



Advance care planning, serious illness communication, and conversations to facilitate coping for patients with gastrointestinal malignancies: a narrative review

Vinay Rao¹, Dana Guyer², Khaldoun Almhanna², Laura Baum¹

¹Division of Medical Oncology and Division of Palliative Care, Department of Medicine, Yale University School of Medicine, New Haven, CT, USA; ²Department of Medicine, Division of Hematology-Oncology, Alpert Medical School of Brown University, Rhode Island Hospital, Providence, RI, USA

Contributions: (I) Conception and design: L Baum; (II) Administrative support: All authors; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: V Rao; (V) Data analysis and interpretation: V Rao; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Vinay Rao, D.O. Division of Medical Oncology and Division of Palliative Care, Department of Medicine, Yale University School of Medicine, 330 Cedar Street FMP 122, New Haven, CT 06520, USA. Email: vinay.rao@yale.edu.

Background and Objective: Patients with advanced gastrointestinal (GI) malignancies are at high-risk for disease-related complications, treatment-related toxicity, unplanned hospitalizations, poor psychological outcomes, and short life-expectancies. Advance care planning (ACP) and serious illness communication (SIC) are two forms of communication that can help patients with GI malignancies explore the future, especially in the event of worsening health. While there are some limitations to traditional ACP, SIC that focuses on what matters most to patients with GI malignancies in the future (future-focused SIC), has the potential to improve future medical decision-making, help patients cognitively and emotionally process and accept their illness over time, help them feel heard and understood, allow them to positively cope with their disease, and may also help their caregivers in a variety of ways.

Methods: Narrative review using PubMed and Google Scholar to search for relevant literature published between 2010–2022.

Key Content and Findings: We present several key studies that highlight the complex, heterogenous nature of ACP and SIC research and its mixed outcomes for patients with GI malignancies. We also offer suggestions on how to optimize future-focused SIC research in this patient population. In the second half of this article, we suggest a practical approach to conducting future-focused SIC for patients with GI malignancies which includes a communication framework based on the literature and expert-opinion. We also provide practical tips on how to normalize these conversations and how to help patients use these conversations for future medical decision-making.

Conclusions: Future-focused SIC has the potential to benefit patients with advanced GI malignancies in a variety of ways. Optimizing research outcome measures that highlight the patient experience with this communication is crucial to move this area of research forward.

Keywords: Gastrointestinal cancer; advance care planning (ACP); communication; serious illness communication (SIC)

Submitted Nov 05, 2022. Accepted for publication Jul 14, 2023. Published online Jul 26, 2023.

doi: 10.21037/apm-22-1261

View this article at: <https://dx.doi.org/10.21037/apm-22-1261>

Introduction

Case

M.K. was a 55-year-old man with stage IV cholangiocarcinoma. At his first outpatient oncology appointment, his oncologist discussed the incurable nature of the disease, the purpose of his different treatment options, and his preferences for care. M.K. was hoping for more time, better control of his symptoms, and improved quality of life. He enjoyed eating and cooking, spending time with family, and working as a computer software designer. He assigned his daughter as a surrogate decision-maker in the event he couldn't make his own decisions. He started his chemotherapy treatments and met with a palliative care physician, whose role was to support the patient and his family and manage the symptoms from his cancer and his cancer treatment.

Several months after starting treatment, his cancer progressed. His oncologist and palliative care physician met with M.K. and his daughter to discuss second-line chemotherapy. With his permission, they also reviewed what the future might hold. M.K. asked about his prognosis. He wanted to know how much longer he had left and whether he would be alive for his daughter's upcoming wedding in three months. He shared that when his health worsened, he wanted to enjoy the simple things in life, he prioritized being at home, and he wanted to avoid unnecessary suffering at the expense of more time.

Three months after starting second-line chemotherapy, M.K. attended his daughter's wedding. He used a wheelchair for the ceremony, but he was able to stand and dance slowly for the "father-daughter dance", a deeply meaningful moment for everyone. M.K. also started to prepare for the future. He called several friends he had not spoken to recently, paid for his funeral arrangements and made financial preparations for his family. He also started to pray, something he had not done regularly as an adult.

A few weeks after the wedding, M.K. was hospitalized for a small bowel obstruction and septic shock from cholangitis. The options of vasopressors, intensive care unit (ICU) admission, surgery versus decompressive gastrostomy tube (G-tube) placement, and comfort focused care were discussed. M.K. was confused and lacked capacity to make any medical decisions, so the treating physician deferred to his daughter. She knew his priorities from their discussions over the past few months: he wanted to spend time with his family, he valued time at home, he wanted to taste food even for comfort, and he did not want to suffer unnecessarily

if the risks of treatment were high and time was limited. Based on his daughter's expression of M.K.'s priorities, he was transferred to the ICU and started on vasopressors. Over the next five days, he received a venting G-tube, his infection improved with antibiotics, and his mental status returned to normal. When he was able to process what had happened during the hospitalization, he expressed gratitude that he had survived the acute infection and felt his daughter had made the same decision he would have made. He also decided he no longer wanted to pursue aggressive measures like cardiopulmonary resuscitation (CPR), defibrillation, intubation, and mechanical ventilation. He and his outpatient team continued to discuss his goals after his hospital discharge, and as a team, they decided to stop chemotherapy and start comfort-focused care.

M.K. enrolled in hospice care and he died comfortably at home with his family present. His daughter shared with his outpatient oncologist that M.K. was truly at peace when he died. Given the gradual, open, and honest serious illness communication (SIC) that he and his family received from his oncologist and palliative care physician, M.K. and his daughter had several months to process his illness cognitively and emotionally. They were able to make medical decisions that aligned with his values and priorities. Importantly, they felt respected and heard.

Background

Advance care planning (ACP) can be defined as "a process that supports [patients] at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" (1). Historically, this definition applied to all people with and without life-limiting illnesses and involved making decisions in advance about end-of-life (EOL) care, including the receipt of life-sustaining treatments. ACP often included the designation of surrogate decision-makers, also known as healthcare proxies (HCP), and the completion of written documents that supported these decisions. The documents or "living wills" could be completed pre-emptively, prior to the onset of life-limiting illness or to functional or cognitive decline, even years in advance.

In 2020 and 2021, respected leaders in the palliative care community called into question the utility of ACP and the completion of advance directives (AD) (2-4). These authors proposed that the community should shift its efforts and limited research funding away from ACP and toward improving "in-the-moment" medical decision-

making, as this would more effectively improve patient-centered care. They argued that “a substantial body of high-quality evidence now exists demonstrating that ACP fails to improve end-of-life care” (3). Unlike hypothetical scenarios outlined in ADs, real EOL treatment decisions in clinical practice are complex, nuanced, and dynamic. Furthermore, patients’ preferences for future care may be logistically or financially unattainable in the current healthcare system (2-4). ACP performed before a serious illness diagnosis, such as at a Medicare wellness visit or in a lawyer’s office, and in the absence of clinician guidance, is especially problematic. Medical decision-making “requires sophisticated knowledge of prognosis, disease and associated comorbidities, and treatment outcomes” (2). Additionally, patient preferences and values change over time. Some people adapt to disabilities they once considered unacceptable, while others do not tolerate increasing limitations as death nears (5).

This assertion from respected palliative care physicians was met with significant uproar and remains a contentious topic. Critics of this viewpoint argued that ACP has evolved beyond simplistic advanced directives and is now focused on preparing seriously ill patients and their HCPs for future medical decision-making (6). Thus, it is imperative to clearly define ACP and the individual components of decision-making for patients with cancer (4). ACP in clinical practice is more complex than the discreet components of ACP studied in research. Research studies struggle to account for the power of human interactions, the development of longitudinal relationships, and the ability to respond to emotions, as well as the complexities of navigating the healthcare system. Although ACP interventions in prior studies did not improve EOL care outcomes, they did “affect other things that are as meaningful to patients”, such as decreasing surrogate depression, anxiety, posttraumatic stress disorder, and complicated grief, and decreasing caregiver burden (4,7). Thus, while ACP research did not yield the hoped-for and often hyped results, clinically, there is utility in some forms of ACP to prepare patients and families for the future and provide them with the opportunity to engage in values-based discussions on health care decision-making.

In this article, we focus on another form of communication that addresses some of the limitations of traditional ACP, while still helping patients share what matters most to them now and in the future. SIC is communication between a clinician, a patient with a serious illness, and the patient’s family, and is comprised of four main components: assessment of the patient’s

medical knowledge of the illness and prognosis, sharing information according to the patient’s preferences and responding empathically to emotion that arises from this information, exploration of the patient’s goals, values, and priorities with open-ended questions, and providing a clear medical recommendation about next steps for care (8). SIC is a broad term that applies to both “in-the-moment” shared-medical decision making—commonly referred to as “goals of care” conversations—and conversations intended to help patients prepare for the future, similar to traditional ACP. SIC conversations that focus on the future differ from traditional ACP in that a patient must be diagnosed with a serious illness, a clinician must be involved in the conversation, and the goal of these conversations is to help patients explore the future more generally without focusing on specific treatment options. The Serious Illness Conversation Guide (SICG), created by Adriadne labs, uses a seven-item checklist that addresses the four components of SIC and elicits patients’ future goals and values in the event of worsening health (9,10). This type of mindful, directed conversation helps patients’ voices be heard, helps them prepare for future medical decision-making, and helps them gradually learn to cope with their illness and prognosis in a way that balances “hopes for the future and a perspective of life engagement with a growing awareness of the possibility of experiencing advanced disease or dying” (8).

Rationale and knowledge gap

We will use the term “future-focused SIC” to describe SIC that focuses on what the future may look like and given that, what matters most to the patient now and in the future. This type of communication occurs between a patient with cancer, a health-care proxy, and a clinician. There is limited research investigating the use of future-focused SIC and its associated outcomes for patients with gastrointestinal malignancies.

Objective

We will highlight studies that examine the effect of ACP and future-focused SIC on a variety of patient- and caregiver-centered outcomes and provide a practical guide for how to conduct future-focused SIC in everyday clinical practice. Though there are many potential benefits to future-focused SIC, including intangibles such as caregiver burden and emotional wellbeing, we will focus on medical

Table 1 Search strategy summary

Items	Specification
Date of search	4 August 2022
Databases and other sources searched	PubMed, Google Scholar
Search terms used	“advance care planning”, “serious illness communication”, “goals of care”, “gastrointestinal malignancies”, “gastrointestinal cancers”, “medical decision making”
Timeframe	2010–2022
Inclusion and exclusion criteria	Inclusion criteria: English
Selection process	Vinay Rao searched the literature independently and selected the articles included in this review. All other authors reviewed the manuscript and agreed with the inclusion of the selected articles

Table 2 Leading causes of cancer-related deaths worldwide in 2020 (11)

Cancer site	New deaths in 2020 worldwide—% of all sites
Lung	18.0
Liver	8.3
Stomach	7.7
Female breast	6.9
Colon	5.8
Esophagus	5.5
Pancreas	4.7
Prostate	3.8
Rectum	3.4

Table 3 Five-year relative survival rates for distant disease at the time of diagnosis (12)

Cancer site	5-year relative survival rate (%) for distant disease at time of diagnosis
Anus	33.5
Rectum	15.4
Colon	14.2
Stomach	5.3
Esophagus	4.8
Liver/intrahepatic bile duct	3.1
Pancreas	2.8
Gallbladder	2.3

decision-making, which includes values-based, congruent patient and surrogate decision-making. We present this article in accordance with the Narrative Review reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-1261/rc>).

Methods

This narrative review covers a broad overview of the available literature relevant to ACP and SIC for patients with GI malignancies (*Table 1*). We used PubMed and Google Scholar to search the following terms “advance care planning”, “serious illness communication”, “goals of care”, “gastrointestinal malignancies”, “gastrointestinal cancers”, and “medical decision making”. We used an inclusion timeline between 2010 and 2022 to capture studies most relevant to current GI oncology practice. The recommended approach to conducting future-focused SIC

is based on informal consensus among communication and palliative care experts in clinical practice.

Future-focused SIC for patients with gastrointestinal malignancies

The clinical trajectory of gastrointestinal malignancies

Cancers of the pancreas, biliary tract, liver, esophagus, stomach, colon, and rectum are some of the leading causes of cancer-related deaths worldwide (*Table 2*) (11). In the U.S., the 5-year relative survival rates for distant disease at the time of diagnosis are extremely low for biliary tract, pancreatic, liver, esophagus, and stomach cancers (*Table 3*) (12). Median overall survival varies depending on primary tumor site, stage, and molecular subtype. Patients with unresectable pancreatic and biliary tract cancers generally have the worst prognoses with median overall

survival of less than 1 year, whereas patients with metastatic colorectal cancer tend to have better prognoses with a median overall survival of 2–3 years (13–15). Furthermore, patients with earlier stage or better prognosis cancers, such as anal cancer, also face significant morbidity, uncertainty, and other hardship while living with a life-threatening or life-limiting illness.

In addition to having high mortality rates, patients with GI malignancies also experience significant morbidity. This includes high rates of emergency department visits and unplanned hospitalizations for uncontrolled symptoms, disease-related complications, and treatment-related toxicity (16). Patients with advanced disease may experience pain, cachexia, nausea, fatigue, bowel dysregulation, and frailty. Furthermore, given the aggressive nature of many of these tumors, active chemotherapy is often multi-agent regimens that can lead to significant toxicity, including fatigue, neutropenia, neuropathy, mucositis, altered taste and oral intake, and other adverse effects. Patients with GI malignancies frequently experience depression, anxiety, helplessness, hopelessness, and difficulty accepting their illness, especially in cancer types with poorer prognoses such as pancreatic cancer (17).

GI malignancies behave unpredictably and have many potential complications, including bowel obstruction, infection, and perforation among others, which can occur with little warning. Each complication, adverse side effect, new or worsened symptom or setback presents patients with a challenge, and during these difficult times, patients must make complex medical decisions. Ideally, choices for care are based on shared decision-making between clinicians and patients, grounding in patient values and preferences. However, certain decisions must be made in haste, particularly in an emergency, such as a bowel obstruction. Furthermore, when patients lack decisional capacity, medical teams must rely on a surrogate to represent the voice of the patient.

Research on ACP and SIC for patients with gastrointestinal malignancies

Research on generalized ACP has shown mixed results (7). In a recent scoping review on ACP interventions including 69 high-quality RCTs from 2010 to 2022 and including patients with a variety of diagnoses not limited to cancer, McMahan *et al.* concluded that although goal-concordant care and patient quality of life (QOL), both of which are challenging to measure, were not improved globally, most

studies did have other valuable outcomes such as reductions in surrogate distress and complicated grief outcomes, improvement in patient and surrogate satisfaction with communication and patient care outcomes, and congruence in decision-making between patients and surrogates or clinicians. Their review also highlighted how ACP research is limited by methodological challenges and study-design heterogeneity. Examples include difficulties defining ACP, lack of clarity on the interventions and outcomes studied, lack of established and reliable methods to measure goal-concordant care, and lack of generalizability caused by measuring outcomes outside the context of regular clinical practice (18). In GI malignancies specifically, there are a limited number of studies that look at the utility of ACP and SIC. We will highlight a few important studies here to exemplify the complex, heterogeneous nature of ACP research in GI malignancies and to show how results are mixed in this patient population as well as the general population.

The Serious Illness Care Program (SICP), which includes the SICG, was first studied in a cluster randomized clinical trial at Dana-Farber Cancer Institute and included patients with gastrointestinal malignancies amongst others (10,19). The intervention included SICP tools, clinician training, and system changes. The intervention arm patients had higher rates of documented conversations, higher quality conversations, and earlier conversations compared to the control arm. Although there was no significant difference in the primary outcomes of goal-concordant care and peacefulness at EOL, the intervention did show significant reductions in the proportion of patients with moderate-to-severe anxiety and depression symptoms at 14 weeks after baseline; the anxiety reduction was sustained at 24 weeks. The use of SICP was also studied in a separate quality improvement study at the Abramson Cancer Center of the University of Pennsylvania and included 31 oncology patients, most of which had GI malignancies (20). Within the intervention group, 90% of patients reported that the SICP was worthwhile, 55% reported that the conversation increased their understanding of their future health, 42% reported an increased sense of control over future medical decisions, 58% reported increased closeness with their physician, and 42% reported increased hopefulness about QOL.

In a randomized controlled pilot study at Memorial Sloan Kettering Cancer Center, Epstein *et al.* created a novel ACP intervention, the Person-Centered Oncologic Care and Choices (P-COCC), combining a patient values

interview with an informational care goals video, and studied its effects for patients with advanced GI cancers in the outpatient setting (21). The P-COCC addresses key components of patients' cancer experiences to help them consider future medical care. In the 33 participants in the P-COCC intervention arm, 97% found the intervention to be acceptable. Despite this, mean Distress Thermometer (DT) scores increased in the P-COCC intervention arm and decreased in the video-alone and usual care arms. There were no significant pre-post changes in other measures of wellbeing (e.g., anxiety, depression, stress) or intergroup differences in decisional conflict. The authors suggest that although there was an increase in DT scores, this may not be of clinical concern since most of the participants in all arms of the trial were below the clinical threshold of 4.

In a qualitative descriptive study at a cancer center in Melbourne, Australia, caregivers of patients with lung and GI cancers with a prognosis of 4 weeks or less were interviewed (22). Caregivers were given 4 vignettes and asked to consider the situations that reflected their own caregiving experiences and respond to semi-structured questions to share their thoughts on ACP. The results suggest that despite some uncertainty about what ACP means, caregivers think that some form of ACP would help patients and themselves. The way caregivers approached ACP was informed by their shared life with the patient, cultural background, life-stage, and previous life- and death-related experiences. The authors suggest that current standardized approaches to traditional ACP may fail to account for patients' and families' personal, shared lives, and cultural expectations and beliefs. They also advocate for a family-centered approach to ACP to improve collaborative EOL conversations, satisfaction with decision-making, caregiver bereavement, and to reduce decisional conflict.

The TAILORED study (Trial of Ascertain Individual Preferences for Loved Ones' Role in End-of-Life Decisions) was a randomized control trial of 166 patients (59% with GI cancers) in which patient-surrogate decision maker dyads assigned to the intervention arm received a nurse-facilitated discussion about what role patients would prefer their surrogates to play in making decisions for them should they lose capacity (23). While neither a traditional ACP conversation nor SIC, the emphasis of the intervention was to support how decisions should be made and who should be involved, rather than deciding on specific treatments for future care. In this process, patients informed surrogates how they wanted them to make medical decisions. Patients chose a decision-making strategy from among substituted

judgment (what the patient would want if they could speak for themselves), deference (what the surrogate thought was best for the patient), or a mixed approach that lay somewhere between these two poles. The study showed that patient-surrogate dyads in the intervention arm were more likely to endorse mutual surrogate decision-making, i.e., balancing what the patient would want with what the surrogate thinks is best. The intervention arm surrogates experienced decreased stress levels and higher satisfaction with involvement in decision-making compared to the control group.

At Massachusetts General Hospital Cancer Center, researchers studied 350 patients with incurable cancers (45% had non-colorectal GI cancers), looking at QOL, depression, anxiety, coping strategies, patient-reported health status, and treatment goal outcomes (24). They found that most patients reported inaccurate prognostic understanding; intriguingly, self-report of a terminally ill health status was associated with worse QOL and increased depression and anxiety, while self-report that the goal of treatment was to "cure my cancer" was associated with better QOL and lower anxiety. In a subgroup analysis of patients who reported a terminally ill health status, they found that the use of specific coping strategies such as positive reframing (looking for something good in what is happening), active coping (taking action to try to make the situation better), acceptance (not resisting the medical reality), and seeking emotional support, improved QOL and mood among patients who accurately acknowledged their poor prognosis. Although SIC includes discussion of prognosis and increases prognostic awareness, discussion about patient values and taking control of what one can control, can promote active coping strategies and thus could improve QOL and mood.

In summary, patients diagnosed with GI malignancies experience significant distress and difficulty coping with their illnesses. Through repeated and progressive conversations about the present and future, patients can gradually confront the ramifications of cancer, recognize and process their emotions, and start to accept the realities of their disease. These conversations also help patients maintain hope and clarify priorities. Optimizing outcome measures that highlight these experiences is paramount to future ACP and future-focused SIC research. In a GeriPal podcast interview, palliative care physician and researcher Susan Block stated, "*people are terrified, ... they may not be thinking [or talking] about these issues, ... they're left alone with this anxiety and not able to move forward psychologically in a*

way that will help them make better decisions when just in time arrives. I think serious illness planning ... allows patients to start talking about it. It detoxifies [the] conversation and the thinking about what's likely to be ahead ... [It is] preparation to engage at a later point when it's more clear what the exact decisions are in a less terrified and more in-control and aware way" (25).

Recommended approach

Our recommended approach targets the novice clinician who would like to use a framework to support serious illness conversations, as well as the skilled clinician seeking additional tips and perspectives on how to improve in both future-focused SIC and goals of care (GOC) conversations (Table 4). Generally, future-focused SIC involves communication before a specific medical decision needs to be made, whereas GOC conversations involve communication at the time of decision-making or when there is an acute change in a patient's clinical status (26). Essential communication skills, including sitting down at eye level with the patient and family, using a calm and gentle tone when speaking, asking for permission before sharing information or giving recommendations, and responding empathically to emotions are fundamental to both types of conversations. In both, a structured format is utilized, including discussing the purpose of the conversation, setting a mutually agreed upon agenda for the meeting, assessing the patient's illness understanding, assessing their preferences for receiving medical and prognostic information, and sharing medical information. Furthermore, both involve discussing the patient's goals, values, hopes, and fears. The difference in the types of conversation is timing. GOC conversations involve sharing serious news and then discussing the question "what do we do now?" GOC conversations may include specific treatment options and the risks, benefits, and alternatives of each option; they often result in concrete medical recommendations balancing patient preferences with what is medically appropriate. Future-focused SIC can occur at times distinct from acute events and may be more generalized than a GOC conversation. Both types of conversations have the potential to provoke anxiety. In the sections below, we will discuss how to navigate these challenges. We outline a suggested framework for these conversation in Table 4.

Future-focused SIC and GOC conversations should start at the time of diagnosis and continue along the patient's disease trajectory. They are vital at transition

points such as hospitalizations, changes in function or QOL, progression of disease, or changes in treatments. While GOC conversations translate into specific medical decisions in the moment, future-focused SIC allow for cognitive and emotional preparation for the future. Patients with GI malignancies may experience acute, sudden worsening in their health, as well as gradual steady decline. At acute transition points, patients and families are often emotionally overwhelmed and unable to process complex medical information (32). These situations epitomize why anticipatory future-focused SIC is valuable; with preparation, patients and families may be better able to switch from an emotional state of mind to a cognitive one. Together, future-focused SIC and GOC conversations should be employed simultaneously along a patient's disease trajectory. While helping patients make decisions in the present, we can also help them identify what may be important to them in the future. This approach fosters a "hoping for the best and planning for alternative scenarios" mentality.

Normalizing the conversation is important so the patient does not feel targeted and so the clinician feels more comfortable and less vulnerable when discussing this emotionally-laden topic. A clinician can normalize the conversation by saying, "One of my responsibilities as your doctor is to help you think about the future..." Clinicians often fear taking away a patient's hope, losing a patient's trust, and undermining their valuable relationships with patients and families. Clinicians should be aware of their own emotional responses and regulate these emotions appropriately. For example, a physician who brings up future-focused SIC but worries that the patient will lose trust, may provide false reassurance to appease the patient. This is confusing and misleading to the patient and undermines the purpose of the future-focused SIC. This physician may need practice in allowing for the discomfort to be present. Embracing silence and practicing restraint are necessary future-focused SIC skills.

Future-focused SIC is intended to get patients and surrogate decision-makers to think about who the patient is as a person, what matters most to them, and what their priorities and core values are. They do not commit patients to specific future treatments. The iterative process of future-focused SIC is more important than the exact outcome of any individual conversation. For example, "If I am no longer able to eat ice cream, I don't want to continue to prolong my life", might, more generally, mean that eating and tasting food are important to the person's QOL. This

Table 4 Suggested framework for future-focused serious illness communication (8,9,26-31)

Key components	Examples and notes
1. Set up the conversation	
Consider the purpose of the conversation	To help the patient prepare for future medical decision-making; to help the patient emotionally prepare for what is to come; to learn about what matters most to the patient; to help the patient feel heard
Prepare before the meeting	Review pertinent medical and prognostic information, prior conversations with other providers regarding care goals and values, advance directives, social supports, etc.
Consider who should be present	The clinician, patient, surrogate, other family members, and other medical team members may be appropriate to include in the meeting
Choose the right environment	Quiet, comfortable, private setting (e.g., clinic exam room) with enough chairs for everyone to sit
Use appropriate body language	Sit at eye level with the patient, use good posture, lean forward, pay attention to what the patient has to say, unfold arms, use appropriate hand gestures, look welcoming, avoid looking at watch or smart phone
Greet the patient and ask about the patient's main concerns and agenda for the visit. Ensure you have heard all of the patient's concerns	<i>"Hi Ms. Jones... I am hoping to talk about a number of things today, but before I begin, what is on your list of things that you would like to discuss today?" "I've heard you say that you want to discuss Is there anything else?"</i>
Explain your agenda, incorporating the patient's requests, to set expectations about what will be discussed. Ask for permission to talk about the future. Ask for feedback about the agenda	<i>"In addition to the concerns you mentioned, I'm wondering if we could talk about the big picture when it comes to your health. I'm hoping we can explore what the future might look like and help you prepare, especially when you need to make difficult medical decisions. Would it be okay if we talked about that as well?"</i>
2. Assess illness understanding	
Ask what the patient knows, but put the onus on the health care providers to share this information	<i>"What have you been told so far about your cancer?" "What have your other doctors shared with you...?"</i> Avoid asking patients what they understand, which can be construed as condescending or a test of patient's knowledge and intelligence
Fill in the information gaps	<i>"May I add a few things about what has happened during this hospitalization?"</i>
Assess preferences for receiving medical information	<i>"Before we continue, I would like to know how you prefer to receive medical information."</i> <i>"Some people want a lot of details about their cancer, whereas others want to know more of the big picture. Which would you prefer?"</i>
Assess preferences for receiving prognostic information	<i>"Do you want to know information about prognosis or life expectancy?"</i> <i>"How much do you want to know about what to expect in the future? Some people want lots of details and statistics, some prefer to focus on the big picture, some want to know their life expectancy in relation to a big life event or holiday, and some would rather not discuss what may happen in the future altogether. What would be best for you?"</i> Most patients want to know the prognosis, however, the types of information and the optimal timing of disclosure varies, so it is important to ask (30,31)
3. Provide medical information	
Deliver a clear, concise statement that aligns your intention to care for your patient and includes the most pertinent medical information and its meaning	<i>"Despite our best efforts, the CT scan shows that the cancer has spread to the liver, and that means the chemotherapy is not working."</i> <i>"I wish that physical therapy had helped more, but I'm worried that you won't be able to care for yourself."</i>

Table 4 (continued)

Table 4 (continued)

Key components	Examples and notes
Tailor prognostic information to the patient's preferences after receiving permission to discuss. Even if a patient asks how much time they have left, it is important to confirm that they are ready to hear that information	<i>"I just want to make sure you are ready to hear this information. Is there anyone else that you would want to be present when I share how much time you may have left to live?"</i>
Types of prognostic information include: curable vs. incurable, life-expectancy, probability of treatment outcomes, best-case and worst-case scenarios, anticipated function and ability to perform daily tasks, and anticipated complications or symptoms of the cancer (8,28)	<i>"I wish we were able to get rid of the cancer completely, but unfortunately this is a cancer that you will eventually die from." "I wish it were different, but I would not be surprised if you died within months."</i>
Give a range for time-based prognoses and avoid specific numbers	Hours to days, days to weeks, weeks to months, months to years, etc.
In cases where more uncertainty exists, clinicians should acknowledge uncertainty while still conveying the seriousness of the illness	<i>"Your oncologist and I know that your cancer is serious, although it is hard to say exactly when you will die from it. When your cancer worsens... [explore values and priorities]"</i>
4. Respond to emotion	
Acknowledge and respond to the patient's and family's emotional responses using an empathic statement (28). Responding to emotion allows patients and surrogates to shift back from an emotional state to a cognitive state so conversation can continue	<i>"This is not what you were expecting to hear" "You were hoping for more time" "I wish this were different" "I can't imagine how difficult it must be to hear this news"</i>
5. Explore the patient's goals and values for the future	
Consider a transition statement that explains why this might be important and try to normalize the process	<i>"Some people find it helpful to think about the best- and worst-case scenario so that they can prepare for the future."</i>
Explore hopes, fears, QOL, acceptable vs. unacceptable states of living, tradeoffs (9,26,27,29). Stop the conversation if the patient needs to pause or doesn't want to continue at that moment	<i>"What are you hoping for now and in the future?" "What are your biggest fears and worries about your health both now and in the future?" "What are your most important goals if your health situation worsens?" "What makes life worth living?" "What brings you joy?" "What abilities are so critical to your life that you can't imagine living without them?" "Have you experienced anything throughout the course of your illness or observed something a family member with serious illness has gone through that you considered unacceptable?" "If you become sicker, how much are you willing to go through in order to gain more time?"</i>
6. Close the conversation	
Express your commitment to revisit the patient's goals and values over time	<i>"I'm hoping we can continue to explore what matters most to you as we continue to treat your cancer"</i>
Express your commitment to care for the patient throughout their disease trajectory regardless of the outcome	<i>"I want you to know that regardless of what happens in the future, I will always be your doctor and will be there with you every step of the way"</i>

CT, computed tomography; QOL, quality of life.

factor should be considered in addition to all other factors. Likewise, in making decisions, a patient's values and goals must also be placed into the context of the medical situation at hand with a thoughtful, balanced discussion about what is medically possible. For example, it may not be possible for a patient to go home at the end of her life, but it could be possible to spend that time with her family in a setting that feels more like home.

For additional communication resources, we recommend (I) the Serious Illness Care Program which includes the conversation guide; training, coaching, implementation, and reference materials; and a system for documenting conversations in the electronic medical records (<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>), and (II) VitalTalk which is an organization that offers many types of resources aimed at strengthening clinicians' communication skills, including workshops, modules and other tips (<https://www.vitaltalk.org/>) (26,27,33).

Code status discussions

Patients who experience cardiopulmonary arrest in the community or in the hospital, by default, will receive CPR, defibrillation if indicated, and intubation followed by mechanical ventilation, unless they have an accessible medical order for "do not resuscitate and do not intubate" (DNR/DNI) (34). In patients with cancer in general, survival from cardiopulmonary arrest to hospital discharge is less than 20% (35,36). For those with metastatic cancer, the rates of survival are significantly less, and survival with a good neurologic outcome or return to baseline level of functioning approaches zero. Patients with advanced cancer who undergo CPR often experience other concurrent poor EOL outcomes, such as caregiver complicated grief, regret, and poor QOL (37,38).

Once a patient is diagnosed with a gastrointestinal cancer, discussions about code status can occur along the illness trajectory. Earlier in the disease course, the decision can be presented as two reasonable options. This conversation may also take the form of future-focused SIC, as it helps the patient think about the future and prepare for future medical decision-making. As a patient's condition worsens, clinicians should revisit this discussion in the form of shared medical decision-making. This GOC conversation should include the patient's overall prognosis, the patient's preferences for how he wants to spend the time he has left, the likely outcome of CPR/intubation after cardiopulmonary arrest, and the alternative of allowing

natural death. Once again, the clinician should make a balanced recommendation based on the medical realities and the patient's values.

A portable order for life-sustaining treatment (POLST) form, also known as medical order for life-sustaining treatment (MOLST) or physician/medical order for scope of treatment (POST/MOST), is indicated for patients who do not want CPR or intubation (39). POLST forms are not ADs. Whereas ADs limit medical interventions in the event of future hypothetical situations of "incurable or irreversible" disease where "death is imminent" or of a state of "permanent unconsciousness" (40), POLST forms are medical orders that guide care patients receive in emergency situations when patients are unable to communicate for themselves. They should be completed after a discussion of diagnosis, prognosis, and treatment options, in the context of serious illness (41).

Completion of healthcare power of attorney form

Despite the differences in opinion regarding ACP described above, there is little debate that people should designate someone to make medical decisions for them if they are unable to do so, and that this process should take place even before being diagnosed with a serious illness (3). A healthcare power of attorney form, also called a Durable Power of Attorney for healthcare (dPOA-h) or health care proxy (HCP), is a document that legally designates a surrogate decision-maker. Each state has different specifications for these documents, but most require either two witnesses, a notary, or both. Most dPOA-h forms have no expiration date but revisiting the document periodically is important particularly if the designated agent is elderly or in poor health. The Department of Health website for each state has downloadable forms and specific requirements for completing dPOA-h documents.

Strengths and limitations of this review

This review provides a broad overview of benefits and challenges of ACP and SIC for patients with GI malignancies. We highlight a few important studies to show the complex, heterogeneous nature of ACP research in GI malignancies, to show how results are mixed in this patient population, and to suggest that patients may experience other benefits from these conversations that are challenging to identify or optimally measure. This narrative review is not, however, an exhaustive review of all available literature

on this topic. There may be other studies, for example using traditional ACP and/or ADs as an intervention in this patient population, that were not included in this review. We highlight a variety of interventions related to ACP, SIC, and medical decision-making using various research designs to give the reader perspective. The authors acknowledge that the recommended approach and suggested framework on how to conduct a future-focused SIC for patients with GI malignancies may come from a limited viewpoint, despite including literature support; many of us learn how to conduct these conversations using the same resources and from the same experts in the field. Nonetheless, there may be other acceptable ways to conduct these conversations, as we acknowledge each patient, clinician, and patient-clinician relationship is unique. In fact, diversity of thought and communication style is highly valued provided the clinician accounts for the patient's and caregiver's needs and preferences.

Conclusions

SIC that focuses on the future can help patients with gastrointestinal cancers consider their illness, prognosis, and goals and values for the future in a meaningful way. These conversations may help with future medical decision-making, help patients cognitively and emotionally process and accept their illness over time, help them feel heard and understood, and allow them to positively cope with their disease. They may also help with caregiver outcomes around coping and grief. Future research should optimize outcome measures that describe these patient and family experiences.

Acknowledgments

We would like to thank those who have taught us how to use communication to alleviate patient suffering. We would also like to thank our patients and their families, whose experiences and voices have taught us what it means to live, even amidst devastating, life-limiting illnesses such as GI malignancies.

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *Annals of Palliative Medicine*, for the series "Palliative Care in GI Malignancies". The article has

undergone external peer review.

Reporting Checklist: The authors have completed the Narrative Review reporting checklist. Available at <https://apm.amegroups.com/article/view/10.21037/apm-22-1261/rc>

Peer Review File: Available at <https://apm.amegroups.com/article/view/10.21037/apm-22-1261/prf>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-1261/coif>). The series "Palliative Care in GI Malignancies" was commissioned by the editorial office without any funding or sponsorship. KA served as the unpaid Guest Editor of the series. The authors have no other conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage* 2017;53:821-832.e1.
2. Sean Morrison R. Advance Directives/Care Planning: Clear, Simple, and Wrong. *J Palliat Med* 2020;23:878-9.
3. Morrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? *JAMA* 2021;326:1575-6.
4. Periyakoil VS, Gunten CFV, Arnold R, et al. Caught in a Loop with Advance Care Planning and Advance Directives: How to Move Forward? *J Palliat Med* 2022;25:355-60.
5. Baum LVM, Friedman D. The Uncertain Science of Predicting Death. *JAMA Netw Open* 2020;3:e201736.

6. Myers J, Steinberg L, Seow H. Controversies About Advance Care Planning. *JAMA* 2022;327:684-5.
7. McMahan RD, Tellez I, Sudore RL. Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review. *J Am Geriatr Soc* 2021;69:234-44.
8. Jacobsen J, Bernacki R, Paladino J. Shifting to Serious Illness Communication. *JAMA* 2022;327:321-2.
9. Bernacki R, Hutchings M, Vick J, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 2015;5:e009032.
10. Karim S, Levine O, Simon J. The Serious Illness Care Program in Oncology: Evidence, Real-World Implementation and Ongoing Barriers. *Curr Oncol* 2022;29:1527-36.
11. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin* 2021;71:209-49.
12. 5 year survival rates based SEER*Explorer, National Cancer Institute, 2022.
13. Biller LH, Schrag D. A Review of the Diagnosis and Treatment of Metastatic Colorectal Cancer-Reply. *JAMA* 2021;325:2405.
14. Tsimafeyu I, Temper M. Cholangiocarcinoma: An Emerging Target for Molecular Therapy. *Gastrointest Tumors* 2021;8:153-8.
15. Yeh C, Bates SE. Two decades of research toward the treatment of locally advanced and metastatic pancreatic cancer: Remarkable effort and limited gain. *Semin Oncol* 2021;48:34-46.
16. Manzano JG, Luo R, Elting LS, et al. Patterns and predictors of unplanned hospitalization in a population-based cohort of elderly patients with GI cancer. *J Clin Oncol* 2014;32:3527-33.
17. Czerw A, Religioni U, Banaś T. Perception of cancer in patients diagnosed with the most common gastrointestinal cancers. *BMC Palliat Care* 2020;19:144.
18. Rosa WE, Izumi S, Sullivan DR, et al. Advance Care Planning in Serious Illness: A Narrative Review. *J Pain Symptom Manage* 2023;65:e63-78.
19. Bernacki R, Paladino J, Neville BA, et al. Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. *JAMA Intern Med* 2019;179:751-9.
20. Kumar P, Wixon-Genack J, Kavanagh J, et al. Serious Illness Conversations With Outpatient Oncology Clinicians: Understanding the Patient Experience. *JCO Oncol Pract* 2020;16:e1507-15.
21. Epstein AS, O'Reilly EM, Shuk E, et al. A Randomized Trial of Acceptability and Effects of Values-Based Advance Care Planning in Outpatient Oncology: Person-Centered Oncologic Care and Choices. *J Pain Symptom Manage* 2018;56:169-177.e1.
22. Michael N, O'Callaghan C, Baird A, et al. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *J Pain Symptom Manage* 2014;47:1064-77.
23. Sulmasy DP, Hughes MT, Yenokyan G, et al. The Trial of Ascertaining Individual Preferences for Loved Ones' Role in End-of-Life Decisions (TAILORED) Study: A Randomized Controlled Trial to Improve Surrogate Decision Making. *J Pain Symptom Manage* 2017;54:455-65.
24. Nipp RD, Greer JA, El-Jawahri A, et al. Coping and Prognostic Awareness in Patients With Advanced Cancer. *J Clin Oncol* 2017;35:2551-7.
25. GeriPal Podcast [Internet]; 2022, August 11 [cited 10/11/2022]. Podcast. Available online: <https://geripal.org/palliative-care-pioneer-susan-block/#summary>
26. Jain N, Bernacki RE. Goals of Care Conversations in Serious Illness: A Practical Guide. *Med Clin North Am* 2020;104:375-89.
27. Ariadne Labs. Serious illness care resources [September 16, 2022]. Available online: <https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/>
28. Back A, Arnold RM, Tulsky JA. Mastering communication with seriously ill patients: balancing honesty with empathy and hope. Cambridge England New York: Cambridge University Press; 2009:158.
29. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014;174:1994-2003.
30. Enzinger AC, Zhang B, Schrag D, et al. Outcomes of Prognostic Disclosure: Associations With Prognostic Understanding, Distress, and Relationship With Physician Among Patients With Advanced Cancer. *J Clin Oncol* 2015;33:3809-16.
31. Hagerly RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol* 2004;22:1721-30.
32. Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*

- 2001;285:2898-905.
33. Vital Talk [October 17, 2022]. Available online: <https://www.vitaltalk.org/>
 34. Rhondali W, Perez-Cruz P, Hui D, et al. Patient-physician communication about code status preferences: a randomized controlled trial. *Cancer* 2013;119:2067-73.
 35. Reisfield GM, Wallace SK, Munsell MF, et al. Survival in cancer patients undergoing in-hospital cardiopulmonary resuscitation: a meta-analysis. *Resuscitation* 2006;71:152-60.
 36. Sehatzadeh S. Cardiopulmonary Resuscitation in Patients With Terminal Illness: An Evidence-Based Analysis. *Ont Health Technol Assess Ser* 2014;14:1-38.
 37. Ardagh M. Futility has no utility in resuscitation medicine. *J Med Ethics* 2000;26:396-9.
 38. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665-73.
 39. Hickman SE, Steinberg K, Carney J, et al. POLST Is More Than a Code Status Order Form: Suggestions for Appropriate POLST Use in Long-Term Care. *J Am Med Dir Assoc* 2021;22:1672-7.
 40. Grautoff S. Advance directives for health care as a resource for assessing treatment goals in the Emergency Department. *Am J Emerg Med* 2022;55:217-8.
 41. Heyland DK. Advance Care Planning (ACP) vs. Advance Serious Illness Preparations and Planning (ASIPP). *Healthcare (Basel)* 2020;8:218.

Cite this article as: Rao V, Guyer D, Almhanna K, Baum L. Advance care planning, serious illness communication, and conversations to facilitate coping for patients with gastrointestinal malignancies: a narrative review. *Ann Palliat Med* 2023;12(5):1059-1071. doi: 10.21037/apm-22-1261