Palliative care: pain management and end of life assistance for HCC on cirrhosis

Friday, June 10° - 16.45-17.05

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Living and Dying Well With End-Stage Liver Disease: Time for Palliative Care?

Chronic liver disease is a major cause of mortality worldwide. Liver transplantation is only available to a subset of patients who meet strict criteria.

Once cirrhosis has developed, it is usually irreversible and can lead to liver failure.

End-stage liver disease (ESLD) is the final decompensation phase in the liver trajectory. It is characterized by episodic, acute exacerbations, often requiring hospitalization.

Life-threatening complications, such as variceal hemorrhage or hepatoma, combine with multiple debilitating symptoms, including ascites, extreme fatigue, pruritus, and cachexia.

Nursing Practice
Review
Liver disease

Nurses are increasingly likely to encounter patients with advanced liver disease and have a vital role in improving end-of-life care for this group.

LIVER DISEASE: PART 1 OF 2

Nursing care for end-stage liver disease

- Experience cognitive decline,
- Affects younger people
- Financial and social problems

Keywords: Liver disease/End-of-life care/Alcohol/Non-alcohol related steatohepatitis

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5 key points

1. Liver disease is the fifth most common cause of mortality in England and Wales.
2. The average age of death from liver disease is 59 - much younger than other causes of death nationally.
3. The most common causes of liver disease - obesity, undiagnosed viral infection with hepatitis B or C, and harmful drinking - are avoidable.
4. 70% of people with end-stage liver disease die in hospital, compared with 55% of the general population.
5. End-stage liver disease involves gradual decline, punctuated with episodes of acute deterioration and some recovery.

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Living and Dying Well With End-Stage Liver Disease: Time for Palliative Care?

- Disease-specific **prognostic tools**, such as the **Child-Pugh or Model for End-stage Liver Disease scores**, are evidence-based markers of some of the major complications of decompensated disease, and patients on the transplant waiting list also have end-stage disease.

- **Palliative care** has well-defined, supportive care goals related to optimizing quality of life and addressing information needs about the illness and prognosis alongside symptom control, psychosocial support, and spiritual care of the patient and their family.

- **Continuity of care** consistent with the patient’s wishes should then be provided through effective care planning.

- **Goals**, interventions, and plans for managing progressive deterioration or a potential episode of acute decompensation can be agreed upon with patients and families and communicated to all those providing care.
Patients with liver disease often have a fluctuating course of complications that needs a team approach to care.

Common presentations of decompensated cirrhosis are:
- Jaundice (icterus);
- Ascites;
- Hepatic encephalopathy;
- Variceal bleeding;
- Sepsis, including spontaneous bacterial peritonitis, septicaemia, chest infection, urinary tract infection;
- Lethargy or weakness;
- Anaemia and chronic gastrointestinal blood loss;
- Nausea and vomiting;
- Pruritis (itching);
- Malnutrition; and
- Peripheral muscle loss.

Complications of chronic liver disease

**Ascites** is often the earliest complication of ESLD; when present it indicates 50% 2-year mortality. *Median survival is 6 months when ascites becomes refractory.*

Most common complication of cirrhosis that leads to hospitalization

*Key transition point in disease trajectory of chronic liver disease*

**Treatment**

Second line (Refractory ascites)

Serial therapeutic paracenteses

Management of refractory ascites

*Serial paracentesis/indwelling catheters*

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Jamie Potosek, Michael Curry, Mary Buss, and Eva Chittenden: *Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation.* JOURNAL OF PALLIATIVE MEDICINE Volume 17, Number 11, 2014

Complications of chronic liver disease

- **Encephalopathy** that is severe or refractory has a 12-month average survival. In an analysis of 178 studies, 30% of ESLD patients with infections died within 30 days, another 30% within 1 year.

**FIG. 1.** Median survival in months for end-stage liver disease (ESLD) patients.26
Complications of chronic liver disease

Renal failure portends the worst outcome; hepatorenal syndrome (HRS) equals a rapid deterioration in kidney function in cirrhotic patients with ascites.

Jamie Potosek, Michael Curry, Mary Buss, and Eva Chittenden: Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation. JOURNAL OF PALLIATIVE MEDICINE Volume 17, Number 11, 2014
Editorial - Kirsty Boyd, Barbara Kimbell, Scott Murray, John Iredale: Living and dying well with end-stage liver disease: Time for palliative care?
Hepatology: 1650-165, 2012
Complications of chronic liver disease

Esophageal Variceal Bleeding
Terminal Bleed

If goals of care focused on symptom alleviation without life-prolongation
Ready availability of dark colored linens/towels
Universal precautions (gown, gloves, face/eye protection)
Suctioning equipment

- Drugs and explicit instruction on how to use them
  *Midazolam 5-10 mg SC q5 minutes PRN*
- *Opioid for pain and dyspnea* (Double the PRN dose
  SC q5-10 minutes)
Symptomatology in patients with palliative cirrhosis according to (revised) Edmonton Symptom Assessment System (ESAS)

**PAIN**

*Quite common in patients with chronic liver disease.*

Etiology:
- Inflammatory adhesions
- Liver capsular distension
- Edema
- Gastro-esophageal reflux
- Musculoskeletal pain (immobility, joints, myalgias)
Symptom Management

PAIN

ESLD patients report similar pain levels as patients with lung and colon cancer.

Physicians may be reluctant to prescribe opioids for those with a history of substance abuse.

Opioids may precipitate or worsen hepatic encephalopathy and some sources recommend against using any opioids in patients with a history of encephalopathy.

Despite these limitations, opioids may be required for management of moderate-to-severe pain particularly at the end of life.

When utilized, initiation at low doses and slow up titration of dosing is generally recommended.


Constipation is a common side effect of opioids and may exacerbate encephalopathy.

### Symptom Management

#### PAIN

**Opioids**
- **Fentanyl** pharmacokinetics/dynamics largely unaltered
- Otherwise generally longer half lives due to decreased elimination, higher bioavailability. 
  > Recommend starting at 50% dose and prolonged dosing intervals (q6h)
- Avoid **tramadol/codeine** which require liver to be converted to active form in liver
- Opioids can be problematic in a population with a high prevalence of substance abuse and are considered a risk for encephalopathy, so careful assessment followed by individualized management and regular review are needed.

**Antiemetics**
- Little or no data on half life for many commonly used antiemetics
- **Metaclopramide** reported as being safe
- Limit daily **ondansetron** to 8 mg due to reduced clearance

**Nonopioid analgesics**
- **Acetaminophen/Ibuprofen** can be used with no change. Reduce dose of naproxen/celecoxib by 50%
- There are no long-term studies of **paracetamol** use in patients with cirrhosis, but at a reduced dose, it is the safest option for mild pain.

**Diuretics**
- **Spironolactone** and **Furosemide** both have no major change in pharmacokinetics

**Sedatives**
- **Lorazepam** - no changes in the clearance/half life
- **Midazolam** – dose reduce on an individual basis
- **Diazepam** – half-life almost doubled. Use with caution
- **Clonazepam** – contraindicated in CLD
- **Oxazepam** – No change in Child A/B but caution in severe liver failure
Evoluzione dei pazienti presi in carico in Cure Palliative Domiciliari

Possibili complicanze in stadio di Cirrosi avanzata e HCC terminale
- Emorragia digestiva (rottura di varici esofagee; gastropatia congestizia, ulcera peptica)
- Ascite
- Encefalopatia epatica
- Peritonite batterica spontanea
- Sindrome Epato Renale
- Coagulopatia

Sintomi dell’HCC in fase terminale
- Astenia – malessere
- Cachessia
- Dolore
- Aumento volumetrico addome
- Ittero
- Prurito
- Sintomi di Encefalopatia epatica (flapping tremor...)
- Emorragia digestiva
It also highlighted *missed opportunities to identify* people with *advanced liver disease* and consider end-of-life care planning.

This has been reinforced by the VOICES survey of bereaved people and their experiences of a relative’s death (DH, 2012).

Survey responses in relation to *liver disease* reflected differences in care, and some respondents reported poor coordination of care.
Current evidence suggests that many people with advanced illness would choose to die at home but that the majority die in hospital...
Given the lack of a clear “terminal phase” and the difficulties of accurate prognostication at an individual level, patients who are likely to be “at risk of dying” from advanced liver disease in the next year are candidates for palliative care.

We suggest that clinical judgement informed by generic indicators, such as recurrent, unplanned hospital admissions and multimorbidity, can help trigger a review.
Typical illness trajectories for people with progressive chronic illness.

- Steady progression with a clear terminal phase, for example in cancer.

- Gradual decline punctuated with episodes of acute deterioration and some recovery, with more sudden – seemingly unexpected – death, for example in end-stage organ failure.

- Prolonged gradual decline, for example in older people who are frail or in those who have dementia.

Patient Experience of ESLD

Prognosis in ESLD is comparable to patients with other types of organ failure.

Clear guidance exists for the palliative care of non-malignant end-stage disease in the kidney, lung, and heart.

FIG. 1. Median survival in months for end-stage liver disease (ESLD) patients.⁲⁶

Jamie Potosek, Michael Curry, Mary Buss, and Eva Chittenden: Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation. JOURNAL OF PALLIATIVE MEDICINE Volume 17, Number 11, 2014

They were intended as a starting point for determining patient eligibility under the Medicare hospice benefit, with the caveat that their accuracy would need to be validated by future research.
Guide for commissioners on end of life care for adults

Issued: December 2011

NICE commissioning guide 42

www.nice.org.uk/cmg42

People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

The body of a person who has died is cared for in a culturally sensitive and dignified manner.

Families and carers of people who have died receive timely notification and certification of the death.

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.
WOULD I BE SURPRISED IF JAMES LEE DIED WITHIN THE NEXT YEAR?
1. **Surprise question**
   "Domanda sorprendente": saresti sorpreso se questo malato morisse nei prossimi 12 mesi?

2. **Patient preference**
   Paziente con malattia avanzata e presenza di alcuni indicatori generali di deterioramento delle condizioni generali, di incremento dei bisogni o scelta del malato di non essere più sottoposto a trattamenti "attivi"

3. **Clinical Indicators**
   Indicatori clinici specifici di malattia avanzata correlati ad alcune patologie (cancro, insufficienza d’organo, fragilità/demenza).
Step 1  The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient’s quality of life now and in preparation for possible further decline?

Step 2  General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as ‘core’ to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc.

PULSE ‘screening’ assessment - P (physical condition); U (upper limb function);
L (lower limb function); S (sensory);
E (environment).

Karnofksy Performance Status Score
0-100 ADL scale.

WHO/ECOG Performance Status
0-5 scale of activity.

Step 3  Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PIPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. ‘Prognosis tools can help but should not be applied blindly’
- ‘The single most important predictive factor in cancer is performance status and functional ability’ - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.
Supportive and Palliative Care Indicators Tool (SPICT™)

There are several tools health professionals can use
• to prompt discussions about end-of-life issues
• to help identify patients at risk of deteriorating and dying with specific disease profiles (SPICT).

For those with liver disease there are triggers that should prompt consideration of end-of-life discussions and planning.

• These include patients with advanced cirrhosis for whom liver transplant is contraindicated,
• Who have experienced one or more of the following complications in the last year
Supportive and Palliative Care Indicators Tool (SPICT™)

Look for clinical indicators of one or more advanced conditions.

Liver disease

Advanced cirrhosis with one or more complications in past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.
Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach.

**Background**

70% of deaths in high-income countries are caused by progressive advanced chronic conditions. Around 1-1.5% of persons suffer from advanced chronic illnesses and have life-limiting prognosis. These patients represent a specific and relevant population. The presence of advanced and progressive illnesses which determine prognosis limitations and the need of a gradual palliative care approach define the concept of first transition.

The WHO recommends promoting early identification of people with chronic conditions in all health services for timely and comprehensive palliative care provision.

The NECPAL CCOMS-ICO© tool has been developed and validated to identify these patients effectively. It has been revised by the Catalan Committee of Bioethics (Spain). According to the experience acquired, and with international cooperation, we have introduced some elements for improvement.
**RECOMMENDATIONS**
FOR THE COMPREHENSIVE
AND INTEGRATED CARE OF PERSONS
WITH ADVANCED CHRONIC
CONDITIONS AND LIFE-LIMITED
PROGNOSIS IN HEALTH AND SOCIAL
SERVICES:
**NECPAL CCOMS-ICO® 3.0 (2016)**

Xavier Gómez-Batiste, Marisa Martínez-Muñoz,
Carles Blay, Jordi Amblàs, Laura Vila, Xavier Costa,
Joan Espaullesa, Jose Espinosa

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**SPECIFIC NECPAL CRITERIA SEVERITY / PROGRESSION / AVANCED DISEASE**

| Chronic Liver Disease | • Advanced cirrhosis Child C. Refractory ascites, hepato-renal syndrom and/or upper digestive bleeding despite treatment. | • Hepatic carcinoma stage C or D |

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Gomez-Batiste%20X%20et%20al.%20NECPAL%20BMJ%20SPCare%20DEF%202012.pdf
A comprehensive assessment is needed for to ensure the right support when discharged from hospital.

The discharge plan from hospital must ensure there is a clear management plan for when the condition deteriorates; close liaison with her GP is also important.

This may be the time to consider referral to community palliative care and the long-term conditions teams.

Some hospices now offer day-case paracentesis for patients with diuretic-resistant ascite.
What Is Palliative Care?

Barriers to PC

Utilization of PC in ESLD

PC and LT: Divergent or Complementary?

Indications for PC in Patients with ESLD

Mina O. Rakoski, Michael L. Volk: Clinical Liver Disease Volume 6, issue 1, 2015, pages 19-21
“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

End-of-life issues for patients with cirrhosis are often not addressed until too late.

**TABLE 1** Potential Barriers to Utilization of PC Services

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Mechanism</th>
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<tbody>
<tr>
<td>Disease</td>
<td>Unpredictable episodes of decompensation</td>
</tr>
<tr>
<td>Patient</td>
<td>Lack of knowledge of disease severity</td>
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<tr>
<td></td>
<td>Uncertainty about prognosis</td>
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<td></td>
<td>Focus on liver-saving interventions</td>
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<tr>
<td></td>
<td>Distrust and misperception of PC (&quot;death panels&quot;)</td>
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<tr>
<td>Physician</td>
<td>Overestimation of life expectancy</td>
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<tr>
<td></td>
<td>Misperception of PC</td>
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<td></td>
<td>Discomfort with end-of-life discussions</td>
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<td></td>
<td>Poor prognosis communication with patient</td>
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<td></td>
<td>Focus on liver-saving interventions</td>
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<tr>
<td>Access</td>
<td>Confusion regarding indications for PC referral</td>
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<tr>
<td></td>
<td>Improving, but potentially inadequate, access to PC services</td>
</tr>
</tbody>
</table>
Indications for PC in Patients with ESLD

A PC referral may be helpful for any patient with a life-limiting illness who is experiencing suffering of any kind (physical, emotional, spiritual, intrafamily conflict). The following are conditions for which a PC referral for a patient with ESLD could be considered:

- Uncontrolled physical symptoms related to ESLD (e.g., pain, cramping, nausea, anorexia)
  - Patient emotional or spiritual distress (e.g., fear of dying; guilt about prior behaviors like alcohol abuse that led to ESLD)
  - Family/caregiver emotional or spiritual distress (e.g., financial distress from taking off from work to care for patient; strain associated with fluctuating mental status and unpredictable hospitalizations[15])
  - Intrafamily conflict about goals of care (e.g., patient has severe hepatic encephalopathy or is intubated and family is uncertain of patient’s desire for LT)

- Accelerating need for medical care or hospitalizations (e.g., refractory ascites requiring weekly paracenteses)
  - Medical team has declined curative or life-sustaining treatment (e.g., patient denied LT listing or removed from the transplant list)

- Patient has declined life-sustaining treatments

- Physician distress about caring for this patient (e.g., difficulty communicating a grim prognosis or lack of curative options)
Palliative care for patients with end-stage liver disease: An overview

Mean direct costs per day for palliative care (PC) patients (with any chronic condition) who were:

A - discharged alive

B - died before and after PC consultation.
Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation

Jamie Potosek, MD, Michael Curry, MD, Mary Buss, MD, and Eva Chittenden, MD

FIG. 1. Median survival in months for end-stage liver disease (ESLD) patients.

Conclusion: Tremendous opportunity exists to integrate palliative medicine into the care of these patients.
Getting it right
The new report from NHS Liver Care and the National End of Life Care Programme

1. delivering good end of life care for people with liver disease

2. suggests that a culture change is required to help healthcare professionals deal with the issue openly and pro-actively

3. ensure that patients and their families get the support they need as early as possible

4. importance of integrating active medical management with palliative and supportive care

5. allowing active treatment of medical crises while preparing the patients, those close to them and the clinical team for the possibility of death.

http://www.yhln.org.uk/data/documents/2013/NHS%20Liver%20Care,%20Getting%20it%20Right%20-%20Improving%20End%20of%20Life%20Care%20for%20People%20with%20Liver%20Disease.pdf
Recognising when it is **appropriate to introduce elements of end of life care** will vary with patient, clinician and disease factors.

A **simple tool** that can sometimes help to inform the process is the ‘**surprise question**’.

**This intuitive approach to a complex question allows integration** of specific diagnostic and prognostic indicators with co-morbidity, functional, nutritional and social factors.
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

The **concurrent care model of palliative care** is a widely accepted model for how palliative care should be delivered.

A **palliative care approach** is focused on improving the **quality of life** for a patient and often involves symptom management and communication about the disease process and overall goals of care.

Patients with life-limiting illness receiving concurrent palliative care receive **high quality communication and symptom support** simultaneous with receipt of other disease directed care.
Migliorare la consapevolezza dei medici rispetto alla loro tendenza a sovrastimare la durata di vita dei malati, specie per quanto riguarda i malati di cancro.

Migliorare le competenze dei medici nella comunicazione della prognosi, della discussione degli obiettivi di cura e della possibilità di essere assistiti in cure palliative.

Aumentare la possibilità di intervento delle cure palliative anche quando sono ancora in atto trattamenti “attivi.”

Global Atlas of Palliative Care at the End of Life

January 2014

Is palliative care cost effective? Studies have demonstrated the cost-effectiveness of hospice and palliative care services. Overall, the utilisation of both hospital-based and in-home hospice and palliative care services significantly reduced the cost of care, while providing equal if not better quality care. However, studies to date are primarily from developed countries. (See literature review in Appendix 5).
The Economist Intelligence Unit (EIU) ha pubblicato e ha messo a confronto le cure di fine vita dispensate in 80 Paesi (2015).

1^ posto
Regno Unito
Australia
Nuova Zelanda.

L'Italia è situata solo al 21° posto.

I criteri di valutazione si basano sulle politiche nazionali generali in:

- Ambito sanitario e socio sanitario,
- Integrazione delle cure palliative nel Servizio Sanitario Nazionale,
- Presenza di Hospice e Unità di Cure Palliative nel territorio nazionale
- Profondo coinvolgimento della comunità sull'argomento
- Formazione.

### Key Points in ESLD

#### At diagnosis of cirrhosis
- Timely and effective patient and family education
- Pattern of symptom progression
- Strategies for improving functional capacity
- Liver health-promotion strategies
- Initial discussion of benefits, risks, and feasibility of liver transplantation

#### Development of multimorbidities such as varices, encephalopathy, hepatocellular carcinoma, ascites, and kidney dysfunction
- Education and communication regarding advance care planning
- Formulating goals of care
- Identifying health care proxies or surrogates
- Implementing advance directives

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### Key Points in ESLD

<table>
<thead>
<tr>
<th>Disease progression</th>
<th>Palliative Care Strategies</th>
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<tbody>
<tr>
<td></td>
<td>• Continuity of care</td>
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<td></td>
<td>• Communication between inpatient and outpatient providers</td>
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<td></td>
<td>• Continuity around patient's goals of care</td>
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<td></td>
<td>• Thoughtful planning regarding interventions</td>
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<td></td>
<td>• Plans for managing progressive deterioration and episodes of acute decompensation</td>
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<tr>
<td></td>
<td>• Documentation of advance care planning and advance directives, making this information accessible to all providers, patients, and their proxies or surrogates</td>
</tr>
</tbody>
</table>
### Key Points in ESLD

<table>
<thead>
<tr>
<th>Increasing symptom burden</th>
<th>Palliative Care Strategies</th>
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<tbody>
<tr>
<td></td>
<td>ESLD-specific approaches to symptom management</td>
</tr>
<tr>
<td></td>
<td>Mild pain—limited to no more than acetaminophen 1 g daily</td>
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<td></td>
<td>Mild to severe pain—low-dose opioids;</td>
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<tr>
<td></td>
<td>Itching—rule out biliary obstruction and treat if bothersome: cholestyramine, colestipol, naloxone for medical management hydromorphone, oxycodone, or fentanyl</td>
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<tr>
<td></td>
<td>Ascites—oral diuretic therapy with/without therapeutic paracentesis with consideration of transjugular intrahepatic portosystemic shunt or indwelling catheters.</td>
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<td></td>
<td>Hepatic encephalopathy—lactulose and rifaximin to control symptoms</td>
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<td></td>
<td>Functional limitations—Involve occupational and physical therapy to maximize functional ability. Caregiver support services and groups</td>
</tr>
</tbody>
</table>
Areas for further research

The most common reasons for referral were end-of-life care and symptom management.


Introduction of palliative care for:

1. patients with ESLD
2. those awaiting transplant can be challenging.

End-of-life discussions can be difficult as patients often focus their hope on obtaining a life-saving transplant.


A strategy of providing palliative care alongside disease-directed therapy while awaiting transplant has:

1. the potential to improve QOL
2. patient satisfaction and
3. reduce hospital admissions without decreasing chances of transplantation.

Jamie Potosek, Michael Curry, Mary Buss, and Eva Chittenden: Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation. JOURNAL OF PALLIATIVE MEDICINE Volume 17, Number 11, 2014
Palliative care clinicians should aim to assist in better defining the **needs** and **expectations** of ESLD patients and assist in **development of appropriate symptom management strategies**.

Medici V, Rossaro L: The utility of the model for end-stage liver disease score: a reliable guide for liver transplant candidacy and, for select patients, simultaneous hospice referral. Liver Transpl 2008;14:1100–1106.

**Early integration of palliative care may also lead to improvement in symptoms and QOL**, and potentially improve a patient’s chance at transplantation.

Jamie Potosek, Michael Curry, Mary Buss, and Eva Chittenden: *Integration of Palliative Care in End-Stage Liver Disease and Liver Transplantation*. JOURNAL OF PALLIATIVE MEDICINE Volume 17, Number 11, 2014
La Legge n. 38
15.3.2010

E’ un provvedimento che sancisce il dovere etico di offrire al malato ed alla sua famiglia il diritto ad accedere alle cure palliative ed alla terapia del dolore. La sofferenza non è più un aspetto inevitabile di un percorso di malattia, un semplice sintomo, ma diventa una dimensione che va affrontata con competenza e per il sistema professionale diventa un obbligo occuparsi del dolore e della sofferenza.

Art. 1.
(Finalità).

1. La presente legge tutela il diritto del cittadino ad accedere alle cure palliative e alla terapia del dolore.
2. È tutelato e garantito, in particolare, l’accesso alle cure palliative e alla terapia del dolore da parte del malato, come definito dall’articolo 2, comma 1, lettera c), nell’ambito dei livelli essenziali di assistenza di cui al decreto del Presidente del Consiglio dei ministri 29 novembre 2001, pubblicato nel supplemento ordinario alla Gazzetta Ufficiale n. 3 del 2 febbraio 2002, al fine di assicurare il rispetto della dignità e dell’autonomia della persona umana, il bisogno di salute, l’equisità nell’accesso all’assistenza, la qualità delle cure e la loro appropriatezza riguardo alle specifiche esigenze, ai sensi dell’articolo 1, comma 2, del decreto legislativo 30 dicembre 1992, n. 502, e successive modificazioni.
3. Per i fini di cui ai commi 1 e 2, le strutture sanitarie che erogano cure pal-
Decreti Master
Istituzione dei cinque master universitari di formazione e qualificazione in cure palliative e terapia del dolore pubblicati.
GU n. 89 del 16 aprile 2012

Accordo Stato Regioni - 7 febbraio 2013
Conferenza Permanente per i Rapporti fra Stato Regioni e Province Autonome ha sancito l’individuazione della Disciplina “Cure Palliative” nell’Area della medicina diagnostica e dei servizi per la categoria professionale dei medici, tra le discipline nelle quali possono essere conferiti gli incarichi dirigenziali di struttura complessa nelle Aziende sanitarie.

Decreto del 28 marzo 2013
Modifica ed integrazione delle tabelle A e B di cui al decreto 30 gennaio 1998, relative ai servizi ed alle specializzazioni equipollenti” sono stati inoltre definiti i servizi e le scuole equipollenti (Ematologia, Geriatria, Malattie infettive, Medicina Interna, Neurologia, Oncologia, Pediatra, Radioterapia, Anestesiologia e Rianimazione).
GU del 22 aprile 2013
Dimensioni strutturali e di processo che caratterizzano la Rete Locale di Cure Palliative

(Redefinition standard strutturali qualitativi e quantitativi - Articolo 5, Comma 3)

Rete Locale di Cure Palliative: si intende una aggregazione funzionale ed integrata delle attività di cure palliative erogate nei diversi setting assistenziali, in un ambito territoriale definito a livello regionale, che soddisfa contemporaneamente i seguenti requisiti:

1. **Strutture organizzative** di erogazione e coordinamento della Rete locale di Cure Palliative
2. **Cure Palliative per qualunque patologia** ad andamento cronico ed evolutivo per la quale non esistono terapie o, se esse esistono, sono inadeguate o sono risultate inefficaci ai fini della stabilizzazione della malattia o di un prolungamento significativo della vita (L. 38/2010, art. 2, comma 1)
3. **Operatività di equipe multiprofessionali dedicate**, ai sensi dell’Art. 5 Comma 2
4. **Unitarietà del percorso** di cure domiciliari
5. **Continuità delle cure**
6. **Formazione continua** per gli operatori
7. **Programmi di supporto psicologico all’equipe**
8. **Misurazione della Qualità di vita**
9. **Cura attiva e globale** e salvaguardia della dignità e autonomia del malato
10. **Supporto sociale e spirituale** a malati e familiari
11. **Programmi di supporto al lutto**
12. **Dilemmi etici**
13. **Programmi di informazione** alla popolazione sulle cure palliative
14. **Programmi di valutazione** della qualità delle cure
• CC è uno strumento che coinvolge tutti i profili professionali....
Grazie ...!