

ASSOCIATION
OF COMMUNITY
CANCER CENTERS

MULTIDISCIPLINARY HEPATOCELLULAR CARCINOMA CARE



EFFECTIVE PRACTICES
IN CARE COORDINATION

TABLE OF CONTENTS

Introduction	4
Effective Practices in Multidisciplinary Hepatocellular Carcinoma Care	4
Disparities in Access to Care and Outcomes for Patients with Hepatocellular Carcinoma	7
Models of Effective Care Delivery	8
Sharp HealthCare	9
Mercy Medical Center	11
Emory Healthcare	13
Improving Hepatocellular Carcinoma Care Coordination and Patient-Centered Communication	16
Call to Action	19
References	20
Acknowledgements	22

INTRODUCTION

Hepatocellular carcinoma (HCC) is one of the most challenging cancers to diagnose and treat.¹ In 2020, the National Cancer Institute (NCI) estimates that there will be 42,810 new cases of liver and intrahepatic bile duct cancers and 30,160 deaths in the United States.² About 75 percent of these cases are HCC.³ Despite rising incidence rates and an estimated 89,950 people living with liver cancer or hepatic bile duct cancer,² there is little information available on managing patients with HCC in community cancer programs.⁴

To learn more about current practices in HCC care management, the Association of Community Cancer Centers (ACCC) launched the Multidisciplinary Hepatocellular Carcinoma Care education program in partnership with the Cancer Support Community (CSC), the American Cancer Society (ACS), the Global Liver Institute (GLI), the Society of Interventional Radiology, and Blue Faery: The Adrienne Wilson

Liver Cancer Association. Phase One of the program saw the establishment of an expert Advisory Committee and Partner Organizations, execution of a multidisciplinary HCC care survey, publication of a comprehensive environmental scan, and the launch of an online provider portal with HCC resources.

In Phase Two, ACCC collaborated with the expert Advisory Committee and Partner Organizations to select and highlight three cancer programs in various care settings to identify effective practices of HCC management. ACCC also created an HCC heatmap tool to visualize certain features of HCC in each state and interviewed care team members from the three cancer programs. Results from this work illustrate the complexities of the disease and care planning and reinforce the value of a multidisciplinary approach. Based on these findings, there is a critical need for strong communication and care coordination across the multidisciplinary cancer care team.

EFFECTIVE PRACTICES IN MULTIDISCIPLINARY HEPATOCELLULAR CARCINOMA CARE

Through its environmental scan, ACCC identified six effective practices in managing HCC in the community setting:

1. Follow national HCC guidelines for testing, staging, and treatment.
2. Work with a dedicated hepatobiliary and transplant multidisciplinary team or collaborate with an external expert tumor board.
3. Conduct regular multidisciplinary evaluations of HCC cases.
4. Establish operational pathways to document adherence to guidelines and quality of care metrics.
5. Promote and support screening through communication and education with community clinicians.
6. Provide patient-centered care by participating in shared decision-making.

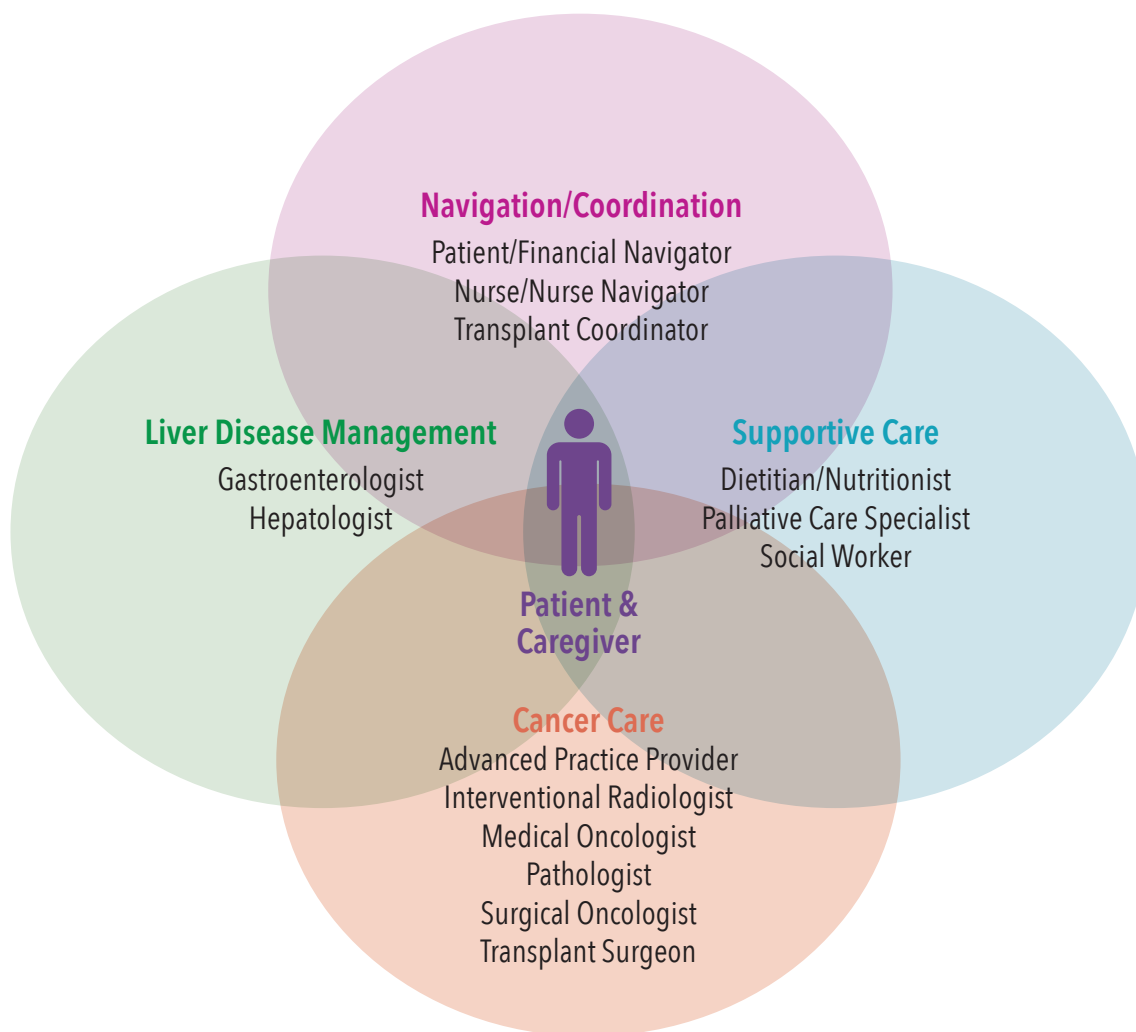
Patients with HCC frequently present with underlying chronic liver disease and other comorbidities, which is why multidisciplinary care is crucial.

The primary risk factor for HCC is cirrhosis of the liver, which can be caused by Hepatitis B and C virus infection, alcohol consumption, and non-alcoholic steatohepatitis (NASH).⁵ Hepatologists have the most in-depth knowledge and understanding of liver disease, and patients' liver health will influence prognosis and determine which HCC treatments can be considered.

In addition to managing comorbidities, a multidisciplinary approach to HCC has been shown to change outcomes: a single-day multidisciplinary liver tumor clinic altered the management plan of 42 percent of patients who already had a care plan prior to the clinic.⁶ Other studies show a survival benefit for HCC patients evaluated by a multidisciplinary team.⁷ Because of the low volume of HCC cases across the U.S., an HCC-dedicated multidisciplinary clinic is not always feasible, yet principles of multidisciplinary care can be implemented regardless of the care setting. In fact, nearly 40 percent of programs surveyed by ACCC have a specialized multidisciplinary gastrointestinal (GI) team, and 85 percent of programs without a specialized multidisciplinary team consult with a tumor board for HCC cases.⁸

Who Is Involved in Multidisciplinary Care of Patients with HCC?

FIGURE 1: Multidisciplinary Care of Patients with HCC



Liver Disease Management

- **Gastroenterologist:** In a setting where there is no hepatologist available to coordinate HCC patient care, a gastroenterologist with experience managing liver disease is ideal.
- **Hepatologist:** Treatment for HCC often depends on the severity of the underlying liver disease, which also impacts the staging algorithm. Continued assessment of the liver disease determines the treatment direction. Also, treating underlying liver disease helps maintain liver function longer and allows for further HCC treatment. This requires ongoing coordination between the hepatologist and clinicians treating the cancer, making the hepatologist the ideal option to coordinate patient care.

Navigation/Coordination

- **Patient/Financial Navigator:** Patient navigators work with patients to resolve barriers to care within the health system. Financial navigators help address financial barriers to care by maximizing insurance coverage, identifying assistance programs and foundation support, and/or working with the care team to lessen the financial burden of treatment.
- **Nurse/Nurse Navigator:** A nurse is often responsible for patient navigation, education, coordination with the multidisciplinary team, monitoring quality of life, and assisting with symptom and side effect management. Often nurses specialize in a certain area of HCC care (i.e., medical oncology, transplant, or interventional radiology) and support patients undergoing each specific treatment.

- **Transplant Coordinator:** Liver transplant is a complex process and often requires months of coordination. A transplant coordinator works with the patients and members of the multidisciplinary team, while managing the transplant wait list process. Transplantation also treats the underlying liver disease.

Supportive Care

- **Dietitian/Nutritionist:** Dietary recommendations can improve liver function and decrease rates of malnutrition, which is common in patients with liver disease. In addition, pre- and post-transplant nutrition is important in maintaining patient health.
- **Palliative Care Specialist:** Palliative care specialists work with the care team to manage the physical and psychological impact of cancer and maintain quality of life for the patient.
- **Social Worker:** Patients with HCC may experience a high burden of psychosocial and logistical needs, and social workers can help manage these needs by connecting patients and families with resources and/or provide counseling support.

Cancer Care

- **Advanced Practice Provider:** Nurse practitioners, physician assistants, clinical nurse specialists, advanced degree nurses, and pharmacists all serve a wide range of functions on the HCC care team. In addition to counseling on medication side effects and interactions and providing direct patient care, they may also conduct assessments, inpatient rounds, procedures, and assist in surgery.
- **Interventional Radiologist:** Liver-directed therapies (LDTs, also known as loco-regional therapy) are common treatments for early and advanced stages of HCC and are frequently used as a bridge to liver transplantation.
- **Medical Oncologist:** More than 50 percent of HCC cases have advanced disease at the time of diagnosis making them unsuitable for surgical therapy.¹² A medical oncologist who is familiar with the HCC treatment landscape is critical to coordinating patient care, especially with advances in targeted therapies, immuno-oncology drugs, and consideration of clinical trials.

- **Pathologist:** While biopsies are uncommon in HCC and blood tests and imaging scans are the most common tools for diagnosing HCC and determining treatment direction, identifying biomarker status is becoming more important as targeted therapies and immuno-oncology therapies are approved as treatment options.
- **Surgical Oncologist:** Depending on the tumor size, location, and overall liver health and patient health, surgical resection of part of the liver while preserving the rest is feasible and can be potentially curative.¹⁰ However, resection is associated with high recurrence rates in the remnant liver.¹¹
- **Transplant Surgeon:** Liver transplant offers the best treatment opportunity for eligible patients with HCC, who account for 17 percent of more than 8,000 liver transplants in the U.S.⁹

Screening

Those who should be screened for HCC and the best screening tests and its intervals continue to be discussed within the healthcare professional community. According to the National Comprehensive Cancer Network (NCCN) Clinical Guidelines, "Screening and surveillance for HCC is considered cost effective in patients with cirrhosis of any cause and patients with chronic Hepatitis B, even in the absence of cirrhosis."¹⁰ The recommended screening test is an ultrasound every six months, either with or without an alpha-fetoprotein (AFP) test. However, the American Association for the Study of Liver Diseases (AASLD) does not recommend screening for those with the most severe cases of liver disease (Child Pugh Class C), unless they are candidates for a liver transplant, because their survival potential is low.¹³

In the ACCC survey, only 16 percent of respondents reported that their cancer program is in a community that has a surveillance program for populations at risk for HCC. This finding was consistent with feedback from the project's highlighted programs. While there is evidence to support screening for this high-risk population, the sites surveyed and interviewed for the current project noted that screening for HCC is not common.

This occurred for several reasons:

- Many patients are not aware of their risk level.
- Providers may not know which of their patients are at risk or are not assessing risk.
- Providers are not familiar with screening for HCC.
- Screening recommendations are often considered burdensome, resulting in poor adherence.

Increasing knowledge on appropriate and effective screening is an important opportunity for the cancer community to partner with the primary care community. Because primary care providers (PCPs) are often the first point of contact for patients with cirrhosis and other HCC risk factors, they play a critical role in early detection efforts.



“In the U.S. only about 30 percent of patients with cirrhosis are being seen by a GI or hepatologist... Screening guidelines can be challenging to understand and implement, so there is a big unmet need in the community to screen patients with cirrhosis, let alone identify patients with cirrhosis better. That’s a really big problem because we don’t know what the denominator is. We don’t know how many people are out there with cirrhosis that are not receiving care and are thus unrecognized as cirrhotic, but those are the people that first present with metastatic HCC. So, education is the first step.”

Joel Wedd, MD, MPH, Director of the Liver Tumor Clinic, Emory Transplant Center, *Emory Healthcare*

DISPARITIES IN ACCESS TO CARE AND OUTCOMES FOR PATIENTS WITH HEPATOCELLULAR CARCINOMA

As with many health conditions, patients’ race, socioeconomic status, and geography influence their treatment access and outcomes for HCC. In a study of racial disparities in HCC that compared southern and non-southern cancer registries, age-adjusted incidence rates of HCC grew more quickly in Louisiana and Georgia compared to any set of non-southern states, and the Black population in all states were more likely to be diagnosed with HCC at a late stage.¹⁴ From 2000 to 2016, there was a decrease in mortality rates among Asian/Pacific Islanders with HCC,¹⁵ however, a separate analysis of data from 1988 to 2012 indicated that HCC incidence rates among specific Southeast Asian subgroups increased over time.¹⁶ Age-adjusted incidence rates for the American Indian and Alaska Native populations are significantly higher than non-Hispanic white populations for both men and women, and the incidence trend is increasing more quickly for American Indian and Alaska Native men compared to their female counterparts and non-Hispanic white men and women.¹⁷

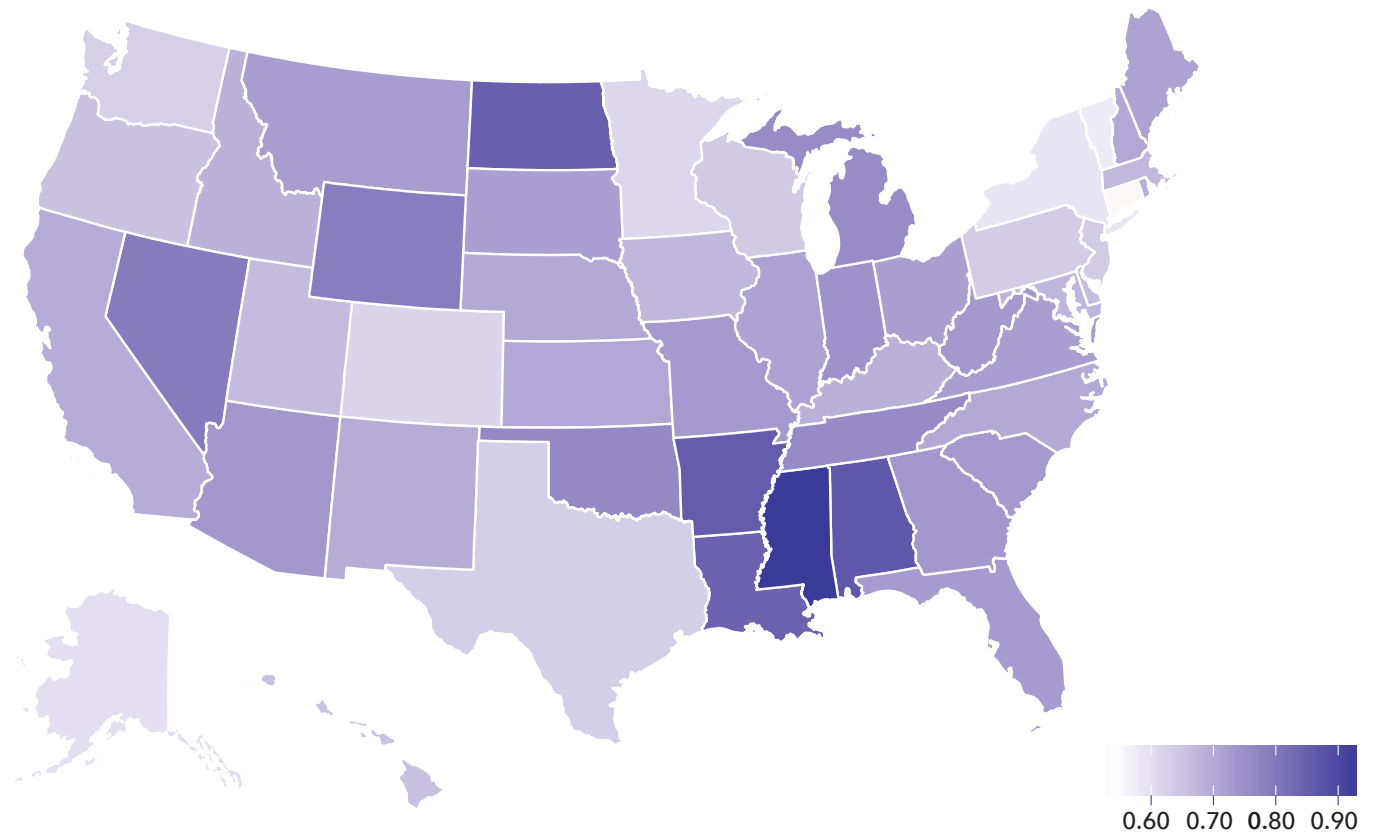
While liver-directed therapy options have improved over time, early research indicates that Black patients with HCC are more likely to refuse surgical interventions compared to their white counterparts, which may signal “insufficient patient-centered decision making.”¹⁸ Patients with HCC are more

likely to receive surgery and treatment for advanced (stage D) disease if they have private insurance, not Medicaid.⁴ Patients are also more likely to receive surgery if they are treated at an academic center. Having private insurance and being treated at an academic medical center are variables associated with improved survival.¹⁹

Not all patients may have access to psychosocial support, like social workers and financial navigators, who can help decrease disparities in access and outcomes. ACCC helps cancer programs close these gaps in a number of ways, such as by helping develop a business case for supportive care and financial advocacy roles. In addition, the effective practices highlighted in this publication can help address disparities in access to quality care.

ACCC developed a heatmap to better understand prevalence, mortality, access to care, and disparities for those with HCC. Liver cancer rates from 2012 to 2016 from the United States Cancer Statistics (USCS) data were used to develop this map, which can be searched by age-adjusted rates, crude rates, number of cases, mortality, and mortality-to-incidence ratio. In addition, National Cancer Institute (NCI) and ACCC member cancer programs are overlaid on the interactive map to show where treatment facilities exist in each state.

FIGURE 2: ACCC Liver Cancer Heatmap: Mortality-to-Incidence Ratio



The highest age-adjusted rates of HCC exist in Washington, D.C., Texas, Hawaii, and New Mexico. The highest mortality rates exist in Washington, D.C., Louisiana, New Mexico, and Mississippi. The high mortality-to-incidence ratio (MIR) in Mississippi, Alabama, Louisiana, and Arkansas is notable and could indicate disparities in access to care. As a comparison, the age adjusted rates of disease for Mississippi are similar to those of New York, Delaware, and Maryland, but the mortality rates and MIR are much lower in these three northeastern states. More research is needed to understand disparities in access to care but ensuring that community cancer centers can provide access to HCC specialists may help bridge the gap between incidence and mortality rates.

Explore ACCC's INTERACTIVE Liver Cancer Heatmap at acc-cancer.org/hcc/heatmap or scan this QR code.



MODELS OF EFFECTIVE CARE DELIVERY

ACCC carried out a combination of on-site focus groups and phone surveys at three ACCC Cancer Program Member sites to better understand effective practices in communication and coordination between the multidisciplinary team and patients. Three varied models of patient-provider communication in the management of HCC are highlighted. These member programs include:

- Sharp HealthCare, a health system with decentralized multi-facility collaboration for HCC management
- Mercy Medical Center, a centralized liver tumor board with outside partnerships to deliver comprehensive services
- Emory Healthcare, a fully integrated liver tumor multidisciplinary clinic.

SHARP HEALTHCARE SAN DIEGO, CALIFORNIA



Sharp HealthCare is a not-for-profit health system serving San Diego county. Within the system are four acute care hospitals, three specialty hospitals, and three affiliated medical groups. Its three cancer centers are based at Sharp Memorial Hospital, Sharp Chula Vista Medical Center, and Sharp Grossmont Hospital. According to the Sharp cancer registry, Sharp HealthCare treated 72 cases of liver cancer in 2018. Most patients with HCC were referred to Sharp by primary care practices or gastrointestinal (GI) specialists, from within or outside the system. Sharp does not have a liver transplant program, but based on a successful bone marrow transplant partnership model, it developed a partnership with the University of California San Diego to provide transplants to patients.

Formalizing Internal Operational Pathways to Standardize Care

Sharp's three cancer center locations support its goal to treat patients as close to home as possible. As an Integrated Network Cancer Program of the American College of Surgeons, Sharp is required to integrate cancer care and comprehensive services across its multiple sites. While currently developing quality

improvement projects to standardize care across these three facilities, Sharp is implementing standard chemotherapy regimens across the health system. There are 45 chemotherapy regimens associated with GI cancers, including HCC. Standardizing operational pathways for chemotherapy across a multi-facility system can help improve care quality and consistency, especially for clinicians who are not HCC specialists.

Working as a Decentralized Team to Improve Care Coordination

Sharp's care model is consistent with 60 percent of ACCC survey respondents who indicated their cancer program does not have a specialized GI multidisciplinary team. Sharp cancer centers operate independently, and each hold weekly general tumor boards along with peer-to-peer communication between colleagues across the health system who offer relevant expertise. If a more complex HCC case presents, clinicians will collaborate with others in the field who see HCC cases more frequently. This collaboration involves coordinated consultation between interventional radiology, hepatobiliary surgery, and the transplant team.

While Sharp does not have a GI-specialized multidisciplinary team, clinicians built a relationship with a local hepatology practice to collaborate via an inter-institutional liver cancer clinic that meets twice per month in an effort to improve care coordination and decrease time to treatment for patients with HCC. The chain of referrals for newly diagnosed patients with HCC can be a challenge. Patients may be sent from primary care or gastroenterology to surgery, then oncology, then the transplant team, and then interventional radiology. This process can take months. By the time patients reach the appropriate physician, their cancer may have significantly progressed. By routing patients through the established inter-institutional liver cancer clinic, they are directed quickly to appropriate treatment, whether that means surgery, interventional radiology, or oncology. Early engagement is vital to achieve the best outcomes.

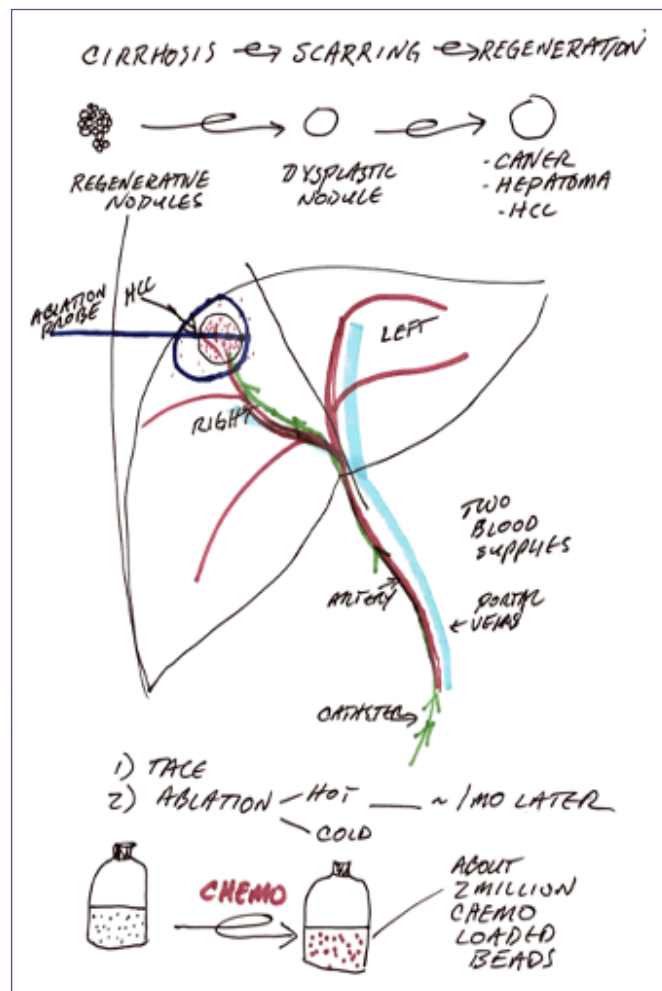
In Sharp's experience, approximately 80 percent of patients with HCC will need liver-directed therapy and the quicker they can be evaluated by an interventional radiologist, the better the outcomes. This applies to patients with loco-regional disease and can also include rare cases of patients with metastatic disease who may benefit from a combination of infusion therapy and locoregional therapy. Five of the interventional radiologists who participate in the liver cancer clinic practice interventional oncology and timely access to their services can reduce time-to-treatment for recently diagnosed patients with HCC in the community.

Increasing Health Literacy and Patient Engagement in Decision-Making

When improving health literacy and patient understanding of their condition, a picture is worth a thousand words. While communicating with patients, James Lyon, MD, an interventional radiologist at Sharp, often draws a diagram with colored pens as he explains the diagnosis and treatment options, which can get the message across better than written descriptions. This practice not only helps patients better understand their situation but can lead to

improved engagement in treatment decision-making. In Dr. Lyon's experience, his diagrams help illustrate to patients their treatment options and helps them understand exactly what to expect during the treatment process. Research indicates that health literacy influences health outcomes, including use of health services, health self-management, and participation in shared decision-making, all of which can decrease health disparities among patients with HCC.²⁰

FIGURE 3: Example of a hand-drawn diagram used to educate patients with HCC about their diagnosis and treatment.



MERCY MEDICAL CENTER BALTIMORE, MARYLAND



Mercy Medical Center is an urban community hospital with an academic affiliation with the University of Maryland School of Medicine. Care for patients with HCC is coordinated through The Center for Liver and Hepatobiliary Disease at The Melissa L. Posner Institute for Digestive Health and Liver Disease. Three hepatologists serve as the primary points of contact for patients and treat about 50 to 60 patients with HCC at any given time.

Optimizing Communication and Patient Coordination Using a Multidisciplinary Conference

A multidisciplinary conference serves as the focus of treatment decision-making for the team. The conference meets once or twice a month, depending on case load, and includes hepatology, diagnostic radiology, an interventional radiologist, an interventional radiology nurse, a clinical nurse, surgical oncology, and administrative support. Mercy does not have a transplant team but uses outside partnerships to fill this gap in care. The hepatologists present a synopsis of each case for review, and each diagnostic radiologist discusses up to 10 cases per meeting. A hepatologist determines if the patient is a

good candidate for transplant and refers the case to a transplant surgeon for evaluation, which generally takes place the following week. Interventional radiologists discuss recommended liver-directed therapy options. If metastatic disease is suspected, the patient is referred to medical oncology.

While cases await multidisciplinary conference review, treatment planning continues. The team begins to develop a plan by collecting preoperative tests and scans and conducting consultations. The final treatment decisions are made during the conference review. Even if cases clearly align with a specific treatment protocol, the team prefers to review cases together before finalizing treatment decisions.

At the heart of HCC care coordination are an administrative assistant (who is also their liver transplant coordinator) and a registered nurse who manages interventional radiology patients. They work closely together to navigate patients through the process. The administrative assistant onboards patients, schedules appointments, and coordinates collection of scans and lab work. If patients are referred to interventional radiology, the nurse

coordinates appointments and provides patient and caregiver education, either for management while on the transplant waitlist or for procedures unrelated to transplant eligibility. This joint coordination and open communication allow patients to have their questions answered quickly.



“We’ve all been here a good number of years...but I think more than the length of time that we’ve been here is the dedication we have to this patient population because we

recognize that these patients are in challenging situations. And we recognize that no one person has all of the answers for these patients. So, there’s always going to be curve balls and there’s always going to be question marks – unless we all put our heads together and come up with the plan it’s not going to be easy.”

Anurag Maheshwari, MD, Transplant Hepatology Specialist, The Institute for Digestive Health and Liver Diseases, *Mercy Medical Center*

Leveraging External Resources to Provide Comprehensive Services

Patients with HCC receive comprehensive care through a combination of services provided on-site and partnerships with local healthcare facilities. Several HCC interventional radiology treatment procedures are provided on-site; however, patients are referred to Johns Hopkins Medicine or the University of Maryland Medical Center for TARE-Y90 treatment. Patients are referred to the transplant team at the University of Maryland Medical Center for evaluation and transplant and are treated at Mercy before and after transplantation. Mercy’s team is in frequent communication with their University of Maryland Medical Center counterparts. With this partnership, clear communication is vital. For

example, if the two teams have a difference of opinion on the best course of treatment, team members discuss and reach consensus so that that patients receive consistent education and information.

Increasing Access through Outreach Clinics

As with other cancers, treatment protocols for patients diagnosed with HCC encounter significant time and cost burdens. Decreasing the distance that patients are required to travel to receive treatment allows more flexibility in scheduling appointments and can improve treatment adherence. All three hepatologists see patients in offices in the Baltimore suburbs. Anurag Maheshwari, MD, also sees patients at two satellite clinics. He uses a University of Maryland Medical System clinic in Easton, Maryland and visits the Peninsula Regional Medical Center in Salisbury, Maryland every other week. These two locations offer better access to care for the rural population on the Eastern Shore, where 8 percent of the state’s population lives. Historically, local gastroenterologists have referred patients with HCC to Mercy’s hepatologists, so expansion of outreach clinics allows for greater access to comprehensive hepatology services. In addition, every two months, Peninsula Regional Medical Center holds a multidisciplinary HCC tumor board run by Dr. Maheshwari in partnership with local interventional radiology, radiation, and medical oncology providers.

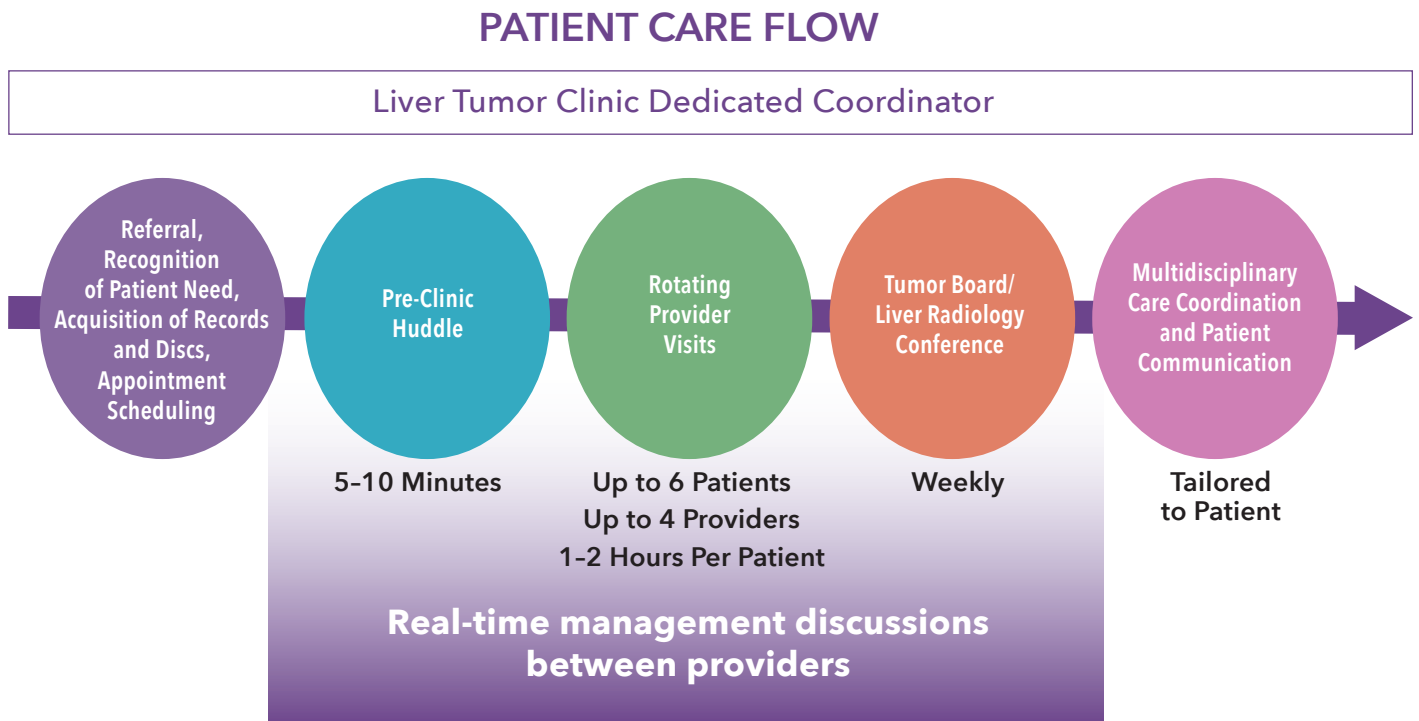
All of these outreach clinics use local labs and imaging services, but on-site imaging and lab services are available at a few of their locations. All patients can be seen at any of these locations for hepatology appointments, but the team tries to keep cancer care treatment appointments at Mercy Medical Center or the University of Maryland Medical Center. A challenge posed by using multiple facilities for imaging is that inconsistencies in imaging quality and interpretation can occur, but because all scans are reviewed in tumor board conference, patients can redo scans on-site, if necessary.

EMORY HEALTHCARE ATLANTA, GEORGIA



When the Emory Liver Tumor Clinic (LTC) launched in 2013, it focused on transplant-eligible patients with intrahepatic HCC and hilar cholangiocarcinoma. The clinic's team has since expanded to include medical oncology, and a dedicated LTC coordinator was hired; it is a joint initiative involving the Emory Transplant Center and Winship Cancer Institute of Emory University. During the clinic, the team conducts rotating visits, while the providers and LTC coordinator discuss potential options with patients and can update any scans and tests, if necessary. After clinic, patients' scans are reviewed during a weekly liver-only tumor board. Once reviews are complete, patients are contacted to discuss their recommended course of treatment.

FIGURE 4: Emory Liver Tumor Clinic Patient Care Flow



“Clustering” Care to Improve the Patient Experience

The LTC structures patient care to “cluster” or deliver a series of consultations at the same time and place. Many patients must travel from outside of the Atlanta area, so the goal of the “clustering” is to minimize the number of individual trips patients take to the hospital, which in turn minimizes the time and financial burden on patients. A patient, depending on individual need, usually sees four providers in one afternoon. Because care coordination begins prior to their first visit, it is easier for members of the multidisciplinary team to co-manage patients and arrange follow-up visits. Ultimately, having this cluster-style care model allows the hospital to accomplish three goals:

1. Improve quality and efficiency of care
2. Enhance the patient experience
3. Maintain patients within the health system.

Participation in the LTC also allows clinicians to get a better understanding of a patient’s goals of care, including preferences that could impact treatment decisions. This real-time communication between patients and members of the care team provides clarity around patients’ needs and improves shared decision-making.

With the onset of the COVID-19 pandemic, physical access restrictions, the redirecting of health system and physician resources, patients’ and/or families’ discomfort in traveling to a COVID treatment facility, and other inherent hurdles gave urgency to shift multidisciplinary care by use of telemedicine. This shift was implemented in April 2020, as patient volume has been maintained and efficiency in care has increased for patients and providers. Feedback has been overwhelmingly positive, and this model remains integrated into future/post-pandemic plans for the majority of patients.



Clustering Care Huddle

Hiring a Dedicated Clinic Coordinator

Executing a clinic model like Emory's requires close coordination between multiple specialties across multiple departments. A non-dedicated clinic coordinator who works in several areas at once may not be able to manage patients in a timely manner. In Emory's case, the LTC team made a business case to justify the addition of a dedicated clinic coordinator. Having a dedicated coordinator allows growth; the team anticipates treating 140 patients in 2020, which is about 53 percent of their available capacity. Program growth is possible due to the increased efficiency a coordinator brings to the process; when the clinic runs smoothly, the team can see more patients. The overall impact on patient care and patient outcomes are the most important justifications for hiring a dedicated clinic coordinator. Of note, the business case regarding downstream revenue to the hospital was key to showing ROI (return on investment) and gaining administrative buy-in.

Including Medical Oncology in the Clinic

Medical oncology was added to the LTC in July 2019. Even if a patient is eligible for a liver transplant, surgery, or liver-directed therapy, treatment may not be successful or there may be recurrence. By seeing a medical oncologist early in their treatment journey, patients do not need referrals from a hepatologist if their disease spreads and requires medical oncology. This can decrease or even eliminate delays in care. In addition, post-operative treatment or clinical trial options or treatments may be available to downstage tumors that would make a patient eligible for transplant. Having medical oncology represented in a clinic is important because it provides patients access to clinical trials they may otherwise not have. Since more than 50 percent of patients with HCC present with late stage disease, including medical oncology on the team allows the cancer program to serve all patients.



"There is a tremendous benefit in seeing a medical oncologist, even in early stage disease. There are clinical trial options, including post-operative therapies, that would be

worth discussing. This gives another option for patients in early stage treatment."

Mehmet Akce, MD, Medical Oncologist,
Winship Cancer Institute of Emory University

Making the Business Case for a Liver Tumor Clinic

To make the case to administration for support of a liver tumor clinic, the Emory team outlined the following goals:

1. Improve quality of care: While multidisciplinary care for hepatocellular carcinoma was fairly new in 2013, multidisciplinary clinic models in other cancers had proven to have a positive impact on care and patient outcomes. The team could look at metrics and show related outcomes.

2. Enhance the patient experience: There is a robust body of literature and evidence showing how well-designed multidisciplinary clinical care can positively impact the experience of patients, as well as outcomes. If patients must travel a distance to receive care, creating a "one-stop shop," as well as facilitating follow up and referral needs may be key to increasing satisfaction and decreasing the burden of care.

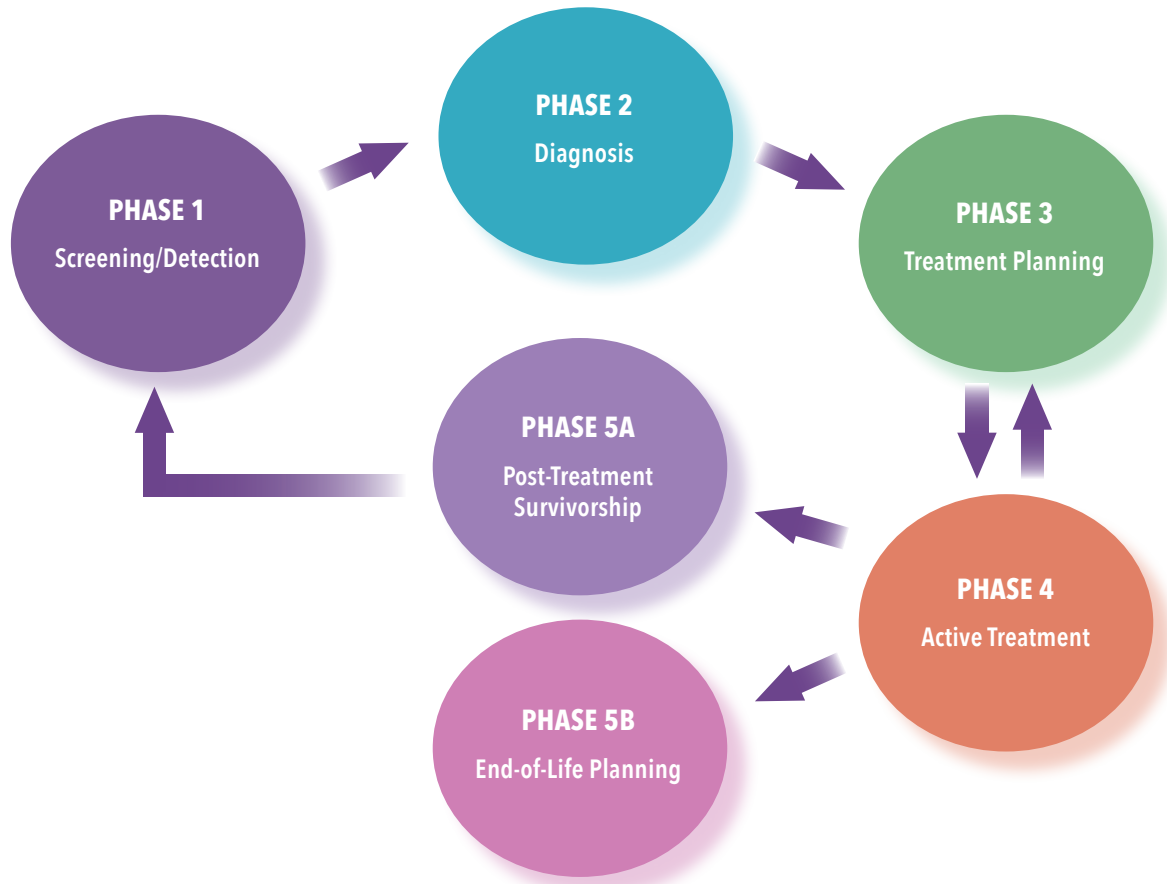
3. Maintain patients within the health system: With a liver tumor clinic, there is opportunity to retain patients within the Emory health system. It is easy to document patients who are seen within Emory's health system via separate specialties and those who stayed within the health system, compared to the number of patients who go back to their community for treatment. The team was able to show administration that they could capture more of the population who might not have previously stayed within the system for treatment.

IMPROVING HCC CARE COORDINATION AND PATIENT-CENTERED COMMUNICATION

As seen throughout the narratives on the three highlighted cancer programs, coordination and communication are integral to the multidisciplinary management of HCC and improving patient-centered care, regardless of the treatment setting. Along the HCC care continuum (Figure 5, below),

cancer programs can take steps to improve care coordination and patient-centered communication, which will help cancer programs address disparities in access to care. These steps (tips) are outlined on pages 16-18.

FIGURE 5. HCC Care Continuum



Improving Care Coordination and Patient-Centered Communication in HCC Treatment

HCC CARE CONTINUUM PHASE 1: Screening/Detection

Care Team Coordination Tips

- Educate PCPs about risk factors for HCC. PCPs may not know their patients have viral hepatitis, cirrhosis, or NASH.
- Work with PCPs and GI specialists to ensure appropriate screening for high-risk patients and referral for suspected HCC. Consider adding an EHR reminder for HCC screening in patients with a cirrhosis or Hepatitis B diagnosis.

Patient-Centered Communication Tips

- Target high-risk populations to increase the understanding of HCC risk, treatment options, and the importance of screening adherence. Patients need to understand that there are treatment options if they are diagnosed. Patients may not talk to their doctor about risk if they do not think it matters.

Improving Care Coordination and Patient-Centered Communication in HCC Treatment (continued)

HCC CARE CONTINUUM PHASE 2: Diagnosis

Care Team Coordination Tips

- Establish a point of contact. In the absence of a formal HCC clinic, an HCC coordinator can help streamline communication among the care team, the patient, and their caregivers (and even referring providers) about the evaluation process. This could be a part-time position or a coordinator or navigator who covers multiple disease types.
- Develop communication pathways for multi-disciplinary care. These pathways will improve standardization, minimize redundancy, and ensure appropriate evaluation.

Patient-Centered Communication Tips

- Tailor communication to address health literacy and be culturally appropriate. HCC is a complex condition often accompanied by other conditions. Consider what treatment team member should be communicating the diagnosis and treatment to patients and how to communicate effectively.
- Create a process for patient evaluation that minimizes burden for the patient, (i.e., clustered appointments to limit the number of times a patient must visit the cancer center).

HCC CARE CONTINUUM PHASE 3: Treatment Planning

Care Team Coordination Tips

- Identify the members of the HCC treatment team. Even if medical oncology does not specialize in HCC, identify a physician champion who can focus on the research and treatment guidelines for treating this disease site.
- Where treatment expertise gaps exist, identify partnership opportunities with external experts and/or programs. Such partnerships help ensure patient access to liver transplant services and resources.
- Establish a process for communication about patient cases across care providers. Schedule these communications (in person or by email) regularly. Document communication in an EHR when possible.
- Consider clinical trial participation. Identify a treatment team member who can help identify patients who may benefit from a clinical trial and match them with available clinical trials.

Patient-Centered Communication Tips

- Implement patient-centered decision-making that seeks to understand patient priorities, values, and preferences. When discussing treatment for all stages of disease, include discussion of treatment goals early and often.
- Employ comprehensive geriatric assessment when appropriate.
- Engage a financial advocate or navigator and screen for financial toxicity. Identifying financial needs and available resources may impact the type or order of treatment(s).
- Find ways to support and encourage family members and other caregivers, especially when a patient with HCC is very sick. Address co-morbidities and behavior issues that may impact disease and progression.

Improving Care Coordination and Patient-Centered Communication in HCC Treatment (continued)

HCC CARE CONTINUUM PHASE 4: Active Treatment

Care Team Coordination Tips

- To help ensure patient access to care close to home, consider transferring care to a local oncologist when appropriate.
- For patients on a transplant wait list, effective disease management will require close coordination between hepatology, transplant surgery, and interventional radiology.
- For patients not on a transplant waitlist but who have loco-regional disease, effective disease management will require close coordination between surgical oncology, hepatology, and interventional radiology.

Patient-Centered Communication Tips

- Including care team members like social work, nutrition, financial navigation, and other psychosocial support is critical to ensure patients have adequate support. Palliative care is an important but often underused resource.
- Engage family members and caregivers to support adherence to treatment.

HCC CARE CONTINUUM PHASE 5A: Post-Treatment Survivorship

Care Team Coordination Tips

- Ensure proper documentation of a survivorship care plan. This should include post-treatment monitoring, surveillance recommendations, and coordination of follow-up care and appointments.

Patient-Centered Communication Tips

- Support behavioral modifications that can maintain health and quality of life, including support for addiction, weight loss or management, and nutrition needs.
- Ensure patients have adequate support for care transitions as appropriate.

HCC CARE CONTINUUM PHASE 5B: End-of-Life Planning

Care Team Coordination Tips

- Engage palliative care, social work, and psychosocial support if not already engaged.

Patient-Centered Communication Tips

- Implement patient-centered decision-making. Focus on patients' goals and values, and engage members of the multidisciplinary care team to help meet those goals and address those values.

CALL TO ACTION

Sharp HealthCare, Mercy Medical Center, and Emory Healthcare illustrate three diverse approaches to providing multidisciplinary care to patients with HCC. In all three models, hepatology and interventional radiology form the clinical focus, but comprehensive care also requires the close coordination of additional HCC specialists, coordinators, and supportive care staff. Partnerships with external experts, programs, and/or resources can fill gaps in care, which has been shown to be effective in the cases of Sharp HealthCare and Mercy Medical Center.

While there are effective practices that can be applied across a range of settings to provide comprehensive HCC care, the ACCC Liver Cancer Heatmap (page 8) indicates that there is room for improvement in ensuring that high quality care is accessible regardless of one's location. Developing a liver tumor clinic, whether it be within a single facility or across multiple facilities, may help decrease time-to-treatment and increase appropriate care referral. For programs where the volume of HCC cases is low, it may not be feasible to build a specialty

clinic, but the route to decreasing HCC mortality is through creative partnerships, which can be across cancer programs or with private practices. As HCC incidence continues to increase, laying a strong foundation of collaboration will help ensure access to quality care for all.

HCC is a difficult disease to manage because of the multiple components of care required. It's difficult to do it all by yourself, especially if your focus is not primarily dedicated toward liver disease. I would recommend partnering with a hepatologist or somebody with dedicated expertise in liver disease management. Having a hepatologist as a partner is going to be invaluable to being able to develop effective treatments and therapy options for these patients."

Anurag Maheshwari, MD, Transplant Hepatology Specialist, The Institute for Digestive Health and Liver Diseases, *Mercy Medical Center*

REFERENCES

1. Mazzanti R, Arena U, Tassi R. Hepatocellular carcinoma: where are we? *World J Exp Med.* 2016;6(1):21-36.
2. National Cancer Institute: Surveillance, Epidemiology, and End Results (SEER) Program. Cancer stat facts: liver and intrahepatic bile duct cancer. Available online at: <https://seer.cancer.gov/statfacts/html/livibd.html>. Last accessed July 16, 2020.
3. American Cancer Society. Cancer facts and figures: 2020. Available online at: <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf>. Last accessed: October 6, 2020.
4. Harlan LC, Parsons HM, Wiggins CL, Stevens JL, et al. Treatment of hepatocellular carcinoma in the community: disparities in standard therapy. *Liver Cancer.* 2015;4(1):70-83.
5. Orman ES, Roberts A, Ghabril M, Nephew L, et al. Trends in characteristics, mortality, and other outcomes of patients with newly diagnosed cirrhosis. *JAMA Netw Open.* 2019;2(6):e196412.
6. Zhang J, Mavros MN, Cosgrove D, Hirose K, et al. Impact of a single-day multidisciplinary clinic on the management of patients with liver tumours. *Curr Oncol.* 2013;20(2):e123-31.
7. Sinn DH, Choi GS, Park HC, Kim JM, et al. Multidisciplinary approach is associated with improved survival of hepatocellular carcinoma patients. *PLoS One.* 2019;14(1):e0210730.
8. Association of Community Cancer Centers. Multidisciplinary hepatocellular carcinoma care environmental scan. Available online at: <https://www.accc-cancer.org/projects/hcc/overview>. Last accessed October 6, 2020.
9. Kwong A, Kim WR, Lake JR, Smith JM, et al. OPTN/SRTR 2018 annual data report: liver. *Am J Transplant.* 2020;20:193-299.
10. National Comprehensive Cancer Network. NCCN guidelines: hepatobiliary cancers (Version 5.2020). Available online at: https://www.nccn.org/professionals/physician_gls/pdf/hepatobiliary.pdf. Last accessed October 6, 2020.
11. Eguchi S, Kanematsu T, Arii S, Omata M, et al. Recurrence-free survival more than 10 years after liver resection for hepatocellular carcinoma. *Br J Surg.* 2011;98(4):552-7.
12. Colagrande S, Inghilesi AL, Aburas S, Taliani GG, et al. Challenges of advanced hepatocellular carcinoma. *World J Gastroenterol.* 2016;22(34):7645-59.
13. Marrero JA, Kulik LM, Sirlin CB, Zhu AX, et al. Diagnosis, staging, and management of hepatocellular carcinoma: 2018 practice guidance by the American Association for the Study of Liver Diseases. *Hepatology.* 2018;68(2):723-750.
14. Franco RA, Fan Y, Jarosek S, Bae S, et al. Racial and geographic disparities in hepatocellular carcinoma outcomes. *Am J Prev Med.* 2018;55(5 Suppl 1):S40-S48.
15. Xu, Jaiquan. Trends in liver cancer mortality among adults aged 25 and over in the United States, 2000-20016. Available online at: <https://www.cdc.gov/nchs/products/databriefs/db314.htm> Last accessed July 16, 2020.
16. Pham C, Fong TL, Zhang J, Liu L. Striking racial/ethnic disparities in liver cancer incidence rates and temporal trends in California, 1988-2012. *J Natl Cancer Inst.* 2018;110(11):1259-69.

17. Centers for Disease Control and Prevention: United States Cancer Statistics. Liver cancer incidence in the American Indian and Alaska native population, United States–2012–2016 (purchased/referred care delivery areas). Available online at: <https://www.cdc.gov/cancer/uscs/about/data-briefs/no13-liver-cancer-incidence-AIAN-PRCDA-2012-2016.htm>. Last accessed July 16, 2020.
18. Wang J, Wang FW. Refusal of cancer-directed surgery strongly impairs survival of patients with localized hepatocellular carcinoma. *Int J Surg Oncol*. 2010;2010:381795.
19. Hoehn RS, Hanseman DJ, Jernigan PL, Wima K, et al. Disparities in care for patients with curable hepatocellular carcinoma. *HPB: (Oxford)*. 2015;17(9):747-52.
20. Batterham RW, Hawkins M, Collins PA, Buchbinder R, et al. Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health*. 2016;132:3-12.

ACKNOWLEDGMENTS

ACCC is grateful to the Advisory Committee, Partner Organizations, cancer program staff, and others who graciously contributed their time to this publication.

Advisory Committee

Nadine Abi-Jaoudeh, MD

Professor of Clinical Radiological Sciences; Director of Clinical Research, Radiological Sciences
University of California Irvine School of Medicine; Society of Interventional Radiology

Ivy Ahmed, MPH, MCHES

Liver Cancers Program Director
Global Liver Institute

Tiffany Brosius, RN, BSN, OCN

GI Medical Oncology Nurse Navigator
Emory Healthcare

Donna Cryer, JD

President & CEO
Global Liver Institute

Hildy Dillon, MPH

Vice President, Education & Support Programs
Cancer Support Community

Matthew Dugan, DO

Medical Oncologist
New England Cancer Specialists

Catherine Frenette, MD, FAST, AGAF, FAASLD

Medical Director of Liver Transplantation, Scripps Center for Organ Transplantation; Director, Liver and Hepatocellular Cancer Program
Scripps MD Anderson Cancer Center

Anurag Maheshwari, MD

Clinical Assistant Professor of Medicine & Medical Director for Liver Donor Liver Transplantation, *University of Maryland*; Transplant Hepatology Specialist, *The Institute for Digestive Health and Liver Diseases, Mercy Medical Center*

Philip A. Philip, MD, PhD, FRCP

Medical Oncologist, *Karmanos Cancer Center at the Detroit Medical Center*; Professor of Oncology and Pharmacy; Director, GI and Neuroendocrine Oncology, *Karmanos Cancer Institute Wayne State University*

Riad Salem, MD, MBA

Vice Chair for Image Guided Therapy; Chief of Vascular Interventional Radiology, Department of Radiology; Professor of Radiology, Medicine, and Surgery
Northwestern University Feinberg School of Medicine

Melissa Walker, RN

Research Nurse Specialist
National Cancer Institute Medical Oncology

Dawn Wiatrek, PhD

Interim Senior Vice President, Patient and Caregiver Support
American Cancer Society

Andrea Wilson Woods

President and Founder
Blue Faery: The Adrienne Wilson Liver Cancer Association

Special Recognition

Emory Healthcare**Mehmet Akce, MD**

Medical Oncologist
Winship Cancer Institute

Tiffany Brosius, BSN, RN, OCN

GI Medical Oncology Nurse Navigator

Frank Eady, LMSW

Social Worker

Bassel El-Rayes, MD

Director of the Gastrointestinal Oncology Program; Associate Director for Clinical Research
Winship Cancer Institute

Angela Majied, RN, CCRN

Liver Tumor Clinic Coordinator; Liver Transplant Coordinator

Gerarda Sanchez, PA-C

Physician Assistant, Interventional Radiology

Marty Sellers, MD, MPH

Transplant Surgeon
Emory Transplant Center

Amy Sherrod, APRN, MSN, CPHON

Director of Care Standardization and Optimization

Lana Uhrig, PhD, RN, MBA

Vice President of Cancer Nursing

Joel Wedd, MD, MPH

Director of the Liver Tumor Clinic
Emory Transplant Center

Catherine Williams

Associate Director, Communications
Winship Cancer Institute

Mercy Medical Center**Ashley Fitzpatrick**

Administrative Assistant and Liver Transplant Coordinator

Anurag Maheshwari, MD

Transplant Hepatology Specialist

Debora Phillips, RN

Interventional Radiology Nurse Coordinator

Sharp HealthCare**Jim Lyon, MD**

Interventional Radiologist

Nancy Harris, MPA

Vice President of Oncology

Association of Community Cancer Centers

Christian G. Downs, JD, MHA

Executive Director

Lorna Lucas, MSM

Director, Provider Education

Leigh Boehmer, PharmD, BCOP

Medical Director

Christina Mangir, MS

Program Manager, Provider Education

Monique J. Marino

Director, Editorial Content and Strategy

Maddelynn Parker

Content Coordinator

Consultant**Amy Copeland, MPH**



Association of Community Cancer Centers

1801 Research Boulevard, Suite 400
Rockville, MD 20850
301.984.9496
acc-cancer.org

A publication from the ACCC education program, "Multidisciplinary Hepatocellular Carcinoma Care." Learn more at acc-cancer.org/hcc.

The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit acc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, LinkedIn, and Instagram; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

© 2021. Association of Community Cancer Centers. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without written permission.

This publication is a benefit of ACCC membership.

In partnership with:



Supported by Eisai Inc.

