



HHS Public Access

Author manuscript

Gastro Hep Adv. Author manuscript; available in PMC 2024 June 13.

Published in final edited form as:

Gastro Hep Adv. 2024 ; 3(5): 634–645. doi:10.1016/j.gastha.2024.04.003.

Serious Illness Communication in Cirrhosis Care: Tools to Improve Illness Understanding, Prognostic Understanding, and Care Planning

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Abstract

Patients with cirrhosis frequently experience an unpredictable illness trajectory, with frequent hospitalizations and complications. Along with the uncertain nature of the disease, the possibility of a lifesaving and curative transplant often makes prognostic discussions and future care decisions challenging. Serious illness communication (SIC) refers to supportive communication whereby clinicians assess patients' illness understanding, share prognostic information according to patients' preferences, explore patients' goals, and make recommendations for care that align with these goals. SIC includes 3 key components: (1) illness understanding; (2) prognostic understanding; and (3) care planning. In this piece, we explore current barriers to early implementation of SIC in cirrhosis care and share possible solutions, including adopting a multidisciplinary approach, delivering culturally competent care, and training clinicians in SIC

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Ethical Statement:

The study did not require the approval of an institutional review board.

Reporting Guidelines:

Not applicable for this article type.

Conflicts of Interest:

The authors disclose no conflicts.

core skills. By use of a case example, we aim to demonstrate SIC in action and to provide clinicians with tools and skills that can be used in practice.

Keywords

Serious Illness Communication; Illness Understanding; Prognostic Understanding; Care Planning

Introduction

The illness trajectory of patients with cirrhosis is often unpredictable. Due to their frequent hospitalizations and progressive decompensations, these patients often exist in a tenuous state between the possibility of receiving a lifesaving liver transplantation (LT) or dying from complications of liver failure. Because of this unpredictable illness trajectory, conversations about prognosis and decisions about future care are challenging yet paramount. Despite the importance of having these conversations, there is a well-recognized gap in communication in medicine. Several studies have demonstrated that healthcare providers overestimate their ability to communicate.^{1,2}

It is therefore essential that clinicians learn serious illness communication (SIC) skills. SIC can be defined as emotionally supportive communication that takes place between a patient—usually one with a health condition that carries a high risk of mortality or morbidity—and a clinician, who can create a safe space to discuss their patient's illness, its effects, and meaning.³ By assessing illness understanding, sharing prognostic information according to patients' preferences, and exploring patients' goals and priorities, clinicians are better able to make care recommendations based on these goals.^{3,4}

There is a commonly held belief that SIC contributes to increased patient anxiety, depression, ambivalence, and hopelessness; however, the opposite is true.^{5,6} When patients do not understand their illness, prognosis, or care options, they may be more likely to choose high-intensity treatments that are not consistent with their values and may not sustain their lives meaningfully.⁷ SIC has been associated with reduced patient and family emotional distress, increased satisfaction with care, and often leads to the delivery of goal-concordant care.⁸ Having SIC can help clinicians and patients build trusted relationships and ensure that patients and their surrogate decision-makers feel supported, understood, and in some control of what might otherwise be a very unpredictable, uncertain disease course.³ SIC also has the potential to mitigate inequities and decrease disparities in the care of patients with serious illnesses.⁹

In this piece, we define and review barriers to the implementation of SIC in cirrhosis care through its 3 critical components: (1) illness understanding; (2) prognostic understanding; and (3) care planning.¹⁰ We then review potential strategies to improve SIC. Using a case example, we provide gastroenterology and hepatology clinicians with specific frameworks and actionable tools that can be utilized to improve SIC in the care of patients with cirrhosis. Prior to introducing the case, it is essential to review the definitions of illness understanding, prognostic understanding, and care planning, to explore prognostic models in cirrhosis, and to understand current barriers to the implementation of SIC in cirrhosis care (Figure 1).

Illness Understanding

To make decisions about future care, it is important that patients understand their illness.¹¹ Illness understanding can be defined as the cognitive and emotional processes through which individuals comprehend and make sense of their own medical condition.¹² It encompasses knowledge about the illness, its causes, symptoms, prognosis and treatment options, and is impacted by emotional and psychological responses to the illness experience. Illness understanding is also influenced by factors, such as education, cultural beliefs, personal experiences, and social support systems. Because prognostic understanding is discussed separately, for the purposes of this piece, illness understanding refers to knowledge about liver disease, cirrhosis, and its potential complications.

It is important to note that illness understanding can be difficult to assess both in research and in practice. Health literacy assessments, such as the “Newest Vital Sign” or the “Test of Functional Health Literacy in Adults,” can be helpful. In one study of 276 patients undergoing LT evaluation, low illness understanding, as assessed by the Newest Vital Sign was associated with frailty and not being waitlisted for transplant. A recent publication described a new patient cirrhosis knowledge assessment tool, though further validation is needed.¹³ Ongoing efforts are needed to develop tools to assess illness understanding in cirrhosis specifically.

In multiple chronic diseases, such as heart failure and chronic kidney disease, poor health literacy and disease knowledge have been associated with worse health outcomes.^{14,15} Because most of the management of chronic disease takes place outside of health facilities, patients who know more about their condition are more likely to participate in their care, adhere to medications, and experience better outcomes.¹⁶

Prior studies have highlighted deficits in illness understanding among patients with cirrhosis. In one study, when compared to patients with gastrointestinal malignancies and inflammatory bowel disease, patients with cirrhosis were found to have the poorest understanding of their illness.¹⁷ In this study of 379 patients, those with advanced liver disease were found to have poorer illness understanding than those who were more compensated. Another study conducted in 150 outpatients with cirrhosis highlighted deficits in disease self-management.¹⁸

It is not surprising that patients with cirrhosis have poor illness understanding and deficits in self-management—cirrhosis is a very complex illness with multiple potential complications, including ascites, bleeding, and hepatic encephalopathy, requiring patients to have a detailed understanding of their disease process and its management. For example, for the treatment of ascites, patients must follow strict salt-restricted diets, weigh themselves daily, and take diuretics. For the management of encephalopathy, patients and their care partners must be quick to recognize subtle signs of confusion and increase lactulose intake. Patients are often on many different medications (with potential side effects) and may have multiple appointments with different healthcare providers.

In liver disease specifically, better illness understanding has been associated with increased self-efficacy, ability, and willingness to engage in treatment. In a study of 146 patients with

metabolic dysfunction-associated steatotic liver disease, for example, a higher degree of illness understanding was positively associated with better nutritional habits.¹⁹ Similarly, in a study of 159 patients with alcohol-associated liver disease, improved illness understanding increased patients' confidence to self-manage their liver condition, independent of illness severity.²⁰ Lastly, in a study of 123 outpatients with cirrhosis, higher cirrhosis disease knowledge was associated with reduced healthcare utilization and costs.²¹

It is important that clinicians proactively assess and improve the illness understanding of their patients with cirrhosis to empower them in their future medical decision-making. Validated tools have been developed to assess illness understanding in patients with cirrhosis. One such tool, known as the "Cirrhosis Knowledge Questionnaire," is a 7-item questionnaire that assesses knowledge and self-management of variceal bleeding, ascites, and hepatic encephalopathy in patients with cirrhosis.²² Another tool, "My Cirrhosis Coach," assesses 6 domains—medical use and accessibility, medication obstacles, lactulose use, diuretic use, beta-blocker use, and dietary sodium use.²³ Simple educational interventions have been found to improve patients' illness understanding in prior work. Web-based, patient-facing educational tools, such as those developed through Cirrhosis Care Alberta (CirrhosisCare.ca), are also helpful for healthcare providers to both assess and address illness understanding.²⁴ Tools such as these need to be accessible to patients, both from a language and health literacy perspective. While these tools can certainly help to inform healthcare providers about areas that require improved education, they require further application in practice and may need to be tailored to patients' individualized conditions, rather than be utilized to assess patients' understanding about cirrhosis more generally. More tools should be developed to address specific conditions for patients with cirrhosis (ie compensated vs decompensated cirrhosis vs hepatocellular carcinoma).

Prognostic Understanding

Patient understanding of prognosis is imperative for medical decision-making and planning for the future. Prognosis is not just about estimations of life expectancy—it is also about quality of life.²⁵ Therefore, it is important to consider 3 different types of prognosis in cirrhosis²⁶:

1. Time-based prognosis: Estimating life expectancy so that patients can prioritize what is important to them
2. Functional prognosis: Prognosticating patient's level of physical and cognitive function which can be helpful for planning and goal setting
3. Uncertain prognosis: Preparing patients for the unpredictable illness trajectory of cirrhosis which can allow them to anticipate a range of possible future outcomes

Individualizing conversations based on the type of prognostic information patients find most helpful is imperative.

Similar to illness understanding, measuring patient prognostic understanding can be challenging. Historically, in research on prognostic awareness, researchers have characterized patients as "lacking prognostic awareness" if they rate themselves to be healthy or perceive the goal of treatment to be curative when it is not.²⁷ Tools to assess

prognostic understanding, such as the Prognostic Understanding Perceptions Scale, have been studied in the cancer population, but these tools have not been applied to patients with cirrhosis.²⁸ Further work is needed to develop and validate such tools in patients with cirrhosis.

In addition to challenges in assessing prognostic understanding, discussions about prognosis in patients with cirrhosis can also be difficult because of unpredictable and uncertain illness trajectories, including sudden and severe decompensating events leading to acute hospitalizations.²⁹ Often, conversations about prognosis only take place once these events occur, and many times, this is too late as patients may become too sick to make decisions for themselves.³⁰ Additionally, patients with life-limiting illness may have inaccurate or overly optimistic perceptions of their prognosis.³¹ In a study of 70 patients with cirrhosis and their outpatient hepatologists, patients were found to be more optimistic in predictions of their prognosis compared to their hepatologists.³² Also, the hepatologists' predictions of prognosis more closely aligned with what may be predicted by their patients' Model for End-stage Liver Disease (MELD) scores compared to patient predictions. When patients have overly optimistic expectations about their prognosis, they may make decisions about their care that may be more intensive (ie intubation, pressor initiation, cardiopulmonary resuscitation) than the decisions they would make if they had a more accurate understanding of their prognosis.

Prior studies have shown that patients with cirrhosis want to know their prognosis early on in their illness course. One qualitative study analyzed 31 patient and 26 multidisciplinary clinician viewpoints on content, timing, and initiation of prognosis-related conversations.³³ In this study, patients desired information about the cause of their liver disease, how to prevent complications, and recommendations about how to manage their condition in order to provide context for prognosis discussions. Patients and clinicians both supported early conversations and advocated for continued conversations as complications developed.³³

Although patients prefer earlier conversations that allow them more time to process prognostic information, the uncertain and unpredictable nature of the illness trajectory in cirrhosis poses a barrier for clinicians facing decisions about when to engage in SIC. Therefore, SIC conversations likely need to take place at multiple time points over the course of a patient's illness trajectory, such as when patients get hospitalized, develop a new decompensation, or get diagnosed with a new comorbid medical condition. In addition to the unpredictable disease trajectory in cirrhosis, another barrier for clinicians is that currently available prognostic prediction models focus predominantly on time-based prognosis, rather than functional or uncertain prognosis. Before understanding how these barriers can be addressed, it is important to highlight the nuances of currently available prognostic models in the context of SIC in cirrhosis care.

Current Prognostic Models in Liver Disease—The 2 most commonly used prognostic models for cirrhosis are Child-Turcotte-Pugh (CTP) and MELD scores. One-year survival rates for CTP class A have been predicted at 100%, CTP class B at 80%, and CTP class C at 45%.³⁴ CTP scores, however, have limitations in their ability to predict prognosis. Components of the score, including ascites and encephalopathy, are subjective parameters

and it is unclear how to classify patients if they are well-controlled on medications for these symptoms.

The MELD score was introduced given it was better able to predict survival compared to CTP.³⁵ MELD scores above 40 predict a 71% 3-month mortality, 30–39 predict a 53% 3-month mortality, 20–29, a 20% 3-month mortality, 10–19, a 6% 3-month mortality, and <9, a 2% 3-month mortality^{36,37} Ultimately sodium was added to the score (MELD-Na) given it had better predictive power for mortality compared to the MELD score alone.³⁸ The most recent adaptation of the score, MELD 3.0, is even more accurate in predicting prognosis than MELD-Na.³⁹

Even the new MELD 3.0 score, however, does not include all factors that are known to impact prognosis in liver disease. It is becoming increasingly apparent that factors such as malnutrition, frailty, and sarcopenia are important in predicting mortality in cirrhosis, yet these factors are not part of the MELD scoring system.³⁷ For example, the liver frailty index, which consists of 3 performance-based tests (grip, chair stands, and balance), has been shown to predict waitlist mortality independent of the MELD score.^{40,41}

There are additional prognostic tools that can be utilized in unique patient populations, such as those with acute-on-chronic liver failure (ACLF). Mortality rates in ACLF can be exceedingly high over very short time periods. Recently, the Multi-Organ Dysfunction and Evaluation for Liver Transplantation Consortium developed a model known as Sundaram ACLF-LT-Mortality to predict 1-year mortality in patients with ACLF who underwent transplant.⁴² In this study, older age, metabolic syndrome (higher body mass index and diabetes), and respiratory and circulatory failure were independently predictive of higher 1-year mortality post-LT.

With advancements in technology, artificial intelligence, and electronic health records, there is an opportunity to develop more accurate prognostic predictive tools. The use of data from electronic health records, including notes, radiology, laboratory values, medications, and vitals can contribute to deep-learning models that can help to predict in-hospital mortality, 30-day readmissions, and prolonged length of stay.⁴³ This type of modeling can be applied to patients with cirrhosis to help predict mortality. Additionally, machine learning and artificial neural networks have been successfully utilized to better predict mortality in patients with cirrhosis as compared to MELD.³⁷

As technology continues to advance, it is probable that current and longitudinal data will be increasingly utilized to support prognostication in cirrhosis care. Despite these advances, the need to frame these prognostic tools in the context of the unpredictable illness trajectory of patients with cirrhosis remains.

Care Planning

The third critical component of SIC is care planning. Care planning is a new framework that reconceptualizes advance care planning (ACP) as a holistic process over a patient's illness trajectory that encompasses not only advanced decisions related to future goals of care but also in-the-moment medical decision-making.⁴⁴

Once patients better understand their prognosis, they may be able to make more informed decisions about their care moving forward. Care planning is the component of SIC in which providers help patients and their care partners to: (1) identify goals and values that are reflective of patient preferences, (2) help with in-the-moment decision-making in the setting of major medical decisions, and (3) assist with ACP early in the course of illness, including designation and preparation of surrogate decision-makers, and documentation of preferences for goals of care including preferences for end-of-life care.⁷ Care planning has been demonstrated to increase satisfaction and reduce emotional distress in patients with chronic illnesses.⁸ Many patients with cirrhosis report that they are open to having conversations about their values and the care they would want to receive.⁴⁵ Moreover, care planning discussions that take place early in the disease course, and prior to a decompensating event, have been shown to be in line with the wishes of many patients with cirrhosis.⁴⁶

Barriers to Care Planning

Transplant.: One important barrier to care planning is the fact that many patients with cirrhosis have the possibility of receiving a curative LT. This can limit opportunities to assess patient values and preferences for care, especially given the unwritten rule that many transplant centers require that patients remain full code while awaiting transplantation.⁴⁷ This is largely driven by the metrics by which transplant centers are judged—1-year patient and graft survival are very important and thus do-not-resuscitate documentation is often discouraged. In one single-center study of 171 patients awaiting LT, no (0%) patients had documented care planning forms and they had low rates of documented surrogate decision-makers.⁴⁸ A multicenter qualitative study found that transplant clinicians often viewed nonaggressive care options, such as do-not-resuscitate code statuses, as contradictory to the pursuit of transplant.⁴⁵

However, rates of care planning remain low even in patients who are transplant ineligible. These rates are significantly lower than the rates of advance directive completion in the general population and in those with serious illnesses more generally, which range from 32% to 38%.⁴⁹ In one single-center study of 58 patients who were not transplant candidates, 0% of patients had care planning discussions documented in postdischarge transition clinics.⁵⁰

Limited clinician education in and capacity to conduct SIC.: There are also many clinician barriers to care planning. In a study assessing the communication skills of 12 gastroenterology fellows across 4 US training programs, fewer than 50% of the trainees were able to successfully conduct a care planning discussion for standardized patients with liver disease.⁵¹ Another survey study of 45 US transplant hepatology fellows found that many lacked comfort in addressing care planning.⁵² In a national survey study of almost 400 US hepatologists and gastroenterologists, over 80% of respondents believed that care planning discussions with patients occurred too late.³⁰ Insufficient communication between clinicians and families about goals of care was highlighted as important barriers to early engagement in care planning.³⁰

Lack of time to conduct SIC in clinical practice has been cited as an additional barrier for clinicians.⁵³ In addition, lack of reimbursement for having SIC or for referral to palliative care has been identified issues.⁵⁴ More recently, however, Medicare has adopted new billing codes for SIC (care planning in particular) to provide provider reimbursement in exchange for having these discussions.⁵⁵ Further work is needed to improve implementation of SIC processes into clinical practice.

Surrogate decision-makers.: Patients with cirrhosis often develop hepatic encephalopathy or critical illness which renders them incapable of making their own medical decisions. Surrogate decision-makers should therefore ideally have a prior understanding of the patient's values and wishes and implement these. However, if care planning between providers and patients does not take place in the presence of surrogate decision-makers or does not happen early enough, surrogate decision-makers may not know patients' wishes and preferences and, therefore, may not feel comfortable making decisions. Additionally, the lack of collaboration of providers with surrogates can lead to a surrogate's lack of awareness of the patient's illness severity when the time comes to make a medical decision.⁵⁶

Cultural humility in SIC.: Lastly, there are racial and ethnic disparities in care planning among patients with cirrhosis. Black, Asian, American Indian/Alaska Native, and Hispanic patients with cirrhosis have been shown to have lower odds of dying at home or with the use of hospice or palliative care services when compared to Caucasian patients.⁵⁷ These disparities may be related to insufficient cultural humility training leading to late or absent care planning, as reported by hepatology and gastroenterology clinicians in a national survey study.⁵⁸ A deeper understanding of the root causes for these disparities in care planning for patients with cirrhosis is needed so that interventions can be developed that promote patient-centered care.

How Can We Improve SIC in Cirrhosis Care?

Much of what we have learned about improving SIC originates from the oncology literature. The American Society of Clinical Oncology guidelines provide the following recommendations for SIC: (1) development of core communication skills; (2) involvement of care partners early in the illness course; (3) overcoming barriers to communication, such as language, health literacy, or cultural barriers; (4) discussing goals of care and prognosis in a way that is tailored to each patient's needs while acknowledging prognostic uncertainty; (5) discussing treatment options; and (6) discussing end-of-life care early.^{59,60} It is important to note that there is not a single approach to SIC that will work for all patients, all clinicians, and all practice settings—general concepts can be adapted to fit particular scenarios.

SIC is a shared responsibility among patients' multidisciplinary team, including primary care, social work, spiritual care, and palliative care, and that different components of SIC can be managed by different and multiple members of a multidisciplinary team. For example, gastroenterology, hepatology, and primary care clinicians may best support patients in improving their illness and prognostic understanding and treatment decision-making, while providers in social work, spiritual care, and/or palliative care may help to support aspects of SIC such as identifying surrogate decision-makers, exploring goals

and values, and documenting early, upstream conversations. This allows for a patient's goals to be better understood by multiple team members in advance of an acute event. Early involvement of additional members of a patient's support system such as extended family and religious or community leaders can also be beneficial in improving the delivery of culturally competent care. Clearly outlining which providers are going to lead the various components of SIC is helpful to avoid ambiguity about responsibilities and lack of accountability that could delay the delivery of information and documentation of preferences.

For patients who have significant palliative care needs, particularly when related to symptom management, psychosocial concerns, caregiver burden, or more, a referral to specialty palliative care may be helpful. Patients and families may have misperceptions of palliative care as end-of-life care or may feel like their clinicians are giving up on them, which has been demonstrated in qualitative interviews of patients with cirrhosis and their families.⁶¹ However, when provided a standardized definition of palliative care, patients and families may become more open to a referral. We suggest the following language to define palliative care with patients and families: "Palliative care is specialized medical care for people facing a serious illness that focuses on providing patients with relief from symptoms and stress of a serious illness with the goal of improving quality of life for the patient and the family. Palliative care is appropriate for patients at any age and at any stage in a serious illness and can be provided along with curative treatment."⁶²

The remainder of this section will focus on how to improve core SIC skills in cirrhosis care and how to address illness understanding, assess prognostic awareness, deliver prognostic information, and discuss treatment options using a case example. As previously discussed, there are multiple clinician barriers to SIC, including concerns about inadequate communication skills training. Multiple evidence-based training programs have been used to teach SIC skills for clinicians. Three examples of these trainings that use communication frameworks that have been previously adapted for patients with cirrhosis are Best Case/Worst Case (BC/WC), the Serious Illness Conversation Guide (SICG), and VitalTalk ADAPT.

The BC/WC communication tool was first developed to support high-stakes surgical decision-making and SIC among older adults. The BC/WC tool uses scenario planning to prepare patients and their care partners for future outcomes in the face of prognostic uncertainty through the use of a handwritten graphic aid and narrative storytelling where the "best case," "worst case," and "most likely" scenarios are described. The goal of using the BC/WC tool is not to predict the future, but instead to forecast multiple potential futures in order to guide medical decision-making centered on patients' personal goals and values.⁶³ The BC/WC tool has been adapted for use in the liver transplant evaluation setting to promote patient prognostic understanding.⁹

The SICG was first published in 2012 by Ariadne Labs as a multicomponent, structured communication intervention, which aimed to guide more frequent, higher quality, and earlier conversations with patients about their goals, values, and priorities.⁶⁴ The SICG has been applied in multiple randomized control trials, mostly in the oncology literature.⁶⁵⁻⁶⁷ In one

trial, an adaptation of SICG, called the Serious Illness Care Program, resulted in significant reductions in the proportion of patients with moderate to severe anxiety and depression symptoms.⁶⁶ SICG has also been adapted to cirrhosis care and an example of how it has been applied in the context of liver transplant candidacy was recently published.⁶⁰

VitalTalk was also developed in 2012 by palliative care physicians funded by the National Institute of Health. The ADAPT talking guide provides a 5-step approach to discussing prognosis: (1) ask, (2) discover, (3) anticipate, (4) provide information, and (5) track emotion. It has also been studied in the context of a randomized control trial, where adaptation of VitalTalk as part of a communication-priming intervention led to both a significant increase in patient-reported goals of care conversations and to an increase in patient-reported quality of these discussions.⁶⁸

While BC/WC, SICG, and VitalTalk have been studied in diverse patient populations and through randomized controlled trials, their application has not yet been studied in all patient populations. In one study of 24 Japanese physicians, VitalTalk pedagogy was felt to be novel and beneficial, but cultural adaptations in expression and response to emotion were felt to be required.⁶⁹ Further study of these tools in diverse patient populations is necessary.

Case Example

By use of a case example, we will demonstrate the use of BC/WC and SICG to enhance illness and prognostic understanding in a patient with cirrhosis in 2 different phases of the illness trajectory—first in the inpatient setting where the patient is diagnosed with ACLF and second in the outpatient setting when the patient presents with decompensated cirrhosis. While BC/WC supports in-the-moment care planning, SICG can be utilized to support care planning. We will not be employing VitalTalk ADAPT in our case example, but it remains an important tool for clinicians to have SIC.

Case—Mr Garvy (Mr G) is a 34-year-old man with active alcohol use disorder (complicated by prior pancreatitis, 2 offenses for driving under the influence, and several admissions for alcohol withdrawal) and alcohol-associated cirrhosis. Mr G was admitted to the hospital 3 months ago with new-onset ascites. He was started on diuretics and met with addiction psychiatry who prescribed acamprosate to help with alcohol cravings. In the last 3 months, he has continued to drink up to 10 shots of vodka per day. Mr G notes that 3 weeks ago, he developed jaundice. Five days ago, he developed a fever and presented to the hospital. He was diagnosed with sepsis secondary to a urinary tract infection and was treated with antibiotics. He required vasopressors to maintain his blood pressure and was transferred to the intensive care unit.

In the setting of his critical illness, his creatinine has been rising and he is developing a worsening metabolic acidosis. Urine studies and urine microscopy are consistent with acute tubular necrosis. His MELD 3.0 score is 33 and he remains on low-dose vasopressors. His liver transplant team has explained to him that he is unfortunately not a transplant candidate given high-risk alcohol use. Because of his age and lack of other comorbid medical problems, he was initiated on dialysis. You are meeting him in the intensive care unit and he asks, “What is going to happen next?”

Using the BC/WC framework, you initiate a serious illness conversation (Table 1, Figure 2). During this conversation, we have highlighted several teaching points on how to respond to emotion (using the NURSE [name, understand, respect, support, explore] mnemonic), ask permission before sharing prognosis, and use hope/worry and “I wish” statements (Table 2).

With continued treatment of his infection, Mr G’s blood pressure improved and he was able to transition to outpatient hemodialysis. He was discharged from the hospital after a 3-week stay. Since his discharge, hemodialysis has been challenging—it has been difficult to remove fluid with each session because of his labile blood pressure. He therefore has large-volume ascites and lower extremity edema. He has also continued to drink alcohol and is still not a liver transplant candidate. His MELD 3.0 score is now 37. This is your first outpatient appointment with Mr G since his hospitalization.

You initiate a second SIC conversation based on the SICG to assess illness understanding, share prognosis, and care plan (Table 3).

Two weeks after your conversation in the office, Mr G returns with his mother. He is much sicker at this visit—he comes in a wheelchair. Together, you are able to discuss his illness and his limited time. He reiterates that he would like to avoid rehospitalization and shares with you and his mother that being at home is important in the time that he has left. He agrees to home hospice, which you are able to help arrange with the assistance of a multidisciplinary team. Over the next few visits, Mr G declines further and ultimately passes away at home.

The future of SIC in cirrhosis care.: While multiple barriers to conducting SIC have been identified and several communication tools have been developed, there is still much work to be done to improve SIC in practice for patients with cirrhosis. As technology advances, there are opportunities to advance SIC. Decision aids, for example, which often use print, video, or web-based media, are designed to improve illness understanding and promote informed decision-making about future medical care.⁷⁰ Decision aids can support nuanced decisions and recognize diverse perspectives.⁷¹ While some decision aids are more focused on information sharing, others are structured to address risks, benefits, and alternatives to treatment. Multiple studies have demonstrated that decision aids improve the quality and efficiency of decision-making and increase patient participation in decision-making.⁷² Decision aids to improve SIC have rarely been studied in cirrhosis care. In one single-site randomized control trial, a 5-minute ACP video decision support tool for patients with decompensated cirrhosis significantly improved patient knowledge of end of life care and informed their preferences for intubation and resuscitation.⁷³ Further work is needed to develop and study SIC frameworks and decision aids that could be used to improve SIC in cirrhosis.

Additional research priorities in SIC in cirrhosis include application of SIC tools to broader patient populations to ensure that they can be used in diverse populations, assessment of communication and responsibility-sharing in multidisciplinary teams, and evaluation of communication interventions in real-world settings to better understand the scalability, sustainability, and impact of these interventions on patient outcomes.

Conclusion

Patients with cirrhosis face unique challenges to the implementation of SIC, both because of the nature of their illness (unpredictable trajectory with the option of curative transplant) and because of clinician-related barriers, particularly related to limited communication training. Ultimately, enhancing the quality and consistency of SIC in cirrhosis care can lead to improved patient illness and prognostic understanding, informed decision-making, and a shift toward care that is truly congruent with patient goals, values, and preferences. It is vital that further research investigates innovative and effective strategies for improving SIC within cirrhosis care to optimize patient outcomes and experiences.

Funding:

Nneka Ufere received clinical, translational, and outcomes research award from AASLD and Sojourns Scholar Award from Cambia Health Foundation (NIDDK L30DK126237).

Abbreviations used in this paper:

ACLF	acute-on-chronic liver failure
ACP	advance care planning
BC/WC	Best Case/Worst Case
CTP	Child-Turcotte-Pugh
LT	liver transplantation
MELD	Model for End-stage Liver Disease
SIC	serious illness communication
SICG	Serious Illness Conversation Guide

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Serious Illness Communication

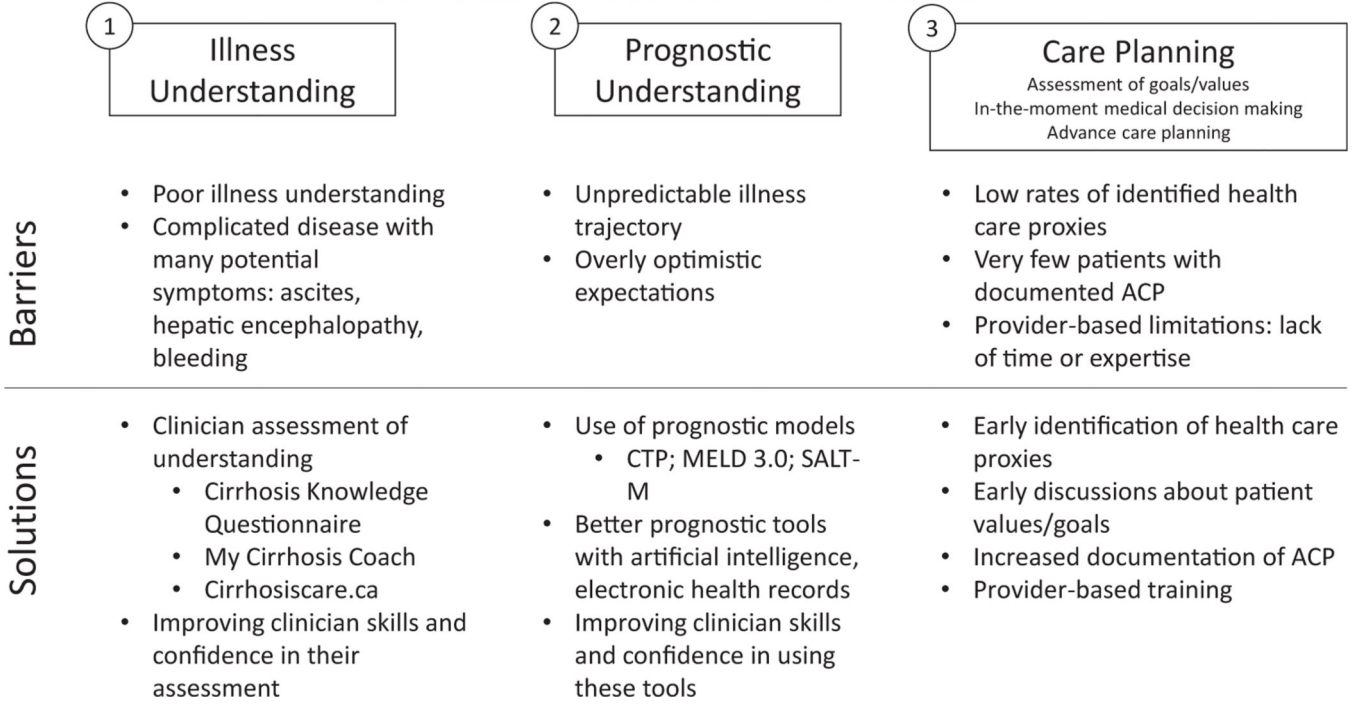


Figure 1. Serious illness communication components.

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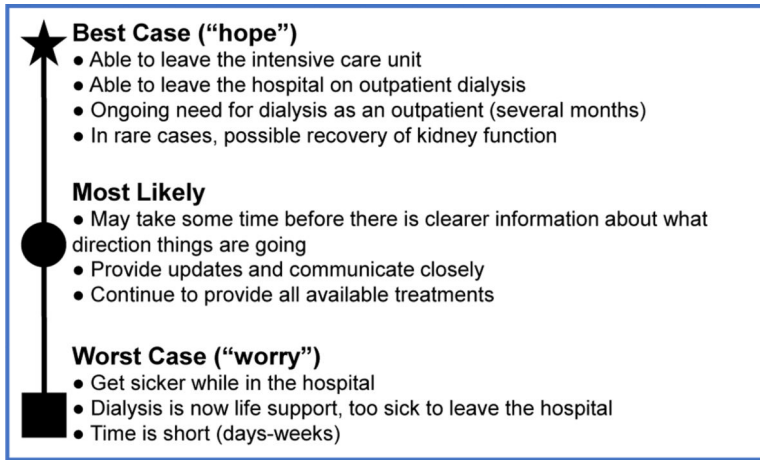


Figure 2.
Best Case/Most Likely/Worst Case.

Table 1.

Best Case/Worst Case Scenario SIC Dialogue

Dialogue	SIC skill
You: What have you heard from the team about what is going on right now?	Setting up the conversation
Mr G: I know my liver is not doing well and that I cannot get a new liver. I also know I had an infection in my urine and that they started me on dialysis because my kidneys were not working well.	Assessing illness understanding
You: Would it be okay if we talked about what the future could look like, both what we are hoping for and what we are worried about?	Asking permission
Mr G: Yes, that would be helpful.	
You: In the best case scenario , you no longer need life support and you are able to leave the ICU. Because of how sick you are, you will likely still be in the hospital for several days to recover further. In the best case, you will be able to go home, but while at home, you still may need to be on dialysis because your kidneys have not fully recovered. In some cases, people are able to come off dialysis before going home. This is what we are hoping for.	Sharing information: best case
Pause: Allow silence. Validate and explore emotions.	Hope/Worry statement
You: I wonder if it would be okay if we talked about what could happen if things do not go as well as we are hoping for?	Asking permission
Mr G: It is hard to think about, but I do like to know what is going on.	
You: While we are hoping for this best case, there is also the possibility that you could get sicker while you are in the hospital. Unfortunately, in the worst case scenario , that would mean that you would not survive this hospitalization. This is what we are worried about.	Sharing information: worst case
Pause: Allow silence. Validate and explore emotions.	Hope/Worry statement
Mr G: I am going to try to stay positive.	Responding to emotion
You: We share your hope that things will get better. You have been through so much, so quickly.	
Mr G: Yes, it's been a lot.	
You: I wonder if it would be okay to talk about what to expect in the coming days?	Asking permission
Mr G: Yes.	
You: It is most likely that we will have clearer information about what direction things are going over the next several days. We will continue to provide all of the treatments to help you get through this and we will communicate closely with you and your family.	Sharing information: most likely
Pause: Allow silence. Validate and explore emotions.	Responding to emotion
You: Our team is going to be here to support you through this, every step of the way.	Offering support

Table 2.

Skills to Support SIC

Skill	Use	Suggested phrases
Responding to emotion	Naming the emotion that the patient seems to be experiencing	"I can see that this is surprising to you."
	Express understanding of the emotion	"Many people in your situation may feel frustrated or even angry. I wonder if you have felt that way?"
	Respecting and validating the emotional response	"I can't imagine how difficult this is for you."
	Supporting patient and family in response to emotion	"You are so strong. You have been through so much."
	Exploring emotions using phrases such as "tell me more"	"We will be here to help you and support your family."
	"I wish" statements allow for both alignment with the patient while also acknowledging the reality of the situation	"Can you tell me more about what worries you?"
Asking permission	Ask permission to assess understanding and readiness before discussing prognosis	"I wish we had more options."
Hope/Worry	Using hope/worry to align with patients' hopes while also expressing concern	"Would it be okay if we talked more about what to expect from this illness?"
		"I hope we will be able to consider other treatment options. I worry that they may do more harm than good."

Table 3.

Illness Understanding, Prognosis Sharing, and Care Planning SIC Dialogue

Dialogue	Teaching points
Set up the conversation and assess	
You: I would like to talk together about what's happening with your liver disease and what matters to you. Would this be okay?	Asking permission
Mr G: Yes, this would be okay.	Establishing care partner
You: Are there any people who are important to you that you would like to include in this conversation?	
Mr G: I would rather talk alone first.	
You: Okay, that makes a lot of sense.	
Mr G: Thank you.	
You: I can't imagine how scary this all must be.	Responding to emotion
Mr G: Yeah, it's been a lot.	
You: First, I want to get a sense of what you understand about what is happening with your liver now. What have other doctors told you about your future or what to expect with your liver disease?	Assessing illness understanding
Mr G: I know that my liver is sick and they told me I can't get a new liver. I read scary things on the internet.	
You: What have you read?	
Mr G: That I could get very sick again. That I could die.	
You: How much information about what might be ahead with your health would be helpful to discuss today?	
Mr G: Well, I want to know what you think about my future.	Asking permission
Share information	
You: Can I share my understanding of what may be ahead with your health?	Asking permission
Mr G: Yes, please. I want to know what you think.	
You: Unfortunately, your liver disease is very severe and what that means is that your time might be shorter than we had hoped for.	Giving a warning statement ("unfortunately")
Pause: Allow silence. Validate and explore emotions.	
Mr G: (sits in silence, looks down)	Sharing prognosis
You: I can't imagine how overwhelming this must be.	Responding to emotion
Mr G: I don't know what to say.	
You: I wish I had better news.	Wish statement
Pause: Allow silence. Validate and explore emotions.	
Mr G: So what's next?	
You: Before we talk about a plan moving forward, I was wondering if it would be okay if I asked you a little bit more about what's important to you?	Asking permission

Teaching points

Dialogue

Mr G: Okay.

Explore goals and values

You: If your health were to get worse, what would be most important to you?

Exploring what is important

Mr G: Well, I hate hospitals so I would rather not spend time there. The food is terrible, I hate the smell, and I can never sleep. I would rather be home with my mom.

Exploring worries

You: What are your biggest worries?

Mr G: I'm afraid this is going to go really fast. I just feel so sick. I'm afraid of not feeling better.

You: You've been through so much.

Responding to emotion

Mr G: Yea, I still can't believe it's happening.

You: We are here to support you through this.

Offering support

Pause: Allow silence. Validate and explore emotions.

You: How much do the people you care about know about what's going on with your health and what's important to you?

Exploring care partner's awareness of patient's wishes

Mr G: I haven't talked to anyone much about this. My mom knows I'm very sick. I know she's worried. I don't know how to talk to her about it.

You: This is such a hard situation for both of you. Having talked about all of this, what are your biggest hopes?

Exploring hopes

Mr G: I would like to feel better.

Recommend next steps

You: Given what we've talked about today, is it okay if I make some recommendations moving forward?

Asking permission

Mr G: Okay.

You: I'm hearing you say that being at home and not feeling so sick are really important to you. And that being able to talk to your mom about this is important too.

Reflecting what you heard back to the patient

You: Keeping that in mind, and what we know about your liver disease, I recommend that we continue to treat your symptoms so that you can feel better. If it sounds right to you, I would like to suggest that we meet together with your mom so that she also understands the situation with your health, what to expect, and what's important to you

Recommending next steps based on patient's goals values

Mr G: That sounds good.

Making a plan to involve the care partner

Close

You: We will do everything we can to support you through this and to make sure you continue to get the best care possible.

Offering support

Mr G: Thank you.

Note: The serious illness conversation guide (SICG) divides SIC into several components demonstrated above: (1) set-up, (2) assess, (3) share, (4) explore, (5) close.