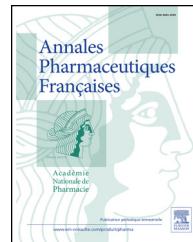




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ORIGINAL ARTICLE

Illness representation and treatment beliefs in liver transplantation: An exploratory qualitative study



Les représentations de la transplantation hépatique et les croyances relatives aux médicaments associés : une étude qualitative exploratoire

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KEYWORDS

Illness representations;
Medicine beliefs;
Liver transplantation;
Graft rejection;

Summary

Background. — The objective of this study was to gain detailed insight concerning liver transplanted patients' representations about transplantation, graft rejection and immunosuppressive drugs to adapt the educational follow-up.

Patients and methods. — Semi-structured interviews were conducted with 8 patients. Each interview was recorded and fully transcribed. The verbatim was first coded according to the themes of the Common Sense Model and an inductive approach for the remaining text.

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Immunosuppressive medicines

Results. — Transplantation is perceived both as a recovery and a new chronic condition. Participants feel powerless in the face of the risk of graft rejection. This risk is perceived as out of control as it is not associated with specific symptoms and external causes. The individual knowledge gained about transplantation relies on real-life experience shared between patients. Many participants feel anxiety. It responds to stress caused by immunosuppressant medication intake, routine check-ups, potential side effects and chronicity of immunodepression. Messages stressing the importance of the tacrolimus in the medication therapy are strengthened by a pre-discharge pharmaceutical consultation.

Discussion and conclusions. — This study suggests that healthcare providers should systematically seek to determine illness representations to optimize the educational follow-up. The patient education program for liver transplanted patients should include three types of intervention: individualized education, behavioral intervention and psychological support. It should provide a support for stress management and acceptance of the new chronic condition. The involvement of a clinical pharmacist is relevant.

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MOTS CLÉS

Représentations en santé ;
Croyances sur les médicaments ;
Transplantation hépatique ;
Rejet du transplant ;
Immunosuppresseurs

Résumé

Introduction. — Cette étude a pour objectif de décrire le contenu des représentations individuelles sur la transplantation, le rejet et les immunosuppresseurs de patients transplantés hépatiques afin d'adapter leur suivi en éducation thérapeutique.

Patients et méthodes. — Des entretiens semi-directifs ont été conduits auprès de 8 patients. Les entretiens ont été entièrement enregistrés puis retranscrits. L'analyse des verbatims a tout d'abord été réalisée suivant les thèmes du Common Sense Model puis selon une approche inductive pour le texte restant.

Résultats. — La transplantation est perçue à la fois comme une guérison et une maladie chronique. Face au rejet du transplant, les participants se sentent impuissants : il n'est défini par aucun symptôme spécifique. Il est associé à des causes externes et paraît hors de contrôle. Le partage d'expérience entre patients joue un rôle important dans la construction des connaissances. De nombreux participants se sentent anxieux. Cette anxiété répond aux stress induits par les immunosuppresseurs, les examens médicaux réguliers, les effets indésirables potentiels et l'immunodépression chronique. L'entretien pharmaceutique avant la sortie d'hospitalisation renforce les messages relatifs à l'importance du tacrolimus dans la thérapeutique médicamenteuse.

Discussion et conclusions. — Cette étude suggère l'utilité de l'exploration systématique des représentations des maladies afin d'optimiser le suivi des patients. Le programme d'éducation thérapeutique pour les patients transplantés hépatiques doit comprendre trois dimensions : un suivi éducatif individualisé, une intervention de type comportementale et un soutien psychologique. Il doit fournir un soutien dans la gestion du stress et dans l'acceptation de la chronicité de l'immunodépression. L'implication d'un pharmacien clinicien dans le suivi du patient transplanté est pertinente.

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Background

In 2012, 1161 liver transplantations (LTx) were performed [1]. In Tx, adherence is multifaceted: it includes adherence to IMS, co-prescribed drugs and lifestyle recommendations. Non-adherence to IMS drugs rates from 15% to 50% [2–4] and from 3% to 47% for clinical appointments [2,4]. Dhrancy et al. [5] reported that non-adherence to IMS reaches 60% in LTx in France. Poor adherence after Tx is associated with an increase of healthcare, late acute rejection episodes, graft loss, death and costs [3,6]. O'Carroll et al. [7] estimated that approximatively 10% of liver transplanted patients died due to non-adherence. Reasons for non-adherence are diverse: misunderstanding of the objectives

of the treatment, complex medication regimen, insufficient information, side effects, unawareness of side effect management, treatment duration, beliefs and costs [8–10]. The French health care system fully reimburses the Tx-related costs. The mean cost of LTx is estimated at 52,000€ and the follow-up care amounts to 8400€ over three years [11]. Depending on dosage forms, tacrolimus costs between 0.98€ to 10.54€ per capsule per day [12].

In LTx, a relationship has been demonstrated between IMS adherence and beliefs; low adherence is related to the perceptions that patients hold about their transplant and medications [7,10,13]. Quantitative studies do not explain the patients' experiences of illness and the process underlying the patients' adherence to medicines. Some qualitative

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