

A Brief Psychological Intervention to Improve Adherence Following Transplantation

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Abstract:

Poor adherence is recognized as a major contributor to morbidity, mortality, decreased quality of life, higher medical costs, and over-utilization of health care services among transplant recipients. While there is universal recognition that poor adherence negatively impacts transplant outcomes, interventions designed to improve adherence have not been the focus of much attention in the transplant literature. The purpose of this article is to describe a brief, theory-based and individually tailored intervention to promote adherence. This intervention is currently used with all liver transplant recipients at our institution. The main goal of the intervention is to reduce the effects of known barriers to adherence by providing recipients with the education, skills, and resources needed to optimize adherence. Adherence is measured at 1, 3, 6, and 12 months post-transplant and additional adherence booster sessions are provided as needed. This intervention has been very favorably received by patients, caregivers, transplant physicians, and nurse coordinators.

Key words: Adherence; Liver Transplantation; Psychology

Introduction

Adherence to the medical regimen both before and after transplantation is of critical importance in optimizing short- and long-term health outcomes. Good medical outcomes following transplantation can be attributed, in part, to adequate adherence, i. e., the degree to which patient behaviors correspond with agreed upon medical recommendations. Likewise, higher levels of morbidity and mortality following transplantation can be attributed, in part, to nonadherence. In light of its significance, adherence is a focus of both formal and informal clinical assessment, is often considered in the context of patient selection decisions, and is the source of debate within the ethics of transplantation [1, 2]. Despite its clinical significance, there is a surprising lack of innovative strategies designed to enhance adherence among adult transplant recipients. The purpose of this article is to describe a brief, theory-based and individually tailored psychological intervention to promote adherence among transplant recipients.

Adherence to Medical Recommendations Following Transplantation

While there may be some variation in the post-transplant medical regimen across transplant centers and organ types, there is some consistency in the activities and responsibilities required of most adult transplant recipients. Medical recommendations following transplantation are generally designed to prevent or attenuate acute and chronic graft rejection, opportunistic infections, malignancies, secondary complications, and toxicities associated with immunosuppressive medications. Consequently, most adult transplant recipients must take a cocktail of

medications daily (immunosuppressants and other drugs), follow a schedule of blood work and biopsies, attend routine follow-up clinic appointments, engage in home monitoring of vital signs, communicate regularly with their transplant coordinator, follow dietary and exercise guidelines, avoid prolonged sun exposure, and maintain abstinence from alcohol, nicotine, and illicit substances.

Published reports indicate wide variation in adherence rates following transplantation. Adherence to medications has been the primary focus of researchers, due largely to the critical role that immunosuppressant medications play in preventing graft rejection and loss. As many as 20% to 50% of adult transplant recipients may show evidence of nonadherence to immunosuppressant medications [3,4]. Adherence to other post-transplant behaviors is less frequently the focus of empirical study, although there is emerging evidence that a significant minority of patients have problems adhering to recommendations pertaining to exercise, diet, substance use, monitoring of vital signs, and weight loss [3, 4].

Published rates of adherence, or nonadherence, to the post-transplant medical regimen should be viewed with some caution for several reasons. First, there is considerable variability in how nonadherence is

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defined by researchers. For instance, medication nonadherence has been defined as the number of doses missed or delayed over a designated time period, the number of drug holidays taken by patients, and simply not following the transplant team's prescribed medication regimen. Second, many different methodologies have been used to measure adherence, including patient self-reports, the reports of others (caregivers, coordinators, physicians), structured clinical interviews, questionnaires, pharmacy refill histories, biochemical assays, and medication monitoring devices. Third, nonadherence with one component of the post-transplant medical regimen (e.g., medication taking) does not necessarily translate into nonadherence with other components (e.g., diet, nutrition) of the regimen [4]. This suggests that each behavior should be examined separately, and conclusions about a patient's overall adherence should not be based solely on one component of the medical regimen. Finally, while the optimal level of adherence is likely considered to be 100% by transplant professionals, the clinical threshold for nonadherence has yet to be determined for specified post-transplant behaviors. That is, how nonadherent with medication use or lifestyle modifications can a patient be before experiencing medical consequences associated with such nonadherence?

Predictors of Nonadherence After Transplantation

Identifying predictors of nonadherence after transplantation has not been the focus of much systematic study to date. Nevertheless, this is an important area of inquiry because the development of effective interventions depends, in part, on isolating specific risk factors for nonadherence. The adherence literature in general suggests that variables potentially affecting adherence behaviors can be grouped into four major categories: sociodemographic characteristics (e.g., age, sex, ethnicity, geography, family income), disease- and/or treatment-related variables (e.g., symptom profile, disease severity, medication side-effects, chronicity of illness, complexity of medical regimen), patient-specific factors (e.g., past adherence behaviors, psychological conditions, memory problems, attitudes and beliefs about the regimen's effectiveness), and environmental variables (e.g., family support, physician-patient relationship, access to health care, health care coverage).

Within the transplant literature specifically, several variables have been found to be associated with nonadherence. These include factors that are generally static and not able to be targeted for change in treatment, including younger age, cognitive impairment, and less education [3, 5-13]. Of more relevance to those developing interventions to improve adherence, there are several correlates of nonadherence that are amenable to change. These include inadequate regimen knowledge, depression and anxiety, low social support, substance abuse, life stress, barriers to medication access, and a poor physician-patient relationship [3, 5, 9, 10, 12, 14-38].

Nonadherence and Post-Transplant Outcomes

The clinical consequences of nonadherence following transplantation are potentially very substantial. It has been estimated that as many as half of all graft failure and one-quarter of all deaths following transplantation are primarily due to nonadherence with the medication regimen and other aspects of the medical regimen [5, 15, 39, 40]. Lower levels of adherence are also associated with more hospital admissions, longer hospital stays, over-utilization of health care services, and lower quality of life [5, 41, 42]. Moreover, nonadherence that is inadequately assessed by the transplant program or not fully disclosed by the transplant recipient can lead to medication changes that are unwarranted, unnecessary, and potentially deleterious.

In addition to the clinical consequences, there are noteworthy economic costs associated with nonadherence. These include the costs of increased health care utilization, of treating preventable morbidities, of missed workdays or employment opportunities, and of developing new medications. Patients identified as nonadherent with medications have been found to have higher medical costs following transplantation [55]. Clearly, the reported relationship between nonadherence and clinical and economic outcomes highlights the need for interventions targeting adherence behaviors in transplant recipients.

The Adherence Intervention

In the sections that follow, we describe a theory-based and individually tailored psychological intervention to promote adherence following transplantation. The rationale for the intervention is based on the high incidence of nonadherence in this patient population and the substantial impact of nonadherence on transplant outcomes. It is our contention that transplant programs bear responsibility for developing, implementing, and evaluating adherence-based interventions.

Clinical Context and Implementation

At the University of Florida, adult liver transplant recipients and their primary caregivers are required to participate in a 90 to 120 minute adherence intervention prior to hospital discharge. Using a didactic and interactive approach, the intervention aims to develop patients' sense of self-control, self-evaluative, and self-corrective responses to facilitate autonomy and adaptation with post-transplant health care. An a priori decision was made to include all adult transplant recipients in the intervention rather than only those patients who have multiple risk factors for nonadherence. The consensus among the transplant team members was that the intervention would proactively provide valuable information and skills to both improve adherence in patients with known risk factors and to prevent future adherence difficulties in patients with an otherwise favorable adherence history. The intervention is delivered bedside in the patient's hospital room by a psychologist who is part of the

transplant team. A treatment manual guides the implementation of the intervention. The timing of the intervention is contingent upon several factors, including the medical and mental status of the patient, the availability of the primary caregiver, and whether the post-transplant coordinator has completed the standard educational session with the patient. While the current protocol was developed for intervention with liver transplant recipients, we are now expanding this intervention throughout all adult transplant programs at our institution (kidney, kidney-pancreas, heart, lung).

Treatment Goals

Using a collaborative framework, the treatment goals of the program include: (a) defining the recipient's role in managing post-transplant healthcare, (b) assessing, and changing when indicated, attitudes and beliefs about adherence, (c) reducing risks associated with nonadherence, (d) promoting self-efficacy and autonomy towards healthcare, (e) developing intrinsic motivation and fostering commitment towards adherence, (f) shaping behavioral intent and goal setting strategies toward the post-transplant medical regimen, and (g) reinforcing effective recipient-caregiver relationships.

Theoretical Considerations and Practical Strategies for Change

The intervention is rooted largely in cognitive-behavioral theory [43, 47], the health belief model [48], self-perception theory [49-51], and motivational interviewing [52]. Cognitive-behavioral strategies are used throughout the intervention to help patients better understand and appreciate the relationship between their thoughts and behavior. Within this context, recipients learn how their attitudes and beliefs contribute to both positive and negative health behaviors. Using elements of the health belief model, the psychologist assesses the patient's perceptions about the benefits and limitations of following the medical regimen and the potential barriers to optimal adherence. The degree of self-efficacy and readiness to adopt the prescribed post-transplant medical regimen are also assessed and targeted throughout the intervention. Motivational interviewing aims to promote internal motivation, autonomy, and responsibility within individuals toward their health care.

In our experience, motivational differences exist between patients awaiting transplantation and those who have received transplantation. During the pre-transplant phase, patients and their support network recognize adherence to medical advice as a necessary condition for safeguarding their transplant candidacy and are, therefore, highly motivated toward optimal adherence [16]. Following transplant, however, there are fewer external pressures that influence adherence behaviors and there is an even greater need for intrinsic motivation.

Motivation towards positive health behavior can be facilitated when health professionals support independent initiative, provide empathy, avoid coercion, offer choices within the treatment regimen

whenever possible, and educate patients about the rationale for recommended behaviors. Coercing the transplant recipient into following medical recommendations and imposing health care values on the transplant recipient will likely not be effective at promoting long-term adherence. Besides ethical compromise, this approach often fails because patients feel that their opinions and choices are minimized and disrespected, and this can lead rapidly to defensive argumentation, active or passive refusal to follow the medical regimen, and a strained physician-patient relationship. A more effective strategy is to support the transplant recipient in developing goals for post-transplant care and to provide assistance in achieving these goals. In addition, patients often have a need for autonomy. Supporting such autonomy within the context of transplantation involves encouraging the patient to exercise behavioral choices and options. In accordance with self-determination theory, patients independently regulate their behavior after perceiving a sense of volition and then choose actions that are essential in achieving their personal goals [53].

Stages of the Intervention

Stage 1: Introduction to the adherence program

The intervention is introduced to patients as a proactive, supportive intervention that will provide them with the skills to achieve optimal post-transplant health. Since the intervention occurs only after the standard post-transplant educational session is conducted by the transplant coordinator, we review the transplant team's expectations and medical recommendations. We acknowledge during the session that patients often tell medical staff what they perceive these professionals want to hear [54] and, therefore, we ask the patient and caregiver to speak frankly with us about their thoughts, attitudes, beliefs, and expectations regarding the medical recommendations. The purpose of this initial stage, therefore, is to establish rapport in which the patient feels that he or she can openly discuss concerns, anxieties, or issues about post-transplant health care and expected adherence behaviors. To accomplish this goal, inquiries about adherence must be unbiased and nonjudgmental. Since transplant recipients vary in their readiness to begin the post-transplant medical regimen, one of the therapeutic goals of this initial stage of the intervention is to address any ambivalence the patient and caregiver may have and to shift the balance in favor of adherence.

Stage 2: Adherence education

Education is a vital component of promoting adherence. While some patients follow medical advice simply because they are instructed to do so by their physician, many patients desire a complete understanding of the medical regimen, an appropriate rationale for each aspect of the regimen, and information about expected health outcomes. Indeed, it is our contention that patients are more likely to adhere to the post-transplant medical regimen when

they fully understand its rationale. Consequently, this stage of the intervention explicitly reviews all of the recommended post-transplant health behaviors, why each is important and how each is associated with the goal of promoting positive health outcomes or preventing negative health outcomes. In addition, we review with patients our definition of adherence, the health benefits associated with good adherence, the medical ramifications associated with poor adherence, and various rates of nonadherence among adult transplant recipients. A working knowledge of the medical issues related to post-transplant care and a close collaboration with transplant physicians is important for all team members.

Stage 3: Understanding the meaning of transplantation and expectancies towards future health care

One method for enhancing motivation to adhere to the prescribed medical regimen is to initiate a dialogue with the transplant recipient about the meaning that he or she ascribes to transplantation. In general terms, meaning-making is an intrapsychic process in which we offer ourselves explanations for why an event has occurred. Meaning defines purpose and level of importance regarding aspects of our life to guide us towards the development of goals and to motivate us through the challenges of life. The various meanings ascribed by transplant recipients to their gift of life has potentially significant implications for future adherence and long-term psychological adaptation. In the session, we facilitate a discussion about such meaning, which allows us to assess what roles the patient believes he or she, the caregiver, and the transplant team should fulfill within their post-transplant health care. This therapeutic dialogue provides an opportunity for us to help shape the attitudes and core beliefs of transplant recipients, in order to promote a greater sense of responsibility and control for their own health care in the months and years after transplantation.

Stage 4: Examining common barriers to adherence

This stage of the intervention involves close examination of some of the common barriers to good adherence. The common barriers were identified through a search of the transplant literature, discussions with transplant coordinators and physicians, and interviews with transplant candidates and recipients. These barriers include difficulty understanding the regimen, problems managing or organizing the medical regimen, ineffective strategies for managing stress, financial problems, other practical problems (e.g., transportation), problems within the social support network, psychological distress (e.g., depression, anxiety), and substance use or abuse.

Resources and skills for preventing and overcoming these barriers are provided in a written guide, but are reviewed and discussed with transplant recipients during this stage of the intervention. Patients are informed that barriers to adherence are common and expected among transplant recipients. Patients are encouraged to identify those barriers that they

encountered during the pre-transplant period, as well as barriers that may develop during the post-transplant period. This encourages patients to actively consider their own personal and environmental strengths and limitations relative to the post-transplant medical regimen and expectations for adherence. Patients and their caregivers are informed that the success of transplant is greatly determined by the strategies employed to prevent and to overcome these barriers. This "self-empowerment" engages patients in their own care plan.

Stage 5: Problem-solving

During this stage of the intervention, the focus shifts toward developing effective problem-solving strategies to deal with common barriers to adherence and behaviorally rehearsing these strategies in session. Transplant recipients are asked to participate in two exercises within this stage of the intervention. In the first exercise, the patient and caregiver are presented with several vignettes depicting common post-transplant adherence barriers. They are instructed to discuss possible resolutions for overcoming these barriers, as well as to identify ways in which these barriers might have been prevented. In the second exercise, patients are challenged to identify barriers specific to them and their personal circumstances. They are instructed to examine their personal characteristics, cultural issues, religious beliefs, family circumstances, and other factors and how these variables might interfere with or promote optimal adherence. For each identified barrier, an action plan is developed for preventing its occurrence in the future or for attenuating its negative effects on adherence.

Stage 6: Planning for and coping with setbacks

Patients are informed that, despite good intentions, they are likely to experience setbacks in following the post-transplant medical regimen. Within this stage of the therapeutic process, the psychologist helps the patient to develop effective strategies for coping with setbacks, including how to minimize self-defeating thoughts and feelings that are commonly associated with unexpected setbacks in adherence. Patients are given a template for examining setbacks, which includes reviewing the events leading up to the setback, determining whether any warning signs were present and overlooked, and implementing strategies designed to cope effectively with the setback. Active coping strategies are emphasized, including those that facilitate information seeking, consultation with health care providers, and soliciting social support.

Stage 7: Developing a self-reinforcement program

The next stage of the intervention is based on the simple premise that individuals are more likely to maintain behavior when rewarded for it. Therefore, we work with patients to develop a self-reinforcement program that can be used to maintain positive health behaviors. A specific exercise is used in which patients are asked to identify behaviors to target for reinforcement, select appropriate rewards for completion of these behaviors,

and plan a reinforcement schedule. Recipients are also encouraged during this time to develop some regular activities or rituals related to their organ transplant, which may include celebrating the anniversary of their transplant surgery every year, writing letters to the donor family and/or transplant team, or attending a transplant support group where they can share their experiences and expertise with those who are still awaiting transplantation. The rationale for such rituals is to retain the prominence that the transplant event and its associated meanings have in the life of the recipient and the donor family, thereby helping to facilitate optimal adherence.

Stage 8: Signing a behavioral health commitment

At the conclusion of the intervention, recipients are asked to formally state their behavioral commitment to post-transplant adherence. We assist patients in creating a document that specifies their goals for post-transplant health care and their commitment to achieving these goals through optimal management of the prescribed medical regimen. When completed, the transplant recipient, caregiver, and transplant psychologist all sign the commitment statement. This explicit act of creating and signing a commitment statement reinforces the patient's sense of values, intentions, and beliefs, while stimulating his or her perception of self-control, personal effectiveness, and intrinsic motivation towards long-term adherence.

Program Evaluation

To systematically examine the effectiveness of the intervention, adherence is measured at 1, 3, 6, and 12 months post-transplant and then at subsequent outpatient clinic appointments thereafter. During

these assessments, inquiries regarding level of adherence and factors hindering adherence are systematically measured using semi-structured interviews and questionnaires that we have developed and evaluated. In addition, we examine blood assays to corroborate self-reports of adherence, obtain coordinator ratings of adherence, and collect data on health service utilization. Finally, booster sessions designed to assist patients who are having adherence difficulties are scheduled as needed during these outpatient clinic visits.

Conclusion

Much has been written about adherence to the transplant regimen and there are at least three noteworthy conclusions that can be extrapolated from this literature. Nonadherence occurs with higher than desirable frequency following transplantation, the consequences of nonadherence are significant and health-compromising, and there is an urgent need for the development, implementation, and evaluation of interventions designed to maximize sustained adherence. In this article, we have described a brief psychological intervention that can be delivered in an efficient and cost-effective manner after transplant surgery and prior to hospital discharge.

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