

UCLA

UCLA Previously Published Works

Title

Lung Transplant or Bust: Patients' Recommendations for Ideal Lung Transplant Education

Permalink

<https://escholarship.org/uc/item/84t7s445>

Journal

Progress in Transplantation, 24(2)

ISSN

1526-9248

Authors

Davis, LaShara A
Ryszkiewicz, Eric
Schenk, Emily
et al.

Publication Date

2014-06-01

DOI

10.7182/pit2014432

Peer reviewed

Lung transplant or bust: patients' recommendations for ideal lung transplant education

Context—Effective lung transplant education helps ensure informed decision making by patients and better transplant outcomes.

Objective—To understand the educational needs and experiences of lung transplant patients.

Design—Mixed-method study employing focus groups and patient surveys.

Setting—Barnes-Jewish Hospital in St Louis, Missouri.

Patients—50 adult lung transplant patients: 23 pretransplant and 27 posttransplant.

Main Outcome Measures—Patients' interest in receiving specific transplant information, the stage in the transplant process during which they wanted to receive the education, and the preferred format for presenting the information.

Results—Patients most wanted information about how to sustain their transplant (72%), when to contact their coordinator immediately (56%), transplant benefits (56%), immunosuppressants (54%), and possible out-of-pocket expenses (52%). Patients also wanted comprehensive information early in the transplant process and a review of a subset of topics immediately before transplant (time between getting the call that a potential donor has been found and getting the transplant). Patients reported that they would use Internet resources (74%) and converse with transplant professionals (68%) and recipients (62%) most often.

Discussion—Lung transplant patients are focused on learning how to get a transplant and ensuring its success afterwards. A comprehensive overview of the evaluation, surgery, and recovery process at evaluation onset with a review of content about medications, pain management, and transplant recovery repeated immediately before surgery is ideal. (*Progress in Transplantation*. 2014;24:132-141)

©2014 NATCO, The Organization for Transplant Professionals
doi: <http://dx.doi.org/10.7182/pit2014432>

LaShara A. Davis, PhD,
Eric Ryszkiewicz, MPH,
Emily Schenk, BA,
John Peipert, MA, MSW,
Claire LaSee, MPH, MSW,
Carol Miller, RN, BSN, CCTC,
Greg Richardson, RN, CCTC,
Gene Ridolfi, RN, MHA,
Elbert P. Trulock, MD,
G. Alexander Patterson, MD,
Amy Waterman, PhD

Saint Barnabas Medical Center, Livingston, New Jersey (LAD), Palo Alto Medical Foundation, Sutter Health, Sunnyvale, California (ER), Washington University School of Medicine, St. Louis, Missouri (ES, CL), David Geffen School of Medicine, University of California, Los Angeles (JP, AW), Barnes-Jewish Hospital, St. Louis, Missouri (CM, GR, GR, EPT, GAP)

Corresponding author: LaShara A. Davis, PhD, Renal and Pancreas Transplant Division, Saint Barnabas Medical Center, 94 Old Short Hills Road, Livingston, NJ 07039
(e-mail: ldavis@barnabashealth.org)

To purchase electronic or print reprints, contact:
American Association of Critical-Care Nurses
101 Columbia, Aliso Viejo, CA 92656
Phone (800) 899-1712 (ext 532) or
(949) 448-7370 (ext 532)
Fax (949) 362-2049
E-mail reprints@aacn.org

Although current demand outpaces the supply, patients with end-stage lung disease who are able to get lung transplants can have up to a 75% lower risk of death and significantly better quality of life than patients who stay on the waiting list.¹⁻³ More than 100 transplant centers across the United States ensure that the approximately 1700 patients waiting for a lung

transplant (based on Organ Procurement and Transplantation Network data as of November 2, 2012) know about and are prepared for a successful transplant. Federal regulations for solid-organ transplant dictate that patients must receive information about the evaluation, the surgery, postoperative treatment, alternative treatments, and medical and psychosocial risks.⁴

Formative studies, most commonly with kidney patients, have been undertaken to learn about the specific educational needs of patients.^{5,6} For example, researchers have identified that ideal kidney transplant education should address: recipients' transplantation fears,⁷ patients' quality of life and psychosocial needs,⁵ and patients' readiness to accept their illness.⁸ Less is known about the educational preferences of patients with end-stage lung disease. One recent qualitative study of lung transplant patients and their support persons identified that patients wanted more information on practical issues, life after transplant, and transplant recipients' experiences.⁹ Researchers in that study also identified the need for modifications in the content, timing, and method of presenting the information, but failed to specify what would improve informed decision making.

Patients with end-stage lung disease grapple with many issues and complications before transplant, requiring a clear understanding of their treatment and medication regimens.^{2,10,11} Because most lung transplant recipients will experience at least 1 episode of acute rejection within the first year, excellent posttransplant education for these patients is critical.¹² Additionally, patients can have difficulty completing their blood work, monitoring blood pressure, and performing spirometry, especially as their time since transplant increases.^{13,14} Lung recipients are also likely to postpone, skip, or reduce doses of immunosuppressive medication.¹⁵ Published studies with patients have demonstrated how posttransplant computer-based education strategies and home monitoring education can increase adherence to overall posttransplant home care regimen,^{16,17} taking immunosuppressant medications,¹⁸ performing spirometry,^{16,17,19} and checking for signs of skin cancer.^{20,21} To date, however, research exploring the entire range of education needed for lung patients, especially before transplant, has been neglected.

Although transplant programs routinely offer education during the evaluation phase, consisting of some combination of printed materials, videos, the ability to speak one-on-one with an educator, and group sessions,²² what they provide before, during, and after transplant varies considerably. In order to develop ideal educational resources for patients awaiting lung transplant, a mixed-methods study of 50 lung transplant candidates and recipients was conducted to identify their interest in receiving specific transplant information, the stage in the transplant process during which they wanted to receive the education, and the preferred format for presenting the information.

Methods

Participants and Procedure

A combined sample of 284 transplant patients (229 transplant recipients and 55 transplant candidates) were

identified from the Organ Transplant Tracking Record database at Barnes Jewish Hospital Transplant Center (BJTC). For this exploratory study of patients' views on lung transplant education, we sought a sample of approximately 50 patients to participate in the study, either in the focus group and survey or the telephone survey alone. We reached thematic saturation after recruiting approximately 25 focus group participants. We then sought approximately twice as many survey participants to meet minimal sample size requirements for descriptive and bivariate statistical tests. Patients who lived a distance from the transplant center and/or were in fragile health were more appropriately included as participants who completed the telephone survey only.

Twenty-eight focus group patients (20 transplant recipients and 8 pretransplant patients) provided written consent for participation and were given a \$25 gift card for participating in 1 of 7 focus groups. Twenty-two participants (15 pretransplant and 7 posttransplant) completed the telephone survey and gave verbal consent, although their participation was not incentivized. The protocol was approved by the hospital's institutional review board (IRB # 201202162).

Focus group participants completed the survey before the session began. The 7 focus groups were led by the first author (L.A.D.) and lasted 60 to 80 minutes. A semistructured interview guide was used and sessions were audio taped and transcribed verbatim.

Lung Transplant Education Survey

The survey and focus group strategies complemented each other by creating a clearer picture of the experiences, perspectives, and educational needs of lung transplant patients during evaluation, immediately before surgery, and after transplant. The 107-question survey asked posttransplant patients to answer questions retrospectively about their educational preferences whereas pretransplant patients answered questions about what they would ideally want now.

Preferred Education Topics. Transplant topics of potential interest to patients were determined after an assessment of existing patient education materials and educational content that was covered by most transplant centers. We obtained examples of web and print lung educational content available at BJTC and other US transplant centers.²³⁻³² After assessing the education resources, we compiled a comprehensive list of all lung education topics addressed by at least 2 transplant centers and narrowed down the topic areas into 10 key categories (Table 1). In addition, we also reviewed the educational information for lung recipients mandated to be provided by the Organ Procurement and Transplantation Network/United Network for Organ Sharing (eg, information about the evaluation,

Table 1 Patients' interest in lung transplant education topics

Educational topic ^a	% Extremely interested ^b (n = 50)	α coefficient
Mandated information		0.90
The benefits of having a transplant	56	
Medicines you will take to prevent organ rejection	54	
An explanation of what happens during surgery	50	
Donor risk factors that could affect the success of the transplant	50	
Other risks of getting a transplant	48	
Risks of getting a disease from the donor	46	
The 1- and 3-year success rates of this transplant center	44	
Information about what my insurance will and won't pay for	42	
The 1- and 3-year success rates of US centers nationally	37	
Information about what Medicare will pay for	33	
Other treatments I could get instead of transplant	29	
My right to refuse a transplant	14	
Information about Barnes Jewish Transplant Center		0.84
Contact information for your transplant coordinator	52	
Transplant qualifications of the surgeons	37	
Roles of the members of the transplant team	30	
Location of the transplant center	29	
Information about short-term housing, nearby hotels, and restaurants ^c	27	
Information about where to park for medical appointments	24	
Information about transplant outcomes		0.87
How long you would wait on the waiting list at this transplant center	50	
Specifics about what happens after patients get placed on the waiting list at this center	42	
How long you would wait on the waiting list at US centers nationally	33	
Specifics about what happens after patients get placed on the waiting list at US centers nationally	28	
Characteristics of deceased donors providing organs at this center (eg, age, blood type)	16	
Characteristics of deceased donors providing organs at US Centers nationally (eg, age, blood type)	10	
Information about risks and benefits of transplant		0.79
Diseases that affect the organ that I need (eg, kidney, liver, lung, pancreas)	38	
How the organ that I need works (eg, kidney, liver, lung, pancreas)	32	
Information about evaluation		0.84
What my evaluation results mean	49	
A checklist of steps you will have to take to get a transplant	48	
An explanation of the medical tests required for evaluation	46	
How you know when evaluation is complete	41	
An explanation of other tests required for evaluation (eg, psychological and financial)	38	
Information about transplant costs		–
Out-of-pocket expenses I may have to pay	52	
Information about waiting for transplant		0.89
What will happen when a matching organ becomes available for you	50	
How long patients should expect to wait for a transplant	50	
When I am officially listed for transplant	48	
How to plan life while waiting for a transplant	44	
What I have to do to stay listed for a transplant each year	40	
How patients are placed on the waiting list	38	
How a matching donor is found	32	
Information about surgery		0.81
An explanation of what the day of surgery and the stay in the intensive care unit will be like	44	
How long patients should expect to be in the hospital after surgery	34	
Information about pain and pain management after surgery	30	
Information about visiting hours for family and friends ^c	26	
Information about recovery after transplant		0.86
Under what conditions should you contact your transplant coordinator immediately	56	
What to expect as you recover	48	
How long recovery will take	46	
How often you will have to return to the transplant center	36	
Information about transplant medications		0.85
What you can do to help your transplant last as long as possible	72	
Side effects possible with these medications	48	
Other medicines you might take	44	

^a Educational topics in which 50% or more of respondents were very interested are highlighted in bold.

^b Each patient was asked about their level of interest in each topic and rated on the following scale: "extremely interested," "very interested," "moderately interested," "slightly interested," or "not interested."

^c These items were removed from their respective scales because of their low correlation with the other items.

the surgery, postoperative treatment, alternative treatments, and medical and psychosocial risks) and ensured that each of these topics was included in the possible educational content.

Ten main topics encompassing 50 subtopics were developed, including (1) BJTC specifics, (2) transplant outcomes, (3) transplant risks and benefits, (4) evaluation, (5) transplant costs, (6) waiting for transplant, (7) surgery, (8) transplant recovery, (9) transplant medications, and (10) federally mandated information. To assess what type of educational information was most needed by lung transplant patients, participants were asked to rate their interest in receiving information about each of the 50 topics individually (eg, "1- and 3-year success rates of this transplant center" and "How long you would wait on the waiting list at this transplant center"). Responses were recorded by using a Likert-type, 5-item response scale including the following options: "extremely interested," "very interested," "moderately interested," "slightly interested," or "not interested."

Summary scales for each key topic category were created by summing the patients' responses to the items in each category (Table 1). As an example, since the response options for these items ranged from 1 to 5, a scale with 10 items would have a theoretical summary score range from 10 to 50. Although the educational instrument was not validated, this exploratory thematic assessment allowed us to obtain patients' opinions of all types of commonly provided transplant information at our center and nationally and to find out when they would like to receive this information.

Ideal Time Period for Presenting Education. To determine when educational information should optimally be provided, participants answered when they would most like to receive information about each topic by using a 5-point response scale: before evaluation starts, when undergoing evaluation, when at the hospital getting and recovering from a transplant, after leaving the hospital, or never. Patients could indicate their interest in receiving education at 1 time point, multiple time points, or never.

Ideal Format for Education. Finally, patients answered how often they would have used various educational resources, including pamphlets, audiovisual materials, or discussion with other transplant patients and professionals by using 4 Likert-type responses: "very often," "sometimes," "rarely," or "never."

Focus Group Interview Guide

The focus group interview guide was designed to expand participants' discussion about their educational preferences and feelings about being a lung transplant

patient. Some topics discussed were "What topic or information about lung transplant was most memorable for you?" "Where did you get your transplant information?" "What information would have been most helpful to you (at various time points)?" "What, if any, of the information you received scared/reassured you?" and "Are there education items that would be better conveyed in a different format or at a different time?"

Survey Data Analysis

All statistical tests were 2-tailed, used an α level of 0.05, and were conducted with SAS software, version 9.3 (SAS Institute, Inc). Descriptive statistics were used to assess the proportion of patients who indicated they were "extremely interested" in receiving information about each of the 50 topics. The Cronbach α was used to assess the internal consistency of each topic category scale. Items with low correlation with the total scale or whose removal would result in a higher α coefficient were omitted. Student t tests were performed to determine if there were differences in the domain scales by groups of education level (college degree vs no college degree), sex (female vs male), race (white vs other), and age (<59 years vs \geq 59 years, split at median). To determine when educational information should ideally be provided for the topics patients found "extremely important," the proportion of patients who wanted to get this information at different time points along the transplant process was calculated. To establish the ideal education format to be provided, the proportion of patients' responses to how often they would use each education resource was calculated. Responses for pretransplant and posttransplant patients were compared by collapsing responses to 5 or greater in each category for each question by using χ^2 test where possible, and Fisher exact test otherwise. Then, comparisons of how often patients would use each format were tested across the aforementioned demographic groups by using χ^2 and Fisher exact tests.

Focus Group Analysis

All focus group audio files were transcribed and cross-checked with field notes for accuracy. Consistent with recommended procedures for focus group analysis,³³ 2 independent coders analyzed the transcripts and coded each individual line with the core concept discussed. Discrepancies were discussed until consensus was reached. Preliminary codes were assigned on the basis of the question or topic to which they referred (eg, memorable messages, scary patient information, and education improvements). Additional codes were developed for novel information and concepts that were not present in the preliminary coding process. The sample size was deemed sufficient as saturation was found in themes for topics of interest.

Results

Participants/Procedure

Of the 50 patients who participated in the study, 46% (n=23) were pretransplant and 54% (n=27) were posttransplant. Of the pretransplant patients, 65% (n=15) did not participate in the focus group and took the survey on the phone, and 35% (n=8) participated in the focus group and took the survey face to face. Of the posttransplant patients, 26% (n=7) did not participate in the focus group and took the survey on the phone, and 74% (n=20) participated in the focus group and took the survey face to face. Therefore, pretransplant patients were less likely to participate in the focus groups owing to their more fragile health (35% of pretransplant vs 74% of posttransplant patients, *P* = .01). No significant differences were found in the demographic composition between pretransplant and posttransplant patients. Pretransplant patients were on the waiting list for a mean of 1.2 years, and among posttransplant patients, a mean of 2.3 years had elapsed since the transplant had occurred. Patients in the study were primarily more than 50 years old (median age for full sample = 59 years, for recipients = 60 years, for candidates = 58 years), white (87.0%-92.6%), and male (52.2%-66.7%; Table 2). We did not offer new education or intervene with the patients educationally otherwise, so we have assumed that all the participants, regardless of their mode of assessment, received the same educational program in the transplant center.

What Educational Content Is Most Important?

Focus group analysis revealed that many patients relied primarily on the transplant center to provide them with educational information about transplant. Both pretransplant and posttransplant patients reported that the amount of information received was overwhelming and because of their fragile health, they often relied on their caregiver to remind them of important pieces of information that they may have forgotten. One patient recalled:

The initial evaluation, yeah I was very grateful that there was a caregiver required to come along with me because I was . . . overwhelmed . . . it wasn't till later that night . . . "Hey do you remember this?" What? What are you talking about? It was just so much information.

Survey data analysis revealed that patients were extremely interested in information about how to make their transplant last (72%), when to immediately contact their coordinator (56%), transplant benefits (56%), immunosuppressants (54%), possible out-of-pocket expenses (52%), coordinator's contact information (52%), donor risk factors that could affect a successful transplant (50%), how long they should expect to wait

Table 2 Demographic data for lung transplant patients

Characteristic	Before transplant (n=23)	After transplant (n=27)	<i>P</i>
Age, y			.73
26-47	21.7	18.5	
48-58	30.4	18.5	
59-64	26.1	33.3	
65-71	21.7	29.6	
Sex			.30
Female	47.8	33.3	
Male	52.2	66.7	
Race			.79
White	87.0	92.6	
African American	8.7	7.4	
White and American Indian	4.3	0.0	
Ethnicity			.30
Non-Hispanic	100.0	95.5	
Hispanic	0.0	4.5	
Education			.21
Some high school	4.4	0.0	
High school or equivalent	17.4	37.0	
Some college	39.1	18.5	
Bachelor's degree	21.7	14.8	
Advanced degree	17.4	29.6	

on the waiting list (50%), the waiting times at BJTC specifically (50%), what happens after a matching organ becomes available (50%), and when they undergo surgery (50%; Table 1).

Patients' focus on learning more about topics related to living longer and having a successful transplant was echoed and expanded in focus group discussions. One patient summarized this feeling well:

I was only concerned with Number One, going through all the tests to make sure I was qualified for listing . . . But the bottom line was . . . am I going to get on the list and how long do I have to live?

Patients also mentioned the importance of medications to maintain their transplant in the face of possible rejection. One patient stated: "If you can only take 10 pages out of that book (to learn), it would be the med(ication)s . . . The rest of the stuff, you'll figure that out."

Additionally, participants identified the importance of developing educational resources to support their caregivers through the transplant process, often calling them "lifelines." Patients often reflected on what type of information would have been most helpful for their caregivers. One patient noted: "One thing you could put together would be . . . what a caregiver needs to do to get prepared at home."

Other patients reflected on how emotionally difficult the transplant process was for the caregivers.

Table 3 Differences in information preferences by demographic groups

Type of information (scale range)	Mean score ^a								
	Education level			Sex			Age		
	College degree	No college degree	<i>P</i> ^b	Female	Male	<i>P</i> ^b	<59 years	≥59 years	<i>P</i>
Mandated (12-60)	50.1	45.3	.05	51.1	44.8	.02	47.6	47.0	.82
Barnes Jewish Transplant Center (5-25)	20.3	18.7	.23	20.3	18.8	.29	19.2	19.5	.79
Transplant outcomes (6-30)	21.6	21.22	.81	23.2	20.2	.08	20.5	22.1	.38
Risk and benefits (2-10)	8.0	7.6	.48	8.4	7.3	.07	7.5	8.80	.37
Evaluation (5-25)	21.5	20.3	.24	21.8	20.2	.14	20.8	20.9	.94
Transplant costs (1-5)	4.5	3.7	.01	4.3	3.9	.39	4.1	4.0	.88
Waiting for transplant (7-35)	30.2	28.3	.18	31.7	27.4	.004	28.9	29.3	.81
Surgery (3-15)	12.7	11.8	.17	13.7	11.2	<.001	12.3	12.1	.85
Recovery (4-20)	18.1	16.6	.03	18.3	16.5	.01	17.0	17.3	.74
Medications (3-15)	13.6	13.0	.26	14.0	12.7	.02	13.3	13.2	.93

^a Higher scores indicate greater interest.

^b Significant *P* values are bolded.

One patient stated: “I thought for the supporters the nuts and bolts of it might be kinda easy to pass along. But what they went through emotionally, I don’t know that you can prepare ‘em.”

Patients often felt that their caregivers were left to fend for themselves in a complex and often overwhelming hospital environment.

Differences in Information Preferences by Demographic Groups

Using the summary scales for each key topic, we tested for differences in levels of interest in topics across demographic groups. Ten topic domain summary scales were developed to summarize patients’ level of interest in the broader topic categories. These scales have the following score ranges, with higher scores indicating a higher level of interest in the topic: mandated information, 12 to 60; information about BJTC, 5 to 25 (1 item removed for low correlation with other items in scale); information about transplant outcomes, 6 to 30; information about the risks and benefits of transplant, 2 to 10; information about evaluation, 5 to 25; information about transplant costs, 1-5; information about waiting for transplant, 7 to 35; information about surgery (1 item removed for low correlation with other items in scale), 3 to 15; information about recovery after transplant, 4 to 20; and information about transplant medications, 3 to 15. Cronbach α coefficients for the topic domain scales were 0.80 or greater, indicating good internal consistency; the α coefficient for the information about risks and benefits scale was acceptable at 0.79 (Table 1).

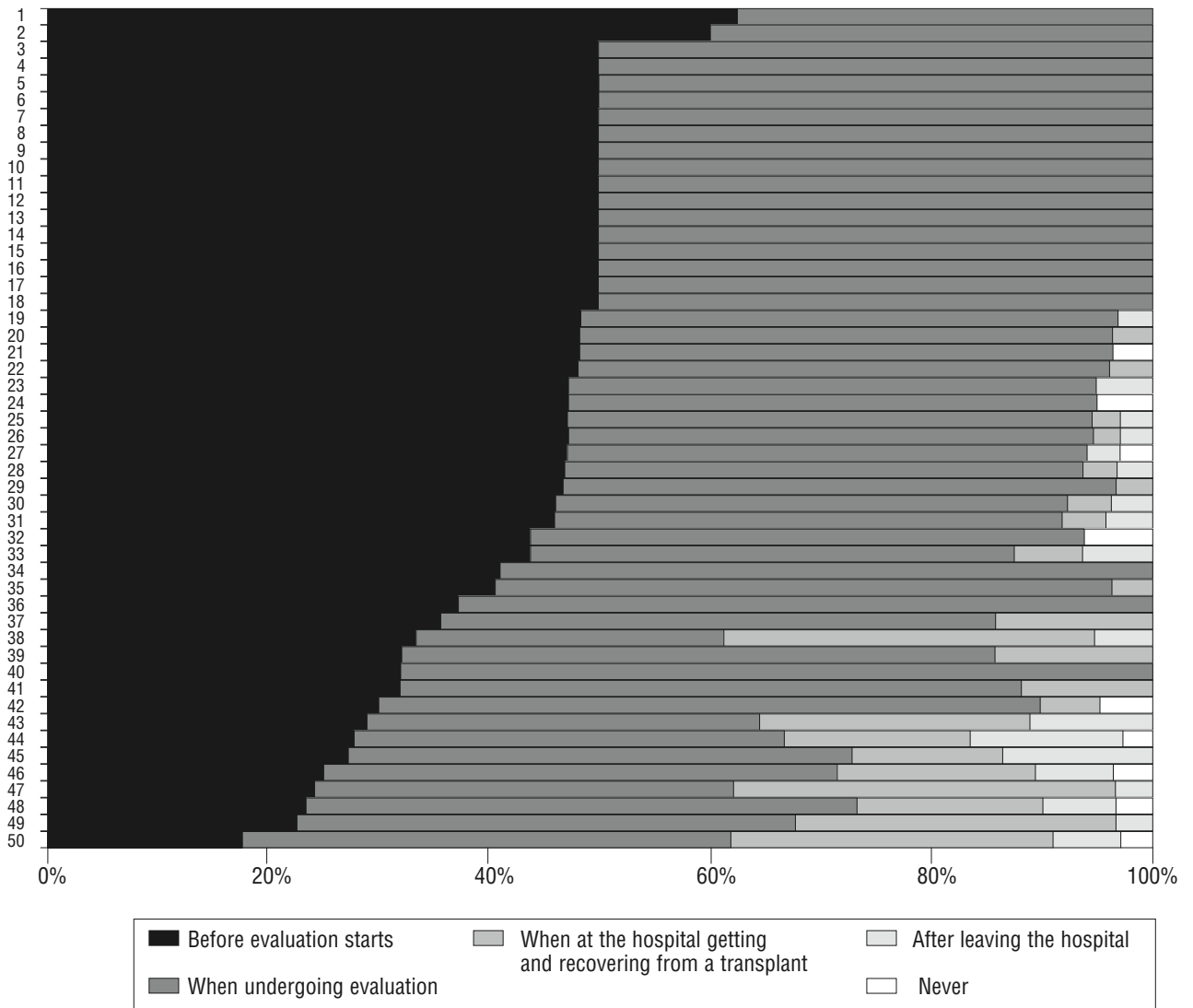
Significant differences across the topic domain scales were observed. Because only 4 nonwhite patients

participated in the study, differences across racial groups were not tested statistically. Regarding education level, compared with patients without college degrees, patients with college degrees had significantly higher levels of interest in mandated information ($P = .05$), information about transplant costs ($P = .01$), and information about recovery after transplant ($P = .03$). Compared with males, female patients had significantly higher levels of interest in mandated information ($P = .02$), information about waiting for transplant ($P = .004$), information about surgery ($P < .001$), information about recovery after transplant ($P = .01$), and information about transplant medications ($P = .02$). Finally, no differences in interest level for any topic domain were observed across patient age groups (Table 3).

When Should Educational Information Be Provided?

When what the patients sought at each educational point was examined, survey data revealed that patients wanted all of the education topics discussed before evaluation starts or when they begin evaluation (see Figure).

Immediately before transplant (time between getting the call that a potential donor has been found and getting the transplant) and after transplant (while in recovery), however, there was a subset of topics that patients were interested in reviewing again (see Figure). Patients were interested in learning more about additional posttransplant medications (34%) and posttransplant care after surgery, including topics such as pain management (33%), immunosuppressants (29%), adverse effects of medications (29%), how to make their transplant last (24%), recovery (17%), under what



Marker	Topic	Marker	Topic
1	Donor characteristics at Barnes Jewish Hospital	26	Out-of-pocket expenses
2	Donor characteristics in United States	27	Transplant coordinator's contact info
3	Planning your life pre/post transplant	28	What insurance will pay for
4	Getting on the waiting list	29	My time on the waiting list
5	What happens after listing in United States	30	Risk of disease transmission
6	What happens after listing at Barnes Jewish Hospital	31	What Medicare will pay for
7	National transplant outcomes	32	Waiting list time in United States
8	Transplant center outcomes	33	Housing, hotels, and restaurants
9	Surgeon's qualifications	34	Finding matching donors
10	Roles of transplant team members	35	What happens when match found
11	Where to park	36	Pretransplant checklist
12	When evaluation is complete	37	Hospital visiting hours
13	Other tests for evaluation	38	Pain management
14	Right to refuse transplant	39	What happens in surgery
15	Alternatives to transplant	40	Listing notification
16	Transplant benefits	41	Transplant day and intensive care unit stay
17	Lung diseases requiring transplant	42	In-hospital recovery time
18	How lungs work	43	How to make transplant last
19	Donor risk factors	44	Contact your coordinator if
20	How to stay listed	45	Frequency of postsurgical follow-up
21	Other risks of transplant	46	Recovery length
22	What evaluation results mean	47	Other medicines
23	Waiting list time at Barnes Jewish Hospital	48	What recovery will be like
24	Transplant center location	49	Medication side effects
25	Medical tests for evaluation	50	Immunosuppression

Figure When patients are interested in receiving information that is extremely important.

Table 4 How often would you use educational resources? (n = 50)

Education source	% of respondents			
	Very often	Sometimes	Rarely	Never
Website or Internet resources	74	18	4	4
Conversation with a transplant professional	68	30	2	0
Conversation with a transplant recipient	62	32	6	0
Transplant support group	54	32	10	4
Pamphlets or brochures (paper materials)	44	46	10	0
Videos or DVDs	32	30	24	14
Audio recordings	24	22	32	22

conditions they should contact their transplant coordinator (17%), and the frequency of postsurgical follow-up (14%).

Ideal Education Format

On the survey, a large proportion reported that they would use Internet resources very often (74%). Patients were also interested in speaking often with professionals (68%) and other patients individually (62%) or through a support group (54%). Many patients reported fear about the uncertainty of their transplant outcome and the possibility of dying, but were more reassured after meeting other lung recipients with successful transplants (Table 4). One patient spoke of this: "I've been here so long . . . 20% of them don't make it after that first year . . . and 1 year, I lost a lot of friends . . . Then you meet somebody [a lung recipient] that's 18 years out and go, 'Yeah!'"

Focus group participants discussed how an electronic or digital form of the educational resources would enable them to not only easily review important topics from different locations but also share the materials with loved ones in different cities who were interested in learning about the transplant process. One patient noted that he digitized the current materials on his own and carried it along with him all the time on his iPad. Many patients suggested that all printed education be made available on the Internet.

Regarding the survey data for education format, no significant differences were found in how often patients would use each format by education level, sex, or age (data not shown).

Overall Recommendations of Patients

Patients were asked to provide suggestions on how to improve the current transplant education. Several patients focused on the emotional and psychological effects of transplant, such as hallucinations or increased emotionality, and requested that additional information be provided to give patients a better understanding of what to expect psychologically. One patient noted:

Half the people in this focus group have had some emotional problems . . . that they considered serious . . . I'm probably at the top of the list. But, people need to be maybe a little better forewarned about that.

Patients also suggested the need to create some educational materials to help children understand the transplant process. Finally, patients requested that the education materials include additional resources to explore if they wanted more information.

Discussion

With limited research available on the educational needs of lung patients, we conducted a mixed method study to understand specific information about the content, type, format, and timing of ideal lung transplant education. Our study revealed that lung transplant patients desire a comprehensive overview of the evaluation, surgery, and recovery process when first beginning evaluation for transplant, in both print and electronic forms. Specifically, patients were most interested in sustaining their transplant, when to contact their coordinator in an emergency, the benefits of transplant, transplant medications, and out-of-pocket costs. Additionally, as their transplant surgery approaches, they want a review of specific education on medications, pain management, and recovery repeated in order to help them successfully maintain their transplant. This need for repetition of specific educational content for lung patients has been echoed in previous studies discussing the optimal timing for transplant education content.^{34,35} Patients who are female and more highly educated are even more interested in mandated transplant information and the recovery process than are other patients.

Our findings suggest that although patients want all the information about transplant presented early, they may not be tuned in to all the details because of their health condition. Patients often found the amount of information given overwhelming, and many chose to

tune out and hone in on only those topics that they deemed relevant on the basis of where they were in the transplant process. Currently, patients receive 1 to 2 transplant education classes, usually split up between pretransplant and posttransplant topics. Lung transplant education might have a greater impact if the information were broken into smaller chunks and clearly labeled with topics relevant to the different time points in the transplant process.

Although patients acknowledged wanting information on nearly all of the education topics early in the process, their top priority was to learn how best to complete whatever steps are necessary to get listed for transplant. This focus may distract patients from learning about crucial topics such as the proper use of immunosuppressants and posttransplant care. One solution, supported by patients in this study, is to review these critical topics immediately before and after surgery. Other research has supported creating specific learning modules or recommendations that can be customized along the patients' transplant progression.³⁵ As such, we developed a series of checklists of the most important information to be learned and actions to be taken: (1) while undergoing evaluation, (2) while waiting for a transplant, (3) immediately before getting a transplant, and (4) after transplant.

Patients also discussed the importance of caregivers who play an essential role in learning with and supporting patients during the transplant experience and their need for education on how to cope with the emotional and psychological demands of transplant. Although current education efforts address the patients' needs, the caregivers are often neglected. Many studies have been conducted that examine the stress, burnout, and other psychological outcomes of being a support person.^{36,37} Because of lung patients' heavy reliance on the caregiver before transplant, caregivers must have education about how to handle the stress they might be facing and resources, such as support groups, geared toward helping the patient have a successful transplant and supporting the caregivers' own needs during this process.

To stay abreast of technological advances, transplant centers should offer education in easily transferable formats for sharing and dissemination and links to such material on the Internet. Although patients expressed interest in having information in digital or electronic format, the importance of having multiple educational formats to address the learning needs of all patients and caregivers was emphasized. This finding supports previous patient education research suggesting that multiple mediums increase the successful delivery of patient education.^{38,39} This study had a few limitations. The reputation of the lung transplant center in which the study was conducted may have influenced

patients' perceptions of their care and expectations of the program's education. Additionally, because of its exploratory scope and the nature of the disease under investigation, this study had a small, nondiverse sample; 90% of the sample was white. Future refinement of this education should be pursued by testing it with larger samples that include more patients who are members of racial/ethnic minority groups.

Several directions for future research were identified. With limited research available in lung, heart, and liver transplant, future studies should employ similar methods to explore patients' educational needs for other organ systems and for patients of different races. Ideally, this newly developed education will be tested in a randomized controlled trial against standard educational materials to assess the impact of each on patients' decision making, knowledge, and transplant outcomes.

Conclusion

Only when lung transplant patients and their caregivers have ideal transplant education can patients prepare for transplant, adhere to their posttransplant regimen, and have the most successful outcomes. An overview of the evaluation, surgery, and recovery process at the onset with a review of content about medications, pain management, and transplant recovery repeated immediately before surgery is recommended.

Acknowledgments

This research was funded as part of a quality improvement initiative through Barnes Jewish Hospital Transplant Center.

Financial Disclosures

None reported.

References

1. Gross CR, Savik K, Bolman RM 3rd, Hertz MI. Long-term health status and quality of life outcomes of lung transplant recipients. *Chest*. 1995;108(6):1587-1593.
2. Smeritschnig B, Jaksch P, Kocher A, et al. Quality of life after lung transplantation: a cross-sectional study. *J Heart Lung Transplant*. 2005;24(4):474-480.
3. Thabut G, Mal H, Castier Y, et al. Survival benefit of lung transplantation for patients with idiopathic pulmonary fibrosis. *J Thorac Cardiovasc Surg*. 2003;126(2):469-475.
4. United States Department of Health and Human Services, Centers for Medicare and Medicaid Services. 42 CFR Volume 5, part 482. Medicare Program; Hospital Conditions of Participation. 2011. <http://www.gpo.gov/fdsys/pkg/CFR-2011-title42-vol5/xml/CFR-2011-title42-vol5-part482.xml>. Accessed September 2, 2013.
5. Myers J, Pellino TA. Developing new ways to address learning needs of adult abdominal organ transplant recipients. *Prog Transplant*. 2009;19(2):160-166.
6. Walden JA, Dracup K, Westlake C, Erickson V, Hamilton MA, Fonarow GC. Educational needs of patients with advanced heart failure and their caregivers. *J Heart Lung Transplant*. 2001;20(7):766-769.
7. Waterman AD, Barrett AC, Stanley SL. Optimal transplant education for recipients to increase pursuit of living donation. *Prog Transplant*. 2008;18(1):55-62.
8. Curtis CE, Rothstein M, Hong BA. Stage-specific educational

- interventions for patients with end-stage renal disease: psychological and psychiatric considerations. *Prog Transplant*. 2009;19(1):18-24.
9. Moloney S, Cicutto L, Hutcheon M, Singer L. Deciding about lung transplantation: informational needs of patients and support persons. *Prog Transplant*. 2007;17(3):183-192.
 10. McSweeney AJ, Grant I, Heaton RK, Adams KM, Timms RM. Life quality of patients with chronic obstructive pulmonary disease. *Arch Intern Med*. 1982;142(3):473-478.
 11. Burker EJ, Carels RA, Thompson LF, Rodgers L, Egan T. Quality of life in patients awaiting lung transplant: cystic fibrosis versus other end-stage lung diseases. *Pediatr Pulmonol*. 2000;30(6):453-460.
 12. DeVito Dabbs A, Hoffman LA, Iacono AT, et al. Pattern and predictors of early rejection after lung transplantation. *Am J Crit Care*. 2003;12(6):497-507.
 13. Dew MA, DiMartini AF, DeVito Dabbs A, et al. Adherence to the medical regimen during the first two years after lung transplantation. *Transplantation*. 2008;85(2):193-202.
 14. Teichman BJ, Burker EJ, Weiner M, Egan TM. Factors associated with adherence to treatment regimens after lung transplantation. *Prog Transplant*. 2000;10(2):113-121.
 15. Kugler C, Fischer S, Gottlieb J, et al. Symptom experience after lung transplantation: impact on quality of life and adherence. *Clin Transplant*. 2007;21(5):590-596.
 16. Goldstein NL, Snyder M, Edin C, Lindgren B, Finkelstein SM. Comparison of two teaching strategies: adherence to a home monitoring program. *Clin Nurs Res*. 1996;5(2):150-166.
 17. DeVito Dabbs A, Dew MA, Myers B, et al. Evaluation of a hand-held, computer-based intervention to promote early self-care behaviors after lung transplant. *Clin Transplant*. 2009;23(4):537-545.
 18. Russell C, Conn V, Ashbaugh C, et al. Taking immunosuppressive medications effectively (TIMELink): a pilot randomized controlled trial in adult kidney transplant recipients. *Clin Transplant*. 2011;25(6):864-870.
 19. LaVelle MB, Finkelstein SM, Lindgren BR, et al. Newsletters and adherence to a weekly home spirometry program after lung transplant. *Prog Transplant*. 2010;20(4):329-334.
 20. Clowers-Webb HE, Christenson LJ, Phillips PK, et al. Educational outcomes regarding skin cancer in organ transplant recipients: randomized intervention of intensive vs standard education. *Arch Dermatol*. 2006;142(6):712-718.
 21. Robinson JK, Turrisi R, Mallett KA, et al. Efficacy of an educational intervention with kidney transplant recipients to promote skin self-examination for squamous cell carcinoma detection. *Arch Dermatol*. 2011;147(6):689-695.
 22. Gordon EJ, Caicedo JC, Ladner DP, Reddy E, Abecassis MM. Transplant center provision of education and culturally and linguistically Competent Care: a national study. *Am J Transplant*. 2010;10(12):2701-2707.
 23. Lung Patient Education. <http://universitytransplantcenter.com/lung-patient-education>. Accessed September 2, 2013.
 24. FAQ: Lung Transplant. http://www.ucsfhealth.org/education/lung_transplant. Accessed September 2, 2013.
 25. Types of Transplants: Lung Transplantation. http://medical-center.osu.edu/patientcare/healthcare_services/transplant/types/lung/pages/index.aspx. Accessed September 2, 2013.
 26. What Is a Lung Transplant? <http://www.uch.edu/conditions/transplant-services/lung-transplant>. Accessed September 2, 2013.
 27. How to Cope After Lung Transplant. http://my.cleveland-clinic.org/services/Lung_Transplantation/hic_How_to_Cope_After_Lung_Transplant.aspx. Accessed September 2, 2013.
 28. Lung Transplantation. <http://www.cfeducation.ca/en/lung-trans.aspx>. Accessed September 2, 2013.
 29. Lung Transplant Education. <http://sickness-and-health.blogspot.com/2010/08/lung-transplant-education.html>. Accessed September 2, 2013.
 30. Educational Resources for Lung Transplantation for Healthcare Professionals. <http://www.thoracic.org/clinical/-the-web/pages/patient-care/educational-resources-for-lung-transplantation-for-healthcare-professionals.php>. Accessed September 2, 2013.
 31. Lung Transplant. <http://patienteducationcenter.org/articles/lung-transplant/>. Accessed September 2, 2013.
 32. Lung Transplantation. <http://www.nlm.nih.gov/medlineplus/lungtransplantation.html>. Accessed September 2, 2013.
 33. Stewart DW, Rook DW, Shamdasani PN. *Focus Groups: Theory and Practice*. Vol 20. Thousand Oakes, CA: Sage Publications; 2006.
 34. Naldi L, Sassi F. Evaluation of patient education. *Cancer Treat Res*. 2009;146:417-423.
 35. Franco T, Warren JJ, Menke KL, et al. Developing patient and family education programs for a transplant center. *Patient Educ Couns*. 1996;27(1):113-120.
 36. Lefaiver CA, Keough VA, Letizia M, Lanuza DM. Quality of life in caregivers providing care for lung transplant candidates. *Prog Transplant*. 2009;19(2):142-152.
 37. Song MK, Devito Dabbs AJ, Studer SM, Arnold RM, Pilewski JM. Exploring the meaning of chronic rejection after lung transplantation and its impact on clinical management and caregiving. *J Pain Symptom Manage*. 2010;40(2):246-255.
 38. Skinner CS, Buchanan A, Kreuter MW, Holt C, Bucholtz D, Strigo TS. Adapting tailored intervention message libraries for new populations. *Health Educ*. 2003;103(4):221-229.
 39. Hankey TL, Elandt NJ. Collaborative approaches to patient education in the family physician's office. *Patient Educ Couns*. 1988;12(3):267-275.