


Millenium - Journal of Education, Technologies, and Health, 2(ed espec. nº10), 185-192.




**PROGRAMA DE ENFERMAGEM DE GESTÃO DE CASOS NO TRANSPLANTE DE FÍGADO – CRITÉRIOS DE TRIAGEM:
ESTUDO QUALITATIVO**

A NURSING CASE MANAGEMENT PROGRAM IN LIVER TRANSPLANT – THE SCREENING CRITERIA: A QUALITATIVE STUDY

**UN PROGRAMA DE ENFERMERÍA DE GESTIÓN DE CASOS EN TRASPLANTE DE HÍGADO - LOS CRITERIOS DE
SELECCIÓN: UN ESTUDIO CUALITATIVO**

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RECEIVED: 04th December, 2021

ACCEPTED: 10th May, 2022

RESUMO

Introdução: O transplante de fígado é o último tratamento numa situação de doença hepática avançada. A gestão de casos é um programa importante na promoção do sucesso do transplante de fígado.

Objetivo: Definir os critérios da fase de triagem para inclusão num programa de gestão de casos de enfermagem em pacientes submetidos a transplante de fígado.

Métodos: Estudo qualitativo longitudinal por meio de estudos de casos múltiplos. Incluímos seis pacientes que foram submetidos a um transplante de fígado. Quatro participantes são do sexo masculino, com idade média de 45 anos. Os dados foram colhidos por meio de análise documental do processo clínico, observação participante e entrevistas não estruturadas. A análise dos dados foi baseada na Teoria Fundamentada de Strauss e Corbin.

Resultados: identificaram-se nove critérios para a fase de triagem: experiências problemáticas ou difíceis durante a transição saúde / doença, falta de confiança nos prestadores, problemas socioeconómicos, hospitalização prolongada, história prévia de não adesão ao regime terapêutico, excesso ou falta de recurso aos serviços de saúde, menor apoio familiar, doença psiquiátrica e sintomas da doença.

Conclusão: Com a identificação desses critérios, podemos incluir os pacientes num programa de gestão de casos e implementar terapêuticas de enfermagem direcionadas às suas necessidades específicas. Este estudo é uma importante contribuição para a prática clínica do enfermeiro, pois permite identificar os casos especialmente vulneráveis, antecipar as necessidades / dificuldades do paciente no processo de transição saúde / doença e implementar a terapêutica em resposta às reais necessidades dos pacientes.

Palavras-chave: gestão de caso; enfermagem; transplante; transplante de fígado

ABSTRACT

Introduction: Liver transplant is the last treatment in a situation of liver disease at an advanced stage. The case management is an important program in the promotion of the success of the liver transplant.

Objective: To define the criteria of the screening phase for inclusion of a nursing case management program in patients who underwent a liver transplant.

Methods: Longitudinal qualitative study via multi-case studies. We include six patients who underwent a liver transplant. Four participants are male, with an average age of 45 years. Data were collected through document analysis of the clinical process, participant observation and non-structured interviews. The data analysis was based on Strauss and Corbin's Grounded Theory.

Results: We identified nine criteria of the screening phase: problematic or difficult experiences during the health/disease transition, lack of confidence in providers, socioeconomic problems, prolonged hospitalization, previous history of non-adherent therapeutic regime, excess or lack of health services' use, lower family support, psychiatric disease and symptoms of the disease.

Conclusion: With the identification of these criteria, we may include the patients in a case management program and implement nursing therapeutics in response to their specific needs. This study is an important contribution to the clinical practice of nurses because it allows identifying the cases that are especially vulnerable, anticipating the patient's needs/difficulties in the health/disease transition process, and implementing therapeutics in response to the patients' real needs.

Keywords: case management; nursing; transplants; liver transplantation

RESUMEN

Introducción: El trasplante de hígado es el último tratamiento en una situación de enfermedad hepática en estadio avanzado. La gestión de casos es un programa importante en la promoción del éxito del trasplante de hígado.

Objetivo: Definir los criterios de inclusión de los casos de fase de cribado en un programa de gestión de pacientes de enfermería en seguros de salud y trasplantes.

Métodos: Estudio cualitativo longitudinal mediante estudios de casos múltiples. Incluimos a seis pacientes que se sometieron a un trasplante de hígado. Cuatro participantes son hombres, con una edad promedio de 45 años. Los datos fueron recolectados mediante análisis documental del proceso clínico, observación participante y entrevistas no estructuradas. El análisis de datos se basó en la teoría fundamentada de Strauss y Corbin.

Resultados: Identificamos nueve criterios de la fase de cribado: experiencias problemáticas o difíciles durante la transición salud / enfermedad, falta de confianza en los proveedores, problemas socioeconómicos, hospitalización prolongada, historia previa de régimen terapéutico no adherente, exceso o falta de servicios de salud ' uso, menor apoyo familiar, enfermedad psiquiátrica y síntomas de la enfermedad.

Conclusión: Con la identificación de estos criterios, podemos incluir a los pacientes en un programa de manejo de casos e implementar la terapéutica de enfermería en respuesta a sus necesidades específicas. Este estudio es un aporte importante a la práctica clínica del enfermero porque permite identificar los casos especialmente vulnerables, anticipar las necesidades / dificultades del paciente en el proceso de transición salud / enfermedad e implementar terapias en respuesta a las necesidades reales de los pacientes.

Palabras Clave: Manejo de caso; Enfermería; transplante; trasplante de hígado

INTRODUCTION

Chronic liver disease affects 30 million people all over the world (Xiao et al., 2019). Liver transplant is the last treatment in a situation of liver disease at an advanced stage. For the transplant to be successful, people who underwent a liver transplant need to adapt to the new condition. This situation required new competences of self-care. The way that these clients manage their therapeutic regime has a relevant impact on results, and this is the biggest challenge for the individuals who underwent a liver transplant. To maintain transplants and optimize health outcomes is fundamental to promote self-management of liver transplant recipients (Ko, Bratzke, Muehrer & Brown, 2019).

Given the high risk of mortality and morbidity associated with chronic liver disease and transplant, it is fundamental to guide patients from pre- to post-transplant. It is critical to help patients to make the best choices, encourage desirable behaviours to the success of the transplant, and help them to socially integrate (Garcia, Lima, La-Rotta & Boin, 2018).

In the current model to follow the patients after liver transplant, all the clients are observed by the nurses of the inpatient and outpatient care. After a liver transplant, the patients stay in the hospital for 22 days, on average. The follow-up by the nurses of the inpatient care occurs in the post-operative surgery stage, three and six months after the patients go home. The follow-up by the nurses of the outpatient care occurs when the patient has the doctors' follow-up. In this follow-up, the nurses focus on the vigilance of the patients, namely monitoring vital signs in 57.07% of their actions (Mota, Bastos & Brito, 2018). The most important nursing phenomenon to the nurses' practice in liver transplantation was infection susceptibility, which occurred in 67.3% of the cases (Mota, Bastos & Brito, 2018). This is mainly due to the fact that opportunistic infections are the major cause of the mortality after liver transplant (Mohanraj & Rangnekar, 2018) The management of the therapeutic regime is important for the nurses only in 16.4% of the cases (Mota, Bastos & Brito, 2018).

To help patients in all transition processes, nurses need to implement case management programs tailored to each patient's needs. The aim of this study was to define the criteria of the screening phase for inclusion in the program of a nursing case management program in patients who underwent a liver transplant.

1. THEORETICAL FRAMEWORK

In the transplant process, the concept of self-care is central because the patient needs to enhance his or her capacity to take care of him or herself in new and challenging tasks of self-care, from the pre-transplant to the different post-transplant stages. The individual's social and cultural conditions and health literacy influence the self-care (Dols, et al., 2020). So, the issues focused on the patients' psychosocial and behavioural development have a relevant impact on the transplant results (Garcia, Lima, La-Rotta & Boin, 2018). The type of self-care is a crucial aspect when we talk about the self-care phenomenon, inasmuch that it may condition the individual's ability and behaviours to promote health, prevent disease, keep healthy and manage the disease. The type of self-care is a personal constraint that could influence the transition process. As a personal factor, the type of self-care could influence the patient's management of the therapeutic regime.

Bastos (2015) defines four styles of management of the therapeutic regime: the responsible style, the formally guided style, the independent style and the negligent style. The responsible style characterizes people with high responsibility in the management of the therapeutic regime; these individuals have intrinsic motivation, a good perception of self-efficacy and good family support. The formally guided style characterizes people that follow the recommendations of the health professionals but do not have a critical position. The independent style characterizes people with an internal locus of control regarding health and disease. The negligent style characterizes people that have a behaviour of non-adherence to the therapeutic regime. The personal constraints have a significant impact on the way people experience the health/disease transition.

During the health/disease transition, people are more vulnerable to risks, and this may affect their health (Meleis, Sawyer, Messias & Schumacher, 2000). However, the whole process needs a healthy compensatory adjustment because it has a significant impact on the success and quality of life of individuals who underwent a liver transplant.

The vulnerability occurs when the internal or external factors hinder the option for the coping strategies that facilitate the transition process, and the patient is exposed to a risk situation, prolonged recovery and ineffective adaptation (Bastos, 2015).

Transplant is a primordial condition to integrate into a case management program. The case manager has an important role in the promotion of the success of the liver transplant. He or she is a fundamental resource in the pre-transplant period, regarding the reduce of patient's fear and anxiety. In the vulnerable period after the liver transplant, he or she has a paramount role in education and incentive (Moayed et al., 2018). The function of the case manager is to coordinate the aspects related with health, patients' education, results' monitoring and support in behaviour change (Joo & Huber, 2019). It is critical that the case manager pays attention to all dimensions of the patient because he or she needs to evaluate de patient's needs: planning, education and monitoring of the patient's real needs (Joo & Huber, 2019). In the liver transplant, the therapeutic regimen management style of clients is predominantly responsible (Mota, Bastos & Brito, 2017). However, it is vital to identify more vulnerable patients, who may benefit from being integrated into a case management

program when undergone to a liver transplant. With this program we can develop and plan nursing therapeutics adequate to the diversity and complexity of the transition experience (Meleis, Sawyer, Messias, & Schumacher, 2000) and put intentionality in the nursing action.

2. METHODS

This paper describes a longitudinal qualitative study via multi-case studies (Yin, 2017). The study was longitudinal and the authors followed the six cases during eight months (from May to December 2015). A case study allows an investigation that preserves the holistic and significant characteristics of real-life events – the individual cycle of life, the organizational and administrative processes, the change occurred in urban regions, the international relationships and the maturation of some sectors (Yin, 2017). As a result, the object of the study using a case study methodology are the phenomena in the real context, and the frontiers between phenomena and context are not clear, so the researcher uses multiple data sources (Yin, 2017). The multi-cases studies allow discovering convergences between several cases. This study took place in a transplant centre in the north of Portugal where there is performed, on average, 70 liver transplants per year.

2.1 Sample

The study included six participants, out of 150 patients who underwent a liver transplant. The instrument of characterization of the therapeutic regime style (Bastos, Brito & Pereira, 2017) was applied to these participants. The definition of the participants to include in the study was based on the following criteria: score > 3 in the independent or negligent style (defined as a result of the application the characterization therapeutic regime style instrument), living in the metropolitan area of the hospital, aged over 60 years and with maximum five years of a liver transplant. 14,7% of 150 patients had score > 3 in the independent or negligent style.

From the six participants (living in the metropolitan area of the hospital), three had a score > 3 in the independent style, and the other three had a score > 3 in the negligent style. Four participants are male, with an average age of 45 years (31-56). The distribution of the participants by the time of liver transplant is as follows: one participant with one year of transplant, one participant with two years, three participants with four years, and one participant with five years of transplant.

Participants' reason for needing liver transplantation was alcohol (two participants), hepatitis C virus (one), familial amyloidosis polyneuropathy (one), polycystic disease (one) and autoimmune disease (one).

2.2 Data collection instruments and procedures

The data were collected by document analysis of the clinical process, participant observation and interviews. The researcher is a member of the nursing team where the study took place, which facilitated the observational process because the participants act more naturally.

The data collection took place in the hospital (when the participants went to the appointments) or at the participants' home. The researchers took field notes about the observation, the reports of the families' patients and the reports of the health professionals. Data were collected from May to December 2015. During this period, the number of contacts varied between two and 16 contacts, according to the participants' needs and their availability. The authors concluded the data collection upon reaching theoretical data saturation (Morse, 2004).

The study was approved by the and its Ethics Committee 's Hospital with reference number 229/13(144-DEFI/183-CES). All standard ethical procedures and data storage processes were adopted: confidentiality and anonymity. The participation in the study was voluntary and all the patients gave their informed consent. Furthermore, they could leave the study whenever they so wished. The end of the investigation was prepared because the researcher and the case manager are the same person, because at the end of the study, the continuity of the participants' care was secured.

2.3 Data analysis

Interviews, clinical process and participant observation notes were transcribed verbatim, removing identifying features or names to preserve the participants' anonymity. The authors named the data of clinical process (PC), the interviews with patients (P), patient's family (PF) and health professionals (HP), assuring the data's codification.

Data were subjected to analysis following Strauss and Corbin's (2015) Grounded Theory. According to the authors (Strauss & Corbin, 2015), data analysis is a constant comparison method. The researcher compares each new data extract with previous data analysed, and searches differences and similarities between each set of data. The authors grouped similar data and named categories.

3. RESULTS

The screening of the patients to be included in a case management program is the first phase of the program. In this phase, the researchers understood in which areas can the case manager implement nursing therapeutics. The authors identified nine areas that induce vulnerability in patients: problematic or difficult experiences during the health/disease transition, lack of confidence in care providers, socioeconomic problems, prolonged hospitalization, previous history of non-adherence to the therapeutic regime, excess or lack of health services' use, low family support, psychiatric disease, and symptoms of the disease.

Problematic or difficult experiences during the health/disease transition

During the health/disease transition, the patients see in the liver transplant the resolution of their health problems. The resolution of the health problems emerges associated with improvement of the symptoms of liver disease. If the well-being does not take place, the patients experience a difficult transition.

“I had moments when I thought that would not survive... I had complications” (P1).

“[...] convinced me that, with the transplant, I would be well... but...it went wrong... too bad...” (P6).

“A lot of post-operative complications” (PC6).

The transition difficulty emerges associated with the death when the patients had complications during the surgery because they saw in the transplant the opportunity of their lives. They believe that the resolution of their problems is focused on their motivation and the providers’ professionalism.

“I have always believed... I have a lot of willpower, but the providers’ professionalism is fantastic” (P1).

Lack of confidence in providers

The patients need to believe in care providers. Good interaction between patients and care providers is a facilitator of a healthy transition. The homecoming preparation is very important because the patients need to feel confident in the moment of coming home, especially when they stayed in the hospital for a long time.

“One day I did not have conditions to go home, but in next day I had... I have been 92 days in hospital... I do not understand... I needed an explication” (P6).

“They want to help you... you need to cooperate” (FP6).

Prolonged hospitalization

If the patients stayed in the hospital for a long time when they underwent a liver transplant, they see their case as a failure.

“I stayed 92 days in hospital... My case is bad...” (P6).

“I would rather go to jail than to the hospital [...] When I went home, my disease went away” (P6).

When the transplant does not occur according to the patient’s expectations, patients may experience a very difficult transition. The prolonged hospitalization and lack of confidence in care providers induce more vulnerability in the patients. They need to feel support, and the information about their health condition is very significant for the transition process.

Low family support

After a liver transplant, the patients’ main support is the family. Having the support of family is a condition to have a transplant surgery, but after the transplant, the engagement of family is not the same.

“I feel that no one cares for me... my family forgets that I have limitations...” (P4).

“[...] who always stayed with me is my wife, I need her help” (P6).

“My wife did everything for me” (P3).

However, when the family does not help, or the patient feels alone, it is a factor of vulnerability.

“I divorced after the transplant...” (P1).

“[...] I went to talk with my family and... nothing” (P5).

“I am divorced... I had the transplant and I feel that nobody cares about me” (P4).

The family support can be emotional, instrumental or informational.

Socioeconomic problems

The socioeconomic problems are an area with relevance for both the patients and the providers because it has a high impact on how the patients manage their therapeutic regimen.

“I need to go to the pharmacy, but I do not have money” (P5).

“Sometimes I do not have money to go to the hospital follow-up, the transport is expensive” (P5).

“Unhappy because he [the patient] has a lot of social difficulties” (HP5).

“[The patient] complains a lot about the costs and often suspends the prescribed medication” (PC6).

The socioeconomic problems have a significant impact on the way the patients use health services. Sometimes clients refuse to go to the hospital for appointments because they have no money to pay the transporter. As a result, the strategy of patient monitoring must be redesigned.

Previous history of non-adherence to the therapeutic regime

A previous history of non-adherence to the therapeutic regime has a significant impact on how the patient manages his or her therapeutic regime.

“I was very irreverent... I did not take the medication... I did not go to the doctor...” (P2).

“I did not want to know anything about my disease” (P2).

“She [the patient] did not take the medication before the transplant... she was an adolescent” (PC2).

“I never went to the doctor before my liver transplant... the family doctor does not know anything about this disease” (P5).

Excess or lack of health services’ use

The use of health services could be an important factor to screen the patients because it offers a clear idea of the kind of use each patient has. The patient can go to the health services too many or too few times.

“I go to the doctor when I feel very ill... I wait to see if I will get better” (P1).

“When I have any problem, I go to the hospital” (P2)

Psychiatric disease

The psychiatric disease can have a significant effect on how the patients manage their therapeutic regime and, consequently, on the success of the transplant.

“I had a depression, and I did not have any reason to do anything... I did not take the medication” (P4).

Symptoms of the disease

The symptoms of the disease can be a facilitator or inhibitor of healthy transitions. They are a facilitator when they increase the patients’ awareness of the new conditions of the transplant. Conversely, they can be an inhibitor when the patients feel bad and think that the transplant did not increase their health condition.

“I was icteric” (P2).

“I had vomiting and diarrhoea” (P3).

“A lot of diarrhoea during the night... he [the patient] hides it from his wife” (PC3).

“I had a big belly... 16 litres” (P6).

“I had a lot of pain” (P6).

When the patients do not feel better, they can give up the providers’ therapeutic proposal.

4. DISCUSSION

A model designed to do the follow-up of patients who underwent a liver transplant must take into account their individual characteristics. If we think in a case management program structure of the Department of Health (2004), nurses need to attend to the patients’ needs for inclusion of a nursing case management program.

The way how the patients experience their health/disease transition has a significant impact on the transplant results. Depending on the meaning that the patients ascribe to the transplant, the transition can be healthy or pathologic. The transition can be healthy if the patients do not exhibit signs and symptoms of the disease after the liver transplant. As a result, the patients have more plans for the future and envisage their life with more longevity. In a pathologic transition, patients exhibit signs and symptoms of the disease. This situation is particularly difficult if the patient did not display signs and symptoms of the disease before the liver transplant. Patients experience an aggravation of their health condition and are not prepared to manage a complex therapeutic regime. In a liver transplant situation, it is critical that the patients are aware of the change related so that they have behaviours of search and maintenance of the health (Meleis, Sawyer, Messias & Schumacher, 2000).

The lack of confidence is another criterion to screen patients to the case management program identified. Confidence is the basis for the success of any therapeutic regimen. Caregivers can gain the patients’ confidence by establishing an empathic relationship, offering support and comfort in situations of high vulnerability, anxiety and stress (Bramhall, 2014). It is paramount that the patient feels honesty and availability in health professionals. Effective communication is the basis of the relationship between the patient and the health professionals, that is why in a context of prolonged hospitalization, transparency, honesty and confidence are fundamental in the process of preparation to homecoming because communication difficulties result in inconsistent information/messages (Wittenberg-Lyles, Goldsmith & Ferrell, 2013).

The previous history of non-adherence to a therapeutic regimen is a critical criteria because it can influence the way how the patient manages their current therapeutic regimen. According to Serper and collaborators (2015), 15% of the patients who underwent a liver transplant lost the liver because they did not take the medication. Thus, it is fundamental to understand why patients do not follow the guidelines of health professionals to increase the effectivity of the intervention plan (Moayed et al, 2019).

The economic situation has a significant impact on the implementation of the model for monitoring the patients who undergo a liver transplant, as it is directly related to the way the person will use health services.

The patient’s economic difficulties may lead to the need to redesign the monitoring, insofar that the patient refuses more intense monitoring due to the financial situation he or she experiences. The person’s professional situation determines their economic situation, and unemployment may already exist in the pre-transplant or emerge after the transplant, depending on the person’s workplace and his or her

employer. A study developed by Barros and colleagues (2013) found that in the socioeconomic classes with lower incomes, the percentage of patients who did not purchase all the medications prescribed due to lack of money is 20.9%.

The family support is characterized by the type of relationship between the patient and his or her family prior to the transplant, and the need to change roles may arise after the transplant. The family frequently takes on the responsibility based on familial relationships and on the fact that nobody else takes on this responsibility. The support offered by the family can be financial or related to health management (Hochheimer et al., 2019). The family states that the lack of knowledge about the disease and its management is a barrier to supporting the patient who underwent a liver transplant.

The psychiatric disease assumes extreme relevance in the evaluation of clients since studies show that 52% of clients show psychiatric illness as depression, anxiety, comprehension, concentration and memory problems; and 13.3% have needed to take medication for psychiatric problems in the past during 30 days (Weinrieb et al., 2001). Despite the impact of mental illness, this is not a definitive contraindication for transplantation, whereby people with severe psychiatric illness with adequate social support can have great long-term results (Martin, DiMartini, Feng, Brown, & Fallon, 2013). Thus, in the assessment of people with psychiatric illness or substance use illicit activities should take into account their entire social support network, identifying the caregiver that will support the entire health logistics and ensure the proper medication (Martin, DiMartini, Feng, Brown, & Fallon, 2013).

The symptoms of the disease can be called reminders when they trigger in the person the perception of complications in the chronic disease, leading the person to seek help taking into account with a view to solving the problem, thus having a positive effect; or on the contrary, having a negative effect leading the individual to perceive even more disease, which often leads to willing to give up.

The criteria of vulnerability have a significant impact on how the patient receives his or her medication, diet and physical activity regime, and how he or she integrates the health professionals' guidelines. All of these criteria influence each other mutually. The management of these main liver transplant events by the patient will indicate better health or higher vulnerability for him or her and, therefore, has a significant impact on his or her quality of life. Thus, these events indicate how the disease management process is taking place, and whether these process indicators are also criteria of vulnerability per se, inducing more disease in the patients and, therefore, a higher need for a more complex intervention.

The referencing principle must be taken into account because throughout the health/disease transition, inhibiting factors (vulnerability criteria) may emerge to a healthy path that predisposes the individual to higher vulnerability, thus deviating him or her from the sense of success.

For referencing to be successful, it is essential that the team recognizes the criteria for activating the case management model, namely the criteria for activating the patient's case management model with any of the vulnerability criteria defined as part of the screening process. Therefore, cases that are not included at the time of admission to the transplant list can be referenced in any of the treatment stages. The patients' screening will be conducted as early as possible, before hospital admission if possible, or immediately after that, as it has a significant impact on the success (Garcia-Fernandez et al., 2014).

CONCLUSION

With the implementation of a case management program based on the criteria defined in the screening phase, it is possible to define clinical pathways and create decision-making systems to promote the celerity of the process, according to each patient's needs.

The selection criteria of the screening phase to integrate a nursing case management program in patients who underwent a liver transplant are: problematic or difficult experiences during the health/disease transition, lack of confidence in providers, socioeconomic problems, prolonged hospitalization, previous history of non-adherence to a therapeutic regime, excess or lack of health services' use, low family support, psychiatric disease, and symptoms of the disease.

Although the methodology used in this research and the number of participants does not allow the generalization of conclusions, it allows the knowledge produced to be transferred to similar situations. So, this study is an important contribution to the clinical practice of nurses because it allows identifying the cases that are especially vulnerable, anticipating the patient's needs/difficulties in the health/disease transition process, and implementing interventions in response to the patients' real needs.

In this program, health professionals are centred in each patient, with the care being centred in the person, rather than in the system. Therefore, the intentionality and intensity of accomplishment depend on how each person experiences the health/disease transition process.

In future research, it is fundamental develop studies of implementation a case management program in liver transplant and assessment the impact on quality of life and health costs.

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