INTRODUCTION

End stage liver disease is a major health problem in Egypt and the number of patients is continuously increasing. It is a health crisis of alarming proportions up to nine million Egyptians, who have been exposed to hepatitis C, and tens thousands are expected to die yearly unless they receive a liver transplant. According to studies done in Egypt, about thirty percent of people are infected with HCV, quarter of cases leads to cirrhosis and liver failure, and treatment options are limited for HCV carriers with end stage liver disease ***(Gonwa & Wadie, 2011).*** **Egypt** has the highest prevalence of hepatitis C in the world ***(Wahib et al., 2005)***. Moreover, the strict criteria for living donors limit the number of livers available for transplant. Liver transplantation is the ideal treatment for these cases and also saves patient's life from complications of liver disease ***(Guichelaar et al., 2007)***.

Traditionally, liver transplantation outcome is a field of interest to both clinicians and researchers. For patients, the decision to have a liver transplant is often made in an effort to improve their quality of life and to reduce their risk of mortality and morbidity. In addition to scientific interest in health-related quality of life (HRQOL), clinicians have increasingly become interested in how liver transplantation may affect not only patient's survival but also their quality of life ***(David & Jacobson, 2007).***

An understanding of the issues pertaining to quality of life (QOL) is essential for any disease or health condition. It is particularly important in orthotopic liver transplantation (OLT) recipients, there is a large cohort of living recipients, and many of them now reach their first and second post-surgery decades. In addition, OLT patient and graft survival rates are the highest that they have been since the inception of liver transplant procedures, with the current overall 3-year patient survival at 79% ***(Gabriel & Bowling 2004; Tome et al., 2008).***

The HRQOL research presents a challenging goal for clinicians as it is necessary to convert information based on patient self assessment and subjective reports into a quantitative measurement that can be standardized and applied to large patient populations. In addition, its interventions and outcomes are based on patient driven objectives, priorities, interpretations, and satisfaction rather than solely physician based medical objectives and goals such as mortality, morbidity, length of life, and survival rates ***(Chan et al., 2011).***

Going back home from hospital is not always a smooth process. Many studies from all over the world have repeatedly reported that many people who have been discharged from hospital to home, especially the elderly, encounter a variety of problems in the first weeks after their return home. Problems after discharge include dependence on others with regard to household activities, lower levels of independence in activities of daily living and self care deficits ***(Mailey et al., 2011).***

The post discharge problems reported were difficulty with reading medication labels or instilling eye drops, not getting the help they needed, not being aware of available services, informational deficits, symptom distress, social problems and emotional problems as anxiety and uncertainty ***(Banker, 2010).*** Home care reduces the costs and should focus on a chronic care model of patient education and on empowering both the patient and the family to take responsibility for the care ***(Grattagliano et al., 2011).***

Significance of the Study

The numbers of patients undergoing liver transplantation are increasing in Egypt, and this is expected to continue given the high prevalence of liver diseases. Nursing has a significant role and responsibility for planning, administering, and evaluating the care of the liver transplant patient as a member of the team. The community health nurse's role goes beyond hospital care and extends to the post operative home care to help the patient return smoothly to normal life. This needs an effort from the nurse's side to educate and train the patient and his family caregiver in issues as diet, medications, monitoring vital signs, and record keeping. Needs assessment is used to determine the programs requiring attention and the way to best meet these needs ***(Cherqui et al., 2009).***

AIM OF THE STUDY

The study aims to evaluate the effect of home care on quality of life of patients undergoing liver transplantation. This aim was achieved through fulfillment of the following objectives:

Objectives:

1- To evaluate liver transplant recipients' knowledge regarding home care provided to patients undergoing liver transplantation.

2- To design and implement a home care program based on the identified patients' needs.

3- To evaluate the effect of the home care provided on the quality of life (QOL) of patients undergoing liver transplantation.

Research Hypothesis:

Implementation of the home care program will improve liver transplant recipients’ quality of life.

REVIEW OF LITERATURE

Part I: Liver Transplantation

A. Anatomy and Physiology of the Liver

The liver is a vital organ present in the body and it plays a major role in metabolism and has a number of functions in the body, including glycogen storage, decomposition of red blood cells, plasma protein synthesis, hormone production, and detoxification ***(O'Connor et al., 2012).*** The liver is a reddish brown organ with four lobes of unequal size and shape. A human liver normally weighs 1.44–1.66 kg (3.2–3.7 lb), and is a soft, pinkish-brown, triangular organ. It is of the largest internal organ (the skin being the largest organ overall) and the largest gland in the human body. It is located in the right upper quadrant of the abdominal cavity, resting just below the diaphragm ***(Aloia et al., 2007)***.

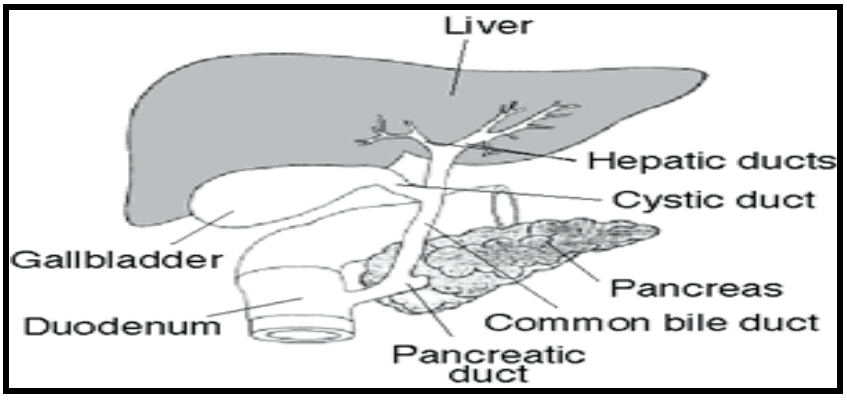

Figure (1): Anatomy of liver. Adopted from ***Aloia, T; Adam, R; and Samuel, D. (2007).***

The liver lies to the right of the stomach and overlies the gallbladder. It is connected to two large blood vessels, one called the hepatic artery and one called the portal vein. The hepatic artery carries blood from the aorta, whereas the portal vein carries blood containing digested nutrients from the entire gastrointestinal tract and also from the spleen and pancreas. These blood vessels subdivide into capillaries, which then lead to a lobule. Each lobule is made up of millions of hepatic cells which are the basic metabolic cells. Lobules are the functional units of the liver ***(Guerra et al., 2012).***

The various functions of the liver are carried out by the liver cells or hepatocytes. Currently, there is no artificial organ or device capable of emulating all the functions of the liver. Some functions can be emulated by liver dialysis, an experimental treatment for liver failure. The liver is thought to be responsible for up to 500 separate functions, usually in combination with other systems and organs ***(Yassen et al., 2005).*** The liver supports almost every organ in the body and is vital for survival. Because of its strategic location and multidimensional functions, the liver is also prone to many diseases ***(Hoofnagle, 2004).***

B. History of Liver Transplantation

The first human liver transplant (LT) was performed in 1963 by a surgical team led by Dr. Thomas Starzl of Denver, Colorado, United States. Dr. Starzl performed several additional transplants over the next few years before the first short-term success was achieved in 1967 with the first one-year survival

post transplantation. Despite the development of viable surgical techniques, liver transplantation remained experimental through the 1970s, with one year patient survival in the vicinity of 25% ***(Pelletier et al., 2009).***

The liver is the second most commonly transplanted major organ, after the kidney, so it is clear that liver disease is a common and serious problem in this country. It is important for liver transplant candidates and their families to understand the basic process involved with liver transplant, to appreciate some of the challenges and complications that face liver transplant recipients (people who receive livers), and to recognize symptoms that should alert recipients to seek medical help ***(Watson et al., 2007).***

The introduction of cyclosporin by Sir Roy Calne markedly improved patient outcomes, and the 1980s saw recognition of liver transplantation as a standard clinical treatment for both adult and pediatric patients with appropriate indications. Liver transplantation is now performed at over one hundred centers in the USA, as well as numerous centres in Europe and elsewhere ***(Asberg et al., 2007; Sandhu et al., 2012).*** One-year patient survival is 80–85%, and outcomes continue to improve, although liver transplantation remains a formidable procedure with frequent complications ***(Goetzmanna et al., 2009).***

In 1983, the US National Institutes of Health established, by consensus, that LT was to be considered out of the experimental realm and was to be clinically accepted as definitive therapy for end-stage liver disease (ESLD) ***(Mazzaferro et al., 2009)***. The combination of improvements in rejection rates and

in surgical technique led to an enormous expansion of the field during the 1980s, with expansion from 3 centers in 1982 to more than 120 centers today. In 1999, 4,500 procedures were performed, up from approximately 100 in 1982. Currently, approximately 16,000 patients are on the liver waiting list ***(Porrett et al., 2006).***

An-increasing number of centers worldwide is performing living donor liver transplants (LDLT) for selected patients. This provides potentially life-saving therapy to many patients who otherwise would die awaiting organs from deceased donors. In Egypt, living-donor liver transplant has been performed more frequently during the past few years, driven by the absence of a law that permits use of deceased donor organs and by the need to decrease mortality of patients with end-stage liver disease ***(Hoofnagle, 2004).***

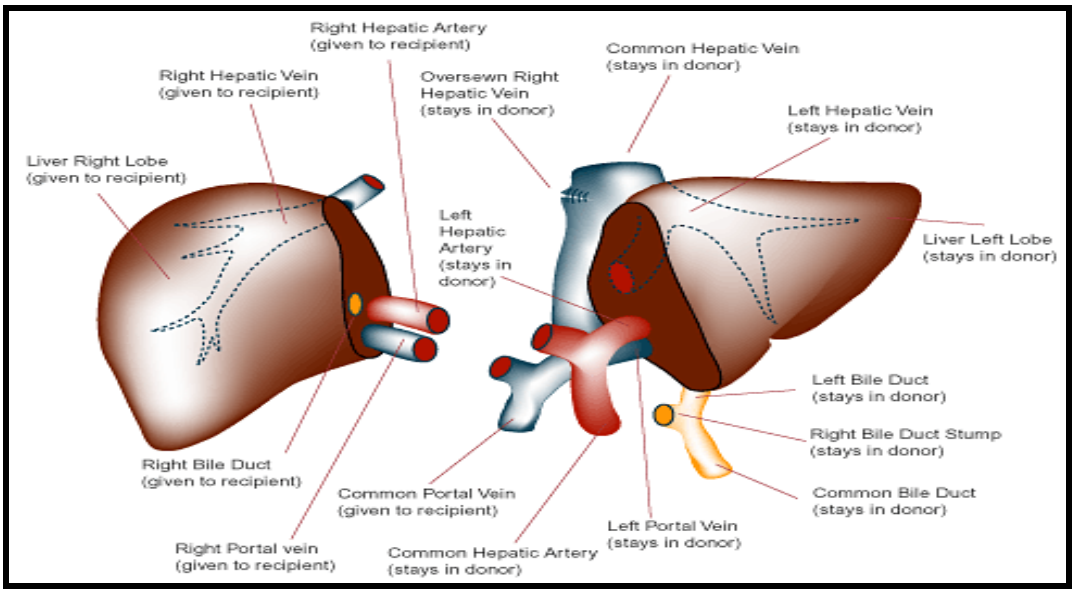

Figure (2): Liver Transplantation.
Adopted from ***Watson, C., Gimson, A., Alexander, G., Allison, M., Gibbs, P. and Smith, J. (2007).***

Liver transplantation is considered as a viable treatment option for patients with acute liver failure and end stage liver disease. In liver cirrhosis, transplantation is generally considered when a patient has suffered from either a complication of portal hypertension or a manifestation of compromised hepatic synthetic function ***(Steinman et al., 2011).*** However, given the high costs, mortality rate, and the paucity of donor organs, transplantation is currently justified only in the case of long-term prognosis, and psychological, intellectual, financial and family support ***(Aguado et al., 2009).*** Accordingly, patients may be considered as current, future or inappropriate-candidates. Selection consists of a search for contraindications and the primary care physicians are actively involved in this process ***(Heckman et al., 2008).***

C. Liver Transplantation Indications

- Liver transplantation is the surgery to remove a diseased or injured liver and replace it with a healthy whole liver or a segment of a liver from another person, called a donor. A successful liver transplant is a life-saving treatment for people with liver failure, a condition in which the liver no longer works as it should ***(Kotton et al., 2010)***.
- Liver transplantation is the replacement of a diseased liver with a healthy liver from another person (allograft). The most commonly used technique is orthotopic transplantation, in which the native liver is removed and replaced by the donor organ in the same anatomic location as the original liver ***(Yehia & Blumberg, 2009).***

- The most common reason for needing a liver transplant is cirrhosis. Cirrhosis as shown in figure (3) can be caused by many different types of diseases that destroy healthy liver cells and replace them with scar tissue. The common causes of cirrhosis are long-term infection with the hepatitis C virus, drinking too much alcohol over time, autoimmune liver diseases, long-term infection with the hepatitis B virus, and his buildup of fat in the liver and hereditary liver diseases ***(Kulik et al., 2012).***

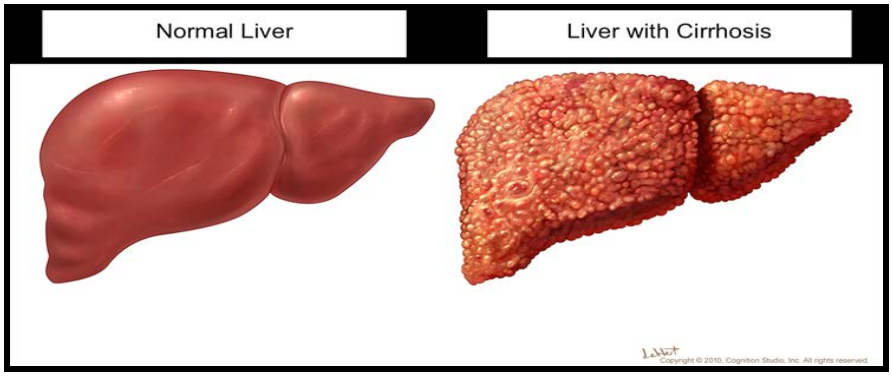

Figure (3): Liver cirrhosis.
Adopted from ***Kulik, L., Atassi, B. and van Holsbeeck L. (2012).***

- Liver transplantation is potentially applicable to any acute or chronic condition resulting in irreversible liver dysfunction, provided that the recipient does not have other conditions that will preclude a successful transplant. Uncontrolled metastatic cancer outside liver, active drug or alcohol abuse and active septic infections are absolute contraindications. While infection with HIV was once considered an absolute contraindication, this has been changing recently ***(Danzinger-Isakov & Kumar, 2009).***

- Acute liver failure (ALF) happens suddenly. Drug-induced liver injury (DILI) is the leading cause of ALF in the United States. The most common cause of DILI is an overdose of acetaminophen (Tylenol). Chronic liver failure, also called end-stage liver disease, progresses over months, years, or decades. Most often, chronic liver failure is the result of cirrhosis, a condition in which scar tissue replaces healthy liver tissue until the liver cannot function adequately ***(Abdo, 2012).***
- The most common reason for needing a liver transplant is cirrhosis caused by chronic hepatitis C, followed by cirrhosis caused by long-term alcohol abuse. Many other liver diseases also cause cirrhosis, including chronic hepatitis B and autoimmune hepatitis ***(Heckman et al., 2008).***
- Hepatitis C virus (HCV) induced end stage liver disease is the most common indication for orthotopic liver transplantation (OLT) ***(O'Connor et al., 2012).*** In Egyptian patients who have undergone living donor liver transplant, hepatitis C virus related end stage liver disease is the main indication for transplant ***(Yassen et al., 2005).***
- Liver transplantations are necessary for patients who have severe acute liver failure or chronic, irreversible, and progressive liver disease which does not respond to alternative medical and surgical interventions ***(Aloia et al., 2007)***.

D. Diagnosis of End Stage Liver Disease

The diagnosis includes signs of compensation, namely jaundice, ascites, bleeding oesophageal or gastric varicies. Additional laboratory tests include those exploring liver synthetic function, such as serum albumin and prothormbin time, while serum bilirubin investigates the ability of the liver to conjugate and excrete bilirubin. A low platelet count suggests portal hypertension and hypersplenism. The imaging studies include abdominal ultrasound, CT scan or magnetic resonance ***(Guerra et al., 2012).***

E. Contraindications of Liver Transplantation

The contraindications for LT may be absolute or relative. Absolute contraindications include widespread malignant disease, severe sepsis, irreversible cognitive neurological deficits, active psychosis, and active addiction to drugs and/or alcohol. Relative contraindications include portal vein thrombosis, severe cardio-pulmonary or renal disease, past multiple abdominal operations, positive hepatitis B antigen, personality disorder, history of psychiatric disorders, history of alcohol and/or drug addiction, depression, neurosis, history of use of psychotropic/ neuroleptics, limited family and social support, limited ability to adhere to therapies and inadequate motivation ***(Hoofnagle 2004; Jang et al., 2010; Kulik et al., 2012).***

F. Types of Liver Transplantation:

Types of liver transplantation as stated by ***Danzinger-Isakov & Kumar (2009)***:

1. ***Cadaver donor:*** The donor liver is obtained from a person who is diagnosed as brain death whose family volunteer to donate the organ for transplantation. People who receive cadaver donors wait on the national computer list until a suitable donor becomes available.
2. ***Living donor****:* A healthy family member, usually a parent, sibling, or someone emotionally close to the patient, such as a spouse, volunteers to donate part of their liver for transplantation. The donor is carefully evaluated by the team to make sure no harm will come to the donor or recipient.
3. ***Auxiliary transplantation*****:** Part of liver of a healthy adult donor (living or cadaver) is transplanted into the recipient. The patient's diseased liver remains intact until the auxiliary piece regenerates and assumes function.

G. Screening for Donor

1. Living donor transplantation is a multidisciplinary approach. All living liver donors undergo medical evaluation. Every hospital which performs transplants has dedicated nurses that provide specific information about the procedure and answer questions that families may have. During the evaluation process, confidentiality is assured on the potential donor**.** Every effort is made to ensure that organ donation is

not made by coercion from other family members. The transplant team provides both the donor and family thorough counseling and support which continue until full recovery is made ***(Watson et al., 2007).***

2. All donors are assessed medically to ensure that they can undergo the surgery. Blood type of the donor and recipient must be compatible but not always identical. Other things assessed prior to surgery include the anatomy of the donor liver. However, even with mild variations in blood vessels and bile duct, surgeons today are able to perform transplantation without problems. The most important criterion for a living liver donor is to be in excellent health ***(Aguado et al., 2009)***.
3. CT scan is performed for evaluation of a potential donor. The image shows an unusual variation of hepatic artery. The left hepatic artery supplies not only left lobe but also segment. The anatomy makes right lobe donation impossible. Even used as left lobe or lateral segment donation, it would be very technically challenging in anastomosing the small arteries ***(Pelletier et al., 2009).***
4. Before transplantation, liver-support therapy might be indicated (bridging-to-transplantation). Artificial liver support like liver dialysis or bioartificial liver support concepts are currently under preclinical and clinical evaluation ***(Mazzaferro et al., 2009)***.

5. Virtually all liver transplants are done in an orthotopic fashion, that is, the native liver is removed and the new liver is placed in the same anatomic location. The transplant operation can be conceptualized as consisting of the hepatectomy (liver removal) phase, the anhepatic (no liver) phase, and the postimplantation phase ***(Pompili et al., 2005)***.
6. The operation is done through a large incision in the upper abdomen. The hepatectomy involves division of all ligamentous attachments to the liver, as well as the common bile duct, hepatic artery, hepatic vein and portal vein. Usually, the retrohepatic portion of the inferior vena cava is removed along with the liver, although an alternative technique preserves the recipient's vena cava ***(Neuberger et al., 2009).***

H. Post Transplant Complications

Generally, a high postoperative complications rate is related primarily to technical complications or infection ***(Asberg et al., 2007; Sandhu et al., 2012).***

1. **Early complications** include haemodynamic and respiratory problems, metabolic disturbances, bleeding and coagulopathy, renal dysfunction, neurological dysfunction pain, and infections. The patient will be susceptible to infection due to his/her state of chronic ill health or acute liver failure pre operatively; this will then be compounded by the introduction of