Chivers, C., Regli, S. H., Hanson, C. W., Bekelman, J. E., Rareshide, C. A. L., O'Connor, N., Schuchter, L. M., Shulman, L. N., & Patel, M. S. (2020). Effect of integrating machine learning mortality estimates with behavioral nudges to clinicians on serious illness conversations among patients with

- cancer: A stepped-wedge cluster randomized clinical trial. *JAMA Oncology*, 6(12), e204759. <https://doi.org/10.1001/jamaoncol.2020.4759>
- Marcia, L., Ashman, Z. W., Pillado, E. B., Kim, D. Y., & Plurad, D. S. (2018). Advance directive and do-not-resuscitate status among advanced cancer patients with acute care surgical consultation. *The American Surgeon*, 84(10), 1565–1569. <https://doi.org/10.1177/000313481808401005>
- Mariotto, A. B., Enewold, L., Zhao, J., Zeruto, C. A., & Yabroff, K. R. (2020). Medical care costs associated with cancer survivorship in the United States. *Cancer Epidemiology, Biomarkers & Prevention: a Publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*, 29(7), 1304–1312. <https://doi.org/10.1158/1055-9965.EPI-19-1534>
- Mayland, C. R., Ho, Q. M., Doughty, H. C., Rogers, S. N., Peddinti, P., Chada, P., Mason, S., Cooper, M., & Dey, P. (2021). The palliative care needs and experiences of people with advanced head and neck cancer: A scoping review. *Palliative Medicine*, 35(1), 27–44. <https://doi.org/10.1177/0269216320963892>
- McNiff, K. K., Caligiuri, M. A., Davidson, N. E., Farrar, W., Fisher, R. I., Glimcher, L. H., Hanners, R. B., Hwu, P., Johnson, C. S., Pisters, P. W. T., Thompson, C. B., Reddy, A. S., Jagels, B., Kolosky, J. A., Ross, T., & Bird, K. (2021). Improving goal concordant care among 10 leading academic U.S. cancer hospitals: A collaboration of the Alliance of Dedicated Cancer Centers. *The Oncologist*, 26(7), 533–536. <https://doi.org/10.1002/onco.13850>
- Meropol, N. J., Schrag, D., Smith, T. J., Mulvey, T. M., Langdon, R. M., Jr, Blum, D., Ubel, P. A., Schnipper, L. E., & American Society of Clinical Oncology (2009). American Society

- of Clinical Oncology guidance statement: the cost of cancer care. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 27(23), 3868–3874. <https://doi.org/10.1200/JCO.2009.23.1183>
- Moore, P. M., Rivera, S., Bravo-Soto, G. A., Olivares, C., & Lawrie, T. A. (2018). Communication skills training for healthcare professionals working with people who have cancer. *The Cochrane Database of Systematic Reviews*, 7(7), CD003751. <https://doi.org/10.1002/14651858.CD003751.pub>
- Morrison, R. S., Meier, D. E., & Arnold, R. M. (2021). What's wrong with advance care planning?. *JAMA*, 326(16), 1575–1576. <https://doi.org/10.1001/jama.2021.16430>
- Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N., & Walton, T. (2018). Provider tools for advance care planning and goals of care discussions: A systematic review. *The American Journal of Hospice & Palliative Care*, 35(8), 1123–1132. <https://doi.org/10.1177/1049909118760303>
- Ng, S., & Ozdemir, S. (2023). The associations between prognostic awareness and health-related quality of life among patients with advanced cancer: A systematic review. *Palliative Medicine*, 37(6), 808–823. <https://doi.org/10.1177/02692163231165325>
- Ness, S., Kokal, J., Fee-Schroeder, K., Novotny, P., Satele, D., & Barton, D. (2013). Concerns across the survivorship trajectory: Results from a survey of cancer survivors. *Oncology Nursing Forum*, 40(1), 35–42. <https://doi.org/10.1188/13.ONF.35-42>
- Odejide, O. O., Salas Coronado, D. Y., Watts, C. D., Wright, A. A., & Abel, G. A. (2014). End-of-life care for blood cancers: A series of focus groups with hematologic oncologists. *Journal of Oncology Practice*, 10(6), e396–e403. <https://doi.org/10.1200/JOP.2014.001537>

- Paladino, J., Bernacki, R., Neville, B. A., Kavanagh, J., Miranda, S. P., Palmor, M., Lakin, J., Desai, M., Lamas, D., Sanders, J. J., Gass, J., Henrich, N., Lipsitz, S., Fromme, E., Gawande, A. A., & Block, S. D. (2019). Evaluating an intervention to improve communication between oncology clinicians and patients with life-limiting cancer: A cluster randomized clinical trial of the Serious Illness Care Program. *JAMA Oncology*, 5(6), 801–809. <https://doi.org/10.1001/jamaoncol.2019.0292>
- Paladino, J., Fromme, E. K., Kilpatrick, L., Dingfield, L., Teuteberg, W., Bernacki, R., Jackson, V., Sanders, J. J., Jacobsen, J., Ritchie, C., & Mitchell, S. (2023). Lessons learned about system-level improvement in serious illness communication: A qualitative study of Serious Illness Care Program implementation in five health systems. *Joint Commission Journal on Quality and Patient Safety*, 49(11), 620–633. <https://doi.org/10.1016/j.jcjq.2023.06.013>
- Paladino, J., Koritsanszky, L., Neal, B. J., Lakin, J. R., Kavanagh, J., Lipsitz, S., Fromme, E. K., Sanders, J., Benjamin, E., Block, S., & Bernacki, R. (2020). Effect of the Serious Illness Care Program on health care utilization at the end of life for patients with cancer. *Journal of Palliative Medicine*, 23(10), 1365–1369. <https://doi.org/10.1089/jpm.2019.0437>
- Paladino, J., Sanders, J., Kilpatrick, L. B., Prabhakar, R., Kumar, P., O'Connor, N., Durieux, B., Panzone, J., Welch, C., Morgans, A., Bhanvadia, S. K., Mossanen, M., Shenhav-Goldberg, R., Chandrasekar, T., Pinkhasov, R., Shapiro, O., Jacob, J. M., Basnet, A., Bratslavsky, G., & Goldberg, H. (2022). Association of race with cancer-related financial toxicity. *JCO Oncology Practice*, 18(2), e271–e283. <https://doi.org/10.1200/OP.21.00440>
- Parikh, R. B., Manz, C. R., Nelson, M. N., Ferrell, W., Belardo, Z., Temel, J. S., Patel, M. S., & Shea, J. A. (2022). Oncologist perceptions of algorithm-based nudges to prompt early

- serious illness communication: A qualitative study. *Journal of Palliative Medicine*, 25(11), 1702–1707. <https://doi.org/10.1089/jpm.2022.0095>
- Patel, T. A., Heintz, J., Chen, J., LaPergola, M., Bilker, W. B., Patel, M. S., Arya, L. A., Patel, M. I., Bekelman, J. E., Manz, C. R., & Parikh, R. B. (2024). Spending analysis of machine learning-based communication nudges in oncology. *NEJM AI*, 1(6), 10.1056/aioa2300228. <https://doi.org/10.1056/aioa2300228>
- Patel, M. I., Kapphahn, K., Dewland, M., Aguilar, V., Sanchez, B., Sisay, E., Murillo, A., Smith, K., & Park, D. J. (2022). Effect of a community health worker intervention on acute care use, advance care planning, and patient-reported outcomes among adults with advanced stages of cancer: A randomized clinical trial. *JAMA Oncology*, 8(8), 1139–1148. <https://doi.org/10.1001/jamaoncol.2022.1997>
- Patel, M. I., Sundaram, V., Desai, M., Periyakoil, V. S., Kahn, J. S., Bhattacharya, J., Asch, S. M., Milstein, A., & Bundorf, M. K. (2018). Effect of a lay health worker intervention on goals-of-care documentation and on health care use, costs, and satisfaction among patients with cancer: A randomized clinical trial. *JAMA Oncology*, 4(10), 1359–1366. <https://doi.org/10.1001/jamaoncol.2018.2446>
- Piggott, K. L., Patel, A., Wong, A., Martin, L., Patel, A., Patel, M., Liu, Y., Dhesy-Thind, S., & You, J. J. (2019). Breaking silence: A survey of barriers to goals of care discussions from the perspective of oncology practitioners. *BMC Cancer*, 19(1), 130. <https://doi.org/10.1186/s12885-019-5333-x>
- Pinto, S., Lopes, S., de Sousa, A. B., Delalibera, M., & Gomes, B. (2024). Patient and family preferences about place of end-of-life care and death: An umbrella review. *Journal of Pain*

and Symptom Management, 67(5), e439–e452.

<https://doi.org/10.1016/j.jpainsymman.2024.01.014>

Pintova, S., Leibrandt, R., Smith, C. B., Adelson, K. B., Gonsky, J. P., Egorova, N., Franco, R., & Bickell, N. A. (2020a). Impact of high-quality goals-of-care discussions on oncologist productivity. *JCO Oncology Practice*, 16(3), e290–e297.

<https://doi.org/10.1200/JOP.19.00381>

Pintova, S., Leibrandt, R., Smith, C. B., Adelson, K. B., Gonsky, J., Egorova, N., Franco, R., & Bickell, N. A. (2020b). Conducting goals-of-care discussions takes less time than imagined. *JCO Oncology Practice*, 16(12), e1499–e1506.

<https://doi.org/10.1200/JOP.19.00743>

Politi, M. C., Yen, R. W., Elwyn, G., O'Malley, A. J., Saunders, C. H., Schubbe, D., Forcino, R., & Durand, M. A. (2021). Women who are young, on-white, and with lower socioeconomic status report higher financial toxicity up to 1 year after breast cancer surgery: A mixed-effects regression analysis. *The Oncologist*, 26(1), e142–e152.

Poort, H., Zupanc, S. N., Leiter, R. E., Wright, A. A., & Lindvall, C. (2020). Documentation of Palliative and End-of-Life Care Process Measures Among Young Adults Who Died of Cancer: A Natural Language Processing Approach. *Journal of Adolescent and Young Adult Oncology*, 9(1), 100–104. <https://doi.org/10.1089/jayao.2019.0040>

Proctor, L. (2008). Editor's Notebook: A quotation with a life of its own. *Patient Safety and Healthcare Quality*. <https://www.psqh.com/analysis/editor-s-notebook-a-quotation-with-a-life-of-its-own/>

Prod'homme, C., Jacquemin, D., Touzet, L., Aubry, R., Daneault, S., & Knoops, L. (2018).

Barriers to end-of-life discussions among hematologists: A qualitative study. *Palliative Medicine*, 32(5), 1021–1029. <https://doi.org/10.1177/0269216318759862>

Raghavan, D., & Legnini, M. W. (2016). Value in oncology: Balance between quality and cost. *American Society of Clinical Oncology Educational Book. American Society of Clinical Oncology. Annual Meeting*, 35, 9–13. https://doi.org/10.1200/EDBK_100003

Rai, A., Chawla, N., Han, X., Rim, S. H., Smith, T., de Moor, J., & Yabroff, K. R. (2019). Has the quality of patient-provider communication about survivorship care improved?. *Journal of Oncology Practice*, 15(11), e916–e924. <https://doi.org/10.1200/JOP.19.00157>

Raskin, W., Harle, I., Hopman, W. M., & Booth, C. M. (2016). Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?. *Clinical Oncology (Royal College of Radiologists (Great Britain))*, 28(3), 209–214. <https://doi.org/10.1016/j.clon.2015.11.011>

Reddy, A., González, J. B., Rizvi, A., Nortje, N., Dalal, S., Haider, A., Amaram-Davila, J. S., Bramati, P., Chen, M., Hui, D., & Bruera, E. (2023). Impact of an institution-wide goals of care program on the timing of referrals to outpatient palliative care. *Journal of Pain and Symptom Management*, 66(6), e666–e671.

<https://doi.org/10.1016/j.jpainsymman.2023.08.019>

Rocque, G. B., Dionne-Odom, J. N., Sylvia Huang, C. H., Niranjana, S. J., Williams, C. P., Jackson, B. E., Halilova, K. I., Kenzik, K. M., Bevis, K. S., Wallace, A. S., Lisovicz, N., Taylor, R. A., Pisu, M., Partridge, E. E., Butler, T. W., Briggs, L. A., Kvale, E. A., & Patient Care Connect Group (2017). Implementation and impact of patient lay navigator-

- led advance care planning conversations. *Journal of Pain and Symptom Management*, 53(4), 682–692. <https://doi.org/10.1016/j.jpainsymman.2016.11.012>
- Salins, N., Ghoshal, A., Hughes, S., & Preston, N. (2020). How views of oncologists and haematologists impacts palliative care referral: A systematic review. *BMC Palliative Care*, 19(1), 175. <https://doi.org/10.1186/s12904-020-00671-5>
- Sanders, J. J., Curtis, J. R., & Tulsky, J. A. (2018). Achieving goal-concordant care: A conceptual model and approach to measuring serious illness communication and its impact. *Journal of Palliative Medicine*, 21(S2), S17–S27. <https://doi.org/10.1089/jpm.2017.0459>
- Schenker, Y., Althouse, A. D., Rosenzweig, M., White, D. B., Chu, E., Smith, K. J., Resick, J. M., Belin, S., Park, S. Y., Smith, T. J., Bakitas, M. A., & Arnold, R. M. (2021). Effect of an oncology nurse-led primary palliative care intervention on patients with advanced cancer: The CONNECT cluster randomized clinical trial. *JAMA Internal Medicine*, 181(11), 1451–1460. <https://doi.org/10.1001/jamainternmed.2021.5185>
- Schulman-Green, D., Lin, J. J., Smith, C. B., Feder, S., & Bickell, N. A. (2018). Facilitators and barriers to oncologists' conduct of goals of care conversations. *Journal of Palliative Care*, 33(3), 143–148. <https://doi.org/10.1177/0825859718777361>
- Secunda, K., Wirpsa, M. J., Neely, K. J., Szmuiłowicz, E., Wood, G. J., Panozzo, E., McGrath, J., Levenson, A., Peterson, J., Gordon, E. J., & Kruser, J. M. (2020). Use and meaning of "goals of care" in the healthcare literature: A systematic review and qualitative discourse analysis. *Journal of General Internal Medicine*, 35(5), 1559–1566. <https://doi.org/10.1007/s11606-019-05446-0>

- Seevaratnam, B., Wang, S., Fong, R., Hui, F., Callahan, A., Chobot, S., Gensheimer, M. F., Li, R. C., Nguyen, D., Ramchandran, K., Shah, N. H., Shieh, L., Zeng, J. G., & Teuteberg, W. (2024). Lessons earned from a multi-site, team-based serious illness care program implementation at an academic medical center. *Journal of Palliative Medicine*, 27(1), 83–89. <https://doi.org/10.1089/jpm.2023.0254>
- Siegel, R. L., Giaquinto, A. N., & Jemal, A. (2024). Cancer statistics, 2024. *CA: A Cancer Journal for Clinicians*, 74(1), 12–49. <https://doi.org/10.3322/caac.21820>
- Smith, G. L., Banegas, M. P., Acquati, C., Chang, S., Chino, F., Conti, R. M., Greenup, R. A., Kroll, J. L., Liang, M. I., Pisu, M., Primm, K. M., Roth, M. E., Shankaran, V., & Yabroff, K. R. (2022). Navigating financial toxicity in patients with cancer: A multidisciplinary management approach. *CA: A Cancer Journal for Clinicians*, 72(5), 437–453. <https://doi.org/10.3322/caac.21730>
- Starr, L. T., Ulrich, C. M., Corey, K. L., & Meghani, S. H. (2019). Associations among end-of-life discussions, health-care utilization, and costs in persons with advanced cancer: A systematic review. *The American Journal of Hospice & Palliative Care*, 36(10), 913–926. <https://doi.org/10.1177/1049909119848148>
- Takvorian, S. U., Gabriel, P., Wileyto, E. P., Blumenthal, D., Tejada, S., Clifton, A. B. W., Asch, D. A., Bottenheim, A. M., Rendle, K. A., Shelton, R. C., Chaiyachati, K. H., Fayanju, O. M., Ware, S., Schuchter, L. M., Kumar, P., Salam, T., Lieberman, A., Ragusano, D., Bauer, A. M., Scott, C. A., ... Parikh, R. B. (2024). Clinician- and patient-directed communication strategies for patients with cancer at high mortality risk: A cluster randomized trial. *JAMA Network Open*, 7(7), e2418639. <https://doi.org/10.1001/jamanetworkopen.2024.18639>

- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Schepp, K. (2010). Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Annals of Oncology : Official Journal of the European Society for Medical Oncology*, 21(6), 1145–1151. <https://doi.org/10.1093/annonc/mdp534>
- Temel, J. S., Greer, J. A., El-Jawahri, A., Pirl, W. F., Park, E. R., Jackson, V. A., Back, A. L., Kamdar, M., Jacobsen, J., Chittenden, E. H., Rinaldi, S. P., Gallagher, E. R., Eusebio, J. R., Li, Z., Muzikansky, A., & Ryan, D. P. (2017). Effects of early integrated palliative care in patients with lung and GI cancer: A randomized clinical trial. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 35(8), 834–841. <https://doi.org/10.1200/JCO.2016.70.5046>
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, 291(1), 88–93. <https://doi.org/10.1001/jama.291.1.88>
- The National Academies of Sciences, Engineering, and Medicine Roundtable on Quality Care for People with Serious Illness. (2024). *Changing public perceptions to build awareness, knowledge, and uptake of palliative care: An evidence-based approach*. <https://www.nationalacademies.org/our-work/webinar-series-on-changing-public-perceptions-to-build-awareness-knowledge-and-uptake-of-palliative-care-an-evidence-based-approach>
- Tucker-Seeley, R. D., & Thorpe, R. J. (2019). Material-psychosocial-behavioral aspects of financial hardship: A conceptual model for cancer prevention. *The Gerontologist*, 59(Suppl 1), S88–S93. <https://doi.org/10.1093/geront/gnz033>

- Volandes, A. E., Zupanc, S. N., Lakin, J. R., Cabral, H. J., Burns, E. A., Carney, M. T., Lopez, S., Itty, J., Emmert, K., Martin, N. J., Cole, T., Dobie, A., Cucinotta, T., Joel, M., Caruso, L. B., Henault, L., Dugas, J. N., Astone, K., Winter, M., Wang, N., ... Paasche-Orlow, M. K. (2023). Video intervention and goals-of-care documentation in hospitalized older adults: The VIDEO-PCE randomized clinical trial. *JAMA Network Open*, 6(9), e2332556. <https://doi.org/10.1001/jamanetworkopen.2023.32556>
- Walshe, C., Roberts, D., Appleton, L., Calman, L., Large, P., Lloyd-Williams, M., & Grande, G. (2017). Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. *PloS One*, 12(1), e0169071. <https://doi.org/10.1371/journal.pone.0169071>
- Walczak, A., Henselmans, I., Tattersall, M. H., Clayton, J. M., Davidson, P. M., Young, J., Bellemore, F. A., Epstein, R. M., & Butow, P. N. (2015). A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psycho-Oncology*, 24(3), 287–293. <https://doi.org/10.1002/pon.3635>
- Walczak, A., Mazer, B., Butow, P. N., Tattersall, M. H., Clayton, J. M., Davidson, P. M., Young, J., Ladwig, S., & Epstein, R. M. (2013). A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation. *Palliative Medicine*, 27(8), 779–788. <https://doi.org/10.1177/0269216313483659>
- Wasp, G. T., Cullinan, A. M., Anton, C. P., Williams, A., Perry, J. J., Holthoff, M. M., & Buus-Frank, M. E. (2022). Interdisciplinary approach and patient/family partners to improve serious illness conversations in outpatient oncology. *JCO Oncology Practice*, 18(10), e1567–e1573. <https://doi.org/10.1200/OP.22.00086>

- Weeks, J. C., Catalano, P. J., Cronin, A., Finkelman, M. D., Mack, J. W., Keating, N. L., & Schrag, D. (2012). Patients' expectations about effects of chemotherapy for advanced cancer. *The New England Journal of Medicine*, 367(17), 1616–1625.
<https://doi.org/10.1056/NEJMoa1204410>
- Wheeler, S. B., Spencer, J. C., Pinheiro, L. C., Carey, L. A., Olshan, A. F., & Reeder-Hayes, K. E. (2018). Financial impact of breast cancer in black versus white women. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 36(17), 1695–1701. <https://doi.org/10.1200/JCO.2017.77.6310>
- White-Means, S. I., & Osmani, A. R. (2017). Racial and ethnic disparities in patient-provider communication with breast cancer patients: Evidence from 2011 MEPS and experiences with cancer supplement. *Inquiry : A Journal of Medical Care Organization, Provision and Financing*, 54, 46958017727104. <https://doi.org/10.1177/0046958017727104>
- Wilson, K. G., Chochinov, H. M., McPherson, C. J., LeMay, K., Allard, P., Chary, S., Gagnon, P. R., Macmillan, K., De Luca, M., O'Shea, F., Kuhl, D., & Fainsinger, R. L. (2007). Suffering with advanced cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 25(13), 1691–1697.
<https://doi.org/10.1200/JCO.2006.08.6801>
- Wood, G. J., Clepp, R. K., Lee, J., Twaddle, M. L., Ogunseitan, A., Neagle, J., & Szmuiłowicz, E. (2024). Outcomes of a multisite mentored implementation approach to promoting goals of care conversations. *Journal of Pain and Symptom Management*, 68(2), 163–170.e2.
<https://doi.org/10.1016/j.jpainsymman.2024.04.024>
- Wright, A. A., Keating, N. L., Ayanian, J. Z., Chrischilles, E. A., Kahn, K. L., Ritchie, C. S., Weeks, J. C., Earle, C. C., & Landrum, M. B. (2016). Family perspectives on aggressive

cancer care near the end of life. *JAMA*, 315(3), 284–292.

<https://doi.org/10.1001/jama.2015.18604>

Wright, A. A., Keating, N. L., Balboni, T. A., Matulonis, U. A., Block, S. D., & Prigerson, H. G.

(2010). Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 28(29), 4457–4464.

Wright, A. A., Thompson, E., Nguyen, M. V., Wescott, P., Barry, M. J., Lathan, C. S., &

Keating, N. L. (2022). The SHARE study: Pilot study of a communication intervention designed to elicit advanced-stage cancer patients' preferences and goals. *Journal of Palliative Medicine*, 25(11), 1646–1654. <https://doi.org/10.1089/jpm.2021.0655>

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson,

V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 300(14), 1665–1673.

<https://doi.org/10.1001/jama.300.14.1665>

Xia, Q., Kularatna, M., Virdun, C., Button, E., Close, E., & Carter, H. E. (2023). Preferences for

palliative and end-of-life care: A systematic review of discrete choice experiments. *Value in Health : the Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 26(12), 1795–1809. <https://doi.org/10.1016/j.jval.2023.07.005>

Yabroff, K. R., Mariotto, A., Tangka, F., Zhao, J., Islami, F., Sung, H., Sherman, R. L., Henley,

S. J., Jemal, A., & Ward, E. M. (2021). Annual report to the nation on the status of cancer, part 2: Patient economic burden associated with cancer care. *Journal of the National Cancer Institute*, 113(12), 1670–1682. <https://doi.org/10.1093/jnci/djab192>

- Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10(1), 19–28. [https://doi.org/10.1002/1099-1611\(200101/02\)10:1<19::aid-pon501>3.0.co;2-6](https://doi.org/10.1002/1099-1611(200101/02)10:1<19::aid-pon501>3.0.co;2-6)
- Zafar, S. Y., & Abernethy, A. P. (2013). Financial toxicity, part 1: A new name for a growing problem. *Oncology (Williston Park, N.Y.)*, 27(2), 80–149.
- Zakhour, M., LaBrant, L., Rimel, B. J., Walsh, C. S., Li, A. J., Karlan, B. Y., & Cass, I. (2015). Too much, too late: Aggressive measures and the timing of end of life care discussions in women with gynecologic malignancies. *Gynecologic Oncology*, 138(2), 383–387. <https://doi.org/10.1016/j.ygyno.2015.06.001>
- Zaros, M. C., Curtis, J. R., Silveira, M. J., & Elmore, J. G. (2013). Opportunity lost: end-of-life discussions in cancer patients who die in the hospital. *Journal of Hospital Medicine*, 8(6), 334–340. <https://doi.org/10.1002/jhm.1989>
- Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2009). Health care costs in the last week of life: associations with end-of-life conversations. *Archives of Internal Medicine*, 169(5), 480–488. <https://doi.org/10.1001/archinternmed.2008.587>
- Zheng, Z., Han, X., Zhao, J., Banegas, M. P., Tucker-Seeley, R., Rai, A., Fedewa, S. A., Song, W., Jemal, A., & Yabroff, K. R. (2020). Financial hardship, healthcare utilization, and health among U.S. cancer survivors. *American Journal of Preventive Medicine*, 59(1), 68–78. <https://doi.org/10.1016/j.amepre.2020.02.016>
- Zhi, W. I., & Smith, T. J. (2015). Early integration of palliative care into oncology: evidence, challenges and barriers. *Annals of Palliative Medicine*, 4(3), 122–131. <https://doi.org/10.3978/j.issn.2224-5820.2015.07.03>

APPENDICES

Appendix A

Scoping Literature Review

Purpose

To identify research published between July 2014 to July 2024 describing interventions aimed at the oncology care team and intended to enhance GOC discussions.

Methods

I conducted a PubMed search using the terms and parameters below. The search returned 211 publications. These were manually reviewed for the following:

- Limited to studies conducted in the US or Canada (for applicability of findings)
- Limited to interventions focused on adult patients with cancer, not young adult or pediatric
- Limited to randomized clinical trials and other prospective study designs, secondary analyses (quantitative or qualitative) those studies, or evaluations of quality improvement interventions
- Limited to oncology team interventions, not specialty palliative care interventions; for instance, the Greer et al., 2023 clinical trial testing tested palliative care visits for metastatic breast cancer, seeking to enhance documentation of EoL care discussions (among other outcomes) was removed

Search terms:

- (((communication*[MeSH Terms]) OR (advance care planning*[MeSH Terms]))) AND ((cancer[Title/Abstract]) OR (oncology[Title/Abstract])) AND ((serious illness communication[Title/Abstract]) OR (serious illness conversation[Title/Abstract]))
- ((cancer[Title/Abstract]) OR (oncology[Title/Abstract])) AND ((serious illness communication[Title/Abstract]) OR (serious illness conversation[Title/Abstract]))
- (((communication*[MeSH Terms]) OR (advance care planning*[MeSH Terms]))) AND ((cancer[Title/Abstract]) OR (oncology[Title/Abstract])) AND (goals of care[Title/Abstract]))

Filters applied to all searches: in the last 10 years, Humans, English

Results

Thirty-three studies were identified; 27 with quantitative results and six with qualitative results. Studies with quantitative results are summarized in Table A1. Nine of the included articles were also identified by Cripe et al. (2021), as reflected with the asterisk in the table; for those studies, I cross-referenced my summary information with the summary generated in their systematic review.

Table A1

Scoping Review Summary of Oncology GOC Intervention Studies, (July 2014 – July 2024)

Adaji et al., 2024. Enhancing Oncologists' Comfort with Serious Illness Conversations: The Impact of Serious Illness Conversation Guide (SICG) Training. Study type: QI Evaluation
<u>Objectives:</u> Evaluate the impact of SICG training on providers' comfort in engaging in serious illness conversations <u>Participants:</u> Clinicians: oncologists and advance practice providers; 505 pre-training survey respondents, 513 post-training survey respondents <u>Intervention:</u> Main: In-person, virtual training workshop <u>Outcomes and Measures:</u> Primary: 4 questions assessing knowledge bout and confidence in conducting serious illness conversations Secondary: Qualitative analysis of open question: "What is the most useful insight or tool you gained from this training?" Measurement: Pre and post-training survey <u>Results:</u> Following training, 95% of respondents rated themselves as prepared to have SIC, versus 57% of respondents before. A 66% difference was achieved in strongly agree/agree ratings in the post versus pre survey items.
Anaka et al., 2022. Changing Rates of Goals of Care Designations in Patients With Advanced Pancreatic Cancer During a Multifactorial Advanced Care Planning Initiative: A Real-World Evidence Study Study type: QI evaluation

Objectives:

Improve GOC designations in patients with advanced pancreatic cancer using a system-wide QI initiative.

Participants:

Patients: 471 patients with newly diagnosed advanced pancreatic cancer

Intervention:

Main: Education materials for patients and families, and healthcare workers; standard GOC medical orders

Patient Selection: Screening

Outcomes and Measures:

Primary: GOC documentation frequency and timing

Measurement: Review of cancer registry and medical records

Results:

Documented GOC increased over the 5 year study period from 7.8% to 50.0%. The proportion of GOC notes documented by medical oncology (vs palliative care physicians) increased from 0% to 52.1%. GOC documentation was later in those receiving palliative chemotherapy versus those who did not (median 130 days from diagnosis [95% CI, 76.019 to 183.981] v 36 days [95% CI, 28.107 to 43.893]; $P < .001$).

Annadurai et al., 2021. Impact of a Novel Goals-of-Care Communication Skills Coaching Intervention for Practicing Oncologists

Study type: clinical trial

Objectives:

To assess the impact of a communication training and coaching intervention for oncologists during GoC discussions.

Participants:

Clinicians: 11 solid tumor oncologists seeing advanced cancer patients at four hospitals; 11 control

Intervention:

Main: Communication skills training program (an interactive training session and four joint visits with coaches)

Patient Selection: By oncologist

Outcomes and Measures:

Primary: Skill attainment following training

Secondary: Discussion of patient values

Measurement: Recorded encounters with validated tool

Results:

Intervention oncologists were more likely to elicit patient values (55% vs. 0%; $p = 0.01$). There was no difference in overall mean skills employed.

Apostol et al., 2015*. Association of goals of care meetings for hospitalized cancer patients at risk for critical care with patient outcomes

Study type: clinical trial

Objectives:

Describe the use of GOC discussions in patients with advanced cancer at risk for critical care. Evaluate associations between these discussions and outcomes.

Participants:

Patients: Inpatients with advanced cancer and risk factors for critical care (supplemental oxygen and/or cardiac monitor) (34 intervention, 52 controls)

Clinicians: Inpatient staff oncologists. Palliative care consultation when requested

Intervention:

Main: Screening for critical care risk, facilitated GOC meetings; booklet and informational brochure

Patient Selection: Screening

Outcomes and Measures:

Primary: Frequency of meetings, outcomes of meetings, survey assessment of patients' needs, goals and perceptions

Measurement: Medical records review, surveys

Results:

With the intervention, 34/86 patients (39%) had a GOC meeting, were less likely to receive critical care (0% vs 22%, $p = 0.003$) and more likely to be discharged to hospice (48% vs 30%, $p = 0.04$). There was no difference in rates of DNR/DNI orders.

Bernacki et al., 2019* Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial

Study type: clinical trial

Objectives:

To evaluate the feasibility, acceptability, and effect of a communication quality-improvement intervention (Serious Illness Care Program) on the frequency of goal-concordant care and peacefulness at the EOL.

Participants:

Patients: Advanced cancer patients with life expectancy < 12 months (134 intervention, 144 control with untrained clinicians and no study materials)

Clinicians: 91 oncology clinicians

Intervention:

Main: Skills-based training of clinicians with follow-up coaching when requested; Letter to prepare patients, conversation guide for clinicians, and guide to aid patient in discussing goals with family

Patient Selection: Surprise question ("Would I be surprised if this patient died in the next year?")

Outcomes and Measures:

Primary: Goal-concordant EOL care and peacefulness at EOL for decedents

Secondary: Therapeutic alliance, anxiety, depression and survival; uptake and effectiveness of clinician training, clinician use of the conversation tool, and conversation duration

Measurement: Surveys of bereaved caregivers; administrative data

Results:

There were no differences in goal-concordant care, peacefulness at EOL, therapeutic alliance or survival. With the intervention, fewer patients with moderate to severe anxiety (10.2% v. 5.0%,

p = 0.05) or depression (20.8% v. 10.6%, p = 0.04) at 14 weeks. 98% of clinicians rated the training as effective; 87% of clinicians reminded had at least one GOCC with a median duration of 19 minutes.

Bickell et al., 2020* Effects of a Communication Intervention Randomized Controlled Trial to Enable Goals-of-Care Discussions.

Study type: clinical trial

Objectives:

Determine if oncologist training affects the prevalence and quality of GOC discussions.

Participants:

Patients: Patients with advanced cancer and life expectancy < 2 years (265)

Clinicians: Trained outpatient solid tumor oncologists (11); untrained oncologists (11) as controls

Intervention:

Main: 2-hour communication skills training with role play, and four coaching sessions

Patient Selection: Randomized by oncologists

Outcomes and Measures:

Primary: Patient-reported frequency and quality of GOC discussions

Secondary: Oncologist communication skill, EOL health care utilization

Measurement: Medical records review, surveys, evaluation of pre/post-training audiotapes

Results:

There were no differences in frequency or quality of GOC discussions. With the intervention, skill to elicit patient values increased (27%-55%), while control did not (9%-0%; P = .01). No differences in deaths, hospitalizations, ICU admissions, or chemotherapy.

Conduit et al., 2021. Implementing 'Goals of Care' discussion and palliative care referral for patients with advanced lung cancer: an outpatient-based pilot project

Study type: QI evaluation

Objectives:

Improve GOC form completion and palliative care referrals for patients with advanced lung cancer in an oncology clinic

Participants:

Patients: 84 patients receiving palliative treatment for advanced lung cancer

Clinicians: Trained oncology providers

Intervention:

Main: Communication skills training course followed by communicating priming

Patient Selection: Screening

Outcomes and Measures:

Primary: GOC discussions documented in EHR

Secondary: palliative care referral; clinicopathological factors

Measurement: Medical records review

Results:

The intervention improved GOC completion (relative risk (RR) 1.29, $P = 0.004$); improvement was not sustained in a follow-up audit (RR 0.98, $P = 0.92$). There was no change in palliative care referral rate (RR 2.5, $P = 0.16$).

Davidson et al., 2022. Promoting timely goals of care conversations between gynecologic cancer patients at high-risk of death and their providers

Study type: QI evaluation

Objectives:

Improve the quality and timing of GOC conversations in women with gynecologic cancers

Participants:

Patients: 220 high risk patients with gynecologic cancers

Clinicians: Ambulatory gynecologic oncology providers

Intervention:

Main: GOC educational program; provider alerts based on defined criteria for prospective identification of patients at high risk of death

Patient Selection: Prospective identification

Outcomes and Measures:

Primary: GOC documentation within 3 visits of high-risk identification

Secondary: Utilization measures; GOC documentation during the last 6 months of life among all established oncology patients

Measurement: Medical records review

Results:

Timely GOC discussion documentation increased from 30.2% to 88.7% ($p < 0.001$) and was sustained over time. Compared to other cancer types, gynecologic cancer patients had a higher rate of GOC documentation (81% versus 9%; $p < 0.001$), a lower rate of chemotherapy in the last 14 days of life (2% vs 5%; $p = 0.051$), and no difference in end-of-life admissions (29% vs 31%; $p = \text{NS}$).

Epstein et al., 2022. Goals of care documentation by medical oncologists and oncology patient end-of-life care outcomes

Study type: QI evaluation

Objectives:

Improve oncologist GOC documentation and EOL care.

Participants:

Patients: 1721 patients (identified as decedents)

Clinicians: Oncology providers

Intervention:

Main: GOC note template in the EHR, including structured EOL discussion field

Patient Selection: Decedents

Outcomes and Measures:

Primary: GOC documentation frequency and timing

Secondary: EOL utilization

Measurement: Medical records review

<u>Results:</u> Patients with a first GOC note >60 days before death had fewer inpatient days (6.7 vs 10.6 days, $p < .001$); patients with GOC notes including EOL discussion >30 days before death had fewer inpatient (5 vs 11, $p < .001$) and intensive care unit days (0.5 vs 1.5, $p < .001$), more hospice referrals (57% vs 44%, $p = .003$), and less chemotherapy ≤ 14 days before death (6% vs 11%, $p = .010$). Oncologist (vs nononcologist) GOC documentation and earlier EOL discussion documentation were associated with less inpatient care and more hospice referrals.
Hanson et al., 2017* Integrating Palliative and Oncology Care for Patients with Advanced Cancer: A Quality Improvement Intervention Study type: QI evaluation
<u>Objectives:</u> Assess impact of communications training and triggers for specialized palliative care consults on frequency of GOC communication for hospitalized patients with metastatic cancer. <u>Participants:</u> Patients: Metastatic cancer, admitted to a single hospital (330); with uncontrolled symptoms (229). Control patients were admitted in first 3 months of project. Clinicians: Inpatient providers and palliative care specialists. <u>Intervention:</u> Main: Communication skills and triggered palliative care consultations Education: Monthly training session for residents, medical students, NPs, PAs Patient Selection: Screening alerts <u>Outcomes and Measures:</u> Primary: Documented GOC discussion during hospitalization Secondary: Screened for pain, dyspnea, spiritual needs; ICU or hospice use; 30-day readmission Measurement: Chart review <u>Results:</u> With the intervention, GOC documentation increased (48% v. 29%, $p = 0.013$); specialty palliative care consults increased (33% v. 18%, $p = 0.026$). There were no differences in rates of symptom screening, ICU transfer, hospice, or 30-day re-admission. Patients with specialty palliative care had more pain screening (91% vs. 81%, $p = 0.020$), spiritual assessment (48% vs. 10%, $p < 0.001$), and hospice referral (39% vs. 9%, $p < 0.001$), and less 30-day readmission (12% vs. 21%, $p = 0.059$).
Hui et al., 2023. Impact of an Interdisciplinary Goals-of-Care Program Among Medical Inpatients at a Comprehensive Cancer Center During the COVID-19 Pandemic: A Propensity Score Analysis Study type: QI evaluation
<u>Objectives:</u> Examine the impact of a multicomponent interdisciplinary GOC program on ICU mortality and hospital outcomes for medical inpatients with cancer <u>Participants:</u> Patients: 12,941 hospitalized patients with cancer (pre $n = 6,977$; post $n = 5,964$) including 1,365 ICU admissions (pre $n = 727$; post $n = 638$). <u>Intervention:</u>

Main: Multicomponent GOC program including patient risk stratification; prompting for GOCC among high-risk patients; monitoring and feedback; GOCC education; support from specialty palliative care and a 'GOC rapid response team'

Patient Selection: Consecutive patients admitted

Outcomes and Measures:

Primary: ICU mortality

Secondary: ICU length of stay, hospital mortality, and proportion/timing of care plan documentation

Measurement: Chart review

Results:

After the intervention, ICU mortality decreased (28.2% v 21.9%; $P = .0001$); ICU length of stay decreased (mean change -1.4 days, $P < .0001$) and in-hospital mortality decreased (7% v 6.1%, $P = .004$). In-hospital DNR orders increased from 14.7% to 19.6% (odds ratio, 1.4; 95% CI, 1.3 to 1.5; $P < .0001$), and DNR orders were established earlier (mean difference -3.0 days, 95% CI, -3.9 to -2.1; $P < .0001$).

Karim et al., 2018* Documenting Goals of Care Among Patients With Advanced Cancer: Results of a Quality Improvement Initiative

Study type: QI Evaluation

Objectives:

To improve the rate of documentation of GOC and referral to palliative care through implementation of a quality improvement initiative.

Participants:

Patients: Advanced lung, breast, colorectal, and pancreatic with life expectancy < 1-year (303)

Clinicians: Outpatient oncologists

Intervention:

Main: Identification of patients, e-mail alert to oncologist, GOC form, QI scorecard of individual physician rates

Patient Selection: Screen of pharmacy records and EHR for palliative systemic treatment

Outcomes and Measures:

Primary: Percent of patients with GOC form in EHR

Secondary: Rate of palliative care referral

Measurement: Chart review

Results:

With the intervention, rates of GOC form in EHR increased from 3% to 31% ($p < 0.01$). Rate of referral to palliative care increased (36–48%).

Leung et al., 2023. The impact of a multidisciplinary goals-of-care program on unplanned readmission rates at a comprehensive cancer center

Study type: QI evaluation

Objectives:

Examine the impact of a multicomponent interdisciplinary GOC program on 30-day unplanned readmission rates for patients with cancer

Participants:

Patients: 7028 admitted patients in the pre-implementation period; 5982 in the post-implementation period

Intervention:

Main: See Hui et al., 2023

Patient Selection: Consecutive admissions

Outcomes and Measures:

Primary: 30-day unplanned readmission rates

Secondary: 7-day unplanned readmission rates, inpatient do-not-resuscitate (DNR) orders, and palliative care consults

Measurement: Chart review

Results:

After implementation, overall 30-day unplanned readmission rate decreased from 24.0 to 21.3%; after adjustment, a significant reduction (OR [95% CI] 0.85 [0.77, 0.95], $p = 0.003$). 7-day unplanned readmission rate also decreased significantly (OR [95% CI] 0.75 [0.64, 0.89]).

Manz et al., 2020. Effect of Integrating Machine Learning Mortality Estimates with Behavioral Nudges to Clinicians on Serious Illness Conversations Among Patients with Cancer: A Stepped-Wedge Cluster Randomized Clinical Trial

Study type: clinical trial

Objectives:

To determine the effect of a clinician-directed intervention integrating machine learning mortality predictions with behavioral nudges on motivating clinician-patient SICs.

Participants:

Patients: 14,607 patients who had an outpatient oncology encounter with the 78 oncology clinicians who received SIC training

Clinicians: 78 oncology clinicians in 8 oncology groups (intervention and control)

Intervention:

Main: Weekly emails to oncology clinicians with SIC performance feedback and peer comparisons; a list of up to 6 high-risk patients scheduled for the next week, estimated using a machine learning algorithm; text message prompts to clinicians on the patient's appointment day to consider an SIC
Patient Selection: high-risk patients ($\geq 10\%$ predicted risk of 180-day mortality) estimated using a validated machine learning algorithm

Outcomes and Measures:

Primary: SIC rates for all patient encounters

Secondary: SICs among high-risk patients and ACP completion for the overall sample and for the high-risk subgroup

Measurement: medical records review

Results:

For all encounters, SICs were conducted among 1.3% in the control group and 4.6% in the intervention group, a significant difference (adjusted difference in percentage points, 3.3; 95% CI, 2.3-4.5; $P < .001$). Among 4124 high-risk patient encounters, SICs were conducted among 3.6% in the control group and 15.2% in the intervention group, a significant difference (adjusted difference in percentage

points, 11.6; 95% CI, 8.2-12.5; $P < .001$). The intervention led to a significant increase in the ACP rate in all patients and high-risk patients.

Manz, Zhang, Chen et al. 2023. Long-Term Effect of Machine Learning-Triggered Behavioral Nudges on Serious Illness Conversations and End-of-Life Outcomes among Patients with Cancer.

Study type: clinical trial

Objectives:

To test the impact of behavioral nudges to clinicians to prompt SICs among high-risk patients.

Participants:

Patients: 20,506 patients with cancer at 9 tertiary or community-based medical oncology clinics in an academic health system

Intervention:

See Manz et al. 2020; here, the study added 24 weeks of follow up

Outcomes and Measures:

Primary: SIC rates for all and high-risk patient encounters

Secondary: EOL outcomes among decedents included inpatient death, hospice enrollment and length of stay, and intensive care unit admission and systemic therapy close to death

Measurement: medical records review

Results:

The intervention was associated with increased SICs for all patients (adjusted odds ratio, 2.09 [95% CI, 1.53-2.87]; $P < .001$) and decreased end-of-life systemic therapy (7.5% [72 of 957 patients] vs 10.4% [24 of 231 patients]; adjusted odds ratio, 0.25 [95% CI, 0.11-0.57]; $P = .001$). There was no effect on hospice enrollment or length of stay, inpatient death, or end-of-life ICU use.

Paladino et al., 2019* Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients With Life-Limiting Cancer: A Cluster Randomized Clinical Trial of the Serious Illness Care Program.

Study type: clinical trial

Objectives:

To evaluate the effect of a communication quality improvement program on the frequency, timing, quality and accessibility of serious illness communication.

Participants:

Patients: Patients with cancer and life expectancy < 12 months (134 intervention). 144 control patients received no study materials and had untrained clinician.

Clinicians: 91 outpatient oncology physicians and advanced-practice clinicians at one hospital (48 intervention, 43 control)

Intervention:

Main: Letter to prepare patients, conversation guide for clinicians, and guide to aid patient in discussing goals with family; skills-based training of clinicians with follow-up coaching when requested

Patient Selection: Surprise question ("Would I be surprised if this patient died in the next year?")

Outcomes and Measures:

Primary: Frequency, timing, and quality of serious illness conversations prior to death and accessibility in EHR

Measurement: Review of EHR for notes that addressed at least one of following: 1. Values or goals; 2. Prognostic understanding; 3. EOL care planning; and 4. Life sustaining treatment preference.

Results:

With the intervention, GOC conversation documentation increased (96% v. 79%; $p = 0.005$) and conversations occurred earlier (median, 143 v. 71 days before death; $p < 0.001$). Conversation documentation had greater focus on values or goals (89% vs 44%, $P < .001$), prognosis or illness understanding (91% vs 48%, $P < .001$), and life-sustaining treatment preferences (63% vs 32%, $P = .004$). More patients had documentation accessible in the EHR (61% vs 11%, $P < .001$). Documentation of EOL care planning did not differ.

Paladino et al., 2020. Effect of the Serious Illness Care Program on Health Care Utilization at the End of Life for Patients with Cancer.

Study type: secondary analysis of clinical trial

Objectives:

To determine the effect of the Serious Illness Care Program on health care utilization at the end of life in oncology.

Participants:

159 patients who died in the Paladino et al. 2019 study

Intervention:

See Paladino et al. 2019 study

Outcomes and Measures:

Primary: Health care utilization using national indicators of aggressive cancer care near the EOL
Measurement: medical records review

Results:

There was no difference in the mean number of aggressive indicators (0.9 vs. 0.9, $p = 0.84$) nor the proportion of patients with any aggressive care (49% intervention [95% CI: 40-57] vs. 54% control [95% CI: 42-67]).

Patel et al., 2018* Effect of a Lay Health Worker Intervention on Goals-of-Care Documentation and on Health Care Use, Costs, and Satisfaction Among Patients With Cancer: A Randomized Clinical Trial.

Study type: clinical trial

Objectives:

Determine how scheduled phone calls with a lay health worker affects rates of documentation of cancer patients' care preferences in a Veteran's Administration Hospital.

Participants:

Patients: Patients with advanced or recurrent cancer (105). Control patients randomized to usual care (108).

Clinicians: Usual care

Intervention:

Main: Twice monthly phone calls with lay health worker; Six-month program with an LHW trained to assist patients with establishing end-of-life care preferences vs usual care (80-hour online training + 4 weeks with palliative care team)
 Patient Selection: Randomization

Outcomes and Measures:

Primary: Documentation of GOC by oncology clinician in EHR
 Secondary: Patient satisfaction with provider, health care use, costs
 Measurement: Chart reviews, decision support

Results:

With the intervention, GOC documentation increased (93% v. 17% in control, $p < 0.001$); provider satisfaction increased, hospice use increased (76.7% vs 48.3%; $P = .002$), ED visit decreased (0.05 vs 0.60; $P < .001$), hospitalizations decreased (0.05 vs 0.50; $P < .001$), and costs decreased (\$1048 vs \$23 482; $P < .001$)

Patel et al., 2024. Spending Analysis of Machine Learning-Based Communication Nudges in Oncology.

Study type: secondary analysis of clinical trial

Objectives:

To evaluate the impact of SIC nudges to clinicians on end-of-life spending

Participants:

Patients: 1187 enrolled patients who died by December 2020; 957 intervention patients and 230 control.

Intervention:

See Manz, Zhang, Chen et al. 2023

Patient Selection: Decedents were assigned to controls or intervention group based on intervention status on the date of their last clinic encounter

Outcomes and Measures:

Primary: mean total and daily health care spending during the last 6 months of life, stratified by acute care use, office/outpatient, systemic therapy, hospice, other therapy, and rehab/LTC
 Secondary: mean spending during the last 3 months and last 1 month of life, stratified as above
 Measurement: accounting system and medical records abstraction

Results:

With the intervention, unadjusted mean daily spending in the last 6 months of life was lower (\$377.96 vs. \$449.92; adjusted mean difference, $-\$75.33$; 95% confidence interval, $-\$136.42$ to $-\$14.23$; $P=0.02$); \$13,747 total adjusted savings per decedent and \$13 million in cumulative savings in the intervention group. Patients in the intervention group had lower mean daily spending for systemic therapy (adjusted difference, $-\$44.59$; $P=0.001$), office/outpatient care ($-\$9.62$; $P=0.001$), and other therapy ($-\$8.65$; $P=0.04$). The intervention was not associated with differences in end-of-life spending for acute care, long-term care, or hospice. Results were consistent for spending in the last 1 and 3 months of life. For patients with SICs, mean daily spending decreased by \$37.92 following the first SIC (\$329.87 vs. \$291.95).

Pintova et al., 2020a* Impact of High-Quality Goals-of-Care Discussions on Oncologist Productivity.
 Study type: clinical trial

Objectives:

Determine if high-quality GOC discussions affect oncologists' productivity.

Participants:

Patients: Patients with metastatic cancer and life expectancy < 2 years (265)

Clinicians: Solid-tumor oncologists randomly assigned from community, academic, municipal, and rural hospitals (11); untrained oncologists (10) were controls

Intervention:

Main: Coaching model of communication skills with role play; 4 coaching visits/evaluations

Patient Selection: By oncologist

Outcomes and Measures:

Primary: Patient-reported high-quality GOC discussions and work relative value unit (wRVU)

Secondary: Patient and provider characteristics

Measurement: Surveys and billing data

Results:

There were no differences in productivity when high-quality GOC discussion occurred versus not (3.6 v 3.7 wRVU/hour; $P = .86$). Hispanic ethnicity and more experienced oncologist were associated with high-quality GOC discussions.

Pintova et al., 2020b. Conducting Goals-of-Care Discussions Takes Less Time Than Imagined.

Study type: Secondary analysis of a clinical trial

Objectives:

Describe the length of encounter during visits where GoC discussions were expected to take place

Participants:

Patients: Patients with metastatic cancer and life expectancy < 2 years (265)

Clinicians: Solid-tumor oncologists randomly assigned from community, academic, municipal, and rural hospitals (11); untrained oncologists (10) were controls

Intervention:

Main: Coaching model of communication skills with role play; 4 coaching visits/evaluations

Patient Selection: By oncologist

Outcomes and Measures:

Primary: Total encounter time

Secondary: Patient-reported high-quality GOC discussions

Measurement: Timed encounters, audiotaped visits, survey

Results:

15 minute median face-to-face time for a GoC discussion (range, 10-20 minutes). No significant difference in encounter time across hospitals. No difference in length of the encounter whether a high-quality GoC discussion took place or not (15 v 14 minutes; $P = .9$). Median encounter time was 18 minutes with cancer progression, compared with 13 minutes for no progression ($P = .03$). Oncologist productivity, patient age, and Medicare coverage affected duration of the encounter.

Reddy et al., 2023. Impact of an Institution-Wide Goals of Care Program on the Timing of Referrals to Outpatient Palliative Care
Study type: QI evaluation

Objectives:

Assess the change in the timing of outpatient palliative care referrals before and after implementing an institution-wide multicomponent interdisciplinary GOC program

Participants:

Patients: 400 randomly selected patients with a supportive care consult; 200 prior to and 200 after intervention implementation

Intervention:

Main: See Hui et al., 2023

Patient Selection: Random

Outcomes and Measures:

Primary: Median overall survival (OS) following first supportive care visit

Secondary: Timing of first supportive care visit and death; presence of medical oncology ACP notes and ADs; patient performance status and symptoms

Measurement: Medical records review

Results:

There was no difference in OS before and after implementation. After implementation, patients had more ACP notes completed by medical oncology (25.5% vs. 4.5%; $P < 0.001$), lower symptom scores, and better performance status.

Schenker et al., 2022. Effect of an Oncology Nurse-Led Primary Palliative Care Intervention on Patients With Advanced Cancer: The CONNECT Cluster Randomized Clinical Trial.

Study type: clinical trial

Objectives:

To assess the effect of a primary palliative care intervention delivered by oncology nurses on patient outcomes.

Participants:

Patient: 672 adult patients with metastatic solid tumors who were undergoing oncological care and for whom an oncologist would agree with the statement "would not be surprised if the patient died in the next year."

Clinician: 17 community oncology practices in western Pennsylvania

Intervention:

Main: 3 monthly visits with an existing infusion room nurse who was trained to address symptoms, provide emotional support, engage in advance care planning, and coordinate care (CONNECT intervention)

Patient Selection: oncologist selection (surprise question)

Outcomes and Measures:

Primary: Patient quality of life

Secondary: Symptom burden, mood symptoms

Measurement: Surveys at baseline and 3 months (Functional Assessment of Chronic Illness Therapy-Palliative care, Edmonton Symptom Assessment Scale, Hospital Anxiety and Depression Scale [HADS])

Results:

With the intervention, no difference in quality-of-life at three months; no difference in symptom burden or mood symptoms. There was a larger estimated treatment effect for patients who received a full dose (3 visits) of the intervention.

Seevaratnam et al., 2024. Lesson Learned from a Multi-Site, Team-Based Serious Illness Care Program Implementation at an Academic Medical Center

Study type: QI evaluation

Objectives:

Evaluate implementation of the Serious Illness Care Program across an academic medical center network, seeking to improve the quantity, timing, and quality of serious illness conversations

Participants:

Patients: Ambulatory oncology and hospital medicine patients

Intervention:

Main: Communication skills training using SICIP; machine learning algorithms to identify eligible patients; prompts for GOCC with EHR documentation across ambulatory oncology and hospital medicine

Patient Selection: Algorithm

Outcomes and Measures:

Primary: Documented goals of care conversations in the EHR

Measurement: Medical record review

Results:

After implementation, providers in ambulatory oncology had GOC notes documented for 4704 patients, and hospital medicine providers for 642 patients.

Takavorian et al., 2024. Clinician- and Patient-Directed Communication Strategies for Patients with Cancer at High Mortality Risk: A Cluster Randomized Trial.

Study type: clinical trial

Objectives:

To test the independent and combined effects of clinician and patient nudges on SIC completion.

Participants:

Patient: 4450 patients with cancer at high risk of mortality, randomized to active control (n = 1004), clinician nudge (n = 1179), patient nudge (n = 997), or combined nudges (n = 1270)

Clinician: 163 medical and gynecologic oncology clinicians across 4 hospitals and 6 community sites within an academic system

Intervention:

Main: clinician text message reminders to complete SICs for patients at high mortality risk (active control); active control plus weekly peer comparisons of SIC completion (clinician nudge); active control plus a preclinic electronic communication for patients (patient nudge); and combined clinician and patient nudges.

Patient Selection: Screening for high risk of mortality ($\geq 10\%$ risk of 180-day mortality).

Outcomes and Measures:

Primary: documented SIC in the electronic health record within 6 months of a participant's first clinic visit after randomization

Measurement: Medical records review

Results:

Rates of SIC completion were 11.2% for the active control arm, 11.5% for the clinician nudge arm, 11.5% for the patient nudge arm, and 14.1% for the combined nudge arm. Compared with active control, the combined nudges were associated with an increase in SIC rates (ratio of hazard ratios [rHR], 1.55 [95% CI, 1.00-2.40]; $P = .049$); clinician nudge (HR, 0.95 [95% CI, 0.64-1.41; $P = .79$) and patient nudge (HR, 0.99 [95% CI, 0.73-1.33]; $P = .93$) were not.

Wood et al., 2024. Outcomes of a Multisite Mentored Implementation Approach to Promoting Goals of Care Conversations

Study Type: QI evaluation

Objectives:

To evaluate the effect of Preference-Aligned Communication and Treatment (PACT) Project PACT on goal-discordant care and resource utilization

Participants:

Patients: seriously ill hospitalized patients (1374 intervention, 4019 propensity-matched control)

Clinicians: clinicians in 9 hospitals

Intervention:

Main: Mentored QI

Patient Selection: Screening

Outcomes and Measures:

Primary: percentage of deceased patients with care discordant with stated preferences

Secondary: end-of-life resource utilization

Measurement: medical records; Medicare claims data

Results:

In the intervention group, rates of discordance between wishes and care were low; patients had lower costs (-976.05 dollars, $P = 0.010$), less ICU admission (OR 0.9, $P = 0.005$), more hospice enrollment (OR 1.81, $P < 0.001$), longer hospice stay (3.35 more days, $P = 0.041$).

Wright et al., 2022. The SHARE Study: Pilot Study of a Communication Intervention Designed to Elicit Advanced-Stage Cancer Patients' Preferences and Goals

Study type: Pilot study

Objectives:

The aim of this study was to pilot test the feasibility and acceptability of an intervention designed to elicit patients' preferences and goals of care and share them with their oncology teams

Participants:

Patients: 53 advanced-stage cancer patients

Intervention:

Main: 2.5-minute video, 3-page brief questionnaire, and a wallet card with question prompts was conducted.

Patient Selection: Screening

Outcomes and Measures:

Primary: Feasibility and acceptability

Secondary: patient anxiety and distress, hope, quality of life, and therapeutic alliance

Measurement: Surveys pre and post intervention

Results:

92% of patients rated experience highly; 83% would recommend the video, 88% the brief questionnaire, and 63% the wallet card; only 34% of participants reviewed the questionnaire with their oncologist. No change in patient anxiety or distress, no reductions in hope or therapeutic alliances with oncologists (all $p > 0.05$); quality of life improved post-intervention ($p = 0.02$).

Appendix B

Table B1*Item Level Scores* by Domain Categories; Source: GOC Implementation Survey*

	Mean score*	Median score	Min score	Max score
Category: Resources				
Leaders at my center allocated the funding necessary to implement our communications skills training program.	1.5	1.0	1	4
Leadership at my center provided sufficient support to those who served as faculty for the trainings.	1.8	1.5	1	3.5
At my center, we had the resources we needed to make timely changes to our electronic health record (EHR) in support of our GOC program.	1.9	1.5	1	4
At my center, we had enough organizational support for an operational improvement initiative of this scale.	2.4	2.0	1	4.5
My center committed the staff / human resources that we needed for an operational improvement initiative of this scale.	2.4	1.8	1	4.5
My center committed the financial resources that we needed for an operational improvement initiative of this scale.	2.3	1.8	1	4.5
Category: Leadership				
Leaders at my center modeled support for our communication skills training program by getting trained early.	2.0	1.5	1	5
Leaders at my center were vocal about their support for communications skills training to oncology clinical staff.	2.0	1.5	1	4.5
At my center, the first providers trained became vocal supporters of training for their colleagues.	1.9	1.8	1	3
Leaders at my center made decisions in a timely way to support our GOC program implementation.	2.0	1.5	1	4.5
Leaders at my center helped reduce or remove barriers to our GOC program implementation.	2.3	1.8	1	4.5
At my center, we had support from department/disease leadership for our GOC program implementation.	1.8	1.5	1	3.5

Category: Incentives				
Leaders at my center created adequate incentives for oncology providers to attend training sessions.	2.8	2.8	1	5
Leaders at my center protected time for oncology providers to attend training sessions.	2.8	2.8	1	4.5
At my center, leaders aligned oncology provider incentives with the objectives of our GOC program.	2.7	2.5	1	5
Category: Culture				
Oncology providers at my center had an overall positive attitude about attending communication skills training.	1.9	1.8	1	3.5
In general, leaders at my center are supportive of evidence-based care delivery improvements.	1.5	1.5	1	2.5
In general, oncology providers are accepting of care delivery improvements that are implemented at my center.	1.9	1.8	1	3.5
My center publicly celebrated successes during our GOC program implementation.	3.0	2.8	1	4.5
My center integrated messaging related to our GOC program into public/patient-facing communications.	3.7	3.8	2	5
Category: Strategic Integration				
At my center, we sought guidance and support from our PFAC as we implemented our GOC program.	2.1	2.3	1	3
During our GOC implementation, my center's strategic plan or goals reflected key aspects of our program.	2.0	2.0	1	3
During our GOC implementation, leadership at my center presented about the program to our Board of Directors.	2.5	2.5	1	4
During our GOC implementation, leadership at my center presented about the program to our PFAC.	2.2	2.3	1	3
Category: Reporting and Benchmarking				
At my center, we created actionable, meaningful reports from our EHR or other HIT systems that supported our GOC program implementation.	2.1	2.0	1	3.5
Sharing reports or dashboards with our oncology providers positively impacted our GOC program implementation.	1.3	1.0	1	2
Sharing reports or dashboards with our executive leadership positively impacted our GOC program implementation.	1.9	1.5	1	5
Category: Adaptability				

At my center, we adjusted our training program during our GOC program implementation, due to feedback from attendees.	2.0	1.8	1	4
At my center, we adjusted our training program during our GOC program implementation, due to logistics or budgetary factors.	3.1	3.3	1	4.5
Category: Champion Role				
As a champion at my center, I found the work of leading our GOC program implementation to be rewarding.	1.4	1.0	1	3
Serving as a champion for the GOC program implementation at my center has been important to me personally.	1.3	1.0	1	2
I feel recognized for my work as a champion for our GOC program implementation at my center.	2.2	2.3	1	3.5
My experience serving as a champion at my center will have a lasting impact on my career path.	2.2	2.0	1	3.5
As a champion at my center, I had a team that substantively contributed to our GOC program implementation.	1.6	1.3	1	3
As a champion at my center, it was difficult to balance my workload with the time needed for the GOC program implementation.	2.6	2.5	1	4
I would like my role as a champion to continue as my center seeks to sustain or grow our GOC program.	1.6	1.5	1	2.5

Appendix C

Table C1*Institutional Alignment Undertaken and Perceived Impact on GOC Program Implementation;**Source: GOC Implementation Survey*

Alignment Item	% (#) Yes	% (#) indicating positive impact*
Connected to billing practices	60% (12)	67% (8)
Aligned with payer programs	50% (10)	40% (4)
Used as exemplar for external accreditors or certifiers	N/A; all asked	55% (11)
Explicitly linked to other cancer center operational priorities	60% (12)	58% (7)

*Rated item as Strongly Agree or Agree

Appendix D

Table D1

Domain Categories Correlations with Implementation Success Items[^]; Source: GOC Implementation Survey*

Domain Category	Implementation Success Items								
	Training implemented successfully	Training improved GOC skills	Useful GOC documentation in EHR	Providers accept GOC documentation	Clinically meaningful PP definition	Used PP to identify patients	Triggered GOC discussions	Integrate GOC into workflows	Providers understand GOC vision
Strategic Integration	0.54	0.39	0.42	0.06	0.43	0.36	0.4	0.37	0.68
Resources	0.66	0.76	0.38	0.46	0.54	0.7	0.76	0.83	0.65
Leadership	0.61	0.8	0.47	0.67	0.66	0.74	0.79	0.88	0.73
Culture	0.6	0.78	0.52	0.57	0.53	0.66	0.77	0.84	0.67
Champion Experience	0.39	0.74	0.71	0.78	0.43	0.17	0.51	0.7	0.75

* Spearman's r correlation

[^]Items are abbreviated; see Table 15 for complete Implementation Success items

Table D2

Implementation Success Items Correlations with Outcome Items; Source: GOC Implementation Survey*

Implementation Success Item	Outcome Items					
	Providers embraced GOC	GOC program changed culture	GOC program improved patient care	Changes became standard	Changes likely to continue	Providers value GOC discussions
Training implemented successfully	0.74	0.38	0.59	0.4	0.51	0.46
Training improved GOC skills	0.92	0.65	0.69	0.55	0.59	0.68
Useful GOC documentation in EHR	0.69	0.57	0.62	0.65	0.57	0.09
Providers accept GOC documentation	0.79	0.69	0.51	0.45	0.57	0.29
EHR improved GOC documentation	0.68	0.76	0.51	0.53	0.55	0.29
EHR increased access to GOC	0.64	0.66	0.47	0.48	0.42	0.39
Clinically meaningful PP definition	0.43	0.53	0.58	0.58	0.5	0.41
Used PP to identify patients for GOC	0.48	0.49	0.54	0.61	0.54	0.36
Triggered GOC discussions	0.6	0.64	0.67	0.73	0.66	0.45
Integrate GOC into workflows	0.86	0.69	0.7	0.72	0.72	0.55
Compelling case for GOC	0.89	0.67	0.65	0.74	0.93	0.37
Providers understand GOC vision	0.78	0.7	0.78	0.87	0.93	-0.02

* Spearman's r correlation

^Items are abbreviated; see Table 15 for complete Implementation Success items and Table 16 for complete Outcome items