

# HIV and Hepatic Failure Contents

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## Learning Objectives –

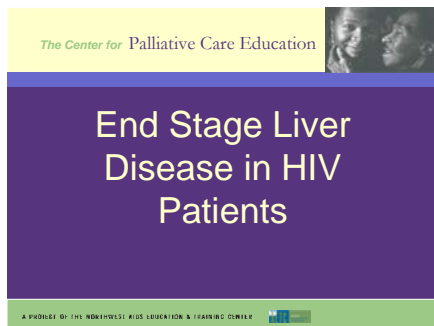
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**At the end of this presentation, participants will be able to:**

- Learn epidemiology and natural history of Hepatitis C virus (HCV)
- Understand assessment, care, and treatment options for patients co-infected with HIV and HCV
- Describe common clinical symptoms of End Stage Liver Disease
- List the Psychosocial issues that patients and care-givers may experience when dealing with End Stage Liver Disease

# End Stage Liver Disease in HIV Patients

*PowerPoint*



### Trainer Suggestion

Introduce yourself and go over the agenda for the session. If there is time in the session and a small enough group, invite participants to introduce themselves and talk about what they are hoping to learn. Invite questions and comments throughout the presentation.

### Scope of the Problem

- The introduction of highly active antiretroviral treatment (HAART) and the effective prophylaxis of opportunistic infections have led to prolonged survival in HIV-infected individuals
- As patients live longer, liver disease has emerged as the leading cause of death in patients with HIV

### Slide Note

The emphasis here should be that some HIV infected patients, namely those with HCV coinfection will live long enough to experience, and perhaps die from other illness, specifically end stage liver disease

### Common Causes of ESLD in HIV+ Patients

- Hepatitis C virus (HCV)
- Hepatitis B (HBV)
- Toxicity secondary to HAART
- Alcohol/substance abuse
- Hepatocellular Carcinoma

#### Slide Note

Coinfected patients with HIV/HCV are at significant risk of developing and dying from ESLD.

### Scope of the Problem

- Hospital admissions since 1996 as a result of chronic viral hepatitis in HIV patients has increased from 9 to 16%
- Mortality in HIV patients with ESLD has increased from 9 to 45%
- The prevalence of coinfection with HCV is greatest in areas where intravenous drug use is the most frequent risk category for HIV transmission

#### Slide Note

These statistics reinforce the fact that coinfecting patients are living long enough to develop ESLD, and that there are significant issues related to morbidity and mortality.

Clinicians working with HIV patients whose history includes intravenous drug use should be aware of, and monitor for coinfection issues.

### Hepatitis C Virus – Natural History

- HCV is an RNA virus
- There are 6 HCV genotypes and more than 50 subtypes
- Lack of vigorous T-lymphocyte response and the high propensity of the virus to mutate appear to promote a high rate of chronic infection
- HCV replicates preferentially in hepatocytes but is not directly cytopathic, leading to persistent infection

## Hepatitis C Virus - Epidemiology

- 3.9 million Americans infected with HCV, of this group, 2.7 million are estimated to have chronic infection
- Currently, approximately 35,000 new HCV infections are estimated to occur each year
  - Estimated prevalence of HCV in the United States is at least 1.8 percent of the population, making it the most common chronic blood-borne infection nationally
  - Because most persons with chronic HCV infection have yet to be diagnosed a fourfold increase in the number of adults diagnosed with chronic HCV infection is projected from 1990 to 2015

## Hepatitis C Virus - Epidemiology

- HCV transmission occurs primarily through exposure to infected blood
- High HCV seroprevalence rates (from 15 to 50 percent) have occurred in specific subpopulations, such as the homeless, incarcerated persons, injection drug users, and persons with hemophilia who were treated with clotting factors before 1992

## Hepatitis C Virus - Treatment

- All patients with chronic hepatitis C are potential candidates for antiviral therapy
- Treatment is recommended for patients with an increased risk of developing cirrhosis
- Combination therapy results in better treatment responses than monotherapy
  - Highest response rates have been achieved with pegylated interferon in combination with ribavirin
  - Trials excluded patients with decompensated cirrhosis and co morbid conditions

## HCV and HIV

- Co infection is common as both share common mode of transmission
- Progresses faster to cirrhosis than patients with HCV alone
- Risk factors associated with higher rates of progression include alcohol use, age, and CD4 counts <200
- Suppression of HIV viral load with antiretroviral therapy may decrease the rate at which liver disease progresses
- Multiple studies evaluating the effect of HCV on the natural history of HIV progression have shown conflicting results

## Scope of the Problem

- Mortality directly attributable to liver failure in coinfecting patients could be increasing for several reasons:
  - While AIDS is effectively prevented by HAART, the therapy does not appear have beneficial effects on HCV infection
  - Drugs commonly combined in HAART can lead to severe toxic hepatitis which is more common in patients with HCV
  - HAART is associated with a transient increase of HCV plasma RNA in coinfecting patients

### Slide Note

Provides an opportunity for learners to assess the role of HAART in coinfecting patients.

### Goals of Treatment for ESLD

- ESLD is life-limiting disease for which the only cure is transplantation
- The goals of treatment include
  - Slowing or reversing disease progression
  - Prevention of superimposed insults
  - Prevention and treatment of complications
  - If indicated, transplantation

### Slide Note

While there are many “titles” for hepatic disease or failure, end stage liver disease is generally the most widely accepted term.

Because of the uncertainty in prognosis, the term “end stage” can be misleading. Many people often think of end stage as impending death, whereas a person with end stage liver disease may have a prognosis of greater than one year. Consistency in the term used in an individual’s clinical practice will need to be clarified with patients and families.

Patients with HIV are not automatically excluded from transplantation. The following is a typical listing for inclusion and exclusion transplant criteria for coinfecting patients:

#### Inclusion

1. Historical documented HIV infection.
2. HIV viral load negative.
3. Limited opportunistic complications.
4. Current CD4+ T-cell count >100/ml for the past 6 months.
5. Meet standard listing criteria for placement on transplant waiting list.

6. Coinfected with chronic HCV and/or HBV.
7. History of compliance with medical protocol.

#### Exclusion

1. Ongoing opportunistic infection or cancer.
2. History of documented resistant fungal or bacterial infection.
3. Does not meet or comply with standard transplant listing criteria.
4. Ongoing substance abuse.
5. Fulminant hepatic failure.
6. History of any neoplasm except cutaneous Kaposi’s sarcoma or hepatocellular carcinoma.

### Goals of Treatment for ESLD

- Transplantation
  - Over 4,000 liver transplants per year in the U.S.
  - As of July 2003, 17,582 patients awaiting transplant
  - Only 1 in 5 patients needing a transplant get one
  - Expensive and only available to a small portion of patients that might benefit

### Slide Note

See previous slide notes for inclusion and exclusion criteria.

To date, there has been no evidence of post-transplant HIV disease progression and no adverse effect of HIV on allograft function.

Acute cellular rejection remains a concern and warrants the appropriate immune suppression protocols.

Concerns regarding poorer long-term outcomes in HCV/HIV coinfecting liver transplant recipients need to be addressed, as does the concern of poorer outcomes in the HCV-infected treatment population as a whole.

## Liver Structure and Function

- Largest organ in the human body (excluding skin)
- Comprises approximately 1/50<sup>th</sup> of the total adult body weight
- Located in the right upper quadrant extending from the diaphragm to the nipple line
- Receives approximately 25% of the cardiac output, nearly 1500 ml of blood per minute

### Slide Note

An understanding of the basic structures and functions of the liver is essential to assessing and treating the clinical manifestations of liver disease.

## Liver Structure and Function



## Liver Structure and Function

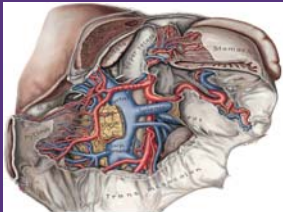
- Receives blood from two sources
  - Hepatic artery – supplies oxygen to liver and biliary system
  - Portal vein – carries blood from small intestine that contains nutrients, drugs, and poisons, prior to entering liver it receives venous drainage from the pancreas that contains insulin, glucagon, somatostatin, and pancreatic polypeptide
  - Once inside the liver it branches into specialized capillary beds that wash hepatocytes directly in portal blood
  - Rich vascularity makes liver prime site for metastatic disease

### Slide Note

The majority of clinical manifestations of liver disease are related to hepatic circulation.

An understanding of hepatic circulation is a key component of effectively managing related manifestations.

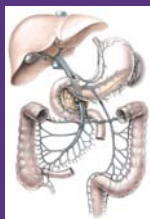
## Liver Structure and Function



## Liver Structure and Function

- Blood flow
  - Normal hydrostatic pressure of portal blood flow is low
  - Resistance to blood flow is minimal, blood passes slowly through the sinusoids to achieve maximum exchange of substances with hepatocytes
  - Changes in the unique structures cause resistant to blood flow and increase portal pressures

## Liver Structure and Function



## Assessment of Liver Function

Test	Normal Range	Value
Bilirubin Total Conjugated	5-17 µmol/L <5 µmol/L	Diagnosis of jaundice; assess severity of disease Gilbert's disease, hemolysis
Alkaline phosphatase	35-130 iu/L	Diagnosis of cholestasis, hepatic infiltrations
Aspartate transaminase (AST/SGOT)	5-40 iu/L	Early diagnosis of hepatocellular disease; follow progress
Alanine transaminase (ALT/SGPT)	5-35 iu/L	ALT relatively lower than AST in alcoholism
Albumin	35-50 g/L	Assess severity of disease
Prothrombin time (PT) (after vitamin K)	12-16 s	Assess severity of disease

### Slide Note

The results provided here are those generally accepted. Each hospital or clinic will determine their own normative values. It is important to understand those tests which assess liver function and those which assess liver damage.

## Assessment of Liver Function

- Most frequently used tests include serum aspartate transaminase (AST formerly SGOT) & Alanine transaminase (ALT formerly SGPT)
  - Both measure levels of enzymes within the hepatocytes
  - Presence in serum is an indication of liver cell necrosis, not liver function
- Tests for direct assessment of liver function include albumin, clotting factors, and bilirubin
- Advantages and disadvantages to all tests
- None should be used alone to assess liver function
- Biopsy is the only definitive diagnostic test for cirrhosis

### Slide Note

Understanding the value and importance of laboratory testing is important, but should never replace the findings from a clinical exam, which remains the hallmark of assessment and diagnosis.

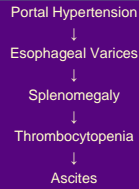
## Cirrhosis

- Clinical symptoms of hepatic failure are ultimately the result of cirrhosis
- Cirrhosis is the end result for all types of liver disease, regardless of the initial cause
- It is an irreversible inflammatory process that causes disruption to liver structures and functions
- Cirrhotic livers have a cobblestone-like appearance, and although most are shrunken, some may be larger than normal, but all are hard upon palpation

### Slide Note

Cirrhosis is a commonly used term, and one that is likely more familiar to patients and families. The public often associates this term with alcoholism, and it may therefore carry certain a stigma. Many patients may not understand end stage liver disease, whereas cirrhosis may be more common.

### Common Clinical Symptoms - Portal Hypertension



### Common Clinical Symptoms – Esophageal Varices

- Hematemesis from bleeding esophageal varices is the most common clinical manifestation of portal hypertension
- Initial symptoms vary from patient to patient
- In slow bleeding intestines may be full of blood for several days before melena occurs
- Patients with slow chronic bleed are likely to be anemic as evidenced by low hematocrit, and may experience physical symptoms such as fatigue, shortness of breath, activity intolerance, pale in color

#### Slide Note

While a common clinical manifestations of ESLD, other causes such as ulcers should also be considered.

Common cause of hospitalization, and for many patients may be the first clinical manifestation of liver disease.

### Common Clinical Symptoms - Esophageal Varices

- Anemia also decreases hepatic oxygen supply causing damage to hepatocytes
- Rupture of large varices produce voluminous vomiting of dark-red blood
- Damage to the liver secondary to decrease arterial blood flow which decreases secondary to hypotension
- Bleeding also causes an increase in intestinal nitrogen absorption that can lead to hepatic coma

#### Slide Note

Depending on the nature of the bleed (slow rectal, versus ruptured varices), this can be a very traumatic and frightening experience for patients and families.

For those at risk, ongoing teaching for patients and families on what might occur is essential.

For patients with advanced ESLD and receiving hospice care in the outpatient setting, hospitalization may be required if the family is unable to cope with the active bleeding.

### Common Clinical Symptoms - Esophageal Varices

- Approximately 65% of patients with varices do not bleed in the initial two years following diagnosis, of those that do, 50% die within 6 weeks
- Overall prognosis for patients with esophageal varices is determined by extent of hepatic failure
- Severe esophageal varices in conjunction with jaundice, ascites, and encephalopathy has an 80% mortality rate
  - One year survival rate is approximately 30%
  - Alcoholics have a worse prognosis

### Slide Note

Discussion of prognosis with patients and families should occur at time of diagnosis, but if it has not, it should occur at this point in the disease trajectory.

Clinicians are often consumed with the management of portal hypertension and fail to discuss what the evidence suggests in terms of prognosis.

### Common Clinical Symptoms - Portal Hypertension Treatment

- All treatment is palliative
- Goals of care are based on patient preference, prognosis, and the benefits and burdens of providing or not providing a treatment
- At all times the goal of treatment is to prevent bleeding through reduction of portal pressure

### Slide Note

All treatments are determined by the patient's prognosis and goals of care.

### Common Clinical Symptoms - Portal Hypertension Treatment

- In approximately 20 – 50% of patients, use of a non-selective  $\beta$ -blocker such as propranolol reduces portal pressure via splanchnic vasoconstriction, and reduction of cardiac output
- Many patients early in their disease will seek aggressive interventions for management of variceal bleeding, for these patients the goals are control of bleeding, hemodynamic stability, prevention of infection, and hepatic encephalopathy

### Common Clinical Symptoms – Management of Variceal Bleeding

- Acute management of variceal bleeding includes
  - Correction of any coagulopathy
  - Replacement of blood products
  - Maintain hemodynamic stability
  - Vasoconstricting drugs
  - Use of Sengstaken-Blakemore tube if indicated
  - Endoscopic intervention

### Slide Note

Again, it is important to have completed advance care planning with patients and families prior to this crisis event.

If advance care planning has not occurred, discussion surrounding goals of care should include current prognosis, what is important to the patient and gives their life meaning, and the extent that current available treatments can assist them with achieving their goals.

There are times when bleeding may be the final event and the goals of care are for a comfortable and peaceful death.

### Common Clinical Symptoms - Portal Hypertension Treatment

- Emergency alternative to sclerotherapy is endoscopic variceal ligation, or banding
- Banding is the preferred treatment for varices that are "spurting" blood, and is less likely to cause aspiration pneumonia or esophageal ulcers
- Other procedures aimed at reducing portal venous pressure, maintaining total hepatic and portal blood flow, and not causing hepatic encephalopathy include surgical creation of portal-systemic shunts and transjugular intrahepatic portosystemic shunt (TIPS)

### Common Clinical Symptoms - Portal Hypertension Treatment

- TIPS is typically performed after other treatments have failed, is the placement of a stent between the intra-hepatic branch of the portal vein and the hepatic vein radical
- 63% experience shunt stenosis within 6 months, 90% within 2 years
- Likely that none of the above treatments will be effective in decreasing portal hypertension for patients at the end of their disease trajectory

### Slide Note

Patients undergoing TIPS should have a thorough informed consent process, especially as it pertains to failure and success rates over time.

### Common Clinical Symptoms – Ascites Assessment

- As with other symptoms associated with hepatic failure, ascites can present with varying degrees of severity, e.g., suddenly or over a period of months
- Patients with fully compensated portal hypertension do not experience ascites, as the amount of fluid accumulated does not exceed the peritoneal lymphatic drainage system's 1200 ml/day capacity
- At the other end of the spectrum are patients that develop hepatorenal syndrome that experience massive ascites and die from rapid onset of renal failure

#### Slide Note

Common symptom associated with ESLD.

### Common Clinical Symptoms – Ascites Assessment

- Two general classes of ascites
  - Exudative (malignant) ascites is when the abdominal cavity is secreting fluid into the abdomen as part of a malignant process
  - Transudative ascites occurs in cirrhosis and CHF and is related to the hemodynamic changes that occur with progressive cirrhosis

#### Slide Note

Patients with ascites are often not seen until their symptoms are severe enough to bring them in for treatment.

Ascites, like other clinical manifestations of ESLD can have a significant impact on quality of life.

### Common Clinical Symptoms – Ascites Assessment

- Edema is primarily the result of low protein, but can also be caused by pressure on the inferior vena cava inhibiting blood return
- Patients are often dehydrated, have a decreased urine output that is highly pigmented, high in osmolarity, and low in sodium
- Patients will have significant muscle wasting, thin extremities, with abnormally large abdomen with visible dilated veins

#### Slide Note

Accurate assessment is essential to effective management of symptoms.

### Common Clinical Symptoms – Ascites Assessment

- Distention is caused by both fluid and air in the dilated intestines
- Earliest signs of ascites (dullness with percussion) are not present until approximately 2 liters of fluid has accumulated
- Other clinical findings include pleural effusions (5-10% of patients, 85% on the right side), that are the result of a defective diaphragm that allows ascetic fluid to pass into the pleural cavity

### Common Clinical Symptoms – Ascites Assessment

- Distended neck veins are the result of an increase in right atrial pressure and intra-pleural pressure secondary to a raised diaphragm
- Infection of the ascetic fluid (peritonitis) may occur spontaneously or as the result of a paracentesis (8% of patients with ascites develop spontaneous peritonitis)

### Common Clinical Symptoms – Ascites Prognosis

- Prognosis is extremely poor
- Approximately 60% of patients with cirrhosis that develop ascites die within 24 months
- Patients with ascites, jaundice, and encephalopathy have the poorest prognosis
- Even if ascites can be controlled (which enhances comfort), patients are still likely to die from other complications

### Slide Note

Because of the common nature of ascites, providers often fail to discuss prognosis with patients.

Prognosis discussion is more important in the presence of other clinical manifestations such as jaundice and encephalopathy.

### Common Clinical Symptoms – Ascites Treatment

- Indications for treatment include ascites that produces clinical symptoms, ascites where the underlying cause is unknown regardless of if symptoms are present, and tense ascites (ascites that causes severe pain)
- Primary goal of treatment is reduction of clinical symptoms and prevention of complications thereby increasing comfort

#### Slide Note

All treatments are palliative, and aggressive management of symptoms is crucial to enhancing quality of life.

### Common Clinical Symptoms – Ascites Treatment

- Treatment options that are based on prognosis and goals of care may include
  - Sodium restriction to 2 g per day
  - Administration of potassium-sparing diuretics such as spironolactone (max daily dose is 400 mg)
  - Paracentesis
  - TIPS
  - Prophylaxis for SBP if indicated

#### Slide Note

As with any treatment options, prognosis, goals of care, and the benefits/ burdens of any treatment and how it supports the patient's goals must be addressed, often more than once.

### Common Clinical Symptoms – Ascites Treatment

- Some patients may require stronger diuretics such as furosemide (max daily dose 160 mg)
- Randomized clinical trials indicate that paracentesis is the treatment of choice, with diuretics being given to prevent recurrence
- Administration of albumin may be appropriate
- Large volume paracentesis without the use of plasma expanders can cause derangement of circulatory function

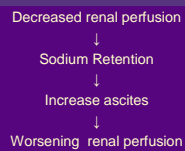
### Common Clinical Symptoms – Hepatorenal Syndrome Assessment

- Considered a late complication of ESLD seen in patients with cirrhosis and ascites
- Defined as the development of acute renal failure in patients with advanced liver disease
- Diagnosis is one of exclusion and results from a decrease in renal perfusion secondary to hemodynamic changes caused by cirrhosis
- Diagnostic criteria include serum creatinine of  $> 1.5$  mg/dl or 24 hour creatinine clearance of  $< 40$  ml/min; absence of shock, ongoing bacterial infection, and fluid loss; and no current treatment with nephrotoxic medications

### Slide Note

This is a diagnosis of exclusion, which requires complete assessment for other potential reversible causes of renal failure.

### Common Clinical Symptoms – Hepatorenal Syndrome Assessment



### Common Clinical Symptoms – Hepatorenal Syndrome Assessment

- Diagnosis of exclusion
- Should be suspected in patients that develop:
  - Oliguria
  - Benign urinary sediment
  - Decreased rate of sodium excretion
  - An increase in plasma creatinine

#### Common Clinical Symptoms – Hepatorenal Syndrome Prognosis

- Approximately 10% of patients with cirrhosis, ascites, and normal renal function develop the syndrome after one year
- Median prognosis after diagnosis is 2 weeks, with the end stage lasting from several days to 6 weeks
- Because of short prognosis, transplant is not an option for the overwhelming majority
- Dopamine and prostaglandins are not effective

#### Slide Note

Poor prognosis overall, especially in the presence of other clinical manifestations.

Frank discussions with patients and families regarding potential treatment outcomes, benefits versus burdens, and goals of care are essential.

#### Common Clinical Symptoms – Hepatorenal Syndrome Treatment

- Approximately two thirds of patients respond to vasoactive drugs used in combination with albumin
- Octreotide administered alone is not effective, but has been reported to be of some benefit when used in conjunction with midodrine
- It is not uncommon for families to inquire about hemodialysis; however, it should not be routinely used as it has not been shown to improve outcomes

#### Slide Note

Unless the patient is on the transplant list, hemodialysis has not been shown to improve outcomes. Clinicians will need to provide families with ongoing support and education regarding the poor prognosis, as well as benefits and burdens.

#### Common Clinical Symptoms – Hepatic Encephalopathy Assessment

- Hepatic encephalopathy is a syndrome observed in patients with cirrhosis of the liver, characterized by:
  - Personality changes
  - Intellectual impairment
  - Depressed level of consciousness

### Common Clinical Symptoms – Hepatic Encephalopathy Assessment

- Other common findings include:
  - Inability to draw concentric circles or five pointed stars
  - Speech is often slow, slurred, monotonous
  - Some patients experiencing fetor hepaticus (odd, sweet smell on breath)
  - Asterixis, or any sustained contraction are classic diagnostic signs that reflect decreased afferent input into the RAS
  - Ultimately decerebrate posturing

### Slide Note

Common clinical manifestation.  
Distressing to patients and families.

### Common Clinical Symptoms – Hepatic Encephalopathy Prognosis

- Prognosis is determined by the magnitude of liver failure
- Patients with jaundice, encephalopathy, and low serum albumin have the poorest prognosis
- Approximately 58% of patients die within 1 year of initial episode of encephalopathy, 67% within 3 years

### Slide Note

Because encephalopathy can be effectively managed, clinicians often fail to discuss prognosis and goals of care with patients. Encephalopathy can often cause a patient to lose decision-making capacity, at least temporarily. For this reason it is critical to complete advance care planning with patients. This includes determining a healthcare proxy, making sure that proxy understands the patient's wishes and agrees to honor them, completing a living will, or at the very least documenting the patient's wishes in the medical record.

### Common Clinical Symptoms – Hepatic Encephalopathy Treatment

- Correction of fluid and electrolyte imbalances, reduction of ammonia levels, and stopping depressant medications metabolized by the liver are the first steps in treatment
- Treatment follows a stepwise approach that is dependent on clinical picture

Common Clinical Symptoms – Hepatic  
Encephalopathy Treatment

- Step 1 requires attempts to identify the precipitating cause – three most common include azotemia secondary to aggressive diuresis, and/or persistent vomiting or diarrhea; overuse of tranquilizers, sedatives, or analgesics; and GI bleeding, other causes include increased dietary protein intake, alkalosis, infection and hypokalemia

**Slide Note**

A stepwise approach can provide clinicians with a systematic approach to effectively managing encephalopathy.

Common Clinical Symptoms – Hepatic  
Encephalopathy Treatment

- Step II requires interventions to reduce the production and absorption of gut-mediated ammonia and other toxins which is accomplished through reduction and modification of dietary protein, altering the enteric bacteria and the colonic environment through the use of antibiotics and lactulose

Common Clinical Symptoms – Hepatic  
Encephalopathy Treatment

- Step III requires the use of agents such as bromocriptine and flumazenil that directly modify neurotransmitter balance, currently these therapies are not widely used, and have not been shown to be highly effective

**Slide Note**

Step III requires further clinical research.

#### Common Clinical Symptoms – Coagulopathy Assessment

- Clinical assessment includes laboratory findings and thorough physical examination to assess for obvious signs of bleeding
- Can exist in the presence of a normal prothrombin time (PT), international normalized ratio (INR) is a more accurate test
- Decreased platelet count can also be evidence of coagulopathy and is most often caused by splenomegaly

#### Slide Note

Coagulopathy can be the most difficult complication of ESLD to manage.

Like gastrointestinal bleeding, bleeding from coagulopathy can be very distressing to patients, families, and clinicians.

#### Common Clinical Symptoms – Coagulopathy Treatment

- Early treatments can include administration of vitamin K, FFP, platelets, and in some patients the administration of desmopressin, a vasopressin analogue that causes a temporary shortening of bleeding time
- Difficult, if not impossible to correct in patients with advanced disease

#### Slide Note

The difficulty in correcting coagulopathy in advanced disease requires ongoing education of patients and families.

The continuous administration of blood products may not be the most appropriate course of treatment, and stopping this level of treatment may be interpreted by patients and families as abandonment.

#### Psychosocial Issues

- Diagnosis often accompanies multiple emotional issues as it impacts physical and psychological well-being, happiness, and overall ability to function
- Studies that specifically examined quality of life for patients with ESLD found that patients reported having a poor quality of life
- Relationships with significant others are strained, and caregivers reported high levels of anxiety

#### Slide Note

For the majority of patients with HIV, the introduction of HAART changed the disease from terminal to chronic.

For the coinfecting patient, HAART allows many patients to live long enough to die of ESLD. The majority of patients and families do not understand the poor outcomes of advanced liver disease.

Surviving HIV only to have progressive liver disease can cause a variety of physical, emotional, and spiritual problems.

Research specifically addressing the psychosocial issues related to coinfecting patients dying from liver disease is lacking.

The literature related to quality of life for the general ESLD population finds that both they and their families report a poor quality of life. The presence of HIV could potentially complicate this issue even further.

## Psychosocial Issues

- Chronic and unpredictable nature, lack of curative treatment options other than transplant, and the various physical complications all create significant emotional and financial burdens for patients and families
- Prognosis from diagnosis can range from months to years, leaving patients and families with uncertainty about the future
- Loss of health status, independence, autonomy, and financial resources contribute to grief and multiple loss issues

### Slide Note

Because the coinfecting population is more likely to either have a history, or be an active user, of intravenous drugs, they may struggle with finding meaning in their lives, illness, and impending deaths.

## Psychosocial Issues

- Many patients and families face the disappointment of not receiving a transplant after months to years on a waiting list, while others must confront the devastation that arises when a transplant fails
- Recognition of grief and loss issues, and when appropriate referrals to counseling resources should be part of the overall treatment plan

### Slide Note

Throughout the course of a patient's illness is important to assess their coping abilities, their support network, and the coping abilities of their support network.

## Implications for Practice

- The effectiveness of HAART is allowing more HIV/HCV coinfecting patients to live long enough to be diagnosed with ESLD
- The only cure for ESLD is transplant, which is not an option for many patients
- Clinicians caring for coinfecting patients must possess or obtain the knowledge and skills required to care for this population

## Contributors

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# Evaluation Forms

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We've developed some evaluation forms to use with our training modules. They consist of unique identifier information about the participant, and questions aimed at gaining information about participant satisfaction and program effectiveness. You may want to adapt these forms and questions to your own evaluation needs.

### HIV and Hepatic Failure

- ▶ [Pre-Training Survey](#)
- ▶ [Post-Training Survey](#)
- ▶ [Follow-Up Survey](#)

\* Please refer to [Evaluating Your Training Session](#) for more information.

# Pre-Training Survey

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Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date: \_\_\_/\_\_\_/\_\_\_      ID: Birth month: \_\_\_ Day: \_\_\_ Last 4 digits of SSN: \_\_\_\_\_

**1. Please rank your current level of skill in working with patients with HIV and hepatitis, by checking one of the following numbers from 1 to 5:**

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. Please rank your current level of comfort in working with patients with HIV and hepatitis:**

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# HIV and Hepatic Failure

## Post-Training Survey

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Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can – if you’re not sure of an answer, just give it your best try.

Date: \_\_\_/\_\_\_/\_\_\_ ID: Birth month: \_\_\_ Day: \_\_\_ Last 4 digits of SSN: \_\_\_\_\_

**1. Please respond to the following questions using the scale below:**

	Not at all		Somewhat		Very much
Did the training hold your interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you learn things in the training that will be useful for your work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How easy-to-understand was the information presented to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were the educational materials, such as slides or handouts, useful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How responsive was the trainer to the audience’s questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel the trainer’s presentation was culturally sensitive?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. What were the strengths of this presentation?**

**3. How could we improve this presentation?**

**4. Would you recommend this training to someone else? Yes  No**

**5. Please rank your current level of skill in working with patients with HIV and hepatitis, by checking one of the following numbers from 1 to 5:**

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**6. Please rank your current level of comfort in working with patients with HIV and hepatitis:**

Extremely uncomfortable			Somewhat comfortable			Extremely comfortable
1	2	3	4	5		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**7. What do you anticipate doing differently in your work as a result of this training?**

**8. How much did this training help prepare you to do the following:**

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide education and training to other clinicians on end-of-life care issues?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocate for better palliative care in your workplace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other roles or activities related to palliative care: <i>(please list here)</i> ? _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. Would you be willing to be contacted in one month for a brief follow-up?** Yes  No

If yes, what is your email address? \_\_\_\_\_

**10. Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!**

## HIV and Hepatic Failure

# Follow-Up Survey

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[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on HIV and Hepatic Failure, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?
2. Please rank your current level of skill in helping patients with HIV and hepatitis:  
(1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)
3. What is your overall rating of the quality of the session?  
(1=Poor; 3=Average; 5=Excellent)
3. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

## Resources

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### **Articles**

Amanda Mocroft; Vincent Soriano; Jurgen Rockstroh; Peter Reiss; Ole Kirk; Stephane de Wit; Jose Gatell; Bonaventura Clotet; Andrew N Phillips; Jens D Lundgren. Is there evidence for an increase in the death rate from liver related disease in patients with HIV? *AIDS* 2005; 19 (18):2117-2125. [Medscape Abstract](#)

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<http://content.nejm.org/cgi/content/extract/350/16/1646>

Bustamante, J., Rimola, A., Ventura, P., Navasa, M., Cirera, I., Reggiardo, V., and Rodes, J. Prognostic significance of hepatic encephalopathy in patients with cirrhosis. *Journal of Hepatology* 1999; 30: 890-895 [PubMed Abstract](#)

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Neff, GW, Sherman, KE, Eghtesad, B. and Fung, J. Review article: current status of liver transplantation in HIV-infected patients. *Aliment Pharmacological Therapy*; 20:993-1000.

Macias, J., Melguizo, I., Fernandez-Rivera, F., Garcia-Garcia, A., Mira, J., Ramos, A, Rivera, J., Pineda, J. Mortality due to Liver Failure and Impact on Survival of Hepatitis Virus Infections in HIV-infected Patients Receiving Potent Antiretroviral Therapy. *European Journal of Clinical Microbiology Infectious Disease* 2002, 21:775-781. [PubMed Abstract](#)

Martinez-Sierra, C. et al. Progression of Chronic Hepatitis C to Liver Fibrosis and Cirrhosis in Patients Coinfected with Hepatitis C Virus and HIV. *Clinical Infectious Disease* 2003; 36; 491-8. [PubMed Abstract](#)