

Developing new ways to address learning needs of adult abdominal organ transplant recipients

Context—The degree to which patients are knowledgeable about posttransplant care can affect outcomes and patients' satisfaction. Transplant team members must identify knowledge gaps, contributory factors, and innovative methods to address learning needs.

Objective—To identify patients' perceptions of their knowledge gaps and identify ways to improve current approaches to patient education.

Design—Nonexperimental.

Setting—Midwestern teaching hospital.

Patients—726 adult abdominal organ transplant recipients.

Intervention(s)—A patient education survey was mailed out to solid-organ transplant recipients who met study criteria. A modified version of the Patient Learning Needs Scale (PLNS) was used to identify the recipients' learning needs. Additional questions on the survey addressed factors that we hypothesized would influence responses to the PLNS and asked patients which methods would help them learn during various phases of the transplant process.

Main Outcome Measure(s)—Statistical analysis was conducted on survey responses.

Results—Overall, PLNS scores were satisfactory in all 4 categories. Analysis of PLNS subscales revealed significantly lower scores in the quality of life/psychosocial subscale compared with the other 3 subscales. Significantly lower scores in the medications and follow-up categories of the PLNS items were found among the group whose length of stay was between 15 to 30 days compared with patients with shorter and longer stays. A variety of different methods are desired by patients in order to get information, especially before transplant. (*Progress in Transplantation*. 2009;19:160-166)

Jaime Myers, RN, MSN, CCTC,
Teresa A. Pellino, RN, PhD
University of Wisconsin Hospital and Clinics (JM), University of Wisconsin School of Nursing (TAP)

Corresponding author: Jaime Myers, RN, BS, CCTC, University of Wisconsin Hospital & Clinics, Abdominal Transplant Program, F8/152, 600 Highland Ave., Madison, WI 53792
(e-mail: jmyers@uwhealth.org)

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Adherence to a complex self-care regime is an essential survival skill for transplant recipients. Research has shown that empowering patients by educating them about their disease process and the care required to maintain health can improve adherence to treatment regimens.^{1,2} Patients report greater adherence when they feel their concerns and knowledge deficits are addressed.^{3,4} Therefore, practitioners must address the learning needs and knowledge deficits of their target population when attempting to teach their patients. In addition to improved adherence to treatment plans, education of patients can increase patients' satisfaction, improve quality of life, reduce anxiety, decrease uncertainty, and facilitate transition phases.⁵⁻⁷ Such education also allows patients and family members a greater sense of control over their illness and disease and facilitates return to normalcy after procedures such as kidney transplant.⁸

Patient Education Practices and Challenges

The importance of education of transplant patients throughout the transplant process is well established. Content recommendations include topics such as evaluation testing, organ allocation, medications needed to prevent rejection, posttransplant infections, and follow-up care needed.⁹ Review of our patient education materials and those used by various other transplant programs, as well as those offered by pharmaceutical companies and professional organizations such as the America Society of Transplantation, shows materials to be similar in terms of content and format. Materials consist largely of written handouts with few images or pictures and focus on the topics recommended in the preceding paragraph.

Before this study, pretransplant preparation and initial teaching of posttransplant care at our transplant center was started during the evaluation period, with

most of this teaching being done at the initial evaluation visit. The next attempt at teaching posttransplant care was done after surgery through daily hour-long classes offered on the transplant unit. Class content differed each day of the week, and patients were given a "test" to complete before discharge in an attempt to assess comprehension. Posttransplant coordinators continued provision of education and filled in information that was missed as needed, primarily through telephone contact after discharge and at clinic visits.

Changes in methods and materials used to educate our patients had not kept pace with changes in health care structure. In the early years of transplant, it was not uncommon for patients to stay in the hospital for months after surgery. As lengths of stay decreased from months to days, patients and family members were forced to learn to perform tasks at home that were once done for them by hospital personnel. Furthermore, as our expertise as a transplant community grew, so did the complexity of the procedures we were offering and thus were having to explain to our patients. For example, we had to teach patients and their families about procedures such as desensitization and deceased cardiac donation transplants. These changes were not unique to our transplant center, nor were the challenges we faced in terms of being able to adequately educate our patients.

Summary of Literature

Little to no evidence is available to support that the content of current patient education materials is congruent with needs and knowledge deficits identified by patients. No published data specifically address the information needs of abdominal transplant recipients. One study looking at information needs of lung transplant patients and their support persons identified the need for more information on practical issues, life after transplantation, and the experiences of transplant recipients.¹⁰

Research on the association of variables such as actual length of stay in the hospital, level of education, sex, marital status, and patients' perceptions of their illness on patients' learning needs is contradictory. Some published data indicate that these variables do affect learning needs,¹¹ whereas other studies have shown no correlation.^{12,13}

When looking at how and when to best provide patient education, it appears that comprehensive, efficient, high-quality patient education is lacking throughout many different aspects of health care, both acute and chronic. When looking at the timing of patient education, one must acknowledge that acutely ill persons do not have the physiological stability or the cognitive energy to learn about home care until near the time of discharge.⁶ Repetition is the key in terms of retention of information. Continued educational interventions at

multiple times increase the likelihood of behavior change and maintenance.¹⁴ In terms of methods, verbal and written information together are more effective than verbal information alone and integration of visual, auditory, and kinesthetic modalities is most effective.^{5,15} Humans have more brain receptors for images and pictures than words, and research from the Institute for Healthcare Advancement has shown a significant improvement in utilization, recall, and adherence of health information when pictures were added to written patient education materials.^{16,17} Healthy persons remember 10% of what they see, 20% of what they hear, 50% of what they see and hear, and 70% of what they see and talk about; therefore, use of movies, slides, and audiovisual materials can enhance effectiveness of patient education.¹⁷

Purpose

The purpose of this project was to identify patients' perceptions of their knowledge deficits after discharge from the hospital following solid-organ transplantation and to identify methods desired by patients to address these deficits. The following research questions were formulated:

1. What specific information do transplant recipients feel they are not well informed of on discharge?
2. What factors affect their lack of knowledge?
3. What methods do they prefer to get this information, and when do they want this information?

Methods

A patient education survey was developed that consisted of 20 multi-item questions (102 total items). Each of the 20 multi-item survey questions addressed either: (1) learning needs of recipients, (2) factors that affected learning needs, or (3) ways to meet the learning needs of the patients. The survey was mailed out to 726 patients who had undergone a solid organ transplant from January 1, 2005 through November 15, 2006. Exclusion criteria included prisoners, miners, death, and primary graft nonfunction. Family members or primary support persons were allowed to complete the survey in place of the patient. Patients who had had a previous transplant were not excluded, but were asked to complete the survey based on their experience with their most recent transplant. Surveys were done only in English; therefore, ability to read English was an assumed criterion. Approval for the survey was obtained from the institutional review board. A letter of consent was mailed with the survey. Consent was assumed with return of a completed survey.

To determine what specific information transplant recipients feel they are not well informed of on discharge, our patient education survey included a modified version of the Patient Learning Needs Scale (PLNS).¹⁸ The PLNS is used to measure patients' perceptions of

learning needs to manage health care at home after discharge. The PLNS is intended to serve various populations of patients; therefore, the questions are quite general. Modified versions have been used with various patient care specialty areas, such as wound care and oncology. PLNS items were modified in our survey to fit our population of patients. Our modified version of the PLNS consisted of 33 items broken into 4 subscales: medications (9 items); health problems (10 items); follow up (9 items); and quality of life/psychosocial issues (5 items). Items were scored by using a 5-point Likert scale, from 1 (not at all informed) to 5 (extremely informed). Internal consistency of the modified PLNS was examined in our sample and found to be high for the total scale and each subscale. The Cronbach α for the total scale was 0.97; the medication subscale was 0.91; health problem subscale, 0.94; follow-up subscale, 0.91; and quality-of-life subscale, 0.95.

Our patient education survey also included demographic and other questions addressing variables that affect learning needs. These variables were based on our experience and research findings of learning needs in other populations of patients. Factors were assessed via a yes/no response in regards to whether it was their first transplant, whether they felt they had a good idea of what life would be like after transplant before having had the surgery, and whether they had a support person involved in learning. They were given various time ranges to choose from to assess factors such as length of hospital stay and length of time on the waiting list. We asked patients to score the degree to which they felt pain, fatigue, medication side effects, feeling overwhelmed, and an inability to attend class affected their ability to learn during the hospitalization. They used a 5-point Likert scale to score each variable independently, with 1 indicating no impact to 5 indicating an extreme impact. We included questions about basic demographic information to assess for differences in sex, race, and educational level.

Finally, our patient education survey included questions about how to meet learning needs, specifically, how and when patients wanted to get the information they were lacking. Patients were asked which things would help them learn more about transplant. They could select a variety of different methods of patient education, such as written materials, group classes, DVDs, and computer resources, and were instructed to choose as many choices as would apply. An "other" category was also listed to allow them to write in any additional ways they would like to get the material. They were asked about the timing (specifically before, during, and after the surgery/hospitalization) of these various materials/methods. Again, they were allowed to choose as many choices as would apply, so they could choose a variety of different methods at a variety of time intervals.

Factor analysis, construct validity, and reliability (Cronbach α) have been demonstrated by the authors of the PLNS.¹⁹ To establish content validity of the items modified from the original version of the PLNS, a group of transplant professionals and patients were asked to complete a Likert scale (from 1 = not relevant to 5 = extremely relevant) in regards to each item. The transplant professionals group consisted of 12 people, 5 transplant nurses, 4 transplant coordinators, a transplant social worker, a pharmacist, and a physician assistant. The patient group consisted of 10 patients who were at least 2 years past a kidney, liver, or pancreas transplant, thereby ensuring that study participants were not included. Items that were deemed not relevant were eliminated from the survey, and several items were reworded and added in order to increase relevancy. A group of experts reviewed our entire patient education survey before distribution to establish content validity, readability, and clarity. This group included the previously mentioned group of transplant professionals and transplant patients as well as a research group from the University of Wisconsin Madison School of Nursing. The research group consisted of 1 faculty member from the nursing school and 4 additional graduate or doctoral students. Once the survey had been deemed appropriate by the various groups, it was assessed for readability. The survey was sent to an expert in the patient and family education center at our institution, who recommended ways to get readability to an eighth-grade level. Revisions were made, and eighth-grade readability was confirmed via the SMOG readability calculator.

Along with the surveys, patients were asked to answer 5 questions that were taken from the transplant test they completed before discharge. They were asked to list 3 signs of rejection, 2 tests that might be done to rule out a possible rejection of the transplanted organ, at least 1 medication they were taking to prevent organ rejection, 3 signs of infection, and 3 things they were asked to record daily (eg, weight, blood pressure, temperature). Subjects were given 1 point for each correct answer; the total possible score for the test was 12. The same 10 patients used to establish content validity of the items were asked to answer these questions to help establish reliability and validity. The mean score of these patients was 10 (83.3%), confirming reliability of this test.

Sample

Four hundred three completed surveys were returned, yielding a return rate of 55%. Demographics and time between completing survey and the date of transplant are summarized in Table 1, and the types of transplants are summarized in Figure 1. Eighty percent of patients reported that this transplant was their first. The population was distributive in terms of sex

Table 1 Demographics of 403 patients who returned surveys^a

Characteristic	% of patients
Time between completing survey and transplant date	
<3 months	1
4-6 months	17
7-12 months	22
>1 year	59
Sex	
Male	60
Female	40
Education	
Less than high school	1
High school	32
Some college	29
College degree	19
Postgraduate	10
Missing	2
Race	
White	84
African American	7
American Indian	0.3
Pacific islander	0.4
Asian	4
Mid-East/Arabian	0.3
Other/missing	4
Ethnic	
Hispanic origin	4.5
Non-Hispanic	68.5
Missing	27
Employment	
Not working	10
Disabled	25
Retired	22
Homemaker	4
Employed full time	28
Employed part time	7
Marital status	
Single (never married)	15
Married	64
Separated/divorced	14
Widowed	4

^a Mean age of respondents was 52.35 years, with a range from 19 to 80 years.

and employment status, but the vast majority of patients in the population were white and had at least a high school level of education (Table 1).

Statistical Analysis

Descriptive statistics were used to identify frequencies, means, and standard deviations of the variables. The Wilcoxon signed ranks test was used to determine which subscales of the PLNS were identified as problematic for patients. Examination of the relationships between knowledge test scores and the PLNS subscales was achieved through correlation analysis. Analysis of variance was used to investigate the effects of variables related to the patient's hospitalization (length of stay, ability to attend class, reported

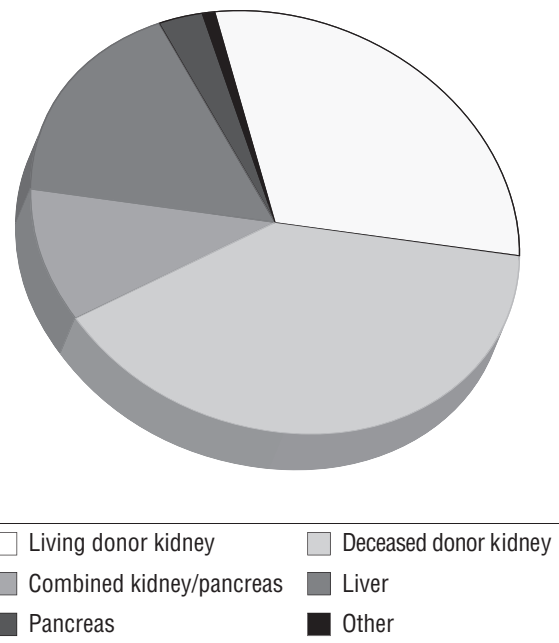


Figure 1 Transplant type (most recent).

pain, fatigue, and feeling overwhelmed) and transplant history on PLNS subscales.

Results

What Specific Information, If Anything, Do Transplant Recipients Feel They Are Not Well Informed of on Discharge?

Overall, PLNS scores were satisfactory in all 4 categories, indicating that patients felt moderately to extremely informed about the items (Figure 2). Patients reported significantly lower scores in the quality of life/psychosocial subscale compared with the other 3 subscales (Table 2). Examples of items in this subscale were, "Where I could get help handling my feelings about my transplant" and "What I can expect long term in regards to my life and health after transplant." The medication and follow-up subscales had the highest scores, and these differed significantly from scores for health problems (Figure 2).

Scores on the knowledge test were also high, with a mean of 10.51 (out of 12) and a standard deviation of 1.70. Significant relationships were detected between scores on the knowledge test and 3 of the PLNS subscales: medications ($r=0.24$), health problems ($r=0.22$), and follow-up ($r=0.16$). Knowledge scores were not correlated with the quality-of-life subscale, which is to be expected as there were no questions on the psychosocial effects of transplant on the test.

What Factors Affect Their Lack of Knowledge?

Interestingly, patients in the group whose length of stay was between 15 to 30 days scored significantly

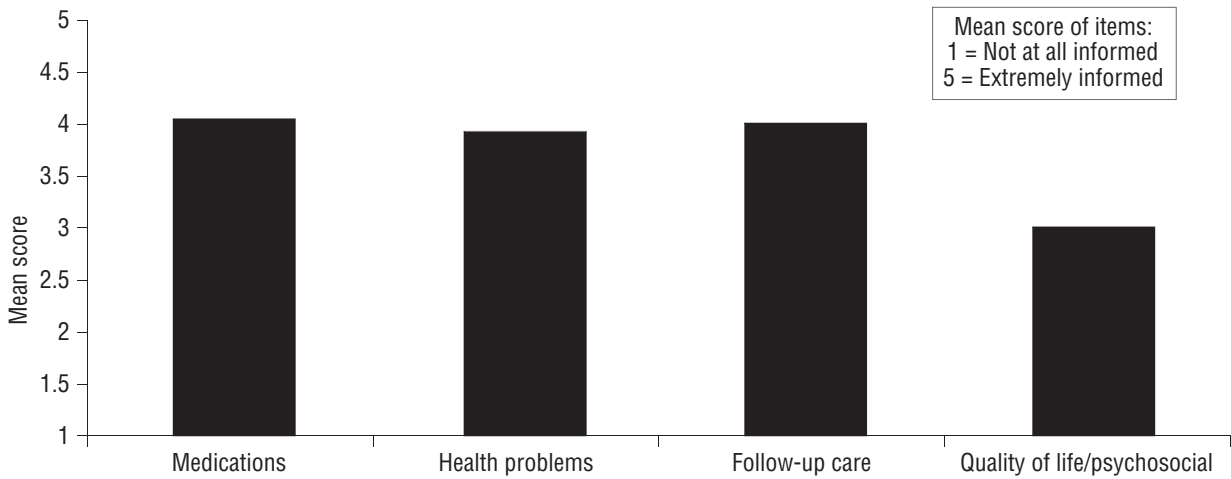


Figure 2 Patient Learning Needs Scale by subscale.

lower in the medications and follow-up categories than did patients whose stay was less than 7 days, 7 to 14 days, and more than 30 days. The group of patients whose stay was 15 to 30 days was also found to have significantly higher scores than the other groups for the effect of inability to attend class, pain, fatigue, feeling overwhelmed, and time in the hospital on their ability to learn while in the hospital. Inability to attend class was associated with significantly lower PLNS scores in the medications and follow-up care categories for all patients.

Patients were asked to answer the survey with respect to their most recent transplant. Patient who reported having previously undergone a transplant did not differ in scores for any of the PLNS categories from patients for whom this transplant was their first ever. Time on the waiting list (as chosen from a range of less than 3 months, 4 to 12 months, 13 months to 2 years, or greater than 2 years) was not associated with any difference in PLNS scores.

In terms of perceptions of their illness, 64% admitted they did not have a good idea of what life would be like after transplant before they had surgery.

What Methods Do They Prefer to Get This Information, and When Do They Want This Information?

Results from this question can be seen in Figure 3. Five different methods of patient education could be

selected at various time intervals in the transplant process. Patients could choose as many of the methods as preferred in all 3 phases. Of note, each of the methods received a higher percentage of patient selection in the “Before transplant” time frame than the same method in the “During” and “After transplant” time frames, indicating that before transplant is when patients would most like to be getting more information. Methods receiving the highest scores in the “Before transplant” time frame included information from health care providers in a 1-on-1 setting (48%), video tapes or DVDs (47%), and computer resources (47%). During the hospital stay, the highest selected method was verbal information in a 1-on-1 setting, with 44% of patients choosing this method, and DVD/video method was the second most popular choice with 33% of patients selecting it. After transplant, the highest selected method was information via DVD/video format (35%), and verbal information in a group setting was the least desired method in this time frame (14%). Of note, DVD format was a favorable approach at all phases.

Discussion

Before we conducted our survey, nursing staff had expressed concern related to observations that patients were leaving the hospital with significant knowledge deficits in regards to their posttransplant care. Results of this survey actually show that patients felt they

Table 2 Wilcoxon signed ranks test for comparison of subscales of the Patient Learning Needs Scale

	Medications and health problems	Medications and follow-up	Medications and quality of life	Health problems and follow-up	Health problems and quality of life	Follow-up and quality of life
Z	-6.36 ^a	-0.31	-14.78 ^a	-6.61 ^a	-14.50 ^a	-15.34 ^a

^a P < .05.

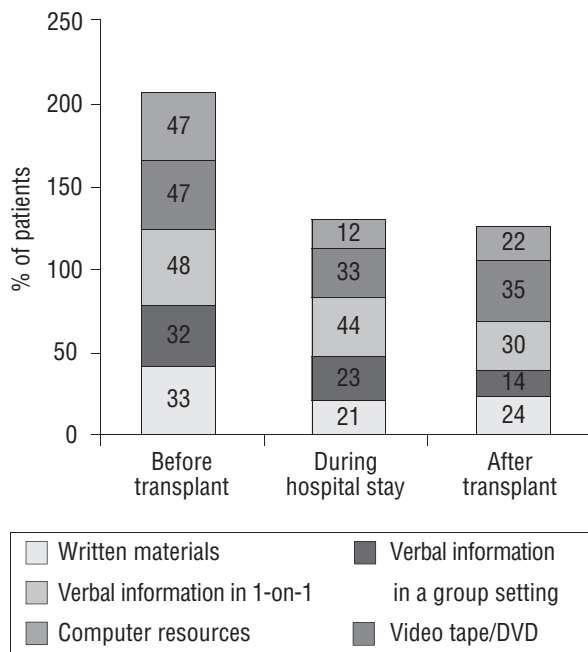


Figure 3 Information resources desired by patients.

were at least moderately informed in terms of the items addressed in the PLNS.

The fact that significantly lower scores were identified in the quality of life/psychosocial items on the PLNS was not surprising. The class content during the survey time frame did not include any information about these items. Most patients met with a social worker during their initial evaluation for transplant, but no further psychosocial intervention was provided unless patients specifically asked, or nursing staff specifically requested, a consultation. Health care providers caring for transplant patients have increasingly acknowledged the high rates of depression and anxiety among our patients and have begun to strategize about how to best address these needs.

Contradictory to our original hypothesis, shorter stays did not contribute to patients' reports of decreased knowledge about items on the PLNS. In fact, lower scores were actually seen in the group of patients whose length of stay was between 15 and 30 days. In examining this finding further, it appears that this group of patients also reported less class attendance and higher rates of pain, fatigue, and feeling overwhelmed when compared with other groups. It may be that the patients whose stay was between 15 to 30 days actually were more ill or had more complications after surgery that prompted their longer hospital stay. Nursing staff may have been less diligent with making sure these patients attended class for several reasons. First, it is more difficult to insist patients who are acutely ill leave their room to attend a group class, and also the nurse is likely to question the benefit that

will be gained from the patient doing so. Second, because discharge is not imminent, the urgency of getting these patients to class may be lost.

The fact that patients who reported that inability to attend class strongly influenced their ability to learn also scored significantly lower on the medication items of the PLNS is an important finding. This finding reinforces the importance of being able to find an alternative method of providing patients with information, especially for those who are unable to attend class.

A limitation of our findings is that the survey was done retrospectively, with most patients having received their transplant more than 1 year before taking the survey (Table 1). Therefore, patients may have had an altered perception of how informed they actually felt after discharge and they may have received information from multiple sources after discharge. Scores might have been different if patients had been given the survey sooner after discharge from the hospital.

Another limitation in our findings is that most of our patients have a high school education or higher, and our sample lacked diversity in terms of race and ethnicity. Therefore, findings may not be generalizable to transplant centers whose populations are more diverse or and less educated.

Implications

This research has prompted changes in our approach to patient education. Although we recognize the 1-on-1 approach to be desirable to patients, it is not always feasible given time constraints and nursing shortages. The video tape/DVD method of teaching also received high scores for all 3 different time intervals and can be a very effective, efficient method for providing patient education. As a result of findings, we created a DVD that provides information to patients on various topics related to transplantation and follow-up care. It is distributed and available to patients before transplant, while on the waiting list, during hospitalization, and after transplant. The DVD is broken up into short topic sections, including preparing for transplant, the surgery, home care following surgery, staying healthy after transplant, medications, rejection and other complications, laboratory testing, posttransplant diabetes, life adjustments, and diet and nutrition. Each section is 5 to 15 minutes long, and patients will be directed as to which sections to watch. There are questions that accompany each section, and patients will be asked to complete these after viewing a particular section.

To keep information that will be presented in the DVD consistent, we reviewed and updated class content and our written patient education materials. A patient education binder was developed that will accompany the DVD. The binder contents are divided into the same topic sections as the DVD to maintain

consistency. The patient learning center is assisting with ensuring readability of the written materials. The binder and DVD will also be available in Spanish.

In order to address the findings from the PLNS, specifically our suboptimal performance in addressing psychosocial issues, we included a section in the DVD and patient education binder called "Life Adjustments." This section provides patients with information on how transplant may affect the "big picture." It addresses issues such as depression and addiction and feeling comfortable asking for help. It identifies resources and support groups for transplant patients to assist with coping and quality-of-life issues.

Our goal is to repeat the surveys after implementation to see if each intervention has had an effect. Further research is needed, for example, analysis of outcome data such as rates of readmissions for preventable complications, rejection episodes, patient satisfaction scores, medication compliance, and depression scores in a further attempt to measure the effect of the new educational materials.

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