



Care of the Cholangiocarcinoma Patient
Clinical Practice Guideline:

THE PATIENT PREPARING FOR LIVER TRANSPLANTATION

GOALS/OUTCOMES:

Patient will verbalize and/or demonstrate outcomes below:

1. Patient and caregiver are able to describe their disease, diagnosis, interventional treatments, and associated signs/symptoms of disease.
2. Patient and caregiver demonstrate understanding of transplant work up, including chemotherapy/radiation and transplant protocol, logistics of transplant wait list, expected pre- and post-transplant care as it relates to their disease process.
3. Patient and caregiver can recognize adverse effects of treatment or worsening of disease during transplant protocol and while on transplant wait list.
4. Patient and caregiver report to nurse coordinator and clinical team for regular follow up and/or with acute issues.
5. Patient and caregiver will have knowledge of all treatments and medications associated with their transplant care.
6. Patient and caregiver have clear understanding of when to contact nurse coordinator/seek emergent medical attention.

ASSESSMENT/INTERVENTIONS

A. Assessment findings with associated reference numbers and evidence based rating:

Nurse coordinator will demonstrate successful teaching/patient care assessment and interventions as listed below, i.e.,:

1. Describing signs/symptoms of disease. 1, IV-A; 5,V-A; 6,IV-A
 - a. Abdominal pain, jaundice, fever, weight loss, dark urine, light stool, N/V, pruritus/scratching of the skin, etc.
2. Identifying expected outcomes mutually with the patient, caregiver, family, and other healthcare providers; including: 1IV-A; 2,IV-A; 3,V-A; 4,IV-A; 5,V-A; 7,V-A
 - a. Education about the process for liver transplantation including information about the diagnosis of cholangiocarcinoma, transplant evaluation, types of donor organs, diagnostic testing, transplant wait time including Model of End Stage Liver Disease (MELD) score and exception points.
 - b. Liver transplant protocol for cholangiocarcinoma and side effects.
3. Coordinating patient scheduling and follow up at regularly scheduled intervals. 1,IV-A; 2, IV-A; 3,V-A; 5,V-A; 6,IV-A
 - a. Management includes guiding patient through transplant evaluation, scheduling stent exchanges, surveillance screening, continued management of underlying liver disease (if applicable).
4. Interpreting results of diagnostic data and facilitating implementation of recommended treatment/interventions. 1,IV-A; 2, IV-A; 3,V-A; 5,V-A; 6,IV-A; 7,V-A
 - a. Diagnostic data to include: Blood Tests (LFTs, bilirubin, GGT, IgG subclasses, tumor markers), imaging (MRI/MRCP is the gold standard for examining bile ducts and extent of disease), endoscopy (ERCP provides most detailed visualization of the biliary strictures and allows brush cytology and intraductal biopsy of bile ducts, FISH is an advanced cytologic test that aids in CCA diagnosis, EUS allows sampling of regional lymph nodes to rule out nodal metastasis, but is not recommended for biopsy or FNA of hilar mass or biliary stricture).
 - b. Biopsy: In most instances, patients with prior biopsy are excluded from liver transplant as the risk of cancer cell seeding is very high.
5. Refines and revises diagnoses regularly based on data collected. 1,IV-A; 3,V-A; 5,V-A; 7,V-A



6. Clearly identifies criteria to contact nurse coordinator. 1,IV-A; 2,IV-A; 5,V-A; 6,IV-A
 - a. Including: changes in clinical status, fever, chills, sign of infection, weight loss, weight gain, GI bleeding, medication refills, if medications are prescribed by physicians at other offices, issues with stents, if going to be outside of 6 hour travel radius, caregiver issues, etc.
 7. Serves as liaison between patient/caregiver and transplant clinical team. 1,IV-A; 2,IV-A; 5,V-A
 - a. The nurse coordinator will help identify: The patient's known or potential physical, psychological, social, or developmental problems. The support and educational needs of the family, caregiver and members of the healthcare team. Any present or potential environmental problem.
- B. Interventions related to assessment findings above with associated reference numbers and evidence based rating:
The nurse coordinator will use institution specific guidelines to:
1. Include the patient and caregiver in the decision making process during transplant evaluation and protocol. 1,IV-A; 2,IV-A; 3,V-A; 5,V-A
 2. Evaluate and explain the effectiveness of interventions and treatment in relation to patient and caregiver response, expected outcomes, and transplant criteria. 1,IV-A; 2, IV-A; 3,V-A; 5,V-A; 6,IV-A;
 3. Use ongoing assessment data to revise the plan and the implementation of interventions and treatment as needed. 1,IV-A; 3,V-A; 4,IV-A; 5,V-A; 7,V-A
 4. Document the patient's clinical and emotional/psychosocial response to treatment and share with the transplant team. 1,IV-A; 2,IV-A; 5,V-A

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