AMERICAN UNIVERSITY OF BEIRUT

EDUCATIONAL PROGRAM FOR LIVER TRANSPLANT PATIENTS

by DIANA GERGES WEHBEH

A project submitted in partial fulfillment of the requirements for the degree of Master of science in Nursing to the Hariri School of Nursing Adult Care Track Faculty of Medicine at the American University of Beirut

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AMERICAN UNIVERSITY OF BEIRUT

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AN ABSTRACT OF THE PROJECT OF

Diana Gerges Wehbeh

for <u>Master of Science in Nursing</u> <u>Major</u>: Nursing (Adult Care)

Title: Educational Program for Liver Transplant Patients

Liver transplant has emerged as a treatment option for end stage liver disease and acute liver failure. These patients go through a complicated process of testing, then a major surgery, after which they need to undergo many changes in their lifestyle especially in the initial period in order to prevent and detect early complications like rejection, among others. Liver transplant is done at the American University of Beirut Medical Center and patients are admitted to the intensive care unit (ICU) after the transplant surgery, then are transferred to an open unit for some time before they go home. There is a coordinator who follows these patients during hospitalization; however there is no structured program that guides them throughout the process from diagnosis until discharge from the hospital. The aim of this project is to review the literature and develop an educational program for patients who are planned for transplant to smoothen the process on the patients and their families and to improve adherence to the medical recommendations.

The educational program was developed based on the literature on the learning needs of liver transplant recipients, and principles of adult and patient education. The program entails two educational sessions provided during hospitalization; one prior to surgery and the second close to discharge. In addition, a booklet was developed for patients to take home as reference. The booklet covers measures to identify and prevent complications following transplant; the medications to be taken, their indications and side effects; as well as lifestyle changes that patients need to undergo. The project implementation and evaluation plans are detailed.

The program is hoped to improve the outcomes of liver transplants recipients by improving their knowledge and skills for coping with this procedure.

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CHAPTER ONE INTRODUCTION

The first human liver transplantation was done in 1963 by Thomas Starlz in Denver (USA) after several attempts in canine models (Song et al., 2014). Since that time, there has been a progressive change in the standards and strategies (immunosuppression technique, drugs pre and post-operative) regarding liver transplantation that saved lives all around the world. Nowadays, liver transplantation is being done in more than 80 countries around the world (Zarrinpar & Busuttil, 2013), yet clinicians and health care providers still face many obstacles, from shortage of organ donors, long term complications of immunosuppressant therapy, non-adherence to medications and medical recommendations ,obesity, to hepatitis C recurrence and toxicities (Zarrinpar & Busuttil, 2013).

A. Background on Liver transplantation

The indications for liver transplantation include: acute liver failure, cirrhosis from chronic liver disease, metabolic disorders, Bud Chiari syndrome, and malignancies. Liver transplantation is considered the only standard of care for such patients. After meeting the inclusion criteria for liver transplantation, an extensive evaluation process is implemented, which includes standard blood tests, tissue typing and other tests including psychological assessment. Finally, after doing the tests, patients are evaluated based on the MELD (model for end stage liver disease) score, which identifies patients who are the sickest and most in need for transplantation

(Sharma & Rakela, 2005). Patients with the highest MELD score are then placed at the top of the waiting list for transplantation.

After being evaluated and placed on the waiting list, regular follow ups are done in order to monitor the MELD score; however the frequency of visiting the transplant clinic depends on the severity of MELD score (Rakela & Sharma, 2005). The timing of the operation is so crucial for patients to improve survival rate (Alqahtani & Larson, 2011). Once a donor is available, the surgery is done and the patient is sent to the intensive care unit (ICU) for hemodynamic monitoring and assessment of the graft in order to improve timely recognition of unexpected complications or any rejection (Feltracco et al., 2011).

In the post-transplant period, patients must be closely followed up in order to prolong survival and improve quality of life. After surgery, patients are given immunosuppressive therapy and are required to take many precautions and undergo major changes in their lifestyle to prevent rejection and other complications.

Survival rates following liver transplantation range between 90% and 70% at one year and 5 years respectively. However, survival depends on the level of illness; for example patients with primary biliary cirrhosis and cholangitis have the highest survival rate (Moreno & Berenguer, 2006). Post-operative complications (short term and long term) remain the major concern for such patients. Early post-operative complications include graft dysfunction, vascular thrombosis, neurological and biliary complications, electrolyte disturbance, pneumonia, and renal dysfunction. As for long term complications they include hypertension, cardiovascular disease, hyperlipidemia, obesity, osteoporosis, recurrent liver disease, renal failure, rejection and infection.

Moreover, 25 % of patients develop diabetes mellitus post liver transplant (Moreno & Berenguer, 2006).

Quite a number of factors may jeopardize patient's safety after liver transplantation; such as noncompliance to medications and non-adherence to the medical management and guidelines. Non- adherence among liver transplant recipients leads to an increased risk of graft failure (Lieber & Volk, 2013). Moreover, nonadherence to post transplant medications, which ranges from 15% to 40% is a striking problem because it leads to early graft rejection, poor quality of life, and is associated with increased post-transplant mortality, thus increasing health care cost (Burra et al., 2011).

A retrospective cohort study was done over a period of six years to evaluate the cost associated with medication non adherence among transplant patients. They measured compliance over a period of three years and cost associated with adverse outcomes (rejection, infection and diabetes). The investigators found that persistent noncompliance to medications accounted for an increase in medical cost by 12,840 US dollars per person over a period of three years (Pinsky et al., 2009).

Graft failure and medication noncompliance can be managed by proper patient education that starts with the initial diagnosis of liver failure until after transplantation. So the aim of this project is to review the literature and develop an educational program for patients who are planned for liver transplant to ease the process for the patients and their families, to improve patient adherence to the medical recommendations, and prevent long term complications.

B. Transplant Services in Lebanon

In Lebanon one hospital is currently performing liver transplantation: the American University of Beirut medical center (AUBMC) and the number of patients undergoing liver transplant is still on the low side. According to the National Organization for Organ and Tissue Donation and Transplantation in Lebanon (NOOTDT-Lb) that was established in 1999 in affiliation with the Ministry of Public Health, a total of 19 liver transplantations were performed between 1985 and 2012 in Lebanon (NOOTDT-Lb, 2015). According to the AUBMC statistics, from 1998 to the present, 21 liver transplants were reported: 15 were for adults and six were for children. There were five deaths at a median of nine days (range 1-56 days) post-transplantation. All the remaining16 survivors are doing well, with normal liver function tests at a median follow-up time of 93 months (range 10-185 months) after transplantation.

At AUBMC, a liver transplantation unit was established in 1998. The transplant team is made up of two transplant surgeons, one transplant coordinator who is a nurse, and a social worker; all are involved in the process of liver transplantation. Moreover, there is a senior transplant procurement manager who is responsible for the donation team and works separately from the transplant team; her main role is to identify potential donors and report deaths to NOODTD-lb. Recently, AUBMC announced its participation in the National Organ Donation project, which aims at improving the process of organ donation in Lebanon.

C. Significance

The process of transplant is complicated and patients need to deal with lots of procedures and treatment; after surgery, their life tends to change. Patients require a lot

of information concerning the three phases of surgery: peri-operative, intra-operative, and post-operative. Education is very important and needs to be tailored to the phase of the transplant and be reinforced quite often. In this regard, Mendes, Rossin, Ziviani Lda, de Castro, and Galvao (2012) assessed the knowledge of liver transplant candidates after an educational intervention in a public hospital in Sao Paulo. Findings revealed a significant improvement in patients' knowledge after the educational intervention. Actually, there was an increase by 12:55% in correct answers after the intervention, and the difference was statistically significant (p=0.0234) (Mendes et al., 2012).

At AUBMC, there is no educational material that addresses all the information that liver transplant patients need. Therefore, the aim of this project is to develop an educational program for liver transplant patients, thus controlling short term and long term complications and improving adherence to the medications and management plan.

Even though the number of liver transplantations done at AUBMC is still low, enrolling patients in an educational program is so crucial in order to help them make a smooth transition with a complication-free recovery and rehabilitation. The educational program will be of a great benefit for patients after being discharged from the hospital with multiple medications and several instructions for lifestyle changes. In this project, the literature on liver transplantation and related educational programs will be reviewed. An educational program will be developed and its implementation and evaluation plans discussed at length.

CHAPTER TWO LITERATURE REVIEW

This chapter describes the pathway for the liver transplant patients, the educational needs and educational principles and modalities. Studies showing the positive impact of educational programs for liver transplant patients on long term outcomes are reviewed.

A. Management Pathway for Liver Transplant Patients

Once the patient has one of the indications for liver transplantation, a thorough workup is done in order to assess suitability for transplantation. The evaluation process involves a multidisciplinary team that is made up of a transplant hepatologist, transplant surgeon, nurse coordinator, social worker, transplant psychiatrist or psychologist and other consultants depending on the need (Rakela & Sharma, 2005).

Each member of the team has a unique role. The transplant hepatologist assesses the medical need for liver transplantation, manages complications of cirrhosis, checks if there are contra indications for liver transplant and finally checks if there is any disease issue that might influence the transplantation outcome. On the other hand, the transplant surgeon assesses surgical techniques and risks of the operation. Whereas the psychologist tackles any history of substance abuse, risk of relapse, and presence of social support (Rakela & Sharma, 2005).

There are relative and absolute contraindications for liver transplant. Relative contraindications include age above 65, malnutrition, and irreversible organ failure that includes cardiac and pulmonary problems, in addition to previous upper abdominal surgeries, poor functional status and social support (Al Qahtani & Larson, 2011). The

absolute contraindications include irreversible cerebral injury, severe cardiopulmonary disease, sepsis, HIV, extra-hepatic malignancies, vascular anomaly, active alcohol or drug use, and psychological problems (Al Qahtani & Larson, 2011).

Once the decision to proceed with transplantation is made, extensive evaluation is performed and includes: 1) blood tests, 2) abdominal imaging, 3) cardiac evaluation, and 4) other standard testing (Alqahtani & Larson, 2011). This evaluation is done in order to check whether or not the patient is suitable for transplantation (Rakela & Sharma, 2005).

Blood tests include CBC, SGOT, SGPT, PT, INR, and Viral serologies, namely hepatitis A, B and C virus, Epstein Barr virus, herpes simplex virus, HIV, and Varicella Zoster. Abdominal imaging includes four phase abdominal computed tomography, abdominal ultra-sound with Doppler. Cardiac evaluation includes ECG, echocardiogram, and cardiac stress test if the patient's age is more than 50. Other standard tests include colonoscopy (age above 50), mammography for all patients, PSA, pulmonary function test if the patient has history of smoking or lung problems, and coronary angiogram.

After the extensive evaluation is complete, the multidisciplinary team decides on whether the patient should be put on the waiting list. The timing of the operation is so crucial to improve survival rate. However, because of the increased number of patients placed on the waiting list, the MELD score was developed to allocate organs (liver) according to the patients' medical condition (Trotter & Osgood, 2004). The MELD score helps in organ allocation and predicts mortality in patients with chronic liver disease (Rakela & Sharma, 2005). It is calculated using the following formula:

MELD= 3.78 X log e(bilirubin) plus 11.2 x log e(INR) +9.57 X log e(creatinine) + 6.4 (Kamath, Kim, Advanced Liver Disease Study Group, 2007).

1. General Pre-operative Medical Care

After the patient is placed on the waiting list, several items are updated and multiple screenings are done. First the MELD score shall be updated frequently, regular follow ups should take place, and blood tests (INR, serum bilirubin and Creatinine) should be taken according to MELD score (Rakela & Sharma, 2005). The table below shows the frequency of blood tests as function of the MELD score.

MELD score	Timing of the blood tests
10	Every 6 months to one year
11-18	Every 3 months
19-24	Monthly
Above or equal 25	Weekly

Table 2.1. Blood tests and MELD score.

Moreover, follow ups are done to check for the possibility of developing hepatocellular carcinoma (HCC), which is confirmed using blood tests and abdominal imaging. Patients with confirmed stage 2 hepatocellular carcinoma with absence of spread receive priority on the waiting list. Patients with stage 3 and 4 HCC are not eligible for MELD update and the tumor is downsized using chemotherapy and radiation therapy (Rakela & Sharma, 2005). Other components of care for patients on the waiting list include immunization with hepatitis B and A vaccine, influenza vaccine each year and pneumococcal vaccine, in addition to yearly PPD test and regular breast/cervical and colon screening, in addition to treating the primary etiology, whenever the reason for liver disease is known (hepatitis B, hepatitis C, hemochromatosis, primary biliary cirrhosis, cholangitis autoimmune hepatitis) with the appropriate therapy (Rakela & Sharma, 2005).

Each country has its own regulations regarding organ allocation; however, there are organ procurement organizations that help in finding organs for sick patients. Once there is a compatible donor, the operation is done and patients are sent to the intensive care unit (ICU) for monitoring.

2. Intensive Care Management

ICU management post transplantation focuses on seven items in order to improve timely recognition of unexpected complications or any rejection (Feltracco et al., 2011). This management includes: Rapid hemodynamic stabilization, correction of coagulopathy, early weaning from mechanical ventilation, kidney function preservation, graft rejection prevention and infection prophylaxis.

Most patients with cirrhosis have either impaired ventricular contractility or dilated cardiomyopathy, which leads to post-operative hypotension. So it is important to optimize liver hemodynamics to prevent inadequate graft perfusion (Feltracco et al., 2011). A pulmonary artery catheter helps in optimizing cardiac output and organ perfusion by providing data that can be used in deciding on fluid therapy; accordingly, it is important post operatively to prevent either excessive fluid administration or severe hypovolemia. Since patients receive multiple transfusions and fluids intra-op, it is important to achieve negative balance in the first day after the operation to reduce the incidence of pulmonary edema (Feltracco et al., 2011).

Thrombocytopenia might occur following liver transplantation and might lead to bleeding so the risk of bleeding must be balanced against the risk of thrombosis. The main focus in ICU is to maintain an INR between 1.2-2 and a platelet count above 50,000. Moreover, clinicians might use recombinant factor VIIa when blood products are usually not enough to compensate for post-operative hemorrhage (Feltracco et al., 2011).

Another aspect that needs to be attended to is early extubation post liver transplantation. However sometimes, some patients experience difficult weaning from the ventilator, especially patients who receive massive transfusions, have inadequate clearance of bronchial secretions, pneumonia and adverse events of immunosuppression therapy (Feltracco et al., 2011).

Accurate intake output monitoring is critical to avoid any renal dysfunction. It is important to do continuous assessment of volume status to avoid having negative balance, hypo perfusion, and renal vasoconstriction (Feltracco et al., 2011). Pulmonary artery catheter aids in the continuous assessment of volume status.

Monitoring of graft function is important to detect any graft dysfunction and it is done based on tests like liver enzymes, bilirubin, and albumin and coagulation factors. Indocyanine green clearance test involves the use of a dye that is eliminated by the liver without extra hepatic metabolism or excretion and measuring its blood clearance. The test provides a sensitive indicator to evaluate liver function and is used to assess the function of graft in a short period of time (Feltracco et al., 2011). Liver biopsy is the

gold standard for the diagnosis of acute rejection; it is done on day 7 post transplantation (Van Ha, 2004).

Immunosuppression is the main therapy used following liver transplantation. The most common used immunosuppressive drugs are calcincurin inhibitors and steroids (Feltracco et al., 2011). Detailed information will be tackled later in chapter three educational programs. Finally, as a result of immunosuppressive therapy, patients post liver transplant are at high risk of acquiring infections either viral or bacterial from different sources. Prophylactic antibiotics are given post-operatively and mostly they cover gram positive and gram negative organisms; moreover antifungal drugs are given too (fluconazole most commonly used). Finally, CMV prophylaxis is not given unless the antigen detection was positive.

B. Educational Needs of Liver Transplant Patients

Educating patients is one of the JCI standards, and it's the responsibility of all hospitals to provide proper education for all patients (Donaldson et al., 1999). It was identified that educating patients about their disease process, treatment plans and prognosis help them to take the proper decisions regarding their health (Donaldson, Routledge, & Pravikoff, 1999).

Nurses play an important role as educators and in affecting patient's behavior, attitude, and life style (Mendes et al., 2012). Clients who are diagnosed with liver failure need continuous nursing interventions to help them modify their life style in order to control disease progression. Educating patients about any disease helps them understand their condition and make health care decisions. Moreover, health education leads to improvement in patients' satisfaction and quality of life (Mendes et al., 2012).

Patients who undergo solid organ transplantation need to learn about new chronic drugs and life style modification that includes hygiene, infection prevention, and monitoring of new organ function.

A study was conducted in Sao Paulo, Brazil in a transplant center in order to identify learning needs of candidates waiting for liver transplantation (Mendes et al., 2012). Fifty five patients participated in this study and a three part instrument was used for the data collection: socio demographic identity, data about chronic liver disease and patient information needs. In order to identify patient's information needs, the researcher prepared 17 suggestions concerning topics related to the liver transplantation process (questions 1-9 tackled perioperative period, questions 10-12 tackled intraoperative period, questions 13-17 tackled post-operative period). Participants were asked to rank 10 topics they would like to learn about before the operation (from the most importance to the least importance). The answers were classified from one till ten where the first answer (most important) was scored ten, the second 9 and so on. Finally, the numbers were added so answers with the highest score were the most important for the candidates. The top three suggestions with the highest score were about care required before transplantation, complications, and care required after transplantation. The perioperative period was found to be the most important for the candidates. The authors recommended that educating liver transplant candidates starts as early as possible because it impacts the long term outcomes of the operation with greater satisfaction for patients and families. Moreover, family members in that study reported having difficulty in dealing with verbal information and they preferred written material (Mendes et al., 2012). Therefore, providing verbal information is not enough; it should

be coupled with written material that the patient and family members can use when needed.

Post-operative teaching should mainly focus on: signs and symptoms of rejection and infection; medication dosage, action, frequency of administration, and side effects; activity restriction; dietary management; and notification of the transplant team in case of any arising problem (Mendes et al., 2012). Patient and family involvement in the pre and post-transplant education helps in the prevention and early recognition of post-operative complications. The family presence can help in case the patient was very sick during hospitalization and not very ready for learning so they can assist the patient once he is discharged home.

Burra and colleagues did a review of the published literature to identify nonadherence rate and identified risk factors for non-adherence among liver transplant patients. They found that non-adherence rate to immunosuppressive drugs ranged from 15%-40%, while non-adherence rate to doctor's appointment ranged from 3%-47%. Risk factors are associated with patient's non-adherence are side effects of the immunosuppressive drugs and patients' perception that the medications they are taking are harmful. The authors concluded that the main interventions that can be done to improve adherence are patient education, counseling, adjusting drug dosages and improving the connections between the patient and health care provider (Burra et al., 2011).

In summary, as patients are discharged following liver transplant, they are subjected to a complex treatment regimen. Non-adherence to the treatment and medication instructions has been identified as a significant problem, and is associated

with complications including infection and rejection, which jeopardize patient's health and quality of life. Thus education must address these areas.

C. Patient Education Principles

The health care provider can use adult learning principles to maximize teaching (Russell, 2006). Adults are interested in learning because they seek to create a change either in their knowledge, behavior, or skills. Many traits encourage adults to learn, such as motivation, experience, level of engagement, and application of the learning (Russell, 2006).

Multiple patient education principles that guide nurses in educating patients have been identified in the literature. Those principles are: 1) setting learning objectives, 2) engagement of the patients in the learning process, 3) helping the patient acquire new skills and knowledge, 4) teaching based on the patients' style, and 5) using a variety of means to facilitate learning (Donaldson et al., 1999).

Motivation emerging from a situation or a life experience can stimulate the adult learner to learn. Accordingly, when the patient is concerned about a disease that is affecting one's life, the patient gets motivated to learn more (Russell, 2006). In addition, counting on the patient's experience is believed to be quite valuable for adults. For meaningful learning, adults seek to correlate present learning with past experience. Counting on one's experience helps to set the ground for another principle of adult learning, which is engagement. The adult's level of engagement must be considered in planning teaching as adults decide what they want to learn based on their level of motivation, in order to facilitate the learning process (Russell, 2006). Finally, as adults are oriented to applying the learning, after giving education to patients, it is important to

include return demonstration in order to make sure that the patients understood the information (Russell, 2006). In planning patient education, and based on these principles, the use of discussion becomes paramount. Patients ought to be given the opportunity to share their experiences and expectations during the teaching-learning process. This approach will be more motivating than a pure didactic approach.

There are multiple learning styles, most of which are based on childhood learning pattern, such as the visual, auditory and kinesthetic style. Those styles can be used to help nurses educate patients about any topic by developing multiple teaching strategies. The different learning styles will help in the development of an educational program for liver transplant patients using a variety of teaching methods to promote learning. Those methods include: in-hospital sessions (visual presentation), written handouts, and finally group discussions.

D. Educational Programs and Associated Outcomes in Liver Transplant Recipients

A study was conducted in Sao Paulo state in a public hospital (Dal Sasso Mendes et al., 2013) in order to test the effectiveness of an educational intervention, using a quasi-experimental one group pretest-posttest design with a total of 15 participants. The sample inclusion criteria included age above 18, MELD score between 6 and25, patients in good clinical conditions, and literate. The educational intervention took place during 2 meetings in an indoor auditorium. Several topics were covered including: general view about liver transplantation, historical aspect of liver transplantation, organ distribution system, surgery, and anesthesia. The participant patients were subjected to a posttest to assess their knowledge after the educational intervention. Patients answered correctly 60% of the questions on material related to before the educational intervention. In general patients scored highest on pretest questions about pre-operative period (70%), followed by intraoperative period (68%), and post-operative period (44%). The lowest correct answers related to immunosuppressant therapy, care needed after liver transplant and complications after the operation. After the educational intervention, it was noted that questions about the postoperative period showed a significant increase in the correct answer rate. The results for the correct answers after the educational intervention are as follows: perioperative period (82.5%), intraoperative period (80%) and postoperative period (68.89%). There was an increase by 12.55% in correct answers after the intervention and the difference was statistically significant (p=0.0234) (Mendes et al., 2013).

Another study was conducted in Sao Paulo in Brazil to evaluate the effectiveness of a pre-transplantation orientation group on general knowledge related to liver transplantation. All patients on the waiting list who were registered at the technical file of the San-Paulo State Health Department were selected. A total of 113 patients were involved in the study. Orientation intervention took place in one session of two hours duration addressing all the information related to the pre-operative, intra-operative and post-operative period. To evaluate the effectiveness of the program, a 17 item questionnaire was given to patients before and after the intervention to assess their knowledge about the transplantation process. The end result was a 59% increase in correct answers after group attendance. Items with significant improvement related to the average length of stay in hospital, use of immunosuppressive drugs, indications for transplantation, frequency of appointments with the surgeon in the first month; physical activities, diet, blood transfusion, and forgetting medication (Guimaro et al., 2007)

In summary, the literature on this topic is limited. Using the learning teaching process, an educational program will be proposed for liver transplant candidates at AUBMC. The detailed program will be discussed in chapter three and it will include in hospital session and written material (booklet).

CHAPTER THREE PROPOSED EDUCATIONAL PROGRAM

This chapter describes the proposed educational program with the associated power point and booklet. According to the Center For Disease Control And Prevention (2012), it is important to make sure that patients are getting proper health education in order to help them understand their disease process, get more involved in the treatment, planning and health care decisions. Most of the literature stresses the importance of patient education. For the purpose of improving patient adherence to medications and prevention of long term complications among transplant patients, an educational program is proposed.

The proposed educational program for liver transplant candidates at AUBMC comprises both face-to-face sessions and a booklet of an educational focus. Two sessions are designed to be offered face-to-face using power point presentations with discussion. Moreover, a patient education booklet will be provided in the second session to cover all the information related to the post-operative period and what is expected from the patients to do at home. All the educational material will be presented to the patient with the presence of a close family member (primary care giver).

The educational information mentioned in the section below provides liver transplant recipients with general information related to liver transplantation. The material is designed to introduce patients to the principles and management expected post transplantation, including all aspects of self-care and changes in life style, thus preparing them to live with a new liver and avoid preventable complications.

A. Pre-Liver Transplant Instructional Material

Once patients have one of the indications for liver transplantation, they will seek medical advice and will take an appointment with the surgeon to evaluate candidacy for liver transplantation. As part of the appointment, a nurse will be available to start familiarizing the patient with general information related to the liver using the face-toface power point instructional format (see Appendix A for the first power point presentation). The advantages behind using power point presentation are: they are easy to design, flexible to change the content whenever necessary and flexible to skip slides or repeat slides. Finally, while using power point presentation once can combine both the visual and auditory learning styles at the same time.

The pre-liver transplantation instructional material will focus mainly on the function of the liver, diseases of the liver that lead to its failure, complications of the diseased liver, indications for transplantation, and the process that patients assume until transplantation is done. This section aims at orienting the liver transplant patients about:

- Identifying the main functions of the liver.
- Identifying the causes of liver failure.
- Describing the various steps that will make you ready for liver transplantation.

B. Post-Liver Transplant Instructional Material

The second presentation will be given after the operation when the patient is transferred from the ICU to the regular floor (see Appendix B for second presentation). The presentation will cover precautions related to infection, general information about medications to be taken and self-care to be done at home. The rationale for designing this material is to help patients:

- Describe indications and important tips related to the medications that you will be taking at home.
- Outline the self-monitoring activities that must be done at home.
- Identify the common complications that you may develop post liver transplant.
- Identify the signs and symptoms of infection to be able to report them early.
- Appreciate the adherence to a new life style to keep the new liver functioning.

C. Booklet (liver transplantation, what do you need to know)

Finally before discharge from the hospital patients at the time of the second educational session when they are in the open unit will be given a booklet that will guide them at home (see appendix C for a copy of the booklet).

Below is the outline to be covered in the booklet.

- I. Managing your medications
- II. Diagnostic tests and follow ups
- III. Self-care
 - a) Wound care
 - b) Prevention of infection
 - c) Alerting symptoms
 - d) Vital signs monitoring
 - e) Daily weight monitoring
- IV. Complications: Recognition and management
- V. Immunizations
- VI. Life style recommendations:
 - a) Nutrition

- b) Smoking cessation
- c) Activity and Exercise
- d) Sexuality
- e) Driving

Multiple strategies have been used to guide the development of the written educational material. The first strategy focuses on the readability of the written educational material using small sentences and big font size (14 or 16). The second strategy is simplifying the educational material using pictures, audiovisual, prioritization of information and finally writing at fifth grade level when not sure about the patients education level. Moreover, effective teaching focuses on using active voice in the present tense, using short words, spelling words properly, keeping sentences short, and avoiding unclear words and technical jargon (Bastable, 2008). The content included in the booklet and power point presentations is based on the research findings on the learning needs of transplant recipients.

The implementation process for this project will take place at different levels. The educational program for liver transplant patients which consists of two power point presentations and a booklet will be submitted for review by expert people (liver transplant surgeon at AUBMC, NOODT coordinator, and the nurse coordinator at the Hepatopancreaticobiliary and Liver Transplantation Unit). After review, it will be sent for approval by the director of liver transplant unit, chairperson of department of surgery, and director of nursing. Following the approval, the educational material will be revised by the patient and family education coordinator (patient education committee). Finally, the booklet will be sent to the public relation office for translation to Arabic and finalization.

CHAPTER FOUR PROGRAM EVALUATION

The educational program will be proposed to the AUBMC hospital administration. The proposal will address the incidence of medication non adherence among transplant patients and the cost associated with such non adherence. Moreover, the importance of patient education in reducing complications and improved patient satisfaction after using an educational program will be discussed. The budget needed to implement the program will be outlined, including human and material resources needed. The prepared pamphlet and presentations will be submitted to the patient affairs office (patient education section) for review. They will be translated into Arabic.

A. Brief Overview of the Implementation Phase

After securing the approval from the administration, the program will be implemented for use at the Hepato-pancreatic-biliary and Liver Transplantation Unit. The nurse coordinator for liver transplantation will be assigned to give the educational information for patients. The patient's significant other or primary caregiver at home will be invited to attend the educational sessions as many patients may be acutely ill or very anxious, which may limit their readiness to learn. The first session will be given when the patient has an appointment with the surgeon to discuss the evaluation process prior to surgery, and the second session will be given after the patient is transferred to the open unit from the intensive care unit. The booklet will be handed to the patient at the second session and he/she will be asked to bring it with him/her at every visit to the clinic after discharge and will be reminded of this again on the day of discharge for a quick review and to answer any questions the patient may still have. Moreover, with every visit to the clinic after discharge, a topic from the booklet will be reinforced by the nurse coordinator according to the patient's preference or queries he/she may have. Program evaluation

B. Evaluation

The program evaluation will take place at three levels: process evaluation, outcome evaluation and impact evaluation.

1. Process Evaluation

Process evaluation (formative evaluation) involves monitoring of the information given to clients and adjusting the information accordingly. A formative evaluation form will be used at the end of each presentation to get the feedback from the patients about the learning objectives, content of the presentations and mode of delivery. The feedback will be used to adjust and improve the educational information offered. Refer to appendix D. Moreover, when the patient visits the transplant team after discharge from the hospital, he/she will be asked about the booklet through the following questions:

- 1. Are you using the booklet to remind yourself of things you need to do to protect yourself?
- 2. How often did you refer to the booklet since you left the hospital?
- 3. What were those topics you checked?
- 4. Do you find the information in the booklet helpful?
- 5. Do you have any recommendations to improve the booklet?

2. Outcome Evaluation

The outcome evaluation will be done after one month from hospital discharge to evaluate whether the educational program achieved its objectives or not. Outcome evaluation will take place using self-report, percentage of times the drug blood levels are within the therapeutic range and the standard deviation of blood levels of immunosuppressive drugs (tacrolimus, Sirolimus, cyclosporine).

Self-report is a subjective form of evaluation that will be used through a questionnaire by interviewing the patient on the day of the doctor's appointment. The questionnaire is adapted from Morisky adherence scale to assess medications adherence (Morisky, Green & Levine, 1986) and consists of five questions asked to check adherence to medications. Yes will be given a score of 1 and No will be given a score of zero. Finally, the numbers will be added and interpretation of results is the following: zero reflects high adherence, 1-2 reflects medium adherence and 3-5 reflects low adherence. Refer to appendix E.

During the first month after discharge, blood levels of the immunosuppressive drugs will be taken on weekly basis and at lower frequencies afterwards. The percentage of times the blood levels are in the therapeutic range will be calculated as an indication of the effectiveness of medication and an indirect measure of adherence to treatment. In addition, at the end of the first month following liver transplantation, the average standard deviation (SD) of the measures for each drug level will be calculated. Standard deviation of each drug reflects the degree of fluctuation between blood levels of each medication taken throughout a period of time. In other words, having a large SD means that the blood level of the drug is fluctuating a lot over time, which may reflect non

adherence to the medications (Dew et al.,2007). The procedure can be repeated at 3, 6 and 12 months afterwards.

3. Impact Evaluation

Another way to evaluate the success of the program is to note its impact on patient outcomes. This evaluation can be made by collecting information about transplant recipients before and after the program implementation. A retrospective medical record review will be done on all transplant recipients and data will be collected on readmission rates and reasons for readmission, mortality, number of biopsies done per patient and the incidence of short term and long term complications. The same data will be collected from transplant recipients prospectively six months after program implementation. Finally, patient satisfaction scores, which are collected from all patients at AUBMC, may be compared before and after implementation of the program.

The nurse coordinator of the transplant unit will be responsible for collecting data concerning all types of evaluation and the data will be stored on the computer for the purpose of follow up and interpretation. Moreover, reinforcement will be done at an individual level if one of the evaluation forms showed patients being non-adherent either to medications or medical recommendations. Attendance of patients to follow up appointments will also be measured.

Conclusion

In conclusion, liver transplant is a complex intervention associated with major life style changes and precautions that patients must undergo after surgery. Non adherence among transplant patients is a significant problem and carries a high risk for graft rejection. Patient education is one of the interventions that can be done to improve adherence to drugs and medical recommendations, thus decreasing the incidence of

short and long term complications. Last but not least, liver transplantation is not enough on its own to save lives, but rather long term adherence is the key for patients to enjoy the state of health they used to enjoy before getting ill.

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APPENDICES

APPENDIX A

PRE-LIVER TRANSPLANT INSTRUCTIONAL MATERIAL

5/6/2015











What Causes Liver disease?

- Viral hepatitis
- · Autoimmune hepatitis
- Wilson disease
 Primary biliary cirrhosis
- Cancer of the liver
- Neuroendocrine tumors
- · Sometimes there is no direct cause for the liver failure











5/6/2015





What Can I Expect after Going Home?

 Following the medical instructions is very important to prevent rejection or any avoidable complications following transplantation.

You will be given general information in the next presentation about what you need to do and know when you go home.

Games

Pick one number from one till 5 Question 1
What are the main functions of the liver?
Question 2
What causes liver disease?
Question 3
Where do organs for liver transplantation come from?
Question 4
Where do you go after surgery?

APPENDIX B

POST-LIVER TRANSPLANT INSTRUCTIONAL MATERIAL

5/6/2015



- Outline the self monitoring activities that must be done at home.
 Identify the common complications that you may develop post liver transplant.
 Identify the signs and symptoms of infection to be able to report them early.
 Appreciate the adherence to a new life style to keep the new liver functioning.













Acute Rejection

- It happens when the immune system recognizes the new liver as a foreign body.
- It is diagnosed by blood tests and liver biopsy.
- It is treated by increasing the dose of the immunosuppressive drugs.



5/6/2015



Long term Complications 1) High blood pressure 2) Diabetes mellitus

- kidney dysfunction 3)
- 4) High blood lipids
- 5) Heart disease
- Osteoporosis/weak bones 6)
- Rejection episodes 7) 8)
- Cancer Mood disorder 9)







5/6/2015



APPENDIX C

BOOKLET (Liver Transplantation, What Do You Need To Know)













Anti-infective medications(anti-fungal, anti-viral and antibiotics)

Once you go home, you will see your doctor on weekly basis for the first month, then on monthly basis.

II. Diagnostic tests and follow ups

How often will the doctor see you?

What are the tests that are ordered after discharge? Diagnostic tests that might be ordered are:

1)Blood tests will be ordered twice per week for the first month after transplantation and then once per week for the second month then twice per modifications are taken once per week until the levels are within the normal range, then they are taken once per month.

2)Abdominal Imaging : in case your liver function tests are not normal, many abdominal scans will be done to check the function of the new liver.













VI. Life style Nutrition: o Focus on eating enough protiens,

calories, vitamins and minerals. o If you are diabetic, you will be referred to a dietatian to give you detailed information about the apprioprate diet to follow.

So what should you eat the first month after transplantation? 1) Eat nutrients that are high in calories: milk products, whole grain, plant

6)Avoid canned food products, smoked meat, fish, chips and salted crack-ers, limit the intake of pickles, olive and salad dressings.

Sexuality and pregnancy:

o You can resume sexual activity once you feel physically well.

o Use condoms to prevent transmission of infections

o Once you plan to get pregnant consult with your doctor because some of the medications you are taking might affect the fetus.

Driving:

o Resume driving within four to six weeks after transplantation, depending on your recovery, complications, and medications you are taking.

o Wear your seat belt while driving.

o Put a towel beneath the seat belt to prevent pressure over abdomen.



Vilal allar Neight	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunda
Weight in kg							
Blood pressure							
Temperature							
Blood sugar							

Smoking: o It's advisable to quit smoking because Nicotine might affect blood levels of immunosuppressive medications you are taking. o There is a smoking cessation program available at AUBMC that will help you in quitting. Activity and Exerci



o After liver transplantation, you will have weak muscles and you will feel tired all the time. o Exercise one month after going home in coordination with your doctor. o Walking is the best thing to do. o Avoid any vigorous activity and heavy lifting during the first year after the operation. o Check with you doctor on how to do regular exercise like walking, swimming, basketball.



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APPENDIX D

FORMATIVE EVALUATION

Please provide us with your feedback about the following items by placing an X for each item in the box that corresponds to your choice. Your feedback is highly appreciated.

Items for	Strongly	Agree	Neither	Disagree	Strongly
evaluation.	agree		agree nor		disagree
	_		disagree		-
The presentation					
was adequate					
The content of the					
presentation was					
clear					
The speaker was					
able to answer all					
my questions					
The power point					
presentation					
helped me					
understand the					
information.					

APPENDIX E

MODIFIED MORISKY SCALE

Answer with yes or no to each item by placing a check mark corresponding to your choice

Item	Yes	No
Do you ever forget to take your prescription drugs?		
Are you careless at times about taking your drugs?		
Do you sometimes stop taking your drugs when you feel		
better?		
Do you sometimes stop taking your drugs if they make you		
feel worse?		
Do you sometimes stop taking your drugs because they are		
expensive?		