National Kidney Foundation™

CANCER RISK AFTER ORGAN TRANSPLANTATION

A report to transplant professionals on recipients' knowledge, awareness of risk, and preventive actions related to malignancy.

An important new study from the National Kidney Foundation.

Overview

INTRODUCTION & BACKGROUND TO THE STUDY

Malignancy is well-known within the medical community as one of many potential health issues for transplant recipients. As with all potential complications of organ transplantation, recipients can be important partners in minimizing the occurrence and impact of post-transplant malignancy. To do so, recipients must know enough about this issue to implement preventive care, recognize warning signs or symptoms, and know the appropriate actions to take. Some may not be seeking that knowledge due to a lack of awareness about such a risk and/or what affects their risk; a skewed sense of its importance relative to other health, social, economic, or other concerns they have; or misperceptions about their ability to change or modify their risk factors.

The National Kidney Foundation has developed resources that support and inform transplant patients and families on a range of post-transplant issues. In order for NKF and others to effectively communicate with transplant recipients about the *malignancy* issue, NKF needed to first understand what recipients know—or think they know—about this subject. To this end, NKF recruited volunteer participants for a series of focus groups in four U.S. cities (Jacksonville, FL; Dayton, OH; Phoenix, AZ; and San Francisco, CA).

PURPOSE OF THE STUDY

The purpose of convening these focus groups was to:

1. Determine what recipients know and don't know about the risks of malignancy compared to, and in addition to, other potential health problems they may encounter after transplant.
2. Find out whether recipients are likely to discuss alternatives to their immunosuppression regimen with their doctors; if not, what do recipients perceive as barriers to such a dialogue about alternatives to their current immunosuppression?
3. Ascertain whether lack of knowledge prevents patients from raising the issue of cancer risk with members of the transplant team, including choices of immunosuppression.
4. Provide health care professionals information about how and when patients wish to be educated about cancer and other risks of transplantation, and how education provided along various points on their transplant journey impacts their ability to recall key messages and engage in helpful prevention activities.
5. To gain insight from patients about how they empower themselves to engage in decision-making regarding choices involving their health, including choices of immunosuppression.

A specially-convened advisory board of transplant, dermatology, primary care and oncology clinicians developed standardized discussion guides to facilitate each of the focus groups. The information gleaned from these discussions went further:

1. To inform the design of a *second*, comprehensive *quantitative* research survey of over 400 transplant recipients that explored this issue with more structure and detail, and from which the advisory board will **compile a report to the transplant community in Fall 2006.**
2. To determine the need for, and content of, further written and online malignancy-related information for transplant recipients and other members of the transplant community from NKF and other transplant programs.
3. To determine how and when to educate patients about any important health issue, such as malignancy, to assure the maximum absorption of key messages most likely to result in positive behavior.

The focus group participants were 50 adult individuals from a variety of cultural, religious and socio-economic backgrounds, and included persons who received organs as long as 28 years ago and as recently as 2005. The participants were kidney, lung, pancreas, liver and heart transplant recipients. Half of the focus groups consisted of participants who have had cancer(s) after transplantation and half were comprised of recipients who have not. Participants had been transplanted in one of the following locations: Atlanta, Gainesville, Jacksonville, Cincinnati, Cleveland, Tucson, San Francisco or Oakland.

The focus group discussions revealed diversity of philosophy towards, awareness about, and action to prevent, cancer after transplantation. Skin cancer was the most well-known malignancy and was discussed most freely. Participants did not identify by name or describe any other types of cancers that they knew could develop after transplantation. When and where study participants learned about their increased risk of cancer after transplantation is largely a function of when and where they received their transplant. Education protocols and content varied from transplant center to transplant center.

Among the messages for clinicians that emerged was that, despite their appreciation for their organ transplant, recipients have unmet educational and psychosocial needs regarding this subject. Among the obstacles preventing cancer-aware patients from asking questions about screening tests and choices with immunosuppression are fear of appearing demanding or "ungrateful," or simply fear of "the C word" itself. Those who have experienced cancer after transplantation are (obviously) more attuned to this particular ramification of their medications; however, they are far from regretful of their decision to receive a transplant.

The report card on the next page is how patients would possibly *evaluate transplant professionals* under three broad but inter-related themes, drawn from the content of conversations in the focus groups. The remainder of this booklet provides clinicians with a glimpse of the comments, feelings and at times poignant insightfulness expressed by group participants as they reflected upon the issue of cancer and transplantation.

The National Kidney Foundation (NKF) is pleased to present to transplant professionals a summary of findings from a qualitative study conducted with organ transplant recipients in March 2006.

TEACHING PATIENTS ABOUT CANCER RISK AFTER TRANSPLANTATION: HOW WELL ARE CLINICIANS DOING?

	Grade
Providing education about cancer risk after a transplant	
Knows when initial education about risks and prevention is most valuable: Timing, media, scope, extension to include family/others, etc.	3*
Incorporates lifestyle, environment and family history into patient teaching	2
Knows the most helpful formats in which to provide on-going education	2
Understands the importance of reminders and repeatedly educating patients	3
Is able to provide one-on-one counseling with patient regarding cancer diagnosis	3
Partnering	
Makes immunosuppression choices with patient input	3
Informs patients over time that they may have alternatives with their immunosuppressant drug regimen	3
Coordinates follow-up with non-transplant, community physician	3
Arranges for dietitian consults, physical therapy, social work consults, etc. as necessary	2
Managing psychosocial aspects of illness	
Encourages patients to join support groups and peer-to-peer counseling	1
Provides pre-operative and ongoing access to professional psychosocial counseling for patients for emotional health issues of transplantation	3
Recognizes patients have a range of emotions following transplant that can impact healing and recovering if not addressed	3

*1. Action is implemented
2. Action is inconsistently implemented
3. Action is rarely implemented

Recommendations for Improvement

- As an absolute minimum standard, formal, well-timed and well-presented information about screening and prevention for medium-long term complications — more elaborate than the standard pre-discharge quiz about medication doses and side effects; offer to include family members or others. This should be repeated continuously, at least at check-up appointments.

- Ensure this process uses effective and compassionate communicators who give the patient and family a sense of having time for them and their questions; be informative but don't be an alarmist.

- Inform patients of possible alternative immunosuppressant agents over time as potential or actual health problems emerge, or as information becomes available about the relative advantages for their circumstances of a different regimen to that with which they began treatment.

- Extend patient and clinician resources about post-transplant health from the transplant centers to the primary care setting to ensure *consistency and continuity* in preventive care messages and ongoing screening.

- Make baseline skin examination a routine part of discharge planning and ensure it is built into annual review.

- Consider sending transplant recipients reminder postcards at the beginning of summer about sun protection strategies and routine skin check-up; don't assume that general community sunburn awareness is sufficiently explicit for immunosuppressed people.

- Issues of mortality, guilt, depression, employment, altered family dynamics, etc. weigh heavily for transplant patients yet receive disproportionately less attention and intervention than their immediate physical problems; professionals need to remain cognizant of these issues in ongoing, longer-term patient care.

- Expand education on diet, lifestyle, environment, family history and impact of attitude and emotions on health and recovery.

The Focus Group Discussions:

Perceptions on Life After Organ Transplantation

I. LIFE AFTER ORGAN TRANSPLANTATION

Each focus group began with a brief conversation about how life is different post-transplant, including perceptions of risks and coping with perceived versus actual problems. For all of the complications of their post-transplant lives, participants agreed that whatever they may be dealing with now is better than how they were before. All said they have a new appreciation of the value of life and that they no longer worry about "the little things."

WHAT DID PARTICIPANTS TELL US?

Life post-transplant is a matter of managing an array of medications, treatments, side effects and possible problems.

- Transplantation is both life-changing and life-defining.
- For some, their post-transplant years have been characterized by a return to a slightly altered normality; life continues, but with new restrictions and concerns. Some described their experience as merely "trading one set of problems for another."
- All indicated that they had been counseled that there would be trade-offs where health issues were concerned, but all were more than willing to take the risk.

"I was worried about living. I figured anything that could happen later I'd just deal with when it happened." — Focus Group Participant

- Some participants have significantly different lives, centered on issues that stem from the organ transplant experience:
  - — Stress of scheduling medications, doctor's appointments, and lab testing
  - — Constant health vigilance and new lifestyle habits
  - — Extensive post-transplant complications, ranging from organ rejection and debilitating side effects from immunosuppressant drugs, to shattered personal relationships and difficulty finding work.

The biggest post-transplant concerns: organ rejection and increased vulnerability to infection

- This is the highest priority following the surgery. Although this concern dissipates somewhat over time, it never completely goes away.
- Participants knew that their reduced capacity to resist common viruses and other illness is attributable to the compromised immune system that results from the medications they take to avoid transplant rejection.
- Among the things that participants said they avoid are:
  - — Crowds
  - — People with colds, coughs and sneezes
  - — Swimming in lakes and outdoor recreation
  - — Hospitals
  - — Smoking
  - — Water from unknown supplies
  - — Direct contact with door handles
  - — Public restrooms
  - — Shaking hands with people
  - — Children and grandchildren
  - — Visiting a dentist or ENT physician without advance medication
  - — The few doctors who don't like to have transplant patients
  - — Direct sunlight (meaning wearing sun screen, a hat and protective clothing when outdoors, and avoiding sun in the midday hours)

Those who have had the most post-transplant complications admit that in the back of their minds they are always wondering, "What comes next?"

The next biggest imperatives are "doing what they want you to do" and "staying on the drugs"

- Participants know that their continued health is heavily dependent on their adherence to treatment protocols, especially their medication schedule.
- Some recognize that their health was compromised precisely because they did not adhere to the instructions given to them. One participant recognized that he was going against doctors' orders when he at least initially refused to give up smoking.

Immunosuppressant drugs: both a blessing and a curse

- Participants acknowledge that the same medications that help prolong their lives by helping to prevent organ rejection also introduce unpleasant and, in some cases, debilitating side effects. But they were quick to point out that these problems are preferable to the certain prospect of death (for some) that would have occurred without the transplant.
- The immunosuppressant drugs mentioned most often included Prednisone (of which they said they were most wary), Cyclosporine, Tacrolimus, Azathioprine and Sirolimus. Some participants' physicians have successfully edited or reduced their patients' use of immunosuppressants over time. Other participants are still using a lengthy list of immunosuppressant drugs years after their surgery, and expect to continue to do so.
- Participants said other drugs can cause problems too: diminished bone mass, "weakened organs" (including the transplant), cancer, skin lesions and diabetes.
- Older study participants said it is a challenge distinguishing between immunosuppressant-related complications and the normal physical breakdown related to aging.

Regarding the connection between specific immunosuppressant drugs and specific complications: "each person is different"

...it is difficult, if not impossible, to make some generalizations about other immunosuppressant drugs because each person's chemistry is different and that while some drugs may have identifiable side effects, each person's response to a drug may actually be very different.

Study participants learn a lot of what they know about the side effects associated with immunosuppressant drugs from drug prescription labels and information sheets.

.....especially if their doctors suggest making changes in their drugs, or if a physician not associated directly with the transplant team prescribes a new drug.

Most study participants are far enough out from the time of their surgery that they only see a transplant physician every three months.

- Almost all have a lengthy list of doctors they see throughout the year. One gentleman brought a list of more than 20 doctors he sees at various times of the year.

Post-transplant life now includes regular consultation with a dermatologist.

- Almost all participants see a dermatologist at least once a year. The majority know that this is because of their heightened risk of developing skin cancer. **A few don't. One was simply told to stay out of the sun and see a dermatologist regularly "because some of your medications can cause skin problems."**

How and when study participants started seeing dermatologists varies according to transplant center and physician. Some only started seeing a dermatologist when they started having skin problems; another was advised to see a dermatologist soon after discharge from the hospital in order to establish a baseline examination against which future changes in skin condition could be measured.

Some of the issues transplant patients have to think about aren't physical.

Learning about life post-transplant appears to be driven most by the protocols of the center where they were transplanted.

- Some participants said that their transplant centers had what they felt were particularly strong pre-op and post-op protocols for preparing transplant recipients for post-op life. One participant applauded his state's program for including psychological counseling for transplant recipients.
- Most recent recipients said they had not been allowed to leave the transplant center until they could prove they were familiar enough with their medications that they could pass an informal "quiz" about use, dosages and possible complications.
- Study participants whose center did not require this did not necessarily receive poor education and preparation but their experiences appear to have been far less comprehensive and formalized.
- Persons who received their transplants 10 or more years ago all reported that early protocols did not extend beyond the most immediate and dire clinical issues.
- Four study participants mentioned receiving very little in the way of education.

Most study participants are disinclined to ask their doctors to change their immunosuppressant drugs because they do not believe they have any choices.

- Some would simply not think to question their transplant doctors' instructions.
- Most, though, simply do not believe it is possible for them to survive without the use of drugs like Prednisone, and have worked with their doctors to reduce the dosage of some of the drugs that cause the most complications.

Participants in the focus groups elaborated on their own experience with their particular combination of immunosuppressants and how they cope with side effects. For one lady, this discussion with her peers was her first information about her post-transplant cancer risk. The issues surrounding medication choices, side effects, and risks of rejection and other complications seemed so central to their very personal transplant experience, that a sequence of more structured questions was developed for the quantitative survey in order to further explore patients' willingness to question and discuss the impact of their medications and the possibility of alternative regimens with their transplant physician.

Among the risks they face post-transplant, cancer is just one of many. And it isn't given much priority until it strikes.

- Participants said they do not knowingly do anything to encourage its development; they similarly do not spend much time worrying about cancer until it actually strikes.
- In addition to infection concerns, participants are far more concerned about:
  - Contracting Cytomegalovirus (CMV) from transplant organs
  - Bird flu
  - Impact of immunosuppressants on transplant organs
  - Traffic accidents
  - Transplant organ "wear-out"

Most study participants perceive their risk of skin cancer to be a result of their weakened immune system; skin cancer is perceived to be an easily-treated condition.

"Skin cancer is such a vague thing that it's hard to think about it as lethal."

— Focus Group Participant

Becoming a transplant recipient requires a person to become a more assertive consumer of health services.

The Focus Group Discussions:

Learning About Cancer Risk

II. LEARNING ABOUT CANCER RISK

Formal notification to recipients of the increased cancer risk associated with organ transplantation varies between transplant centers.

A number of study participants said they were aware there were cancer risks (particularly skin cancer risk) associated with having an organ transplant, but that this possibility was simply too abstract, uncertain and unimportant up against the certainty that they would die without a transplant.

WHAT DID PARTICIPANTS TELL US?

Participants who have had cancer post-transplant describe learning about the condition as a sobering experience.

- Very few said they were angry with anyone for learning about this risk late, or at the time their cancer was detected.
- At the time of transplant their priorities were much shorter in perspective
- Disappointment or depression accompanied hearing this news.

> ***"When you first hear this news, the first thing you think of is, 'What's next?' 'Where will this spread next?'"*** — Focus Group Participant

- Most who have developed skin cancer since their transplant said they learned about this from a physician.
- Participants who are involved in transplant support groups say they became more aware of this risk after hearing support group members talk about it. **One gentleman learned about the cancer risk over breakfast with a "transplant buddy."**

- A few kidney recipients said they became aware of the cancer risk while they were on dialysis and there was a lot of time to talk to the dialysis nurses during their treatments.
- Some participants mentioned that when the risk of cancer was introduced to them, it was in the context of a discussion of the many different conditions and outcomes related to organ transplantation.

All the study participants believe it is important that transplant patients know about the risk of cancer before surgery occurs.

- Most shared this feeling as a reflection of the American culture of the "informed consumer."
- Some also admitted that they probably wouldn't have paid much attention to this information, or any other information that did not have immediate implications, because they were so sick and so focused on staying alive until their transplant surgery.

Knowing about the risk of post-transplant cancer would not have changed anyone's decision to receive a transplanted organ.

- Since no one told them cancer was a certainty, and because cancer strikes so many people in the general population randomly, the risk of cancer post-transplant was not especially relevant for some patients.

Some behaviors and lifestyle habits can contribute to post-transplant health compromises.

- Medications they take to avoid organ rejection also, as several participants put it, "attack" their organs. They accept that some things they are doing under direct medical instruction are in fact detrimental to their health.

- With respect to skin cancer, participants mentioned sun exposure and skin tone/color as bearing on their likelihood of contracting cancer; most suspect that African Americans and others with darker skin have less risk of developing skin cancers than persons with lighter skin.

Several participants have been told by their physicians that staying out of the sun is about the only and most important thing they can do to prevent the onset of skin cancer, because "the damage to your skin that will encourage skin cancer was done a long time ago." This leads participants to believe that there is relatively little they can do to avoid skin cancer.

- The impact of other conditions and factors on the risk of cancer, including smoking, diet, exercise, weight, or family history, were not thought to have a direct and specific contribution to the post-transplant cancer risk. But all are thought to have an effect on one's general health and, as such, to be relevant to one's ability to resist illness of any kind.

Once diagnosed with skin cancer, study participants have turned to a variety of sources of information.

- Many see their dermatologists as the front line of information about skin cancer.
- Other sources perceived to be reliable were mentioned:
  - Other doctors
  - WebMD
  - Hospital-specific publications
  - Transplant center nurses and other clinical staff
  - Information provided by pharmaceutical manufacturers
  - General health magazines
  - Transplant center web sites
  - The National Kidney Foundation (Transplant Chronicles newsletter)
  - UNOS
  - Internet search engines
  - Support groups
  - Regional OPOs
  - Mylabtest.com
  - Insurers
  - Transweb.org

The Focus Group Discussions:

Transplant Patient Education: Who? What? When?

III. TRANSPLANT PATIENT EDUCATION: WHO? WHAT? WHEN?

Study participants wrestled mightily with the issues of "when and where" to talk to transplant recipients about the risks of cancer.

"I didn't know what I didn't know, or what I'd need to know."

WHAT DID PARTICIPANTS TELL US?

Transplant education has evolved considerably over the years. Nationally, protocols do not appear to be uniform; some basic trends are present.

- The amount of education patients got about the transplant process and life post-transplant depends largely on when and where one was transplanted.
- The evolution and interesting array of patient education programs were described:

A participant who was transplanted over 10 years ago described getting little or no education: *"Heck, they just sent us home and hoped we'd survive."*

- More recent recipients tended to have received more formalized pre-operative and post-operative education. Four participants from one state specifically recalled receiving little in the way of formal education about transplant life.
- Others could not proceed to transplant unless they took part in a mandatory hour-long educational session given by members of the hospital's transplant team that addressed the transplant process, preparation for surgery, and life after transplant.
- At other transplant centers, patient education did not necessarily include formal pre-op educational sessions; but did include a screening process to assess the patient's likelihood of compliance and understanding about how they must take care of themselves post-transplant.

- Most of the more recent recipients, regardless of the transplant center, said they received some kind of book or binder that contained information about the transplant process, preparation for transplant surgery, detailed discussion of immunosuppressant drugs, guidelines for life post-transplant and space for recording lab results at regular intervals in the years post-transplant.

There do not appear to be any memorable examples of printed materials that study participants consider to be exceptionally good or "must reads."

- This does not necessarily mean that there are no useful printed materials but none of the participants cited any single publication that they would recommend although several participants did mention the NKF's newsletter *Transplant Chronicles,* as a reliable source of information.
- Incidentally, no one recalled an especially good medium, or teaching approach, or unique learning experience in any other areas of their transplant education. Again, this is not to suggest there are none being implemented – only that no one in this particular cross-section of patients reported any from their own experience.

Transplant center education for patients tends to focus on physical, rather than emotional issues.

- Only a couple of participants said that the education they received either before or after their transplant addressed the equally important emotional issues they might face post-transplant, including depression, guilt, post-traumatic stress disorder, and effects on relationships with spouses and loved ones.
- Family members might actually be the best people to get pre-op education about the post-transplant cancer risk.
- A few study participants, particularly men, suggested that women might be the most effective people to approach patients about the cancer risk because they believe women are more effective and compassionate communicators.

Some participants felt that the male doctors they saw in the hospital were too busy to sit down and have anything more than cursory conversations.

The best and most reliable source of information is someone who has "been there."

- All study participants said they would be more likely to trust guidance and input provided by successful transplant survivors.

> ***"You know the doctors and nurses are knowledgeable. They care about you and want to do their best. But they haven't actually been there. They've never been the person who got the organ. So I have a lot more trust in what someone who's been through what I'm going through tells me."***
> — Focus Group Participant

- Fortunately, many participants were introduced to support groups either when they went onto the transplant waiting list or immediately after their surgery. Many also benefited from the regular contact with transplant "buddies," "mentors" and other transplant survivors and advocates.

> ***"Anyone talking about this cancer issue should be careful to make us aware, but not alarm us."*** — Focus Group Participant

A basic progression of education and reminders is the best way to deal with education about the post-transplant cancer risk.

We asked participants how and when the heightened risk of cancer (for example skin cancer) should be discussed. Here's what they suggest:

When	What
During workup for the transplant waiting list	Tell me about the heightened risk of cancer, but in the context of a number of conditions I will need to watch out for post-transplant. Be calm, factual, constructive and respectful.
Prior to discharge from hospital	Before leaving the transplant center, give me specific instructions: stay out of the sun; set up regular skin exams by a dermatologist; etc.
During check-ups	At 6-12 month intervals thereafter, my transplant check-ups should include a question asking whether I am continuing to see a dermatologist on a regular basis.
Annually	In the spring, send me a postcard reminder to be careful of the sun in the upcoming summer months.

"The best educator is a successful survivor. You want to see someone who looks so good that you'd never imagine that they're a survivor. That's what we all aspire to be."

— Focus Group Participant

PEER ADVICE TO FUTURE TRANSPLANT RECIPIENTS

At the conclusion of each focus group, participants were asked whether they had any information, advice or guidance for someone contemplating organ transplantation. The transplant recipients had a number of suggestions, most of which dealt with the emotional aspects of life post-transplant. Their messages to future transplant recipients are:

"Always remember that although it won't always be smooth sailing, there is life after transplant."

"You may experience depression at the outset. But it gets better."

"You may experience guilt because you believe that someone died so that you could have an organ. But this is not true. What happened is that someone made a decision to share an organ, and your life is saved by it."

"Try to stay in touch with other transplant recipients. Support is good."

"Always ask questions. Be aware of the drugs you are using. If you don't get good answers [from a doctor], find another doctor, or someone who knows what they're doing."

Study participants who have been active in support groups appear to be the best-informed participants in this study.

NKF's Spring 2006 Transplant Education Survey of Patients

Upcoming Report

A comprehensive quantitative research survey of over 400 transplant recipients across the United States explored this issue with more structure and detail during Spring 2006. Here is a list of some of the things we will be including in the upcoming report to the transplant community:

WHERE WE ARE TODAY:

- What patients know
- What else they want to know
- What their biggest worries are
- When they learned about the cancer risk
- Who talks to them about risks and prevention

Patients welcome more information. A total of 68% have a specific information need right now. Even more (76%) seek to learn about an increased cancer risk from their medications, often specifying they would want to talk with their doctor (65%) about their medication regimen if they heard that their medications increase their cancer risk.

- What information sources are more useful
- What prevention steps patients take

There is a lot that patients don't know—or don't remember. Most (70%) feel they have not learned enough about cancer prevention. Some do not recall ever being told about the increased risk of cancer (11%).

Upcoming Report

WHAT PATIENTS WOULD PREFER FOR THE FUTURE (AND HOW THAT DIFFERS FROM TODAY):

- When patients prefer to learn about the cancer risk
- Who they want to tell them about the cancer risk *first*
- Who *else* they want to discuss the cancer risk with
- How often they want reminders about cancer risk and prevention
- What they want to be told
- How they want to learn

Patients report having fewer risk discussions with physicians than they would like. While 70% would like to discuss the cancer risk with a specialist, only 56% report that one ever talked with them about any special risks or prevention steps. Similarly, 73% desire a transplant physician discussion and 67% have had one.

Patients want to hear about the cancer risk early. A total of 74% say they should hear about this before their transplant. This is twice the 36% who recall learning about the increased cancer risk before their transplant.

HOW PATIENT PREFERENCES DIFFER BY:

- Whether or not they have ever been diagnosed with cancer
- Organ received
- Time elapsed since transplant
- Dialysis experience
- Where the transplant was received
- Where the patient lives
- Patient's personal characteristics (gender, age, education, culture)

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Ajai Chari, MD, Hematology Oncologist, New York-Presbyterian Medical Center, New York, NY

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National Kidney Foundation™

National Kidney Foundation
30 East 33rd Street
New York, NY 10016
800.622.9010
www.kidney.org

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