E-Consent

Please complete the E-Consent below.Thank you!

1) Title of Research Study: Provider Perceptions of Symptom Based Management and Palliative Care in End Stage Liver Disease

Principal Investigator: Dan Ganger, MD

Supported By: This research is supported by Northwestern's Department of General Internal Medicine and Division of Gastroenterology and Hepatology.

Conflict of Interest Disclosure:
The following disclosure is made to give you an opportunity to decide if this relationship will affect your willingness to participate in this research study: No Disclosures.

Key Information about this research study:
The following is a short summary of this study to help you decide whether to be a part of this study. Information that is more detailed is explained later on in this form. This research aims to better understand your perception and utilization of symptom based management of palliative care for patients with end-stage liver disease (ESLD). For the purpose of this study, ESLD is defined as cirrhosis and the presence of at least one of the following symptoms: ascites, hepatic encephalopathy, history of variceal hemoorhage or jaundice. You will be asked to complete a 10 minute survey. Your participation is voluntary and your answers are confidential. The primary potential risk of participating in such a research study could be the potential breach of confidentiality or privacy as particpants share personal and sensitive information about their experiences. We will ensure robust confidentiality measures and data protection protocols to mitigate this risk and safeguard the privacy of all participants. The main benefit of being in this study lies in contributing to a deeper understanding of palliative care needs in this specific patient population, potentially leading to improved support for both patients and their caregivers. This research could also enhance healthcare providers' knowledge and empathy, ultimately leading to better quality of care for those facing ESLD.
Why am I being asked to take part in this research study?
We are asking you to take part in this research study because you are 1) over the age of 18, 2) a clinician employed at Northwestern Medicine, and 3) have at least one experience providing care for a patient with end stage liver disease in the last year.

How many people will be in this study?
We expect about 50 people will be in this research study.

What should I know about participating in a research study?
Whenter or not you participate in this survey is up to you. You can choose not to take part. You can agree to take part and later change your mind. Your decision will not be held against you. You can ask all the questions you want before you decide. You do not have to answer any question you do not want to answer.

What happens if I say, "Yes, I want to be in this research"?
You will complete a 10-minute survey on an onlne

○ I Agree
○ I Disagree

platform. There will be no personal information that identifies you (such as your name) in the document, and only the research team will have acess to the document.

Will being in this study help me in any way?
We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include helping researchers better understand how providers can incorporate symptom based management and palliative care services into their provision of care for patients with ESLD.

Is there any way being in this study could be bad for me?
A possible risk for any research is that confidentiality could be compromised - that is, that people outside the study might get hold of confidential study information. We will do everything we can to minimize this risk, as described in more detail later in this form.

What happens if I do not want to be in this research, or I change my mind later?
Participation in research is voluntary. You can decide to participate or not to participate. If you do not want to be in this study or withdraw from the study at any point, your decision will not affect your relationship with Northwestern University/Northwestern Memorial Healthcare. You can leave the research at any time and it will not be held against you. If you decide to withdraw from this study, the researchers will ask you if the information already collected from you can be used.

How will the researchers protect my information?
All computers used to collect and send information collected from participants during the study or to receive or store data at Nortwestern University/Northwestern Memoral Healthcare will be password protected. Electronic information will be stored on secure dedicated servers with appropriate firewalls. The servers are scanned for viruses, and systems are in place to detect attempts at unauthorized entry. The research team will have access to passwords, will collect your de-information, and then enter this information electronically on the study server. Participant names will not be collected or displayed on any documents or data.
Who will have access to the information collected during this research study?
Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy. There are reasons why information about you may be used or seen by other people beyond the research team during or after this study. Examples include: University officials, government officials, study funders, auditors, and the Institutional Review Board may need access to the study information to make sure the study is done in a safe and appropriate manner. We will not ask you about child abuse, but if you tell us about child abuse or neglect, we may be required or permitted by law or policy to report to authorities.

How might the information collected in this study be shared in the future?
We will keep the information we collect about you during this research study for study recordkeeping and for potential use in future research projects.

De-identified data from this study may be shared with the research community, with journals in which study results are published, and with databases and data repositories used for research. We will remove or code any personal information that could directly identify you before the study data are shared. The results of this study could be shared in articles and presentations, but will not include any information that identifies you.

Will I be paid or given anything for taking part in this study?
There is no payment or reimbursement for participating in this study.

Who can I talk to?
If you have questions, concerns, or complaints, you can contact the Principal Investigator Dan Ganger, MD 312 695 4496 or d-ganger@northwestern.edu and Nivetha Saravanan, MD at nivetha.saravanan@northwestern.edu.

This research has been reviewed and approved by an Institutional Review Board ("IRB") - an IRB is a committee that protects the rights of people who participate in research studies. You may contact the IRB by phone at (312) 503-1376 or by email at irbcompliance@northwestern.edu if:
- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

If you want a copy of this consent for your records, you can print it from the screen.
If you cannot print the consent and would like a copy for your records, contact the Principal Investigator with the contact information above.

If you wish to participate, please click the "I Agree" button and you will be taken to the survey.
If you do not wish to participate in this study, please select "I Disagree" or select X in the corner of your browser.

****
****

Clinician Perceptions of Symptom Based Management and Palliative Care in End Stage Liver Disease

Study Title: Clinician Perceptions of Symptom Based Management and Palliative Care in End Stage Liver DiseaseAffiliation: Northwestern UniversityIRB Study Number: STU00221461The goal of this research study survey is to better understand your perception and utilization of palliative care services (PC) for patients with end-stage liver disease (ESLD).For the purposes of this survey, ESLD is defined as cirrhosis and the presence of at least one of the following symptoms: ascites, hepatic encephalopathy, history of variceal hemorrhage, or jaundice.We are asking you to take part in this research study because you are 1) over the age of 18, 2) a clinician employed at Northwestern Medicine, and 3) have at least one experience providing care for a patient with end stage liver disease in the last year.This survey will take about 10 minutes to complete. Your participation is voluntary and your responses are confidential. Your participation will enhance our collective understanding of provider's knowledge and empathy caring for patients with ESLD, ultimately leading to improved quality of care for patients and caregivers. Participants will not be financially compensated. We appreciate your consideration of this important study. Please complete the survey below.Thank you!Principal Investigator: Daniel Ganger, MDContact: d-ganger@northwestern.edu Additional Investigators:Amanda Cheung, MDJoshua Hauser, MDNivetha Saravanan, MD

Creating a de-identified marker involves generating an identifier that does not reveal personal information about the individual. Please enter your unique de-identified marker using the following instructions: __________________________________

Format: [First 3 letters of city of birth]_[Last 2 letters of mother's maiden name]_[Day and Month of birth]

Mother's maiden name: Smith
Date of birth: April 24, 1990
City of birth: Springfield
First 3 letters of city: "Spr"
Last 3 letters of mother's maiden name: "th"
Day and Month of birth: "2404
Putting it all together:

De-identified marker: Spr_th_2404

Which of the following best describes your primary role in the care of adult patients with end-stage liver disease (ESLD)

○ General Internal Medicine
○ Gastroenterologist / General Hepatologist
○ Transplant Hepatologist
○ Transplant Surgeon
○ Palliative Care Clinician
○ Other
○ Prefer not to answer

At which point are you involved in caring for adult patients with ESLD (choose all that apply)

☐ Pre-transplant
☐ Patients referred for liver transplant
☐ Patients listed for liver transplant
☐ Outpatient/long term follow-up after liver transplant
☐ Patients who are transplant ineligible
☐ None of the above

In your experience, end-of-life discussions with patients who have ESLD typically occur

○ Too early
○ At the right time
○ Too late
○ Almost never

Palliative care should be used for patients with (choose all that apply)	☐ Newly diagnosed ESLD ☐ ESLD and undergoing pre-transplant evaluation ☐ ESLD and active on the liver transplant list ☐ ESLD and not candidates for liver transplantation

Patient Perspectives: When patients hear the term "palliative care"

	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree
They feel scared	○	○	○	○	○
They feel abandoned	○	○	○	○	○
They feel anxious	○	○	○	○	○
They feel angry	○	○	○	○	○
They feel hopeful	○	○	○	○	○
They feel secure	○	○	○	○	○
They feel reassured	○	○	○	○	○
They feel prioritized	○	○	○	○	○

Supportive care is given to improve the quality of life of people who have an illness or disease by preventing or treating, as early as possible, the symptoms of the disease and the side effects caused by treatment of the disease. Supportive care includes physical, psychological, social, and spiritual support for patients and their families. Palliative care is a subsection of supportive care.	○ I would prefer to use the term palliative care in clinical practice ○ I would prefer to use the term supportive care in clinical practice ○ I equally prefer the term palliative care and supportive care in clinical practice ○ I have no preference between the terms supportive care and palliative care in clinical practice

Patient Perspectives: When patients hear the term "supportive care" (in lieu of "palliative care")

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
They feel scared	○	○	○	○	○
They feel abandoned	○	○	○	○	○
They feel anxious	○	○	○	○	○
They feel angry	○	○	○	○	○
They feel hopeful	○	○	○	○	○
They feel secure	○	○	○	○	○
They feel reassured	○	○	○	○	○
They feel prioritized	○	○	○	○	○

Attitudes towards Palliative Care and ESLD

	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree
Palliative care can be provided to patients with ESLD at any stage of their illness	○	○	○	○	○

A hepatologist is the best provider to deliver palliative care to patients with ESLD	○	○	○	○	○
A palliative care clinician is the best provider to deliver palliative care to patients with ESLD	○	○	○	○	○
Palliative care can be delivered in conjunction with disease-directed or curative treatments, including liver transplantation	○	○	○	○	○
Palliative care clinicians have enough understanding of ESLD to manage the physical and/or psychological symptoms of ESLD	○	○	○	○	○
Hepatologists have enough understanding of PC to manage the physical and/or psychological symptoms of ESLD	○	○	○	○	○
Patients with ESLD would benefit if palliative care were initiated earlier in the course of their illness	○	○	○	○	○
Patients with ESLD who are on the transplant list should all receive palliative care	○	○	○	○	○
The goals of transplantation and palliative care are the same	○	○	○	○	○
Patients with ESLD undergoing transplant evaluation receive lower quality of end-of-life care	○	○	○	○	○
Patients with ESLD undergoing palliative evaluation are less likely to be approved for liver transplantation	○	○	○	○	○
Patients with ESLD undergoing palliative evaluation receive lower quality disease-directed or curative treatments, including liver transplantation	○	○	○	○	○

Symptom-Based Management

	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree
I feel comfortable assessing patient and caregivers' goals and considering their needs, including psychological, physical, social, financial, and spiritual health burdens	○	○	○	○	○
I feel comfortable with symptom burden assessment and management of ESLD	○	○	○	○	○
I ask all my patients about their surrogate decision makers, (i.e. advance directive, living will, health care proxy)	○	○	○	○	○
I feel comfortable managing pain for patients with decompensated cirrhosis.	○	○	○	○	○
I understand the implications of impaired hepatic metabolism and risk of precipitating encephalopathy when choosing pharmacologic strategies for pain control for patients with ESLD.	○	○	○	○	○
Long-term abdominal drains are feasible and safe in patients for palliative management of refractory ascites.	○	○	○	○	○
Only if the patient agrees to palliative or hospice care will I consider placing long-term abdominal drains for management of refractory ascites in patients who are not candidates for liver transplantation or TIPS	○	○	○	○	○
Regardless of palliative care or hospice involvement, I consider placing long-term abdominal drains for management of refractory ascites in patients who are not candidates for liver transplantation or TIPS in all patients	○	○	○	○	○

I feel comfortable with therapies for palliative management of dyspnea in ESLD.	○	○	○	○	○
I feel comfortable with therapies for palliative management of muscle cramps in ESLD.	○	○	○	○	○
I feel comfortable with therapies for palliative management of pruritis in ESLD.	○	○	○	○	○
I feel comfortable managing hepatic encephalopathy in ESLD including medication administration, dose titration, and waxing/waning course of encephalopathy.	○	○	○	○	○
I feel comfortable evaluating sleep disturbances in ESLD and offering behavioral and pharmacologic interventions.	○	○	○	○	○
I feel comfortable screening for and managing sexual dysfunction in ESLD.	○	○	○	○	○

Possible Barriers to Palliative Care Implementation: These are the barriers most complicating palliative care implementation in ESLD

	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree
Shortage of specialty palliative care providers	○	○	○	○	○
Absence of evidence-based referral criteria	○	○	○	○	○
Lack of role clarity between specialists	○	○	○	○	○
Stigma that palliative care is synonymous with "giving up" on curative treatments	○	○	○	○	○
Lack of provider training	○	○	○	○	○
Competing demands on providers' time	○	○	○	○	○
Prognostic uncertainty	○	○	○	○	○
Unrealistic patient expectations about prognosis	○	○	○	○	○

Unrealistic caregiver expectations about prognosis or survival	○	○	○	○	○
Fear of affecting transplant candidacy	○	○	○	○	○
Cultural factors influencing perception of palliative care	○	○	○	○	○
Lack of palliative care expertise in managing the symptoms of patients with ESLD	○	○	○	○	○
Insufficient recognition of the importance of palliative care in ESLD	○	○	○	○	○

Any additional comments, suggestions, or thoughts you would like to share that are not covered on this survey with regard to palliative care and ESLD? ______________________________