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Guidelines for goals of care discussions in patients with gynecologic cancer

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HIGHLIGHTS

- Goals of care discussions should occur at any point when a major treatment decision is made.
- Electronic medical record algorithms and documentation templates can help integrate goals of care into routine practice.
- Patient-centered communication skills are essential and can improve with evidence-based interventions.

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ABSTRACT

This article represents a distillation of literature to provide guidance for goals of care discussions with patients who have gynecologic malignancies. As clinicians who provide surgical care, chemotherapy, and targeted therapeutics, gynecologic oncology clinicians are uniquely positioned to form longitudinal relationships with patients that can enable patient-centered decision making. In this review, we describe optimal timing, components, and best practices for goals of care discussions in gynecologic oncology.

Contents

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1. Background

Shared decision-making requires both the communication of medical information and elucidation of the individual patient's perspectives and values [1]. Opportunities for shared decision-making occur frequently in gynecologic oncology when patients are diagnosed with potentially life-limiting cancers and must consider the tradeoffs associated with available treatments. Goals of care conversations are integral to shared decision-making. These discussions are aimed at exploring patient preferences and expectations at any time when treatment decisions are being made. There are many misconceptions around goals of are discussions, which are not synonymous with “end of life” conversations. A goals of care discussion can occur at any and multiple timepoints, from the cancer diagnosis to the end of life. The aim of these discussions is to elucidate the patient's values and wishes and to provide a recommendation that supports these values. While goals of care discussions may lead to less aggressive interventions near the end of life, this is not the primary aim of these important conversations. [2,3]. Goals of care discussions also improve patients' satisfaction, trust in their care team, and quality of life by allowing the treatment team to make recommendations that are in line with a patient's values. Importantly, when a patient's quality of life improves, so does that of their caregiver [4,5].

Despite data demonstrating the value of goals of care conversations, no guidelines exist regarding the optimal timing, content, and documentation of these discussions in gynecologic oncology. Over half of gynecologic oncologists wait to initiate goals of care discussions until a major change in functional status occurs, with a large portion of these discussions occurring in inpatient settings and within 30 days of death [6,7]. Most gynecologic oncologists identify code status, advance directives, and transitions to hospice as key components of goals of care discussions. These topics are essential to discuss not just near the end of life, but at any time when a major decision is being made [6]. Barriers to goals of care discussions in gynecologic oncology include inadequate preparation or time, fear of destroying hope, provider emotional discomfort, and the uncertainty inherent in prognostication [8]. Despite clinician hesitation, patients generally appreciate goals of care discussions that are initiated by their healthcare team [9]. The ability to provide a patient-centered recommendation on these important topics requires skill in clarification of the patient's values, delivery of relevant medical information, and response to the emotions elicited. This practice requires commitment on the part of gynecologic oncology providers. While expertise in goals of care conversations has the potential to greatly improve quality of care for both patients and their families, unskilled communication about goals of care may result in care that is inconsistent with patient values and worsen inequities and quality of care for racial, ethnic, and sexual/gender minority groups [10–13].

In the current clinical practice review and guideline article, we aim to identify key questions regarding goals of care conversations in gynecologic oncology. We provide practical guidelines based on available evidence to serve as a framework through which gynecologic oncology care providers can successfully conduct goals of care discussions with their patients.

2. Guideline questions

This clinical practice guideline addresses the following questions: 1) For which patients with gynecologic cancers should goals of care conversations be initiated? 2) What are the key elements and ideal environment for goals of care discussions? 3) What are the best practices for documentation of goals of care conversations with gynecologic oncology patients? 4) What resources are available to help clinicians with their communication skills?

3. Methods

3.1. Guideline development process

The authors developed four guideline questions relevant to goals of care conversations in gynecologic oncology. A literature review was performed focused on the four guideline questions. Two search strategies were used for literature review using MEDLINE (via PubMed). Results were limited to years 1946–2022 in English language only. The first search strategy, focused on gynecologic cancers and goals of care, was performed on August 12, 2022, and yielded 65 articles (Supplementary Table 1). The second search, aimed to capture a broader collection of articles focused on goals of care and cancer, was performed on October 11, 2022. Results were limited to reviews and meta-analyses, yielding 541 articles (Supplementary Table 2). Abstracts were reviewed by one author to determine relevance to the clinical questions of interest, and relevant articles were bookmarked for detailed review. After abstract review, 62 articles were identified that pertained to the guideline questions of interest. Review of these studies was performed to develop clinical recommendations.

4. Clinical question 1: For which patients with gynecologic cancers should goals of care conversations be initiated?

Recommendation 1.1(a): Goals of care discussions should occur soon after diagnosis for all patients diagnosed with an advanced stage gynecologic malignancy.

Recommendation 1.1(b): Goals of care discussions should occur at the time of first recurrence of a gynecologic malignancy and at each subsequent disease progression.

Recommendation 1.2: Elderly or frail patients with gynecologic cancers should have goals of care discussions initiated at diagnosis, regardless of stage.

Recommendation 1.3: Automated alerts in the electronic medical record may be helpful in identification of patients for goals of care conversations.

4.1. Literature review

Goals of care discussions are often erroneously considered synonymous with end-of-life discussions, with over half of gynecologic oncology clinicians deferring these conversations until a major decline in functional status occurs. Less than one third of goals of care conversations are initiated at time of first disease progression or recurrence [6]. A systematic review of goals of care discussions and healthcare utilization found that earlier discussions, defined as occurring more than 30 days before death, were associated with less aggressive interventions at the end of life including fewer emergency department (ED) visits, intensive care unit (ICU) admissions, and deaths in the hospital [14]. While the optimal timing requires an individual assessment of the patient and clinical context, there are no studies demonstrating benefit to delaying important conversations, and several that support earlier goals of care conversations, at least 3 months prior to death [15,16]. A survey of patients with gynecologic cancer demonstrated that the majority

preferred discussion of advance directives and do not attempt resuscitation (DNAR) orders at the time of first progression or even earlier [17].

Older adults with gynecologic cancer represent a unique population for whom goals of care discussions should be initiated early in the disease course. The "geriatric" patient is variably defined by age (≥65–75) or by a combination of age and frailty. A "geriatricassessment" for older patients with cancer has been shown to reduce toxicity and improve outcomes associated with cancer treatment, including lowering the rate of treatment complications, improving physical functioning and quality of life, and decreasing the likelihood of treatment completion [18,19]. This assessment includes evaluation of cognition, nutritional status, physical function, and elicitation of goals of care. A large study of nearly 1500 adults indicate that an inpatient medical admission for patients with metastatic cancer and age > 70 is associated with a 1-year mortality of 64% [20]. In particular, for older patients where surgery is being considered, the American College of Surgeons National Surgical Quality Improvement Program (ACS NSQIP) surgical risk calculator is another tool that can identify patients at a higher risk of perioperative death [21]. While age alone can be a trigger to initiate a goals of care discussion, consideration should also be given to earlier goals of care discussions in patients with gynecologic cancer and other life-limiting conditions including poor performance status, dementia, malnutrition, and end-stage renal or cardiopulmonary disease [20,22].

In the real world setting where time is a limited resource, even well-intentioned clinicians may introduce goals of care discussions later than intended. Electronic alerts identifying patients at high risk of mortality can improve rates of goals of care conversations. Algorithms to alert clinicians to consider goals of care discussions in high-risk patients based on electronic medical record data may be a practical and sustainable strategy [23,24]. In a randomized trial by Manz et al., a validated algorithm was used to identify patients with a ≥ 10% risk of 180-day mortality. Clinicians who were randomized to receive email and text message reminders of patients who were at high risk of mortality were significantly more likely to initiate goal of care conversations with their patients [23]. Additional work is needed to determine how similar interventions may affect other outcome metrics such as patient and caregiver satisfaction, hospice enrollment, and death in the hospital.

5. Clinical question 2: What are the key elements and ideal environment for goals of care discussions?

Recommendation 2.1: The key components of a goals of care discussion are assessment of a patient's readiness to discuss clinical status and prognosis, disclosure of information, elicitation of the patient's values and preferences, and delivery of a patient-centered care recommendation. It is appropriate to introduce advance directives, code status, and/or hospice services in discussion of these recommendations.

Recommendation 2.2: Goals of care discussions should preferably be conducted by the primary oncologist in a supportive environment.

5.1. Literature review

Well performed goals of care discussions require both flexibility to explore patient values and structure to ensure that key information is exchanged to support decision-making. Examples of language that may help facilitate exploration of patient values and preferences are provided in Table 1. In addition, exploring feelings about disease, suffering, and circumstances surrounding death are also important to incorporate, particularly as conversation moves away from cancer-directed treatment [25]. There are several tools that can be provided to patients, such as "Five Wishes" and "Go Wish", that utilize previously validated studies to create materials to help patients explore their values and goals around commonly important issues at the end of life [26–28].

Several studies have demonstrated that prognostic information is highly desired by patients; however, less than half of patients with advanced or end-stage cancer report an understanding of their prognosis [29–32]. An assessment of patient desires for prognostic information is essential to frame goals of care discussions, as this informs decision-making in multiple domains. While many physicians are hesitant to provide this information for fear of providing inaccurate information, avoidance of discussion may result in substantial discrepancy between patient and provider perceptions of prognosis and thus discordant expectations for the future which can impact decision-making. This was exemplified in a small study of patients receiving second or third line chemotherapy for recurrent or refractory advanced ovarian cancer, with half of patients reporting the goal of treatment as cure [33]. The communication of prognostic information, while imperfect, is a core competency for oncology clinicians [34]. While prognostication remains challenging in clinical practice, there are validated, evidence-based tools such as the Palliative Prognostic Score (PPS) that can predict survival with some accuracy and can help ground clinicians in their discussions of prognosis [35]. The "surprise question" ("would you be surprised if this patient died in the next year?") has been validated as a predictor of 12-month mortality in patients with gynecologic cancer [36]. Reflection on this question is a simple and quick way for clinicians to alert themselves to patients who may benefit from goals of care discussions. Recognition of communication "on-ramps" to facilitate discussion of prognosis is a skill that can be learned and utilized to assess a patient's readiness for goals of care conversations, as well as to identify the type of information that is most useful to an individual in their decision-making (Table 2). An exploration of the patient's values/preferences and an assessment of patient's desire for prognostic information are both essential prior to making treatment recommendations.

Following the disclosure of relevant medical information and exploration of individual values, goals of care discussions may also address several concrete items, such as advance directives, code status, hospice services, and/or end-of-life wishes and expectations. Having advance

Table 1
Description of key elements of goals of care conversations and samples language to facilitate discussion.

Key element	Best practice	Example language
Assessing prognostic awareness & disclosing prognosis	Assess what the patient knows to tailor your information; use succinct, straight-forward language; Avoid specific prognosis (e.g., 6 months)	• "What have you been told so far about your cancer?" • "What is your impression of how things are going?" Disclosing: • "I'm worried that time is short—on order of weeks to a few months"
Preferences for information & decision making	How best to relay information	• "What kind of information is helpful to you right now?" • "I hear you talking about time—are numbers something you want to know more about?"
Eliciting goals/fears/tradeoffs	Identify priorities for health, life, family; concerns about the future; reflect on trade-offs of interventions and how these impact goals and fears	• "Before we discuss treatments, may I ask you some questions to help make a personalized recommendation for you?" • "When was your last good day?" • "When you think about the future, what keeps you up at night?" • "If time were limited, how would you spend your remaining time?"
Family Involvement	Ascertaining how much or little do patients want their family involved in conversations & decision making	• "Who would you like to be involved in decisions about your health?"

Table 2
Examples of patient and clinician-initiated language that can lead into goals of care conversations.

Examples of patient (P) and clinician (C)-initiated "On-Ramps"	What a clinician might say?
P: "How long is this going to go on?" "Will I ever be cancer free?"	"Sounds like you are wondering what the future might hold for you. Would it be helpful for me to share where I expect things will go?"
	Avoid: "No one really knows" or "Let's just focus on today"
C: "Now that we've finished chemotherapy, patients often wonder what the future will look like for them. Is that something you've been thinking about?"	

directive paperwork available in outpatient settings may facilitate conversations between patients and their care team or family. While there are many items in a comprehensive goals of care checklist, it is also essential to recognize that not every item may be addressed, or a decision made in a single encounter. Patient readiness to engage in discussion of sensitive topics varies; clinicians should be flexible, explore perceived hesitancies on sensitive topics and avoid dogmatically pursuing their own goals of care agenda to allow discussions to build on each other in a patient-directed manner. Several goals of care conversations may be needed before a major decision can be made.

In a survey of 122 patients with gynecologic cancer, Diaz-Montes et al. reported patients' knowledge of and preferences for information about advance directives, end of life expectations, and DNAR orders. When initiated early in a disease course, these conversations build on each other, utilizing information gathered from early discussions to inform and direct next steps as clinical scenarios evolve. While there was variation in patients' preferred timing to receive this information, more than 95% of patients wanted to discuss these issues with their oncologist at some point. Greater than half of patients preferred for advance directives and code status discussions to occur at the time of first progression or earlier, and similarly, the majority of patients preferred hospice and end-of-life expectations discussions to occur at the time when cancer-directed treatment is no longer a viable option [17]. Although oncologists may avoid advance care planning conversations for fear of eroding hope or eliciting negative emotions from the patient or family, many patients wish to engage in these discussions, and paradoxically, the discussion itself may increase hope [37]. While we often assume that cancer-related factors, such as potential for cure, play the largest role in maintaining hope, a systematic review of hope-associated factors in cancer demonstrated that quality of life, social support, and perceived health contribute the most to feelings of hopefulness [38].

The environment in which goals of care discussions occur can also enhance the efficacy of delivery. Family members or others who can provide emotional support during challenging conversations can reduce grief and mobilize support resources [39]. Patients perceive discussions more favorably when they are conducted by the attending oncologist, highlighting the importance of a long term relationship between the patient and clinician [40]. In patients with hematologic malignancies, goals of care conversations in an outpatient setting with the primary oncologist present were associated with earlier hospice use and fewer admissions to the intensive care unit [41].

6. Clinical question 3: What are the best practices for documentation of goals of care conversations with gynecologic oncology patients?

Recommendation 3.1: Use of documentation templates can facilitate consistent and comprehensive goals of care discussions in gynecologic oncology and allow effective communication between care teams.

6.1. Literature review

Documentation of goals of care discussions is highly variable. In a study of 492 patients with advanced cancer, Ernecoff et al. reported that more than 80% had some type of goals of care documentation in their medical record, defined as commenting specifically on discussion of treatment options, the patient's goals, and the ultimate treatment decision [42]. Documentation of what prognostic information was shared and plans for addressing spiritual/emotional concerns, however, was rare. The only best practice associated with increased documentation of patient goals and values was the use of a template rather than free text [42]. The use of goals of care discussion templates has been described in gynecologic oncology and may help prompt clinicians to consider less frequently discussed aspects of goals of care discussions such as specifics surrounding prognosis [24]. In a retrospective study of patients who died in the hospital or in palliative care units, some type of documentation of prognostic information was present in the chart in a qualitative form in many cases (61%), such as "poor," but rarely in a quantitative form, for example, "weeks to months." The first documented qualitative assessment of prognosis occurred a median of 3.5 months prior to death [43]. Commenting on specifics surrounding prognosis provides helpful insight to other oncologists and other healthcare professionals that may improve consistency of care and allow discussions to progress and build over time. In addition to documentation within the chart, state-specific legal documents are an important way to communicate a patient's preferences on life-sustaining measures and can be found through the National Hospice and Palliative Care Organization (NHPCO, CaringInfo, (www.caringinfo.org/planning/advancedirectivebystate).

7. Clinical question 4: What resources are available to help clinicians with their communication skills?

Recommendation 4.1: Communications skills are teachable and learnable, and evidence-based tools can be used to enhance clinician competency in goals of care discussions.

Recommendation 4.2: Structured decision aids are helpful adjuncts in goals of care conversations.

7.1. Literature review

Appropriate timing and content of goals of care discussions is an important starting point to delivery of patient-centered gynecologic cancer care; however, a clinician's expertise in communication around these topics is equally important. While the skill of clinicians as communicators varies, most physicians require dedicated instruction to attain a skill level appropriate to discuss serious medical information well. Clinicians are limited in their ability to accurately assess their own communication skills, with self-evaluations often discordant with the impressions of patients and families [44]. This highlights the need for all clinicians to actively engage in honing their communication skills, as they do with other clinical skills, and for hospital systems to invest and support clinicians in doing so [45].

Several randomized studies show that interventions such as workshops and coaching sessions, or review of audio recordings with suggestions for improvement, can significantly enhance patient's perceptions of goals of care discussions and improve trust [46,47]. There are several evidence-based workshops available from NCI-funded organizations aimed at enhancing communication skills for healthcare professionals that include VitalTalk (www.vitaltalk.org, Seattle, WA,); Ariadne Labs (www.ariadnelabs.org, Boston, MA); Respecting Choices (www.respectingchoices.org, La Crosse, WI); and the Center to Advance Palliative Care (www.capc.org, New York, NY) [48]. Recognition of the importance of skill acquisition and maintenance as well as time and institutional investment in these endeavors are critical in the delivery of patient-centered cancer care.

In addition to dedicating time to developing communication skills, active and regular self-evaluation may also promote the self-awareness and emotional regulation that can further influence communication. This may occur informally amongst colleagues or more formally in settings such as "Schwartz Center Rounds," a grand-rounds style series aimed to explore psychosocial and emotional components of care [49]. Surveys of clinicians who participated in this forum reported positive change in institutional culture with greater focus on patient-centered care and communication.

In addition to enhancing communication skills, evidence-based decision aid tools can be helpful adjuncts in goals of care conversations. These tools are structured print, video, or web-based media that aim to improve communication of medical information and promote shared decision making [50]. There are several randomized controlled trials of tools to assist in advance care planning in the form of websites, workbooks, and videos. Almost all studies demonstrate that such tools are associated with an increase in patient knowledge, and some show subsequent changes in clinical decision making, such as increased completion of advance directives and decisions for comfort care [51–56]. In a population of patients with malignant glioma, a video tool depicting medical care at the end-of-life resulted in increased patient certainty around of end-of-life decision making and increased preference for comfort measures [57]. The development of decision aids specific to patients with gynecologic cancer may be helpful adjuncts to guide more patient-centered and efficient goals of care discussions.

8. Summary of recommendations

- Goals of care conversations should be initiated early and often in all patients with advanced stage gynecologic malignancies, at the time of recurrence or progression for patients with cancers of any stage, and at any point where important treatment decisions are made.
- Patients with gynecologic cancer and frailty, advanced age, or major medical comorbidities should have goals of care discussions at diagnosis.
- Electronic medical record algorithms and automated alerts may be helpful in identification of patients for goals of care conversation.
- Goals of care discussions should preferably be conducted by the primary oncologist in a supportive environment.
- Delivery of patient-tailored prognostic information and assessment of a patient's values is an essential component of goals of care conversations and should precede a treatment recommendation or decision.
- Additional important components of a goals of care discussion may include discussion of advance directives, code status, hospice, and end-of-life expectations.
- Goals of care discussions are iterative and often occur over multiple encounters.
- Use of documentation templates can facilitate consistent and comprehensive goals of care discussions in gynecologic oncology as well as communication between healthcare teams.
- Evidence-based tools and interventions to enhance communication can improve provider competency in goals of care discussions.
- Structured decision aids are helpful adjuncts in goals of care conversations.

CRediT authorship contribution statement

Pamela N. Peters: Conceptualization, Investigation, Resources, Project administration, Writing – original draft. **Laura J. Havrilesky:** Conceptualization, Writing – review & editing. **Brittany A. Davidson:** Conceptualization, Project administration, Writing – review & editing.

Declaration of Competing Interest

The authors have no conflicts of interest relevant to the current work.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ygyno.2023.05.016.

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