

Implementation of NECPAL and Chronic Liver Disease Screening Tools in Transplant Unit

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### Abstract

**Title:** Implementing Necesidades Paliativas and Chronic Liver Disease screening within the transplant unit

**Problem & Purpose:** Liver disease is often associated with high symptom burden and long hospital course, subsequently leading to decreased quality of life. For patients considered unsuitable for transplantation, the alternative treatment options are supportive management and palliative care (PC). The most significant barrier to early PC is the failure to identify patients who may benefit. Currently, transplant health care professionals have limited PC education, as well as understanding of primary PC and PC service flow. The purpose of this quality improvement (QI) project is to identify non-transplantable liver disease patients' unidentified unmet PC needs, utilizing two validated tools (Necesidades Paliativas [Palliative. Needs]) (NECPAL) and Chronic Liver Disease Questionnaire (CLDQ), and integrate them within routine nursing care activities in the transplant unit.

**Method:** This DNP project was integrated into a Quality Improvement (QI) project guided by the MAP-IT (Mobilize-Assess-Plan-Implement-Track) QI process model. Over a 12-week period, nurses and nurse practitioners (NPs) completed the tools for every non-transplantable liver disease patient. The NECPAL screening tool was used to identify patients in need of PC, and was completed by the NPs. The CLDQ tool was completed by the bedside nurse and was used to assist with identifying symptoms and quality of life.

**Results:** A total of five nurse practitioners and ten staff nurses received education and training on the NECPAL and CLDQ tools from the DNP student project leader. Sixteen non-transplant liver disease patients ages ranging 29 to 68, median age 52, majority (69%) female participated. Percentage of patients who completed the CLDQ and reported symptoms of unmet needs an average of 80%. The most symptoms reported were abdominal bloating and discomfort, worry, and family impact. The percentage of both screening tools goal 100% average (50%, n=9) were completed by the nurses and NPs. The percentage of patients completing the NECPAL an average of 60%, indicated a need for integration of palliative care. The unintended barriers included change in medical director, nurses completing one of the two screening tools, and patients deeming non-transplantable on the transplant service admitted to other units.

**Conclusions:** Implementation of NECPAL and CLDQ tools identified multiple unmet PC needs in non-transplantable liver disease patients. Nurses and nurse practitioners voiced confidence and ease in use of the tools identifying symptoms and clinical indicators for the identification of unmet palliative care needs and to promote incorporation into routine nursing care in liver disease patients who were deemed non-transplantable.

## Introduction

The prevalence of liver cirrhosis has progressed substantially within the past 30 years and the condition accounted for more than one million deaths worldwide in 2010 (Calsina-Berna et al., 2018; Mazzerilli et al., 2018). End-stage liver disease (ESLD) accounts for almost 200,000 hospitalizations annually, hence approximately 50% of patients assessed for liver transplantation (LT) are deemed ineligible (Mazzerilli et al., 2018). Reasons for ineligibility for transplantation are often multifactorial and includes the presence of severe comorbidities, advance hepatocellular carcinoma (HCC), development of muscle wasting and functional decline, or psychosocial issues (Derck et al. 2015; Hansen et al., 2017). Additionally, those who are on the waiting list remain at risk of further decline. As the population ages, the end-of-life (EoL) care burden will increase and the current specialist-based palliative care (PC) system cannot manage all deaths; the responsibility of PC must be borne by all healthcare practitioners (HCP), particularly those in primary or direct care of the patient (Llobera et al. 2017; Walsh et al. 2015).

For patients who are considered unsuitable for transplantation, the alternative treatment options are usually supportive management and palliative care (PC; Hudson et al., 2017; Mazzerilli et al., 2018; Pai & Karvellas, 2015). However, failure to identify people who may benefit is the most significant barrier to early PC (Rush et al., 2017; Murray et al., 2017). Early identification of unmet PC needs and integration of PC needs in to routine nursing care are vital for advance care planning for patients who are awaiting transplantation (Potosek et al., 2014). In the transplant unit of the large inner-city hospital where the quality improvement (QI) project took place it was not unusual for patient's health to decline during the period before the decision about transplant eligibility was made. However, before a PC consultation was requested, often the patient's health had deteriorated, and immediate interventions had been implemented. The purpose of this QI project was to identify non-transplantable liver disease (NTLD) patients' unmet PC needs using two validated tools--Necesidades Paliativas [Palliative Needs] (NECPAL) (Appendix A) and Chronic Liver Disease Questionnaire (CLDQ) (Appendix B) tools—and to integrate findings within routine nursing care in a transplant unit of a large inner-city university hospital.

### **Literature Review**

A literature review was performed on the most common search engines, CINAHL, Pub Med, and Scopus, to evaluate current evidence-based practices and the success of other studies regarding screening tools for ESLD processes, utilizing related search terms “palliative care screening tools,” “end-stage-liver-disease,” “quality of life,” and “palliative care.” Eight studies from three hundred and two were acceptable for this project. The articles were then appraised utilizing the Johns Hopkins Research Evidence tool. The articles included systematic reviews, pre-post experimental, single descriptive or qualitative, well-designed case-control, and cohort studies (Level I-VI, rating A-B). Most of the evidence on the rating scale for quality of evidence ranged from good to high (Table 2). While most of the studies were not directly transplant-related, studies of chronic diseases or life-limiting diseases are comparable.

The early identification of a patient’s unmet PC needs is important and beneficial in the ESLD patient population. The difference between the health care services considered necessary with a specific health problem, and the actual services that the patient received, improved overall QOL (Herr et al., 2014). For example, an ESLD patient presenting with ascites or hepatic encephalopathy on this unit would require immediate medications and a paracentesis to relieve their symptoms. This would decrease the risk of decompensation secondary to an intolerable level of discomfort and the considerable suffering that is often experienced by this population.

Scholzel-Dorenbos et al. (2009) conducted a literature review to explore the interaction between unmet needs and health-related quality of life (HRQOL) in order to design a dementia-specific model for compatibility with the conceptual model of Maslow’s Hierarchy of Needs. The authors found three measurement instruments: Camberwell Assessment of Needs for the Elderly (CANE), Goal Attainment Scaling (GAS), and the Carers' Needs Assessment for Dementia (CNA-D). These tools are valid instruments utilized to assess the needs of the patient’s caregivers. They concluded that HRQOL was directly related to patient unmet PC needs that were unrecognized and not addressed by HCP and informal caregivers.

In Derck et al.'s (2015) prospective cohort study, the authors explored the association of frailty and severity of liver disease with QOL in inpatients with ESLD. Of the 487 patients who completed frailty and QOL evaluations. They found that 42.9% of patients were classified as frail due to the disease process. The authors concluded that frailty is a significant predictor of QOL and patients defined as frail, had substantially lower QOL scores than did the non-frail group. Frailty was proven in this study to be a risk factor for a variety of poor health outcomes in ESLD patients.

Hansen et al. (2017) conducted a prospective, longitudinal descriptive study of 200 patients and 200 caregivers who participated and were followed for approximately 12 months. They identified multiple trajectories of change in physical and psychological symptoms in patients with ESLD and their caregivers that would find some benefit from personalized PC interventions. The authors concluded that specific disease trajectory guides PC interventions and such care should be implemented as patients approach the EoL, before new symptoms develop with the increasing severity of the disease, focusing on both patients and their caregivers as a unit of care.

In Wang et al. (2018), a single descriptive qualitative study was conducted to evaluate a Taiwanese version-PC Screening Tool (TW-PCST) for screening inpatients for potential PC needs. Of the 31,000-patient admitted, 21,596 patients were assessed and screened in a 7-month-period, where each screening took about 4–7 min to be completed. The TW-PCST PC screening tool demonstrated positive sensitivity and specificity in the identification of inpatients with PC needs with either malignant or non-malignant diseases.

Walling et al.'s (2017) systematic review study evaluated guidelines for the medical management of ESLD/cirrhosis and associated quality indicators (QIs). The authors focused on standards for palliative aspects of care and found that early, open, and patient-specific conversation on PC led to better patient outcomes and QOL.

Finally, in a study by Glare et al. (2015), the aim was to validate a simplified method for PC screening and referral based on the existing guideline criteria. Of the 194 patients in patients that were screened, greater than 90% were already diagnosed with advanced disease. The authors

concluded that a one-step scored screening tool based on the PC guideline, is a valid method for identification of patients diagnosed with cancer who might benefit from a PC consult.

These studies all supported the practice change and were all conducted with similar patient groups as NTLD patients. Few of the studies highlighted the vulnerability and frailty of the ESLD population (Derek et al, 2015; Hansen et al.'s 2017). Yet others proved that screening tools were valid instruments to use for identification of PC needs (Scholzel-Dorenbos et al.'s 2009; Wang et al., (2018; Glare et al., 2015). Additionally, one found that open conversations with patients increase QOL (Walling et al., 2017).

### **Theoretical Framework**

Lewin's change theoretical framework fosters radical but seamless change and was appropriate to use for this project, as it minimized the disruptions to operationalized change while improving outcomes (see Figure 7). The MAP-IT (Mobilize-Assess-Plan-Implement-Track) QI process model was also utilized to guide the project (see Figure 8). The first stage of Lewin's theory is unfreezing. In this stage, members of the driving forces and restraining forces collaborated to accomplish the desired goal. This stage encompassed a change agent/leader recognizing a problem, identified the need to change, and summoned others to envision the need for such change (Shirley, 2013). Unfreezing, in this context, was the realization and creation of a sense of urgency for change that was needed. Staff education on the tools and checklist identified unmet symptoms. The overall outcomes were to make changes to professional practice and management that would benefit NTLD patients, all of which depended on staff acceptance, motivation, and support of direct management.

The second stage consists of moving or changing. The focus was centered on what was agreed upon (Christensen & Christensen, 2007). After which, a compromise was met, and preparation for moving from present reality or balance develops, which was the basis of what Lewin refers to as identifying the factors for and against change (Shirley, 2013). For this phase, it was essential to note that the use of the screening tools and a checklist was suitable to use and conventional in both inpatient and outpatient settings. This particular unit provided care for patients who were admitted from the outpatient clinic who were often too sick for transplant and/or have

multi-system organ involvement. The patients sometimes were admitted with a marked worsening of overall health secondary to exacerbation of multiple disease-related problems and other unidentifiable unmet needs. Unmet needs identified included symptoms such as pain, shortness of breath, confusion due to hepatic encephalopathy, anxiety, depression, uncertainty, fear of dying, and social issues. The overall desired outcome of this phase was to increase the staff and provider education, which became vital for proper identification of unmet needs.

The final stage was refreezing, where the proposed change was incorporated and instituted into a new equation of stabilities (Christensen & Christensen, 2007). Within this phase, evaluations of staff education, tool completion compliance, staff/patient acceptance, and use of the PC screening tools were explored. Additionally, necessary reinforcement for areas needing improvement was assessed during this phase. From this, the implementation of the new screening tool was recognized as the new way of identifying unmet needs, that produced a new equilibrium of changes within the transplant unit (Shirley, 2013). The overall outcome of this phase was to ensure sustainability. Lewin's model of change was appropriate for the integration of these screening tools, as it guided changes in the implementation screening process identified by healthcare providers and staff nurses.

### **Methods**

The site of the QI project was a large inner-city hospital. The hospital is located in the northern, mid-Atlantic region of the country, and with an occupancy of approximately 1,000 beds. The transplant program is in line with national standards and accepts patients who have the most severe liver diseases and transplant needs.

The target population was composed of two segments: (a) patient with end stage liver disease (ESLD) who were deemed non-transplantable and (b) nurses and nurse practitioners (NPs) who worked in the transplant unit at the project's site. Nurses and NPs assisted the DNP student in this project. Nurses participated by completing CLDQ tools with patients and families and NPs completed both NECPAL tools with patients and their families. Inclusion criteria for patients were that they were adults and that they had NTLD on the transplant service. Patients who previously

had liver transplantation or deferred for transplantation were excluded. All participants who were patients had been admitted to the Transplant team service at the site of the QI project.

The project leader developed an educational plan and session for the nurses and NPs and education “kickoff,” was started at the end of September. The nursing staff education session consisted of a PowerPoint presentation, handouts, and question-and-answer sessions on the screening tools and an example of scripting conversations or dialogue sample (Appendix E) to have with ESLD patients. Additionally, a NP from the PC team provided a brief education lecture on specifics of primary PC (see Figure 5). The education sessions took place in the conference room on the transplant unit for greater accessibility for the nursing staff, and it lasted for approximately one hour. Other education sessions took place at the charge nurse monthly meeting, and also during the change of shift during huddles to inform, recruit, and remind night shift nursing staff about the project. Education of the screening tools comprised of the project leader discussing each questions and check the appropriate responses with nurses. Project leader explained the listed symptoms on the CLDQ tool and how to identify and incorporate into the patients current plan of routine care on CLDQ tool only. Education for the NPs were similar, where the project leader discussed the questions and check the appropriate responses with NPs. Project leader explained the listed symptoms and clinical indicators on the NECPAL and CLDQ tools and how to identify and incorporate into the patient’s current plan of routine care. The process of identified symptoms and clinical indicators (Appendix A & B), allowed nurses and NPs to utilize their keen assessments skills to notice distressing and intolerable symptoms that could be verbal or non-verbal. The nurses made the provider aware of the findings and initiate PC into routine care. On the other hand, if the NP is completing the tool, when the tools are completed the NP informs the nurse of the findings and teach the nurse how to integrate these findings (Figure 5.) For example, if the patient is complaining of shortness of breath (SOB), then the NP would examine the patient and place an order for a paracentesis for relieve of (SOB), and instructed nurses to provide supportive care such as keeping the head of bed elevated and provide pain relief. The nurses and NPs placed completed



tools in a locked drawer on the transplant unit. The DNP leader collected tools for analysis. The results were reported to the nurse manager for QI purposes.

The project was implemented over 12 weeks from September 23, through December 15, 2019. The NPs and nurses were educated on September 23, 2019 on the screening tools (Figure 6). The transplant charge/resource nurses and transplant NPs were trained, via train-the-champion style education format to identify unmet needs. Nurses were reminded in daily huddles of eligible patients and to complete tools and placed in locked drawer on the unit within the first 1-2 weeks of October of the project. In the weeks of October 2019, the standard practice of the unit was followed in holding weekly listing meetings during which the decision to deem ESLD patients ineligible for transplantation (or the deferral of the decision) was made. Once patients were deemed non-transplantable, the charge nurse was made aware.

The nurses and NPs completed the screening tools within 72 hours of being informed of NTLD status and they integrated the findings of unmet needs by providing symptom management. This included improvement of pain, abdominal discomfort, anxiety and depression with medications and ensure procedures ordered were completed. implemented into daily routine nursing care. The NECPAL screening tool (Appendix A) was used to identify patients in need of PC (Gomez et al., 2017). The Chronic Liver Disease Questionnaire (CLDQ) (Appendix B) was used to identify symptoms (Younussi et al., 1999, 2015). The NECPAL screening tool included four main questions: a surprise question (SQ)—an intuitive question integrating comorbidity; a choice/need question--for PC treatments; a general clinical indicator of severity, and clinical progression question; and a specific clinical indicators of severity and progression per diseases. The CLDQ tool was a questionnaire specific to the liver disease population and was used to evaluate the impact of chronic liver diseases on QOL; it included 29 questions in six domains: abdominal symptom management, fatigue, systemic symptoms, activity, emotional function, and worry.

Data collection was started on August 26 through September 9, 2019 (pre- data implementation phase), and September 23 through December 15, 2019 (Figure 6). The data were collected by five transplant NPs and 10 transplant charge/resource/bedside nurses (champions)

using the NECPAL and CLDQ tools daily (Appendix C & D). The patient or if the patient is unable to communicate, the next of kin was asked questions about unmet PC needs. At monthly lunch and learn meetings, the DNP project leader shared with nurses the data from the collection. The staff gave verbal feedback on tools' items and the questions that they had difficulty with asking the patient that needed clarity at monthly lunch and learn. Pre-data ( gender, received PC-pre-post) collected January thru July 2019 were compared to post data August thru December 2019 (Figures 1a, & 1b).

For the NECPAL tool, the transplant NPs applied all four questions for patient. The surprise question (SQ) is the first section of the NECPAL tool. The SQ consist of a straightforward question regarding HCP expectations about the patient's life expectancy: "Would you be surprised if this patient were to die in the next 12 months?". If the healthcare professional answered "no" to this question, then the patient was considered positive (SQ+). SQ+ patients were considered NECPAL+ when they present at least one additional parameter from the NECPAL tool (request or need for PC; general clinical indicators of severity and progression including comorbidity and resource use; or disease-specific indicators; Appendix A). All patients classified as NECPAL+ were considered to require PC (Gomez et al., 2017). Responses of CLDQ were scored from 1 to 7 scales, ranging from 1 for "all of the time" to 7 for "none of the time" (Sobhonslidsuk et al., 2004).

To report the outcomes, the data collected from each of the tools were analyzed separately. Patient variables such as gender, age, screening tool completion, and PC referral were analyzed and plotted on an Excel spreadsheet (Table 2) and (Figures 1, 1a, 1b). NECPAL tool responses (Appendix A) and the CLDQ domain were plotted using graphs. The tools were completed within 72 hours of admission to identify and integrate findings of unmet needs into daily usual assessments routine nursing care and activate PC referrals (Figure 1c) . The number of ESLD patients admitted to the transplant unit who were deemed ineligible for transplant were asked the questions by the staff members if the patient is unable to communicate, the next of kin was asked questions about unmet PC needs. This was to determine the percentage of compliance in completing the form and also to determine if the patient had unidentified needs. Descriptive statistical measures were

collected, analyzed, and displayed in tables and graphs for a detailed summary of the project's outcome (Table 2).

The completed tools were used for this data collection were stored in a locked file cabinet on the transplant unit for data security and confidentiality. The University of Maryland Baltimore (UMB) Institutional Review Board (IRB) for Non-Human Subjects Research determination was obtained for this DNP project.

## **Results**

Five NPs and 10 staff nurses received education and training on the NECPAL and CLDQ tools from the DNP student project leader. Some of the nurses are certified clinical transplant nurses (CCTN) with 1-2 years of providing care to transplant patients. The NPs are certified registered nurse practitioners (CRNP) with greater than 2 years of providing treatment to transplant patients.

Sixteen NTLD patients participated. Their ages ranging 29 to 68 years (median 52 years) (Figure 1). Most (69%) patients were female (Table 2). Compared to the pre-gender data collected January thru July 2019 were compared to post data August thru December 2019 showed majority males (52%) (Figures 1a, & 1b). The percentage of both screening tools goal 100% average (50%, n=9) were completed by the nurses and NPs (Figure 1c). The percentage of nurse and NPs 100% reported to ease of utilizing the tools as part of their routine assessments and began a conversation with the DNP project leader and nurse educator about how best to incorporate PC needs and to promote optimal QOL for ESLD patients and their families.

The NECPAL tools were completed within 72 hours to identify and integrate findings of unmet needs into daily assessments in routine nursing care to determine need for PC showed that 60% (n=6) of the patients had positive clinical indicators. NECPAL results from 60% of the patients (or their families on their behalf) indicated a need for integration of PC. Some of these clinical indicators included a diagnosis of ESLD, decreased nutritional and functional markers for frailty and loss of activities of daily living, emotional factors, comorbidity, and other markers. Additionally, 80% of the providers answered "no" to question no.1, as to whether they would be

surprised if the patient would die within the next 12 months, this was indicative of a positive NECPAL score indicating the patient would need palliative care (Figure 2).

The percentage of the patients who completed the CLDQ (goal 100%) an average 80%, reported symptoms of unmet needs, such as symptoms of abdominal bloating and discomfort, worry, and family impact. The Chronic Liver Disease Questionnaire (CLDQ) was designed specifically for patients with ESLD and appropriately fits this population. The percentage (goal 100%) an average 80% (n=12) of the participating patients (or families on their behalf) reported distressing symptoms of unmet needs in abdominal bloating and discomfort, worry, or family impact, indicating the patients had a positive result in the questionnaire. In addition, these results also showed a high severity in decreased QOL. The domain(s) exhibiting the most severity (i.e. 90%) included: worry, systemic symptoms, fatigue, and abdominal symptoms (Figure 4). Nurses and NPs voiced confidence and ease in the use of the tools identifying symptoms and clinical indicators for the identification of unmet PC needs to promote incorporation into routine nursing care.

The QI initiative encountered multiple unintended consequences and barriers before and during the implementation timeframe. The unintended consequences and barriers included change in medical director, nurses completing one of the two screening tools, and patients deeming non-transplantable on the transplant service but being physically positioned on other units because of lack of bed availability or because the patient required tertiary level of care before being deemed non-transplantable.

The QI project's initial barrier was centered around the departure of the medical director and lag-time in between the appointment of another medical director. The previous medical director was introduced to the project and the aim and was very supportive of the project and offered to help with any portion of the project that was in his scope of practice. However, there was a change in leadership and this particular medical director was no longer working for the institution and a new medical director assumed the position months later. This new medical director was also very

supportive of the project and offered to help with any portion of the project, as he had collaborated with a similar project at his previous institution.

The second barrier was at week one of the project and included policy change so that only NPs completed the NECPAL too instead of both nurses and NPs. Initially, the nurses and NPs were assigned to fill out both forms on each patient. At week one the DNP project leader decided that the nurses will just fill out the CLDQ, as they were more comfortable with the questions. The DNP and unit educator acted as a facilitator to assists with any questions that arose. The nurse were nervous and felt that the first question (called the surprise question SQ) on the NECPAL tool was more of a diagnosis-related question and as a result felt uncomfortable in answering. The SQ consists of a straightforward question regarding healthcare professionals' expectations about the patient's life expectancy: "Would you be surprised if this patient were to die in the next 12 months?" NPs agreed to complete both screening tools as needed, and the nurses completed only CLDQ tool. Despite receiving education on the tool, nurses also initially felt nervous during the first weeks. The nurses felt nervous about the number of questions (29) on the CLDQ tool and time to complete, however, after project leader demonstrated how to complete, the nurses voiced understanding. With reinforcement education, the nurses became more confident in completing the tool.

The final barrier that was encountered during the project's implementation phase included patients deemed non-transplantable on the transplant service but physically located on other units at intervals due to either bed unavailability or the patient requiring tertiary level of care before being deemed non-transplantable. As a result, the NPs completed both forms with the patient (or family on their behalf).

### **Discussion**

Implementation of the NECPAL and CLDQ screening tools has been shown to reduced barriers to the integration of PC for patients with NTLD (Gomez et al., 2017; Younussi et al., 1999, 2015). This QI project focused on the implementation of these two tools. The NECPAL provider NP (clinical indicator) screening tool and the CLDQ disease-specific questionnaire completed by the nurse for unmet PC needs; informs ongoing palliative care interventions aimed at improving

QOL for NTLD patients and their families. Unmet needs can be identified as pain, shortness of breath, confusion anxiety, depression, uncertainty, fear of dying, and social issues. The most reported symptoms and unmet needs were abdominal bloating and discomfort, worry, and family impact (Figure 3). Continuing education and training for nurses to integrate PC screening and needs assessment can be implemented to improve PC for patients with liver disease and their families. The NEPCAL and CLDQ screening tools can be used to identify clinical symptoms and the need for integration of PC.

The findings in this project are similar to other studies. In this QI initiative, the NECPAL tool showed that 60% (n=6) of the patients had positive clinical indicators for PC. In addition, 80% of the providers answered “no” to question no.1, as to whether they would be surprised if the patient would die within the next 12 months. These responses indicated a positive screen and the patient’s need for PC. In comparison, results were similar to the project. Gomez et al. (2017) study where the authors explored the predictive validity of the NECPAL tool for mortality at 12 and 24 months when used as a screening tool for early identification of PC need. Additionally, the authors found that substantial differences were observed by sample size, gender, disease, and condition. At 12months, the mortality rate was 32.6% for men versus 23.9% for women.

The CLDQ tool in this QI initiative, when compared with results from other studies, showed that 80% (n=12) of the participating (or their families on their behalf) had a positive result in the questionnaire, with the highest scoring symptoms indicating a decreased QOL, where the domain(s) exhibiting the most severity (i.e. 90%) were worry, systemic symptoms, fatigue, and abdominal symptoms. Similarly in their study (Scholzel-Dorenbos et al. 2009) where they developed and assessed the disease-specific instrument CLDQ for measuring health-related quality of life in patients with chronic liver disease. Younosi et al., (2015) study found that the CLDQ tool was short, easy to administer in 10 minutes, and that it produced both a summary score and domain scores, and linked with the severity of ESLD, however had a larger sample size (Figure 4). In a similar study Sobhonslidsuk et al. (2004), had a larger sample size the mean age of ESLD patients

was 49 years, and that the average CLDQ responses were activity and emotion function domains as compared to the projects' results.

The methods changed during the project so that only NPs completed the NECPAL tool. The nurses' felt that the first question appeared to be more of a diagnostic question, for which they felt was out of their scope of practice. The NECPAL tool was completed by the NPs starting at week one. The sample script was revised during the first few weeks and the nurses were re-educated on how to have conversations/dialogue with patients during completion of screening tools and on the 29-item CLDQ tool which increased ease of use, as evidence by verbal acknowledgement of understanding by nurse and NPs.

This QI project had several strengths and limitations. The first noted strength was introduction of PC education and screening tools to identify unmet PC needs on a transplant unit. This created an atmosphere of increasing awareness of PC. The nursing staff (nurses and NPs) voiced confidence and ease in the use of the tools, identifying symptoms and clinical indicators for the identification of unmet PC. The support and advocacy of the nurses promoted the integration into routine nursing care of patients who were deemed non-transplantable. This led to nurses' request of different pain regimen for the NTLD patients as they became more familiar with the patient's level of discomfort and suffering in providing prompt routine PC as needed. Another strength was that ongoing reminders of completing the screening tools was led by unit champions (unit educator, charge nurses, NPs) during the implementation phase indicating nurse empowerment. The number of questions on CLDQ was a limitation as it required more time to complete than the NECPAL, based on the patient's neurological status or availability of next of kin who completed the tool on their behalf, which could affect the validity. Although the sample size was small, it allowed for easier tracking of implementation effectiveness. The QI initiative included NTLD patients admitted or consulted on the transplant service who were not physically located on the transplant unit which made it difficult to complete the tool due to the timing and availability of family members visiting.

## **Conclusion**

Despite many researchers (Gomez et al. 2017; & Younosi et al. 1999, 2015) noting the benefits of using screening tools to assist with the identification of unmet needs for NTLD patients, screening tools are underused in efforts to improve symptom management and QOL. The growing consumption of alcohol leading to ESLD, coupled with the under-identification of unmet PC needs in this population is an impetus for recurrent hospitalization, ICU escalation of care, and even death. This is a multifaceted problem possible stemming from the absence of easy-to-use screening tools to identify PC and symptoms in NTLD; the limited knowledge about PC; and no standard protocol or practice for integrating PC into routine clinical practice.

In this QI project, the implementation of NECPAL and CLDQ tools identified multiple unmet PC needs in NTLD patients (Figure 2 & 3). These identified needs were then integrated into routine nursing care. Future QI projects should include the initiation of the NEPCAL and CLDQ screening tools used to identify clinical symptoms and the need for integration of PC. The incorporation of PC needs promotes optimal end-stage QOL for patients and their families. Ongoing training for nurse practitioners and nursing staff is needed to continue to provide for the identification of patients' PC needs. For future QI projects, these nurse-initiated screening PC tools can be easily implemented on other like units caring for patients with chronic and end-stage diseases.



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Table 1 <i>Evidence Review Table: Timeliness of Palliative Care Referrals in End Stage Liver Disease (ESLD) Patients</i>						
Author, year	Study objective/intervention or exposures compared	Design	Sample (N)	Outcomes studied (how measured)	Results	Level & Quality Rating
Aslakson, et al., 2017	To summarize palliative care assessment tools completed by or with patients or caregivers and identify needs for future tool development and evaluation	Systematic review	46 systematic reviews were eligible for inclusion  ROBIS was used to evaluate the systematic reviews in each domain, then the 7 reviews most relevant and recent high-quality systematic reviews addressing domains or subdomains of palliative care were selected	Published systematic reviews, abstracted information based on key elements from the National Quality Forum criteria for Patient Reported Outcomes in Performance Measurement which were developed by an expert panel and were based on scientific acceptability (i.e., validity, reliability, and responsiveness) and usability  Provided useful information for palliative care in the areas of clinical practice, quality indicators, and evaluation of interventions	1) Although many assessment tools for palliative care exist and address key domains, limited to no tools concentrate on the structure and process, ethical and cultural domains, or patient-reported experience.  2) Limited spirituality tools were tested in palliative care populations  3) Future research should place emphasis on further development of multidimensional tools, especially for the cultural domain; evaluating tools in palliative care populations in domains where this has not been done, especially in the spiritual domain; and evaluating the responsiveness of tools across all domains and subdomains  Limitations Few studies have assessed spirituality tools in palliative care populations. Focused on caregiver areas of burden, strain, and quality of life and did not include other subdomains relevant to caregivers that might be useful for palliative care. Few	1A

					tools had reported information on responsiveness. More detailed literature searches for each tool is needed to determine evidence for responsiveness, some tools included in the review had multiple versions that were not always noted in sources, and future use of these tools should search for different versions that might be more appropriate.	
Baumann et al., 2015	The aim of this study is to determine if early palliative care interventions (EPCI) would reduce the symptom burden and depressive symptoms associated with ESLD.	Well-designed case-control and cohort studies	N=79 Patients were referred for liver transplant evaluation between July 2013 and May 2014.	Formal assessment of patients' symptom burden was conducted using an Edmonton Symptom Assessment System (ESAS) scale, modified to better assess symptomatology specific to ESLD. This liver-specific ESAS had patients evaluate 10 symptoms (pain, fatigue, myalgia, sexual dysfunction, anxiety, sleep disturbance, appetite, well-being, dyspnea, and pruritus) on a 10-point scale. scores greater than 5 were considered moderate to severe  Depressive symptoms were assessed using the Center for Epidemiological Studies Depression Scale (CES-D). CES-D is a 20-item assessment of patient mood, with scores ranging from 0 to 60, and a score of greater than 15 indicating clinically significant depressive symptoms.	1) After EPCI, 50% of moderate-to-severe symptoms improved ( $P < 0.05$ ), and 43% of patients showed improvement in clinically significant depressive symptoms ( $P = 0.003$ ). Notably, patients with more symptoms showed a greater improvement in Center for Epidemiological Studies Depression Scale scores ( $P = 0.001$ ). 2) Demonstrated that EPCI counteracts the progressive worsening of ailing symptoms and specifically improved pruritus, well-being, appetite, anxiety, and fatigue. Palliative care intervention also decreased depression, likely by alleviating distressing symptoms.  Limitations Following the EPCI, 50% of moderate-to-severe symptoms improved ( $P < 0.05$ ), and 43% of patients showed improvement in	4A

					<p>clinically significant depressive symptoms (<math>P = 0.003</math>).</p> <p>Patients with more symptoms showed a greater improvement in Center for Epidemiological Studies Depression Scale scores (<math>P = 0.001</math>).</p>	
Derck, J. et al., 2015	To determine the association of frailty and severity of liver disease with quality of life in this patient population.	Prospective cohort study design	<p>N= 487</p> <p>Both outpatients presenting to liver clinics and inpatients were enrolled from July 2009 to October 2013. Patients were eligible based on 18 years or older and diagnosis with chronic liver disease or cirrhosis, highlighting patients being evaluated or currently waitlisted for liver transplantation. Frailty and QOL were assessed for each patient.</p>	<p>Frailty was measured on a scale from 0 to 5 by grip strength, gait speed, exhaustion, shrinkage, and physical activity, with scores of 3 or higher characterized as frail. Physical, mental, and combined overall quality of life scores ranging from 0 to 100 were assessed using Short Form 36. Pearson correlation and multiple linear regression were used to identify variables associated with QOL</p>	<p>Quality of life was notably low in the study cohort (mean: physical, <math>42.9 \pm 24.1</math>; mental, <math>58.3 \pm 23.2</math>). In multivariate analysis adjusted for demographic and clinical characteristics, frailty was significantly negative associated with physical and mental quality of life. Model for ESLD (MELD) was not associated with quality of life.</p> <p>In ESLD patient referred for liver transplant, diminished QOL appears to be significantly negatively associated with frailty and not with severity of liver disease as measured MELD.</p> <p>Further research study is needed if frailty is shown to be a remediable condition, targeted programs may help decrease frailty and improve quality of life in ESLD patients.</p> <p>Limitations Single center study, employing undergraduate student researchers to administer patient</p>	4A



					assessments. Students acknowledge the clinical knowledge and intuition of a trained physician. Frailty instrument validated in the geriatric community. The health-related quality of life instrument and the physical activity and exhaustion components of frailty are also self-reported patients may have under or overestimated their activity levels or may have misinterpreted questions. Study was not designed to attribute causality between frailty and quality of life, and the proper instrument to measure quality of life in this cohort is debatable.	
Hudson et al., 2017	To design and evaluate a prognostic screening tool to consistently identify inpatients with decompensated cirrhosis at high risk of dying in a year, alongside the development of a supportive care intervention	Pre-post experimental study	N=73 73 admissions were scrutinized- 79.5% male, 63% alcohol-related liver disease, median age 54 during July 2013 and November 2014	1) Consecutive patients admitted as an emergency with a diagnosis of cirrhosis over two distinct 90-day periods were studied retrospectively for the presence or absence of five evidence-based factors associated with poor prognosis  2) These were evaluated against their ability to predict mortality at 1 year. 'Plan-Do-Study-Act' (PDSA) was utilized to combine poor-prognosis screening into the routine assessment of patients admitted with ESLD, and develop a supportive care intervention	1) The presence of three or more poor-prognosis criteria at admission predicted 1-year mortality with sensitivity, specificity and positive predictive value of 72.2%, 83.8% and 81.3%, respectively, and was used as a trigger for implementing the supportive care intervention  2) Following modification from six PDSA cycles, prognostic screening was integrated into the assessment of all patients admitted with decompensated cirrhosis, with the supportive care intervention (developed simultaneously) instigated for appropriate patients	4A

					<p>Limitations The quality improvement (QI) process and integration into usual practice was site specific. Inpatients diagnosed with ESLD were discussed. Patients were provided a suitable structure around which implementation of prognostic screening could be based within a hospital organization.</p> <p>Units were used substitute areas, such as daily board rounds or nursing handoffs, to identify appropriate patients, and also use an alternative 'trigger' for intervention based on provider preferences and the availability of supportive and PC services locally. Identification of patients were tailored to who was admitted as an emergency.</p> <p>Additional research is needed to create vigorous mechanisms which identify patients who access services, either in the community, outpatients or via repeated emergency department visits are required.</p>	
Peng, et al., 2019	To describe symptom prevalence and health-related quality of life (QOL) of patients with end-stage liver disease (ESLD) to improve care.	Systematic review and meta-analysis	N=80 studies: 35 assessing symptom prevalence, 41 assessing health-related quality of life, and 4 both, searched in eight	1) In reference to physical symptoms, most studies focused on one or two symptoms, and only three studies evaluated more than three symptoms at the same time. 2) Only one study systematically reported the average number of symptoms in patients with ESLD	1) ESLD, a common cause of morbidity and mortality, disproportionately affects younger age groups and causes premature death.  2) The symptom prevalence of patients with ESLD is similar to	1A

			<p>electronic databases from January 1980 to June 2018.</p>	<p>using liver-specific Edmonton Symptom Assessment System (ESAS) to evaluate 50 liver transplantation candidates</p> <p>3) Generic health-related quality of life tools was more frequently administered than disease-specific health-related quality of life tools</p> <p>4) The Medical Outcome Study Questionnaire 36-Item Short Form Survey (SF-36) was applied in 36 studies (80%)</p> <p>5) In reference to disease-specific health-related quality of life tools, the Chronic Liver Disease Questionnaire (CLDQ) was applied in 14 studies, followed by the Liver Disease Quality of Life (twice) and the Hepatitis QOL Questionnaire (once)</p>	<p>that of patients with other advanced conditions.</p> <p>3) Given the diversity of symptoms and significantly impaired health-related QOL, multidisciplinary approach and timely intervention are crucial</p> <p>4) Palliative care should be integrated in the care of patients with ESLD</p> <p>Limitations</p> <p>Systematic review of observational studies. No control for all potential confounders, and not all the included studies had comparison groups. Studies were conducted while patients were outpatients or stable after hospitalization; Acute symptoms related to decompensation were not captured. Due to limited articles for symptom prevalence and heterogeneity of the populations, meta-analysis could not be performed in many aspects. Majority of the included studies were from Europe and North America, where the cause of end-stage liver disease, the patterns of comorbidity (e.g. hepatocellular carcinoma), and the factors associated with HRQOL might be different from Asian or African countries.</p>	
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Rush, et al., 2017	To explore the use of palliative care (PC) services in patients with end stage liver disease (ESLD) hospitalized across the United States.	Retrospective nationwide cohort analysis	N=39,349 (0.07%) patients meeting study inclusion. PC consultation was performed in 1,789 (4.5%) ESLD patients	Patient demographics from the database: age, gender, race (white, black, Hispanic, other), length of stay, in-hospital mortality, insurance coverage (yes versus no), and socioeconomic status (zip code income quartiles). The presence of metastatic and non-metastatic cancer was based on the Elixhauser comorbidities for each category.	<p>The rate of PC referral in ESLD increased from 0.97% in 2006 to 7.1% in 2012 (<math>P &lt; 0.01</math>). Similarly, the rate of PC referral in cancer patients increased from 2.9% in 2006 to 11.9% in 2012 (<math>P &lt; 0.01</math>)</p> <p>Limitations Use of retrospective discharge database information is inherently susceptible to coding errors and missing data. Inability to capture outpatient PC referrals, an important source of referral for the service. Rate of referral to these services from hepatology/gastroenterology clinics is unknown and worth further study on a large-scale basis. Data set had no clinical information of types of treatments for the patients and how many were symptomatically stable and not requiring referral to PC.</p>	4A
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Walling, et al., 2017	To evaluate guidelines for the medical management of end stage liver disease/cirrhosis and associated quality indicators (QIs), focusing on standards for palliative aspects of care.	Systematic review and meta-analysis	N=82 articles reviewed for evidence related to relevant quality indicators. Included randomized control trials, non-randomized controlled trials, cohort or case analysis, or multiple time series, and textbooks, opinions, and descriptive studies	<p>1) Experts were offered a report based on a systematic review of the literature that contained evidence regarding the proposed candidate QIs</p> <p>2) Panelists rated QIs prior to a scheduled meeting using a standard 9-point RAND appropriateness scale. These ratings directed discussions throughout a day-long phone conference meeting, and final ratings were then provided by panel members</p> <p>3) Final QI scores were calculated and QIs with a final median score of greater than or equal to 7, and no disagreement was incorporated in the final set</p>	<p>1) 28 candidate QIs, the panel rated 19 as valid measures of quality care. These 19 quality indicators cover care related to information and care planning (13) and supportive care (6)</p> <p>2) Good communication about end-of-life care and early elicitation of preferences have been associated with better quality-of-life outcomes for patients and caregivers</p> <p>3) Most of the identified care processes do not require specialty palliative care teams; primary care and specialist clinicians can integrate these practices into care of seriously ill patients</p> <p>4) These indicators provide a practical first step to measuring how well these goals for patients with cirrhosis are being met. The comprehensive nature of the UCLA/RAND methodology used here supports the content validity of these measures</p> <p>Limitations Palliative care (PC) can be provided throughout the trajectory of illness, and these indicators simply serve as a marker of a minimally acceptable bar of care should be. A tool to measure the quality of PC provided to patients with advanced ESLD using a</p>	1A
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					<p>comprehensive set of measures. However, any quality indicator set is necessarily limited in scope for several reasons and this is also the case for these quality indicators. Topics that have limited evidence for explicit indicators among patients with serious illness proposed indicators on specific topics were not included after review by expert panel. Furthermore, the expert panel did not have non-MD clinician representation, such as social work and nursing, and this should be considered for future work in this area.</p>	
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Wang et al., 2018	This study validated the one-page Taiwanese version-Palliative Care Screening Tool (TW-PCST) for screening inpatients with potential palliative care needs	Single descriptive qualitative study	N=31,453 admitted patients during the surveillance period and 21,596 patients were assessed in the 7-month-period. Screening took approximately 4–7 min to accomplish.	<p>One-page Taiwanese version-Palliative Care Screening Tool (TW-PCST) for screened inpatients with potential palliative care needs</p> <p>Patients admitted to the Taipei City Hospital at the first day of admission.</p> <p>This checklist consists four categories, namely (A) severity of basic disease process, (B) progression of co-morbidity, (C) functional status score according to Eastern Cooperative Oncology Group (ECOG) Performance Status, and (D) frequent exacerbations. Scores vary between 0 and 3.</p> <p>A total of 21,596 patients were screened. AUCs for all cut-off scores varied from 0.84 to 0.88. A total-ABCD score <math>\geq 2</math> gave the highest Youden's index for 90 days and 180 days follow-up periods. The optimal cut-point for 14 days was score <math>\geq 3</math>.</p> <p>The TW-PCST demonstrated a good sensitivity and specificity in identification of inpatients with palliative care needs. A total-ABCD score <math>\geq 2</math> may be considered as a trigger for further referral.</p>	<p>Among the screened patients, 1223 (5.7%) had cancer and 296 (1.4%) had advanced cancer.</p> <p>The results showed that 2078 (9.6%) patients had a score of 2 and 1773 (8.2%) patients had a score of 3 in ECOG.</p> <p>Up to 1713 (7.9%) patients needed helps in making a complex decision and determining the goals of care.</p> <p>Neurologic disease with severely reduced function (3.9%) was the most common non-cancer primary diagnosis. The proportions of patients in different ABCD-total scores ranged from 3 to 14%.</p> <p>Limitations</p> <p>The screening tool only considers the physical disability</p> <p>Dead participants had no overlapping among the three subsets,</p> <p>Assessment was carried out by specialist nurses in different departments</p> <p>Study carried out in only one acute community hospital in Taipei.</p>	6B
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I (1) Evidence from systematic review, meta-analysis of randomized controlled trials (RCTs), or practice-guidelines based on systematic review of RCTs.

II (2) Evidence obtained from well-designed RCT

III (3) Evidence obtained from well-designed controlled trials without randomization

IV (4) Evidence from well-designed case-control and cohort studies

V (5) Evidence from systematic reviews of descriptive and qualitative studies

VI (6) Evidence from a single descriptive or qualitative study

VII (7) Evidence from the opinion of authorities and/or reports of expert committees

Melnik, B.M. & Fineout-Overholt, E. (2014). Evidence-based practice in nursing & healthcare: A guide to best practice (3rd ed.). New York: Lippincott, Williams & Wilkins.

Rating Scale for Quality of Evidence

A: High – consistent results with sufficient sample, adequate control, and definitive conclusions; consistent recommendations based on extensive literature review that includes thoughtful reference to scientific literature

B: Good – reasonably consistent results; sufficient sample, some control, with fairly definitive conclusions; reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence

C: Low/major flaw – Little evidence with inconsistent results; insufficient sample size; conclusions cannot be drawn

Newhouse, R.P. (2006). Examining the support for evidence-based nursing practice. *Journal of Nursing Administration*, 36(7-8), 337-40.



Table 2 *Characteristics of Non-transplantable Liver Disease Patients (n=16)**Characteristic of non-transplantable patient on transplant unit (n=16)*

<b>Descriptive Variables</b>	<b>n</b>	<b>%</b>	<b>Range</b>	<b>Mean</b>	<b>Median</b>
<b>Age</b>	16		29-68	51	52
<b>Gender</b>					
<b>Male</b>	5	31			
<b>Female</b>	11	69			
<b>Patient Outcome</b>					
<b>Deferred</b>	2(16)	13			
<b>Improved</b>	2(16)	13			
<b>Made DNR</b>	7(16)	44			
<b>Not Candidate</b>	5(16)	31			
<b>Died</b>	7(16)	44			
<b>Screening tools complete</b>					
<b>Yes</b>	9	56			
<b>No</b>	7	44			
<b>Number of Listing Meeting</b>					
<b>Meetings</b>	13	100			
<b>Attended</b>	13	100			
<b>Number of non-eligible pt</b>					
<b>Pre-Data (over 8 mths</b>	23				
<b>Post Data (over 3 mths</b>	12				

*Note:* Data collected during implementation phase

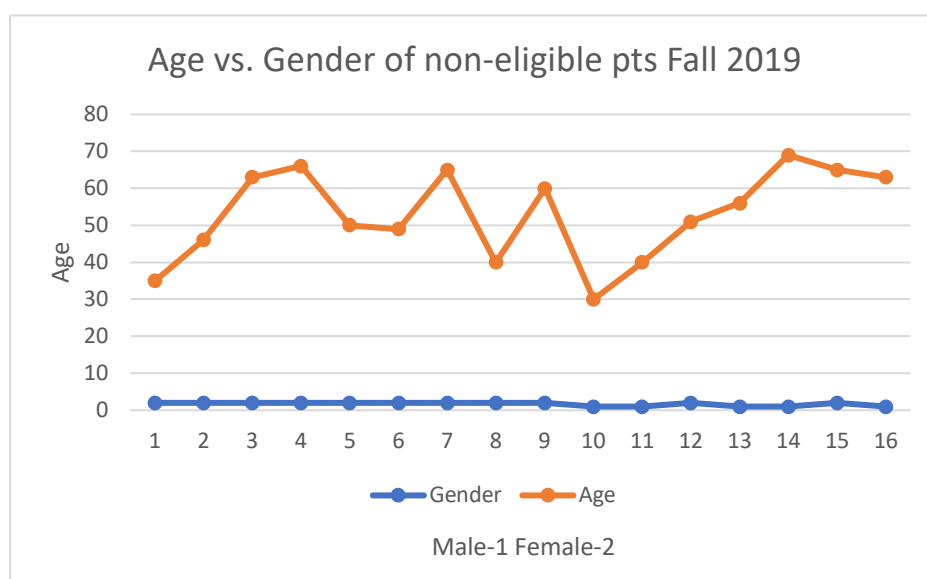


Figure 1. Post Data collection Fall 2019 for gender vs. age of non-transplantable ESLD patients (n=16)

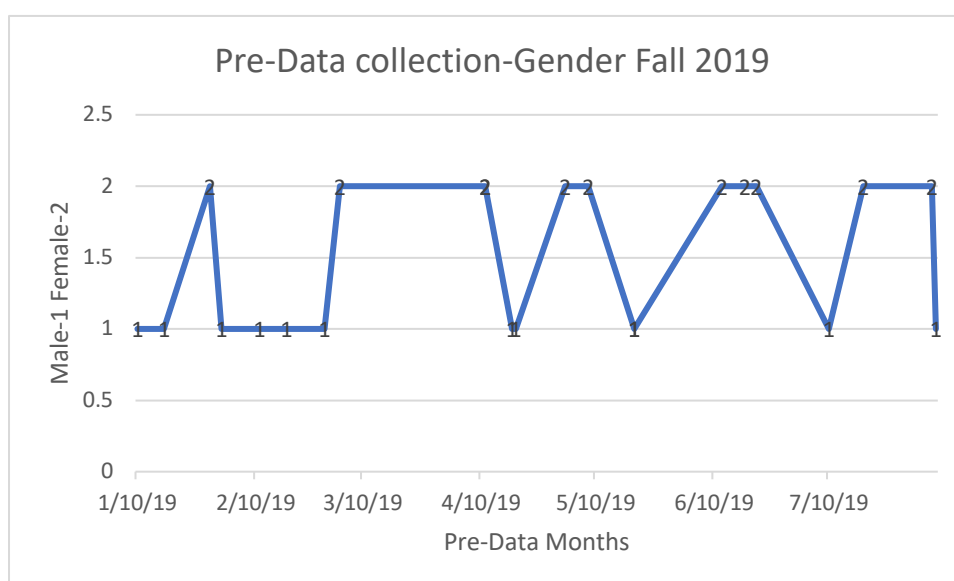


Figure 1a. Pre-Data collection Fall 2019 for gender of non-transplantable ESLD patients (n=23)

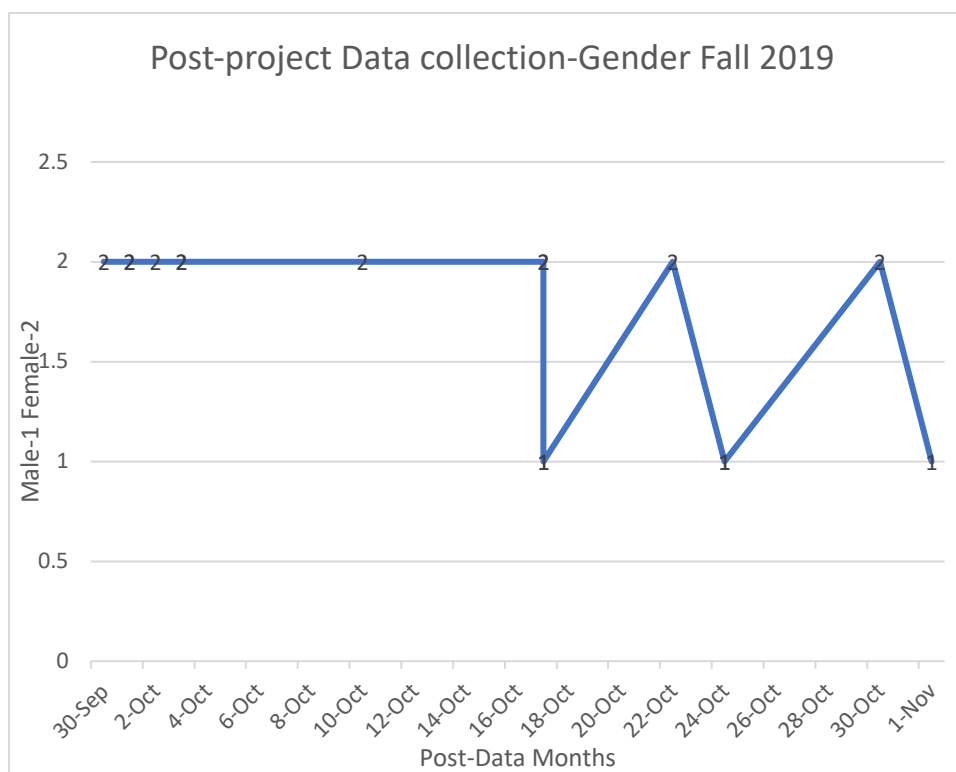


Figure 1b. Post Data collection Fall 2019 for gender of non-transplantable ESLD patients (n=16)

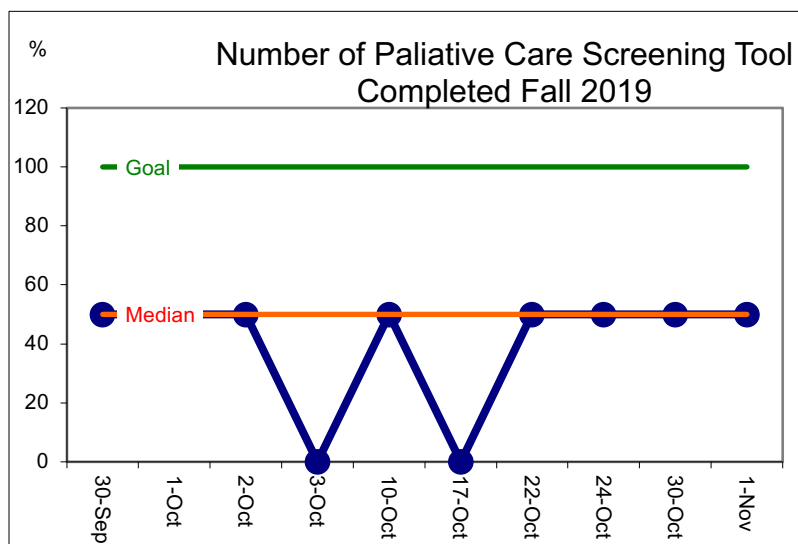


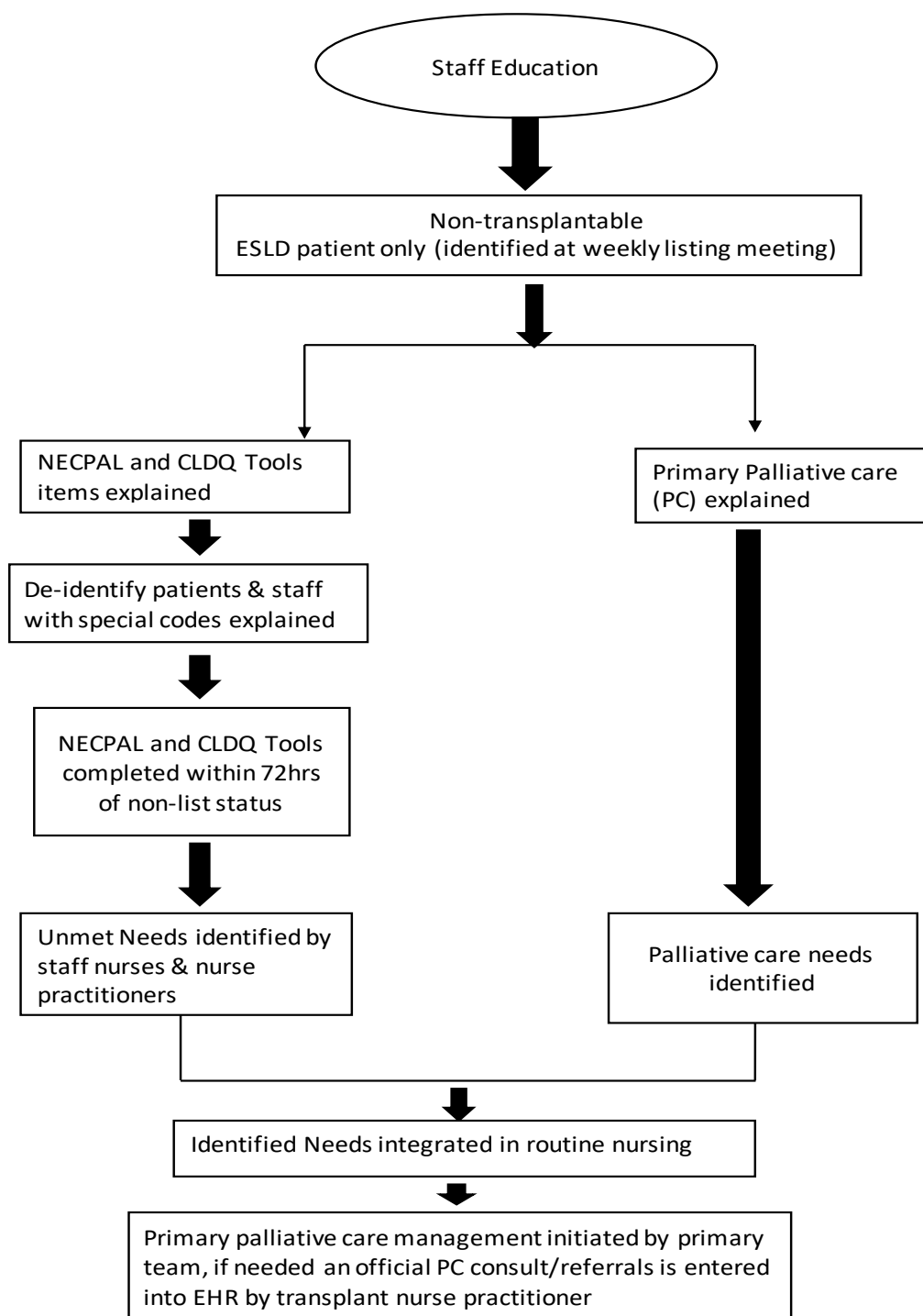
Figure 1c. Screening tools completed Fall 2019 for non-transplant patients (n=16)

*Figure 2.* Data collection on NECPAL tool clinical Indicators Fall 2019 for non-transplant patients (n=16)

All the time	1
most of the tir	2
Neutral	3
some of thetir	4
little of the tir	5
hardly nytime	6
None	7

*Figure 3.* Data collection on Chronic Liver Disease questionnaire (CLDQ) Fall 2019 patient symptoms for non-transplant patients Likert scale responses (n=16)

*Figure 4.* Domain severity of Chronic Liver Disease Questionnaire (CLDQ) Tool Fall 2019 (n=16)

Implementation Plan  
Process Map*Figure 5.* Implementation process map Fall 2019

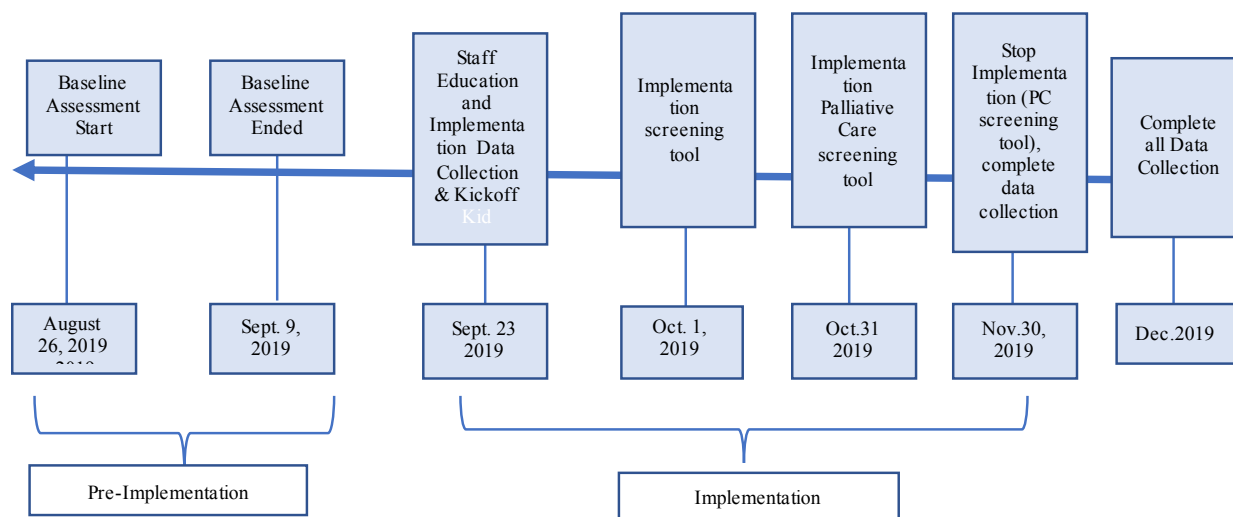


Figure 6. DNP Project Timeline

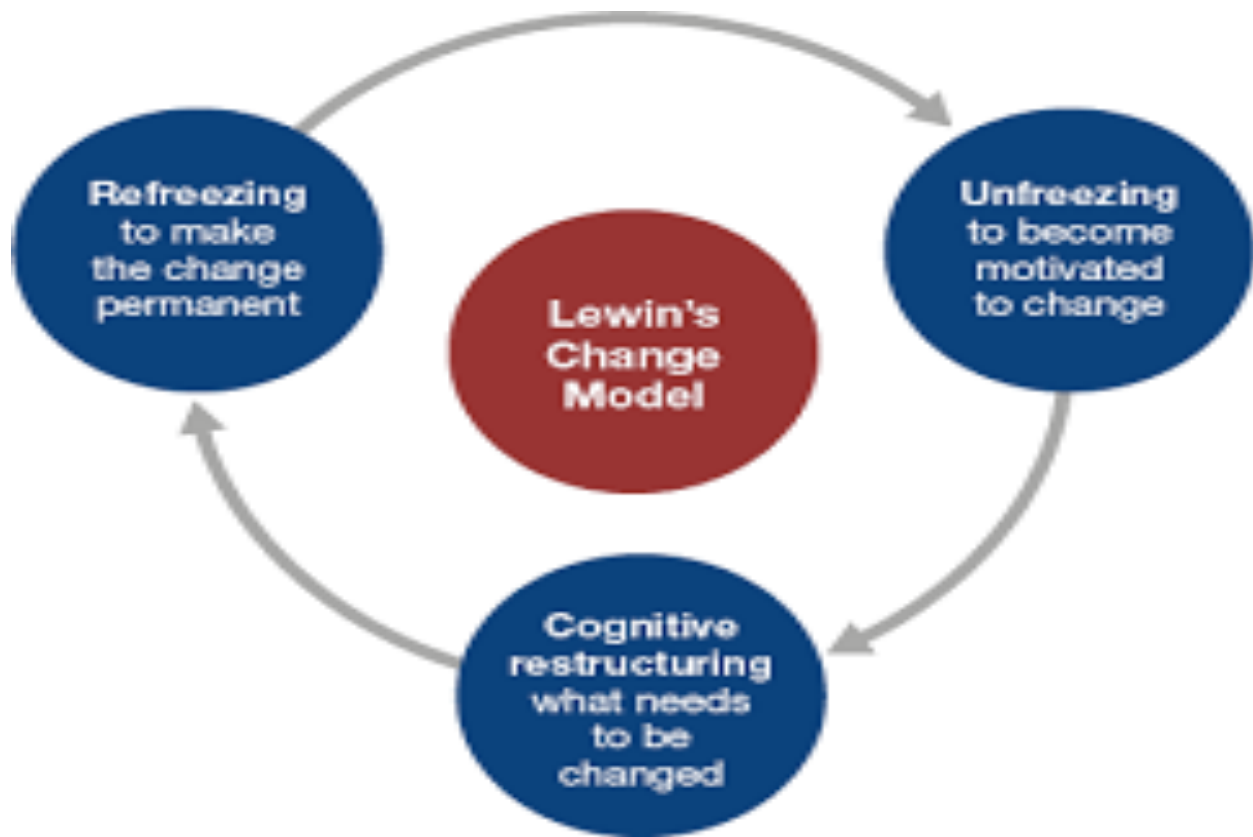
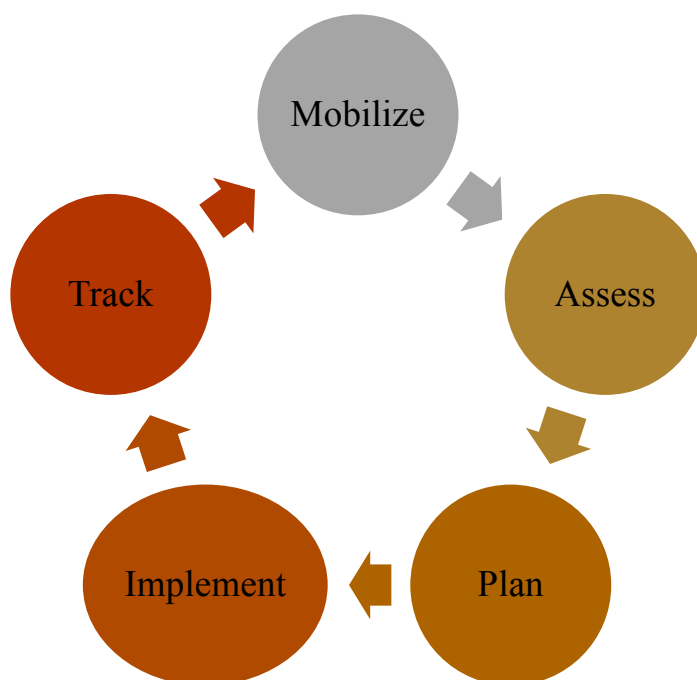


Figure 7. Lewin's Theory of change Model





*Figure 8.* MAP-IT (Mobilize-Assess-Plan-Implement-Track) QI process model

## APPENDIX A

### NECPAL Tool

#### **NECPAL CCOMS-ICO® TOOL (Necesidades Paliativas [Palliative Needs])**

#### **TOOL TO IDENTIFY ADVANCED-TERMINAL PATIENTS IN NEED OF PALLIATIVE CARE WITHIN HEALTH AND SOCIAL SERVICES**

#### **What does the NECPAL CCOMS-ICO® TOOL use for?**

- It is a strategy to identify patients who require palliative care, especially in general health services (primary care, conventional hospital services, etc.)
- The aim of the tool is to identify patients in need of any type of palliative care
- Once the patient is identified, a palliative approach needs to be initiated. That consisting in implementing the recommendations made explicit in the 6 Steps for Palliative Care provision (see details further on)
- Identifying such situation **does not contraindicate nor limit measures of specific treatment of disease** if prescribed or can improve the patients' wellbeing or life quality
- Palliative care can be implemented by any health team in any health service

#### **What does the NECPAL CCOMS-ICO® TOOL NOT use for?**

- To determine prognosis or survival
- To contraindicate, necessarily, symptom control measures for a specific disease or the treatment of diverse processes
- To define the criteria for the intervention of specific palliative care teams. Such intervention would, in all cases, be determined by the complexity of each case and the proposed intervention
- To reject therapeutic curative measures that could improve the patients' quality of life

#### **To whom should the NECPAL CCOMS-ICO® TOOL be administered?** To patients with **advanced chronic diseases**, with the following diagnoses and conditions:

- **Cancer** patient especially affected by the disease
- Patient with **chronic obstructive pulmonary disease (COPD)** especially affected by the disease
- Patient with **chronic heart disease** especially affected by the disease
- Patient with **chronic neurological disease** (including CVA, ALS, MS, Parkinson, motor neurone disease) especially affected by the disease
- Patient with **serious chronic liver disease** especially affected by the disease
- Patient with **serious chronic renal disease** especially affected by the disease
- Patient with **dementia** especially affected by the disease
- **Geriatric** patient who, although not suffering from any of the previous referred diseases, is in situation of **particularly advanced frailty**
- Patient who, although not being geriatric nor suffering from any of the previous referred diseases, suffers from any other **particularly serious and advanced chronic disease**
- Patient who, without being included in any of the previous groups, has recently **being admitted or taken care at home with a higher degree of intensity than expected**

#### **What is considered as being a positive identification?**

Any patient with :

- **Surprise Question** (question 1) with answer '**NO**', and
- At least **other question** (2, 3 or 4) with **POSITIVE** answer, according to the established criteria

#### **What are the 6 Steps for Palliative Care provision?**

They are the basic recommendations for palliative care provision towards the identified patients. They consist of:

1. Identifying Multidimensional Needs
2. Performing an impeccable Model of care
3. Elaborating a Therapeutic Multidimensional and Systematic Plan (Square of Care)
4. Identifying the patients' values and preferences: Clinical Ethics and Advance Care Planning
5. Making the family and the main caregiver participant
6. Carrying out case management, follow-up, continuous and urgent care, coordination and comprehensive actions among different services

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NOVEMBER 2011

## APPENDIX A

### Palliative Care Screening Tool

#### **NECPAL CCOMS-ICO<sup>®</sup> TOOL (Necesidades Paliativas [Palliative Needs])** **TOOL TO IDENTIFY ADVANCED-TERMINAL PATIENTS IN NEED OF PALLIATIVE CARE WITHIN HEALTH AND SOCIAL SERVICES**

**1. THE SURPRISE QUESTION** – an intuitive question integrating co-morbidity, social aspects and other factors  
**Would you be surprised if this patient dies within the next 12 months?**

**No** Yes

**2. CHOICE / REQUEST OR NEED<sup>1</sup>** – explore if any of the following questions is affirmative

**Choice / Request:** Have either the patient with advanced disease or the main caregiver **requested**, in explicit or implicit manner, palliative/comfort treatments exclusively? Do they suggest limitation of therapeutic effort or reject specific treatments or those with curative purposes?

**Yes** No

**Need:** Do you consider this patient **requires** palliative care or palliative treatment **at this moment?**

**Yes** No

**3. GENERAL CLINICAL INDICATORS OF SEVERITY & PROGRESSION** – explore the presence of any of the following criteria of severity and extreme frailty

**Nutritional Markers**, any of the following, in the **last 6 months:**

Severity: serum albumin < 2.5 g/dl, not related to acute episodes of decompensation

Progression: weight loss > 10%

Clinical Perception of nutritional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions

**Yes** No

**Functional Markers**, any of the following, in the **last 6 months:**

Severity: serious established functional dependence (Barthel score < 25, ECOG > 2 or Karnofsky score < 50%)

Progression: loss of 2 or more activities of daily living (ADL's) even though there is adequate therapeutic intervention

Clinical Perception of functional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions

**Yes** No

**Other markers of severity and extreme frailty**, at least 2 of the following, in the **last 6 months:** Persistent pressure ulcers (stage III – IV)

Recurrent infections (> 1)

Delirium

Persistent Dysphagia Falls (> 2)

**Yes** No

Presence of **emotional distress** with psychological symptoms (sustained, intense/severe, progressive) not related to acute concurrent conditions

Yes No

**Additional Factors on use of resources.** Any of the following:

2 or more urgent (unplanned) hospital (or skilled nursing facilities) admissions due to chronic disease in the last year

Need of complex/intense continuing care, either at an institution or at home

Yes No

**Co-morbidity:**  $\geq 2$  concurrent diseases

Yes No

<sup>1</sup> In Mediterranean/Latin countries, where the patient's autonomy is less evident than in Anglo-Saxon/north European countries, the family or team members are usually the ones who request either palliative care, limitation of therapeutic effort, or both measures

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**4. SPECIFIC CLINICAL INDICATORS OF SEVERITY & PROGRESSION PER DISEASES** – explore the presence of specific bad prognosis criteria for the following selected diseases

**CANCER** (it requires the presence of **one single criterion**)

Yes No

Patients with confirmed diagnosis of metastatic cancer (stage IV; and also stage III in some cases –e.g. lung, pancreas, stomach and esophagus cancers) who present low response or contraindication of specific treatment, progressive outbreak during treatment or metastatic affection of vital organs (CNS, liver, severe pulmonary disease, etc.)

Significant functional deteriorating (Palliative Performance Status (PPS) < 50%)

Persistent, troublesome symptoms, despite optimal treatment of underlying condition(s)

**CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)** (presence of **two or more** of the following criteria)

Yes No

Breathlessness at rest or on minimal exertion between exacerbations

Difficult physical or psychological symptoms despite optimal tolerated therapy

In case of having functional respiratory tests (with caveats about quality of testing), disease assessed to be severe: FEV1 < 30% or criteria of restricted severe deficit: CVF < 40% / DLCO < 40%

In case of having arterial blood gases (ABG), accomplishment of oxygen therapy at home criteria or such treatment underway

Symptomatic heart failure

Recurrent hospital admissions (> 3 admissions in 12 months due to exacerbations of EPOC)

**CHRONIC HEART DISEASE** (presence of **two or more** of the following criteria)

Yes No

Heart failure NYHA stage III or IV, severe valve disease or inoperable coronary artery disease

Shortness of breath at rest or minimal exertion

Difficult physical or psychological symptoms despite optimal tolerated

In case of having echocardiography: ejection fraction severely affected (< 30%) or severe pulmonary hypertension (Pulmonary pressure > 60 mmHg)

Renal failure (FG < 30 l/min)

Repeated hospital admissions with symptoms of heart failure/ischemic heart disease (> 3 last year)

### **CHRONIC NEUROLOGICAL DISEASES (1): CVA** (it requires the presence of **one single criterion**)

Yes No

During acute and sub-acute phases (< 3 months' post-stroke): persistent vegetative or minimal conscious state > 3 days  
During the chronic phase (> 3 months' post-stroke): repeated medical complications (aspiration pneumonia despite antidiarrhea measures), pyelonephritis (>1), recurrent febrile episodes some despite antibiotics (persistent temperature post > 1 week of antibiotics), pressure ulcers stage 3-4 or dementia with severe criteria post-stroke

### **CHRONIC NEUROLOGICAL DISEASES (2): ALS & MOTOR NEURONE DISEASES, MÚLTIPLE SCLEROSIS & PARKINSON** (presence of **two or more** of the following criteria)

Yes No

Progressive deterioration in physical and/or cognitive function despite optimal therapy Complex and difficult symptoms  
Speech problems with increasing difficulty communicating  
Progressive Dysphagia  
Recurrent aspiration pneumonia, breathless or respiratory failure

### **SERIOUS CHRONIC LIVER DISEASE** (it requires the presence of **one single criterion**)

Yes No

Advanced Cirrhosis: stage Child C (determined in lack of complications or having treated them and optimized the treatment), MELD-Na score > 30 or with one or more of the following medical complications: diuretic resistant ascites, hepatorenal syndrome or upper gastrointestinal bleeding due to portal hypertension with failed response to pharmacologic and endoscopic treatment and with contraindicated transplant and TIPS.  
Hepatocellular carcinoma: present, in stage C or D (BCLC)

### **SERIOUS CHRONIC RENAL DISEASE** (it requires the presence of **one single criterion**)

Yes No

Serious renal failures (FG < 15) in patients to whom substitutive treatment or transplant is contraindicated

### **DEMENTIA** (presence of **two or more** of the following criteria)

Yes No

Severity criteria: unable to dress, wash or eat without assistance (GDS/FAST 6c), urinary and fecal incontinence (GDS/FAST 6d-e) or unable to communicate meaningfully -6 or less intelligible words- (GDS/FAST 7)  
Progression criteria: loss of 2 or more activities of daily living (ADL's) in the last 6 months, despite adequate therapeutic intervention (non-valuable in hyper-acute situation due to concurrent processes) or difficulty swallowing, or denial to eat, in patients who will not receive enteral- or parenteral nutrition  
Use of resources criteria: multiple admissions (> 3 in 12 months, due to concurrent processes -aspiration pneumonia, pyelonephritis, sepsis, etc.- that cause functional and/or cognitive decline)

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Gómez-Batiste, X., Martínez-Muñoz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., ... Constante, C. (2017). Utility of the NECPAL CCOMS-ICO© tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: A cohort study. *Palliative Medicine*, 31(8), 754–763. <https://doi-org.proxy-hs.researchport.umd.edu/10.1177/0269216316676647>

**APPENDIX B**

## Chronic Liver Disease Questionnaire Screening Tool

**THE CHRONIC LIVER DISEASE QUESTIONNAIRE (CLDQ)—QUALITY OF LIFE INDEX FOR PATIENTS WITH CHRONIC LIVER DISEASE**

This questionnaire is designed to find out how you have been feeling during the last two weeks. You will be asked about your symptoms related to your liver disease, how you have been affected in doing activities, and how your mood has been. Please complete all of the questions and select only one response for each question.

- The CLDQ was the self-administered questionnaire used to assess the quality of life of patients with liver disease of different etiologies and severities.
- It consists of 29 items distributed in 6 domains (abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, and concern), each item being graded in a Likert-type scale with 7 levels of responses.
- The higher scores indicate the minimum frequency of symptoms and consequently better health-related quality of life.
- The score of each domain is multidimensional, with emphasis on the symptoms of liver disease in the last 2 weeks.
- It is performed by summing the answers and dividing by the number of questions understood, with the proportion of variation being 0.056 to 0.224.13
- The final score is obtained by adding the domains and dividing by 6.

The scores range from 0 to 6, with values above 3 as indicative of better quality of life

Questions	0 Domain	1 All the time	2 Most of the time	3 Neutral	4 Some of the time	5 Little of the time	6 Hardly anytime	7 None
1. How much of the time during the last two weeks have you been troubled by a feeling of abdominal bloating?	AS							
2. How much of the time have you been tired or fatigued during the last two weeks?	FA							
3. How much of the time during the last two weeks have you experienced bodily pain?	SS							
4. How often during the last two weeks have you felt sleepy during the day?	FA							
5. How much of the time during the last two weeks have you experienced abdominal pain?	AS							
6. How much of the time during the last two weeks has shortness of breath been a problem for you in your daily activities?	SS							
7. How much of the time during the last two weeks have you not been able to eat as much as you would like?	AC							
8. How much of the time in the last two weeks have you been bothered by having decreased strength?	FA							
9. How often during the last two weeks have you had trouble lifting or carrying heavy objects?	AC							
10. How often during the last two weeks have you felt anxious?	EF							
11. How often during the last two weeks have you felt a decreased level of energy?	FA							
12. How much of the time during the last two weeks have you felt unhappy?	EF							
13. How often during the last two weeks have you felt drowsy?	FA							



Questions	0 Domain	1 All the time	2 Most the time	3 Neutral	4 Some the time	5 Little of time	6 Hardly anytime	7 None
14. How much of the time during the last two weeks have you been bothered by a limitation of your diet?	AC							
15. How often during the last two weeks have you been irritable?	EF							
16. How much of the time during the last two weeks have you had difficulty sleeping at night?	EF							
17. How much of the time during the last two weeks have you been troubled by a feeling of abdominal discomfort?	AS							
18. How much of the time during the last two weeks have you been worried about the impact your liver disease has on your family?	WO							
19. How much of the time during the last two weeks have you had mood swings?	EF							
20. How much of the time during the last two weeks have you been unable to fall asleep at night?	EF							
21. How often during the last two weeks have you had muscle cramps?	SS							
22. How much of the time during the last two weeks have you been worried that your symptoms will develop into major problems?	WO							
23. How much of the time during the last two weeks have you had a dry mouth?	SS							
24. How much of the time during the last two weeks have you felt depressed?	EF							

25. How much of the time during the last two weeks have you been worried about your condition getting worse?	EF							
Questions	0 Domain	1 None	2 Some time	3 Neutral	4 Most of the time	5 All the time	6 All of time	7 All time
26. How much of the time during the last two weeks have you had problems concentrating?	EF							
27. How much of the time have you been troubled by itching during the last two weeks?	SS							
28. How much of the time during the last two weeks have you been worried about never feeling any better?	EF							
29. How much of the time during the last two weeks have you been concerned about the availability of a liver if you need a liver transplant?	EF							

Abdominal Symptoms

(AS): Items 1, 5, 17

Fatigue

(FA): Items 2, 4, 8, 11, 13

Systemic

symptoms (SS): Items 3, 6, 21, 23, 27

Activity

(AC): Items 7, 9, 14

Emotional function

(EF): Items 10, 12, 15, 16, 19, 20, 24, 26

Worry

(WO): Items 18, 22, 25, 28, 29

Younossi, Z. M., Guyatt, G., Kiwi, M., Boparai, N., & King, D. (1999). Development of a disease specific questionnaire to measure health related quality of life in patients with chronic liver disease. *Gut*, 45(2), 295–300. Retrieved from <http://search.ebscohost.com.proxy-hs.researchport.umd.edu/login.aspx?direct=true&db=cmedm&AN=10403745&site=ehost-live>

## APPENDIX C

## Palliative Care Screening Tool Paper Documentation

**NECPAL CCOMS-ICO<sup>®</sup> TOOL (Necesidades Paliativas [Palliative Needs])****TOOL TO IDENTIFY ADVANCED-TERMINAL PATIENTS IN NEED OF PALLIATIVE CARE WITHIN HEALTH AND SOCIAL SERVICES**

**1. THE SURPRISE QUESTION** – an intuitive question integrating co-morbidity, social aspects and other factors  
**Would you be surprised if this patient dies within the next 12 months?**

**No** Yes

**2. CHOICE / REQUEST OR NEED<sup>1</sup>** – explore if any of the following questions is affirmative

**Choice / Request:** Have either the patient with advanced disease or the main caregiver **requested**, in explicit or implicit manner, palliative/comfort treatments exclusively? Do they suggest limitation of therapeutic effort or reject specific treatments or those with curative purposes?

**Yes** No

**Need:** Do you consider this patient **requires** palliative care or palliative treatment **at this moment?**

**Yes** No

**3. GENERAL CLINICAL INDICATORS OF SEVERITY & PROGRESSION** – explore the presence of any of the following criteria of severity and extreme frailty

**Nutritional Markers**, any of the following, in the **last 6 months:**

Severity: serum albumin < 2.5 g/dl, not related to acute episodes of decompensation

Progression: weight loss > 10%

Clinical Perception of nutritional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions

**Yes** No

**Functional Markers**, any of the following, in the **last 6 months:**

Severity: serious established functional dependence (Barthel score < 25, ECOG > 2 or Karnofsky score < 50%)

Progression: loss of 2 or more activities of daily living (ADL's) even though there is adequate therapeutic intervention

Clinical Perception of functional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions

**Yes** No

**Other markers of severity and extreme frailty**, at least 2 of the following, in the **last 6 months:** Persistent pressure ulcers (stage III – IV)

Recurrent infections (> 1)

Delirium

Persistent Dysphagia Falls (> 2)

**Yes** No

Presence of **emotional distress** with psychological symptoms (sustained, intense/severe, progressive) not related to acute concurrent conditions

Yes No

**Additional Factors on use of resources.** Any of the following:

2 or more urgent (unplanned) hospital (or skilled nursing facilities) admissions due to chronic disease in the last year

Need of complex/intense continuing care, either at an institution or at home

Yes No

**Co-morbidity:**  $\geq 2$  concurrent diseases

Yes No

<sup>1</sup> In Mediterranean/Latin countries, where the patient's autonomy is less evident than in Anglo-Saxon/north European countries, the family or team members are usually the ones who request either palliative care, limitation of therapeutic effort, or both measures

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**4. SPECIFIC CLINICAL INDICATORS OF SEVERITY & PROGRESSION PER DISEASES** – explore the presence of specific bad prognosis criteria for the following selected diseases

**CANCER** (it requires the presence of **one single criterion**)

Yes No

Patients with confirmed diagnosis of metastatic cancer (stage IV; and also stage III in some cases –e.g. lung, pancreas, stomach and esophagus cancers) who present low response or contraindication of specific treatment, progressive outbreak during treatment or metastatic affection of vital organs (CNS, liver, severe pulmonary disease, etc.)

Significant functional deteriorating (Palliative Performance Status (PPS) < 50%)

Persistent, troublesome symptoms, despite optimal treatment of underlying condition(s)

**CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)** (presence of **two or more** of the following criteria)

Yes No

Breathlessness at rest or on minimal exertion between exacerbations

Difficult physical or psychological symptoms despite optimal tolerated therapy

In case of having functional respiratory tests (with caveats about quality of testing), disease assessed to be severe: FEV1 < 30% or criteria of restricted severe deficit: CVF < 40% / DLCO < 40%

In case of having arterial blood gases (ABG), accomplishment of oxygen therapy at home criteria or such treatment underway

Symptomatic heart failure

Recurrent hospital admissions (> 3 admissions in 12 months due to exacerbations of EPOC)

**CHRONIC HEART DISEASE** (presence of **two or more** of the following criteria)

Yes No

Heart failure NYHA stage III or IV, severe valve disease or inoperable coronary artery disease

Shortness of breath at rest or minimal exertion

Difficult physical or psychological symptoms despite optimal tolerated

In case of having echocardiography: ejection fraction severely affected (< 30%) or severe pulmonary hypertension (Pulmonary pressure > 60 mmHg)

Renal failure (FG < 30 l/min)

Repeated hospital admissions with symptoms of heart failure/ischemic heart disease (> 3 last year)

### **CHRONIC NEUROLOGICAL DISEASES (1): CVA** (it requires the presence of **one single criterion**)

Yes No

During acute and sub-acute phases (< 3 months' post-stroke): persistent vegetative or minimal conscious state > 3 days  
During the chronic phase (> 3 months' post-stroke): repeated medical complications (aspiration pneumonia despite antidiarrhea measures), pyelonephritis (>1), recurrent febrile episodes some despite antibiotics (persistent temperature post > 1 week of antibiotics), pressure ulcers stage 3-4 or dementia with severe criteria post-stroke

### **CHRONIC NEUROLOGICAL DISEASES (2): ALS & MOTOR NEURONE DISEASES, MÚLTIPLE SCLEROSIS & PARKINSON** (presence of **two or more** of the following criteria)

Yes No

Progressive deterioration in physical and/or cognitive function despite optimal therapy Complex and difficult symptoms  
Speech problems with increasing difficulty communicating  
Progressive Dysphagia  
Recurrent aspiration pneumonia, breathless or respiratory failure

### **SERIOUS CHRONIC LIVER DISEASE** (it requires the presence of **one single criterion**)

Yes No

Advanced Cirrhosis: stage Child C (determined in lack of complications or having treated them and optimized the treatment), MELD-Na score > 30 or with one or more of the following medical complications: diuretic resistant ascites, hepatorenal syndrome or upper gastrointestinal bleeding due to portal hypertension with failed response to pharmacologic and endoscopic treatment and with contraindicated transplant and TIPS.  
Hepatocellular carcinoma: present, in stage C or D (BCLC)

### **SERIOUS CHRONIC RENAL DISEASE** (it requires the presence of **one single criterion**)

Yes No

Serious renal failures (FG < 15) in patients to whom substitutive treatment or transplant is contraindicated

### **DEMENTIA** (presence of **two or more** of the following criteria)

Yes No

Severity criteria: unable to dress, wash or eat without assistance (GDS/FAST 6c), urinary and fecal incontinence (GDS/FAST 6d-e) or unable to communicate meaningfully -6 or less intelligible words- (GDS/FAST 7)  
Progression criteria: loss of 2 or more activities of daily living (ADL's) in the last 6 months, despite adequate therapeutic intervention (non-valuable in hyper-acute situation due to concurrent processes) or difficulty swallowing, or denial to eat, in patients who will not receive enteral- or parenteral nutrition  
Use of resources criteria: multiple admissions (> 3 in 12 months, due to concurrent processes -aspiration pneumonia, pyelonephritis, sepsis, etc.- that cause functional and/or cognitive decline)

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Nurse Practitioner initials (De-identified): \_\_\_\_\_ Date: \_\_\_\_\_

Nurse initials (De-identified): \_\_\_\_\_ Date: \_\_\_\_\_

**APPENDIX D**

<b>Chronic Liver Disease Questionnaire Paper Documentation</b> Questions	0 Domain	1 All the time	2 Most of the time	3 Neutral	4 Some of the time	5 Little of the time	6 Hardly anytime	7 None
1. How much of the time during the last two weeks have you been troubled by a feeling of abdominal bloating?	AS							
2. How much of the time have you been tired or fatigued during the last two weeks?	FA							
3. How much of the time during the last two weeks have you experienced bodily pain?	SS							
4. How often during the last two weeks have you felt sleepy during the day?	FA							
5. How much of the time during the last two weeks have you experienced abdominal pain?	AS							
6. How much of the time during the last two weeks has shortness of breath been a problem for you in your daily activities?	SS							
7. How much of the time during the last two weeks have you not been able to eat as much as you would like?	AC							
8. How much of the time in the last two weeks have you been bothered by having decreased strength?	FA							
9. How often during the last two weeks have you had trouble lifting or carrying heavy objects?	AC							
10. How often during the last two weeks have you felt anxious?	EF							
11. How often during the last two weeks have you felt a decreased level of energy?	FA							
12. How much of the time during the last two weeks have you felt unhappy?	EF							
13. How often during the last two weeks have you felt drowsy?	FA							



Questions	0 Domain	1 All the time	2 Most the time	3 Neutral	4 Some the time	5 Little of time	6 Hardly anytime	7 None
14. How much of the time during the last two weeks have you been bothered by a limitation of your diet?	AC							
15. How often during the last two weeks have you been irritable?	EF							
16. How much of the time during the last two weeks have you had difficulty sleeping at night?	EF							
17. How much of the time during the last two weeks have you been troubled by a feeling of abdominal discomfort?	AS							
18. How much of the time during the last two weeks have you been worried about the impact your liver disease has on your family?	WO							
19. How much of the time during the last two weeks have you had mood swings?	EF							
20. How much of the time during the last two weeks have you been unable to fall asleep at night?	EF							
21. How often during the last two weeks have you had muscle cramps?	SS							
22. How much of the time during the last two weeks have you been worried that your symptoms will develop into major problems?	WO							
23. How much of the time during the last two weeks have you had a dry mouth?	SS							
24. How much of the time during the last two weeks have you felt depressed?	EF							

25. How much of the time during the last two weeks have you been worried about your condition getting worse?	EF							
Questions	0 Domain	1 None	2 Some time	3 Neutral	4 Most of the time	5 All the time	6 All of time	7 All time
26. How much of the time during the last two weeks have you had problems concentrating?	EF							
27. How much of the time have you been troubled by itching during the last two weeks?	SS							
28. How much of the time during the last two weeks have you been worried about never feeling any better?	EF							
29. How much of the time during the last two weeks have you been concerned about the availability of a liver if you need a liver transplant?	EF							

## Abdominal Symptoms

(AS): Items 1, 5, 17

## Fatigue

(FA): Items 2, 4, 8, 11, 13

## Systemic

symptoms (SS): Items 3, 6, 21, 23, 27

## Activity

(AC): Items 7, 9, 14

## Emotional function

(EF): Items 10, 12, 15, 16, 19, 20, 24, 26

Worry

(WO): Items 18, 22, 25, 28, 29

Nurse Practitioner initials (De-identified): \_\_\_\_\_ Date: \_\_\_\_\_

Nurse initials (De-identified): \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX E

### Process and Scripting instructions

Process and Scripting instructions for Chronic Liver Disease Questionnaire (CLDQ) (subjective data)

The CLDQ is used to assess the quality of life of patients with liver disease of different etiologies and severities. It consists of 29 items distributed in 6 domains (abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, and concern), each item graded in a Likert-type scales with 7 levels of responses.

#### Process

1. Nurse Practitioners will identify patients who will not be listed for transplant.
2. Patient names (de-identified) will be added to Research Binder every Thursday after 16:00
3. NP will communicate with Charge or Resource Nurse patient names and add names to the tracking tool in research binder.
4. Research Binder will be stored in locked drawer in charge nurse office
5. Charge or resource nurse will facilitate completion of questionnaire with bedside RN and patient ASAP.
6. Completed questionnaire will be returned to research binder in locked drawer
7. If not completed on same shift as patient identified, Charge Nurse will hand off task to next shift Charge Nurse.

#### Scripting Instructions

1. Use the following script to introduce the survey to the patient:  
“Hello \_\_\_\_\_, I would like to ask you some questions about how you have been feeling over the past two weeks. Some of the questions may seem the same, but they will help me know what bothers you.”
2. Minimize environmental stimuli.
  - a. “Mind if I turn off the TV?”
3. Provide privacy.
4. Give patient a copy of questions and answers.
5. Explain to the patient that they will choose one of the following answers:
  - a. All the time, Most of the time, Neutral, Some of the time, Little of the time, Hardly anytime, Never
6. Reinforce that they are to think about how they have felt over the last two weeks.
7. Do not rephrase the questions.
8. If a patient is unable to answer after 3 attempts, mark the response as NR for no response.

## Process and Scripting instructions for NECPAL TOOL (Objective data-NP only)

NECPAL tool main utility is to activate gradually a comprehensive and person-centered ‘palliative approach’ more focused in the quality of life, including a multidimensional assessment, the review of diseases and treatments, the start of an advance care planning process and case management for integrated care across settings. These actions will improve the quality of care and adequacy of resources of any patient with a complex advanced chronic condition irrespective of prognosis. This required arrangement of care and services is of crucial importance to accept the suitability of screening.

## Process

1. Nurse Practitioners will identify patients who will not be listed for transplant.
2. Patient names (de-identified) will be added to Research Binder in lock drawer every Thursday after 16:00 Listing Meeting
3. NP will add names to the Binder in locked drawer in charge nurse office
4. Each NP will facilitate completion of NECPAL Tool with patient ASAP.
5. Completed Tool will be stored in the lock drawer in the charge nurse/resource nurse office.
6. If not completed on same shift as patient identified, Nurse Practitioner caring for the patient will complete and place in file lock drawer.

## Scripting Instructions

7. Use the following script to introduce the survey to the patient:  
“Hello \_\_\_\_\_, I would like to ask you few questions about your general health and current diagnosis or diagnoses that may identify you for palliative care services. Identifying such situation does not contraindicate nor limit measures of specific treatment of disease, can improve the patient’s wellbeing or life quality.

## Minimize environmental stimuli.

- a. “Mind if I turn off the TV?”
  8. Provide privacy.
  9. Give patient laminated copy of questions and answers.
  10. Explain to the patient that they will choose one of the following answers: Yes or no
  11. If a patient is unable to answer after 3 attempts, mark the response as NR for no response.
- Thank you for your help! Please see Sue Gaines, NP if you have any questions