

THE EXPERIENCE OF PERSONS WITH LUNG TRANSPLANT:

A LITERATURE REVIEW

by

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ABSTRACT

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Lung transplant surgery saves the recipient from the brink of death. However, both the surgery and rehabilitation can be risky, complicated and grueling. One must adhere to an extensive regimen of expensive (and harmful) immunosuppressive drugs to keep the new lungs from being rejected, risk life-threatening infections due to their suppressed immune system, and face the reality of a limited life expectancy (the current survival rate at five years is 45%).

There is a lack of psychosocial, qualitative research on this subject as well as very limited data on employment statistics, although it appears that the majority of recipients do not return to work. This literature review examines relevant print and online materials regarding the process lung transplant recipients experience, and makes recommendations for further research – especially qualitative research regarding vocational rehabilitation.

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CHAPTER 1: RATIONALE FOR LITERATURE REVIEW

Introduction

Have you ever been unable to breathe? Do you remember the panic you felt when you couldn't draw air into your lungs? Or have you ever been so out of breath from exertion that all you could physically manage was to double over and gasp for air? Now imagine being in that condition twenty-four hours a day, and we may have just a glimpse of what it is like for persons with end-stage lung disease. Their only hope for a fresh breath of life is a lung transplant.

Lung transplant surgery saves the recipient from the brink of death. However, it is a risky, complicated, expensive procedure. Both the surgery and rehabilitation can be grueling for the person. One must adhere to an extensive regimen of expensive (and harmful) immunosuppressive drugs to keep the new lungs from being rejected, risk life-threatening infections due to their suppressed immune system, and face the reality of a limited life expectancy. Current survival rates (as of 03/19/04) for deceased donor transplants are 78% for one year, 59% for three years, and 45% for five years (United Network for Organ Sharing [UNOS], 2003 Annual Report). This new life comes at a price.

It was the observation of one researcher (Festle, 2002) that articles in medical journals seem to be written in part to justify lung transplantation. With any new treatment, and especially one with the risk, complications and limited outcomes of lung transplant, patients and medical providers alike need to ask, "Is it worth it – is the ordeal of surgery and the quality of life after surgery worth the price?" It seems reasonable then, that Festle (2002) quotes the researchers from the University of Minnesota: "Quality of life is an important outcome to measure when assessing the utility of costly and innovative therapies" (p. 63).

There is an emerging body of work that assesses Quality of Life (QOL) for lung transplant recipients, most of which is quantitative. There is a small body of qualitative studies, the most notable being *Qualifying the Quantifying: Assessing the Quality of Life of Lung Transplant Recipients* (Festle, 2002). Festle argues that asking open-ended questions in the process of collecting oral histories obtains “clearer, subtler, and fuller explanations than quantitative data permits. People define themselves by more than their diseases, but too often the need to address medical crises mean that much of patients’ humanity is lost, and they feel objectified” (p.85). Open-ended questions can reveal what someone means when they identify their QOL as an 8 on a 10-point scale. Rather than responding to pre-determined categories and definitions, allowing for open-ended responses gives recipients the opportunity to provide their own definitions of quality of life, assign their own values, and indicate their primary areas of need. While one lung transplant recipient may be frustrated most that they cannot work full time, another’s priority may simply be that they are alive and have the ability to move without supplemental oxygen.

A life-changing event, such as a life-saving lung transplant, has the potential to generate a shift or change in a person’s life priorities. Very often the ability to work is considered a component or domain of quality of life, and QOL studies can help discover how the desire to enter the workforce after lung transplantation fits into the recipient’s value system and priorities. One can also get a picture of how posttransplant complications affect all aspects of the recipient’s life; physical as well as social, vocational, and emotional.

The research data with regard to vocational rehabilitation is very limited, perhaps because lung transplantation is a relatively recent procedure. Also, this author’s attempt at conducting a survey of lung transplant recipients proved to be lengthy and difficult. Accessing the medical

community and obtaining the transplant center's Institutional Review Board (IRB) approval to conduct the survey was a lengthy process. In addition, with Health Insurance Portability and Accountability Act (HIPAA) regulations, it is not possible to obtain a mailing list of transplant recipients, or request that a survey be sent to a mailing list. In this instance, the only way to conduct a study was to "piggyback" a survey along with individual "anniversary" surveys sent by the transplant center. To follow this medical center's protocol *and* collect enough data to be statistically significant would have taken a full year after their IRB approval. Therefore, the time required to conduct this research by a party outside the medical center proved to be a significant barrier.

Another possibility for the lack of vocational rehabilitation data for this population is the limited life expectancy. The bulk of the literature deals with medical aspects of rehabilitation, not social/vocational rehabilitation, and the majority of the research is quantitative. However, as the outcomes of lung transplantation improve, the social rehabilitation of lung transplant recipients becomes increasingly important.

Since lung transplant surgery has only been an option since 1986, persons with lung transplant are a fairly new population in vocational rehabilitation. Although return-to-work rates have been published for recipients of other organ transplants, very limited data are available after lung transplantation (Festle, 2002; Paris, et. al, 1998).

With the growing number of successful surgeries and increased longevity due to medical advancements, it is expected that this population will grow. Even at the current rate, with just over 1,000 surgeries per year with a 78% survival at one year post-surgery, and 59% survival past 3 years (UNOS, 2003 Annual Report), this means there is an existing lung transplant population with at least the potential for vocational rehabilitation. At the end of 2002, there were

4,574 persons living with a functioning lung transplant (UNOS, 2003). Therefore, the purpose of this literature review is to examine existing literature on the experience of persons receiving lung transplant, including any reference to post-operative employment or employment data. It will also attempt to review any discussion of lung transplant recipient's posttransplant values, priorities, and perspectives regarding employment. The more information gathered, and the more we learn and understand about the individual's experience, the better equipped medical and rehabilitation providers are to provide quality care and services. This review is intended to add to the body of research on this subject.

Definition of Terms

Sources: UNOS Glossary (<http://www.unos.org/resources/glossary.asp>), and MEDLINEplus (<http://www.nlm.nih.gov/medlineplus/encyclopedia.html>).

Acute Rejection: The body's attempt to destroy the transplanted organ; usually occurs in the first year after transplant.

Allograft (or "graft"): An organ or tissue that is transplanted from one person to another. In this paper, graft/allograft refers to a transplanted lung or lungs.

Antiinfectives: Medications used to counter balance the effect of immunosuppressant drugs by helping the body fight infection.

Bronchiolitis obliterans: Also referred to in the literature as chronic rejection, this is inflammation and fibrosis of the bronchioles (small passages in the lungs) which generally causes an irreversible decrease in pulmonary function. This leads to deterioration and eventually death. If this cannot be managed by adjusting/adding immunosuppressive therapies, retransplantation may be considered.

Chronic Rejection: Slow, continuous failure of the transplanted organ.

Cytomegalovirus (CMV): Virus that affects an immunocompromised host, such as those with HIV/AIDS or organ transplant on immunosuppressive treatment. CMV pneumonia in lung transplant recipients is the direct result of immunosuppressive drugs, and can be life threatening, depending on the strength of the individual's immune system.

Immunosuppressives: Drugs required after surgery to prevent the body's immune response from rejecting and attacking the new organ as "foreign." The challenge is to keep the level of immunosuppressive drugs out of the deadly poison range.

Living Donor: In lung transplantation, two living adult donors each contribute a lobe from one lung to provide two lobes for a smaller recipient. Living donation permanently reduces the donor's vital lung capacity by 15%. A very new procedure, of the 956 lung transplants performed in the U.S. in 2000, just 15 came from living donors (Grady, 2002). Most living donor recipients have cystic fibrosis.

Rejection: Rejection occurs when the body tries to attack a transplanted organ because it reacts to the organ or tissue as a foreign object and produces antibodies to destroy it.

Anti-rejection (immunosuppressive) drugs help prevent rejection.

United Network for Organ Sharing (UNOS): Administers the Organ Procurement and Transplantation Network, which facilitates organ matching and placement, develops organ transplantation policy, and collects and manages data about every transplant event in the U.S. Available via the World Wide Web at <http://www.unos.org>.

CHAPTER 2: DISCUSSION OF THE LITERATURE

Types of Literature

The literature reviewed includes everything this author could access in print and online on the subject relevant to the subject of the experience of lung transplant recipients. This includes newspaper, magazine and journal articles, books, and online resources, such as MEDLINEplus, and the Second Wind Web site – an online resource for lung transplant candidates and recipients – available at <http://www.secondwindstl.org>. The primary resource for lung transplant data is the UNOS Web site (<http://www.unos.org>), including the 2003 Annual Report.

Organization of Literature

The focus of the presentation of the literature is to give as comprehensive an overview as possible of the experience of persons awaiting, experiencing, and surviving lung transplant surgery. Therefore, the literature is presented in a chronological order, following the process of those who have had this experience. After an introduction, which includes an overview (background, current status, and demographics), the literature review is intended to paint an in-depth picture of the process lung transplant recipients experience. Discussion of the long range outlook for recipients will follow, including the latest medical and procedural changes with a eye towards the future. Review of the literature regarding employment after lung transplant will follow. Uniqueness of lung transplant as well as commonalties with other solid organ transplant will be discussed.

CHAPTER 3: REVIEW OF THE LITERATURE

Background and Status

The first successful double-lung transplant surgery was performed at Toronto General Hospital in 1986 (Canadian Medical Association Journal, 2001). Lung transplantation is a relatively new surgical procedure, and approximately seventy medical centers in the U.S. perform this operation (UNOS, 2003). Of these, ten medical centers performed thirty or more lung transplants in 2000 (Barzoloski-O'Connor, 2002). The number of people receiving lung transplants has steadily increased; the majority of recipients have been 35-64 years of age (Smith S., 2002). More than 10,000 lung transplant procedures have been performed worldwide, and have averaged between 1300 and 1400 per year, with 65% of these performed in the United States (Maurer, 2001). In 1993, there were 667 lung transplants performed in the U.S.; eight years later, in 2001, there were 1,054 lung transplants, and 1,041 recipients in 2002. Most of these transplants are from deceased donors; approximately 20 recipients per year receive lung lobes from living donors. As of March 19, 2004, the number of people on the UNOS lung transplant waiting list was 3,914 persons (UNOS, 2003).

Lung transplant is a lifesaver – but only temporarily. The national rates according to the United Network for Organ Sharing Web site (UNOS, 2003 Annual Report) for postoperative survival of deceased donor transplants is 78% for one year, 59% for three years, and 45% for five years. Three-year survival rates for living donor recipients are lower (42%). There are exceptions; the first successful double-lung transplant recipient lived for 15 years after her surgery in 1986, and she died of a brain aneurysm (Canadian Medical Association Journal, 2001). The longest surviving double-lung transplant recipient has been post-transplant for over

17 years (UNOS 2003 data). However, these are exceptions; the medical reality is that, in essence, the recipient knows that they are buying themselves just a little more time to live. The leading cause of postoperative lung transplant mortality is chronic rejection and is the major hurdle limiting long-term survival (Lau & Patterson, 2003); more than 70% of patients eventually develop bronchiolitis obliterans (Wunsch, 1999). Survival rates are slowly improving; death rates in the overall recipient population decreased over the ten years reported (UNOS 2003 Annual Report).

Demographic data from 2001-2003 show the majority of lung transplant recipients as white (87%), with 7% Black, 4% Hispanic, 1% Asian, and 1% Other/Multicultural. There is an approximately equal distribution between male and female recipients, and the data suggests a rise in the proportion of recipients older than 50 years of age; 57% of recipients from 2001-2003 were between 50-64 years of age (UNOS, 2003).

Phases of the Lung Transplant Process

Determining Eligibility for the UNOS Lung Transplant Waiting List

Evaluation. End stage lung disease is the essential criteria to qualify a person for the lung transplant waiting list. Also, the prognosis for the individual must be that they are strong enough to survive the surgery (Maurer, 2001). Those with either emphysema or cystic fibrosis comprise the majority of lung transplant recipients (Key & Lindgren, 1999; Liou, et al., 2001; UNOS, 2003). The typical lung transplant candidate has a life expectancy of less than 18 months, is dependent on supplemental oxygen, and is under age 65. The majority of lung transplant patients have been 35-64 years of age (Smith. S., 2002).

The process of patient eligibility for the UNOS waiting list varies considerably from center to center, particularly in terms of considering psychological and psychosocial factors

(Dew, et al., 2002; Olbrisch, Benedict, Ashe & Levenson, 2002). The transplant evaluation consists of a series of tests, procedures, and assessments that usually take 3-5 days to complete. The results are compiled and the multidisciplinary transplant team reviews the information. Expectations of a poor survival outcome because of medical, psychosocial, or financial reasons are the major contraindications to listing a patient eligible for transplantation (Smith, S., 2002). For example, the Fairview University Medical Center (which is associated with the University of Minnesota) has a mandatory smoking cessation program for recent smokers, which includes a signed contract, documented 4-month compliance, and random urine samples. Their policy states that “Due to the limited supply of donor organs, it is crucial to allocate the organs to those patients who are expected to have optimal outcomes” (Hertz, 2001, p.16).

Other examples of likely contraindications which may disqualify a candidate:

Medical – heart disease, diabetes, history of cancer, obesity, Hepatitis-C; current alcohol/drug abuse; *Financial* – inadequate financial resources to obtain immunosuppressive medications posttransplant; *Cognitive/Psychosocial* – Inability to understand the procedure, risks involved, or comply with follow-up care; psychiatric illness; inadequate support system to assist in both pretransplant and posttransplant care (Hertz, 2001).

In addition, transplant centers require that candidates live from thirty minutes to two hours away from the center (Barzoloski-O’Connor, 2002; Newman, 1999; Tomb, 2002). For many, this requires pulling up stakes and moving close to a transplant center.

Psychosocial Aspects. The patients undergoing evaluation are nearing the end of a long road of coping with deteriorating health. The majority of patients and their families experience conflicting feelings:

- Anxiety about being accepted as a candidate (and being judged physically and psychologically), and eagerness to move forward,
- Daring to hope for a healthy future, combined with fear about the surgery and the possibility the transplant will fail,
- What it will be like to have someone else's organ,
- Worries that an organ won't be available in time (Dew, et al., 2002).

Also, there is likely to be concern with financial issues: payment for procedures and medications, disability status, insurance coverage, and the potential need to relocate near the transplant center. Even with good insurance benefits, expenses for travel, relocating and time lost from work may be a significant economic burden (Dew, et al., 2002). One applicant was told he was not yet at "end stage" development. He was told to either retire from his job if possible, or change his work situation to reduce the stress on his body – with the goal being survival until he had reached "end stage" in order to qualify for the waiting list (Tunison, 2002). In this case, the applicant most likely had to take on financial stress as part of the qualifying process.

In addition to sharing the above concerns, caregivers may experience anxiety about whether they will be perceived as capable and helpful to the patient. A common concern is wondering if they are up to the task – or have the expertise to care for the patient posttransplant (Dew, et al., 2002).

Ethical Issues. The issue of whether patients should be excluded from transplantation on the basis of psychological and psychosocial criteria is controversial in the transplant and medical

ethics communities. Moral and ethical issues arise when transplantation is offered on the basis of psychosocial and behavioral history and/or status. If a behavior or psychosocial status is a criterion for eligibility, great care needs to be taken in its assessment and evaluation. Some programs provide referrals for applicants that need psychosocial interventions, others only identify those who should be excluded as candidates (Dew, et al., 2002).

In the mid-90s, there were three well publicized cases of people with Down's Syndrome who were denied eligibility for the waiting list based on their disability (Sandra Jensen, US; Terry Urquhart, Canada; Jo Harris, Great Britain). Sandra Jensen's case prompted California legislation that prohibits discrimination against people with disabilities who need transplants (*New York Times*, 1997), and media attention in Canada pressured the University of Alberta's decision to reverse Terry Urquhart's eligibility denial (*Maclean's*, 1995). Despite media publicity, it appears that the eligibility status for Jo Harris did not change (Sommerville, 1996).

It was reported in 2001 that surgeons in Melbourne, Australia were refusing to provide heart and lung transplants to smokers. The Australian Medical Association said it was "unconscionable" for a surgeon to take a moral stand on treating a patient. Ethicists said it was discriminatory because lifestyle could be blamed for illnesses such as obesity and some types of cancer (Jauhar, 2003). However, it appears that the 4-month smoking ban at Fairview University Medical Center is based on likelihood of optimal medical outcomes, not a moral judgement. The center's policy addresses the ethical issues of this policy by stating that patients have a responsibility to help themselves achieve the greatest possible success. In addition, "medical professionals feel a strong responsibility to organ donors and their families, and it is our obligation to ensure that high-risk behaviors are eliminated prior to transplantation" (Hertz, 2001, p. 16).

Generally, applicants over age 65 are not eligible; however, this is usually determined on an individual basis (Smith, S., 2002). Although some carefully selected elderly patients have been demonstrated to have outcomes comparable to younger patients, this is still subject to the policy and discretion of the transplant center and transplant team (Dew, et al., 2002; Olbrisch, et al., 2002).

What is underneath all this controversy of eligibility is the fact that there are not enough healthy lungs available for the people who need them. Scarcity of organs and suboptimal recipient survival underscores the critical factor of the process of selection. Mauer's *JAMA* editorial (2001) illustrates the difficulties and medical complexities in "identifying more precisely those patients who can optimally benefit from lung transplant," (p.2721) and challenges clinicians to determine models that do a better job of this. Ann Sommerville, head of medical ethics, British Medical Association, writes about the sad reality that some applicants will not get chosen for transplants: "It is the struggle of conscientious doctors searching for criteria with which to address the obscene dilemma of selecting who will live. For many, time will run out before they get to the operating table. Not all can be treated, so desperate efforts are made to match the big waiting list with the small organ supply" (Sommerville, 1996, p. 499).

One solution proposed is legislation that would designate everyone as an organ donor unless they specifically request otherwise (Brody, 2003; Smith, D., 2002). One lung recipient remarked that "If everyone willing to be a donor became one, there wouldn't be an organ shortage" (Brody, 2003, p. 5). In an effort by the state of Wisconsin to increase transplants, the State Senate passed a bill in January 2004 allowing a state income tax deduction of up to \$10,000 to cover expenses for donors. Similar legislation is pending in Indiana (Napolitano, 2004).

The Wait

Status. When Valerie Vandervort was put on the waiting list, her doctor said, “We have to keep you well for two years” (Vandervort, 2002, para. 4). Because of the scarcity of available organs, the result is long waiting lists. Many people die while on the waiting list (488 in 2001 according to UNOS data), or are taken off the list because they have become too sick for the surgery. As of March 19, 2004 there were 3,914 people on the waiting list for lung transplant, and the median wait time is approximately 2.3 years. The average patient waits over 24 months for a single lung, and approximately 36 months for two lungs (Hertz, 2001). There were 1,041 lung transplant surgeries performed in the U.S. in 2002 (UNOS), which is approximately a third of the current waiting list.

Currently, there is no priority listing for clinical status (Hertz, 2001; UNOS, 2003). Unlike waiting lists for other organs, such as heart or liver, which factor in the severity of the illness, the main selection criteria for lung transplant is who is at the top of the list. This first-come, first-served policy may take away subjectivity in selecting who has the next surgery, but it makes the timing of referrals very important (Barzoloski-O’Connor, 2002). Hertz (2001) states that patients should be evaluated well ahead of the anticipated need if they are to survive in stable condition until the transplantation.

Other primary factors affecting a patient’s wait for lung transplantation are blood type and body size for matching purposes (Barzoloski-O’Connor, 2002). Unfortunately, it is more difficult to get two perfect lungs from an organ donor because often one lung has been damaged or injured. Only 20% to 30% of donor lungs are available for transplant (Smith, S., 2002). Because of this, the wait for double lung is often longer than for single lung transplants (DeMarco, et al., 2001; Hertz, 2001).

Candidates for other transplants may have stopgap medical technologies to keep them alive until surgery – e.g., ventricular assist devices for cardiac patients, dialysis for kidneys (Kurz, 2001). Only oxygen is available for failing lungs, which makes the lengthy waiting list time for lung transplant even more precarious.

Psychosocial Aspects. During the waiting period, the patient and their families/significant others have to deal with the uncertainties about whether and when a suitable donor organ will become available. Candidates are simultaneously faced with the prospects of preparing to live and preparing to die, and must cope with the stress of dying while hoping for a transplant. Not surprisingly, patients and families identify the waiting period as the most psychologically stressful part of the transplant experience. Anxiety disorders are more common in persons with end-stage lung disease, and lung disease, in particular, may have an etiologic relationship to anxiety disorders such as panic disorder (Bright & Craven, 1990; Dew, et al., 2002; Olbrisch, et al., 2002).

During this time, the person experiences worsening organ function and declining health. Patients are increasingly reliant on complicated medical technologies to keep them alive, and coping with increasingly complex medical regimens adds to the stress of the waiting period. Candidates may find themselves wishing for a donor and subsequently experiencing guilt when they reinterpret these thoughts as “wishing for another person’s death” (Bright & Craven, 1990).

One recipient described his waiting experience by saying that his life “just sucked. It was so bad, it was to the point where I wasn’t sure that I wanted to go on like that. I was really wondering if it was worth it to me” (Festle, 2002, p. 75). Ted Tunison says in his online testimonial that he and his partner kept busy as possible, “to avoid thinking about the big IT” (Tunison, 2002, para. 12). In Ted’s case, once he got within three months of when the transplant

center determined he may be called, he was given a beeper in order to be available 24 hours a day. Ted related that getting the beeper was a “big deal” and the “wait becomes ever more serious. . . It is impossible to describe the level of stress and anxiety you live with every day, as you wait and wait and wait” (para. 13). Laura Rothenberg summarized her agony of waiting by saying, “I realize that I am in a different time zone that very few are able to calculate” (Rothenberg, 2003, p. 77).

This situation can place considerable strain on relationships within the family, and the primary players and relationships are vulnerable due to role changes and altered social relationships, because of the changes in their daily lives. Patients and families are likely to be dealing with new perceptions of self at this time (Dew, et al., 2002). Financial concerns may add to these strains. The transplant candidate is most likely unable to work due to declining health, and the primary caregiver (usually a spouse) may need to take substantial time off work. Many candidates and their families/caregivers have to relocate to be close to the transplant center, which can add psychosocial and financial stress.

Even if a transplant takes place, patients face revising their life goals and plans. A concern of healthcare providers is that sometimes the patients have unrealistic expectations regarding posttransplant life (Dew, et al., 2002).

This is a time of great psychological strain, which is why transplant centers place a high emphasis on the importance of patient and family involvement with support groups, because of the benefit of social supports and a supportive environment (Bright & Craven, 1990; Dew, et al., 2002; Olbrisch, et. al., 2002). Patients are referred to both local and national support groups. Local groups should be facilitated by a transplant center moderator (Bright & Craven, 1990; Dew, et al., 2002), and may include correspondence by e-mail listservs. The most well known

national group is the Second Wind website, and can be contacted through the Internet (www.secondwindstl.org). In this way, people are no longer isolated individuals, but are connected with a larger community. A downside of the support groups is that participants often know someone who did not survive the wait, which may induce distress and grief (Dew, et al., 2002; Festle, 2002).

Ethical Issues. The increase of patients with long survival rates on the waiting list has a deleterious effect on survival for patients with poorer prognosis competing for the same organs (UNOS, 2003). This can also increase the average time to transplant, exacerbating problems associated with the organ shortage. Risk-based waiting list prioritizations are growing in popularity, and the UNOS Thoracic Committee is currently investigating a proposal to create a formula to determine priority on the lung transplant waiting list by risk of death and posttransplant survival (UNOS Annual Report, 2003).

The tragic case of Jessica Santillan, the seventeen-year old girl who received a heart-lung transplant with the wrong blood type, received national media attention in February 2003 (Adler, et al., 2003). Not only did the surgeon and hospital come under fire for the grievous procedural error (hospital procedure has subsequently changed), but the hospital ethics committee's decision to perform a second transplant has also been questioned. The committee justified their decision by stating that Jessica's brain damage was "potentially reversible," but she was declared brain dead and taken off life support two days later. The decision for a second operation is understandable as a compassionate response to the victim of an awful error, but in light of the scarcity of organs, it may have been unfair to the several thousand waiting list patients eligible for either a heart or a lung (Lustig, 2003). Although the UNOS has since implemented new procedural policies that specifically assign responsibilities for double-checking that blood types

match (Mecker, 2003; UNOS, 2003 Annual Report), the decision to retransplant in this case – and the ongoing issue of who gets priority – remains in question.

The Call

The candidate's beeper or phone may ring at any hour. The voice on the other line will likely say, "This is a preliminary call. We may have a donor. How are you feeling?" If the candidate is ill, the call goes to the next matching person on the list. When the candidate receives confirmation, they grab their pre-packed bags and get to the transplant center as soon as possible - because for lung transplants, the organs remain viable for only about six hours (Barzoloski-O'Connor, 2002).

Perioperative Recovery

Lung transplant recipients wake up from surgery hooked to a ventilator with their hands tied down so they can't tear it out:

[It was] just the most uncomfortable thing. You can't eat. You can't drink. You can't talk. You can't do anything. You've got a huge hose all the way down your throat into your lungs. And you can't move. It's hard to turn. That's horrible. I wouldn't wish it upon my worst enemy. (Festle, subject interview, 2002, p. 75)

One recipient wrote a note to her nurse to ask if she was alive (Jewett, 2003).

Another recipient who had difficulty getting off the ventilator and out of the intensive care unit said, "At one point during that time, I really thought, 'Did I do the right thing? Should I have done this? I'm never going to get out of here'" (Festle, 2002, p. 82).

Another says, "...it's the hardest I ever...you'll ever do in your life. It was painful, and it was hard, and it was a long road back" (p. 83).

Many are shocked at what they are expected to do in the hours or days after the surgery; e.g., get up and walk while still hooked to the chest tubes, being forced to cough despite searing pain (Festle, 2002, Jewett, 2003). Lungs are much more prone to injury than kidneys and livers, and unlike kidneys and livers, there's no time to do tissue matching – the transplant must be done quickly (Key & Lindgren, 1999). This means that the potential for medical crisis is very high with lung transplantation. What is unique to the lungs is that it is the only organ system to interact directly with the external environment, hence the high risk of infections such as CMV (Barzoloski-O'Connor, 2002). A myriad of severe complications is possible at this early stage: acute rejection; risk of life-threatening infection, especially CMV; hallucinations and other psychiatric disorders, poor lung function requiring ventilator intubation; cardiovascular complications; and side effects from medications (Dew, et al., 2002; Festle, 2002; Greer, Kohn, Hasty & Henderson, 2000; Kurz & Cavanaugh, 2001; Smith, S., 2002).

Most patients are released from the hospital in 7-14 days, but usually need to reside near the transplant center for 6-8 weeks for appointments and therapies before returning home (Smith, S., 2002). Despite the extensive regimen of toxic immunosuppressant drugs and their side effects, ongoing physical tests, rigorous physical therapy and excruciating pain, most recipients express a sense of relief and gratitude after surgery (Dew, et al., 2002; Festle, 2002). One recipient stated that even if they only got the month they already had, it would have been worth every second. A caregiver reflected, "It was the best of times and the worst of times" (Jones, 2002, para.8). Most patients and families are extremely optimistic at this time, and express fewer concerns during this period than almost any other phase in the transplant process (Dew, et al., 2002). Transplant recipient Ted Tunison (2002) shares his story on the Second Wind website:

About a week into my recovery a nurse came into my room to take my temperature, blood pressure, etc. She paused in mid-task, looked at me and asked if I wanted to listen to my new lungs. I had previously heard my old ones through a stethoscope, and they sounded like a cement mixer. I borrowed her stethoscope, but I could not hear a thing. She said to try again. I did, and still nothing. I was becoming frustrated. “What am I doing wrong; I don’t hear a damn thing.” “Be quiet, be very quiet and listen as carefully as you can,” she said. I did as told, and then I heard something. And I heard it again. Then again. And again. It was a gentle whoosh; so gentle it was difficult for my untrained ear to hear. Whoosh. Whoosh. Whoosh. My eighteen-year old lungs were giving me life with each breath that I took. Whoosh. Whoosh. I reached out, took her hand and started to tear. She looked at me and said, “That’s a mighty fine pair of lungs you have.”

(para. 18)

Posttransplant

The two most important factors in early survival and recovery are compliance with the immunosuppressant medication regimen and adherence to physical therapy, especially regular aerobic exercise (Hertz, 2001; Smith, S., 2002). Patients generally take a year before they feel they are fully recovered (Dew, et al., 2002; Festle, 2002; Smith, S., 2002). Approximately 75% of lung transplant recipients (living and deceased donor recipients) survive the first year (UNOS, 2003).

Medical complications. An acute rejection episode (the body’s rejection of the “foreign invader” lung tissue) is most common in the first three months after surgery, and has been shown to be a major risk factor in the later development of chronic rejection or obliterative

bronchiolitis, especially when the acute rejection episodes are recurrent or severe. Prevention, early diagnosis, and treatment with immunosuppressant drugs optimize long and short-term outcomes (Hertz, 2001; Smith, S., 2002). However, “The high rate of acute rejection and subsequent obliterative bronchiolitis clearly indicates that current immunosuppression strategies are inadequate” (Stewart & Patterson, 2001. p. 204).

The lung is the most common site of infection in all organ transplant recipients and infection is the leading cause of morbidity following lung transplantation; 65% of patients experience a lung infection (Smith, S., 2002). Cytomegalovirus (CMV) is the most common viral infection; CMV pneumonia being the most common in lung transplant recipients. These infections result from the suppression of the immune system brought on by immunosuppressant drugs. Antiinfective medications are used to help the body fight infections (Barzoloski-O’Connor, 2002; DeMarco, et al., 2001; Smith, S., 2002).

The mini-pharmacy of immunosuppressant therapy keeps the body from rejecting the new lungs, but the toll on the body is extensive. Heightened risk of infections, high blood pressure, diabetes, high cholesterol, possible development of cancer, reappearance of lung disease, osteoporosis, kidney disease, cataracts, mood swings and personality changes, gastrointestinal problems, muscle cramps and hand tremors are primary side effects (Barzoloski-O’Connor, 2002; DeMarco, et al., 2001; Dew, et al., 2002; Festle, 2002; Henderson, 12/07-14/2000; Hertz, 2001). The cost for these immunosuppressant and antiinfective medications is as much as \$1000/day at first (Kurz & Cavanaugh, 2001) and around \$2500 a month long-term (Barzoloski-O’Connor, 2002), so finding a way to cover this ever-increasing medical expense is likely to be a financial strain.

Psychosocial Aspects. Just as the lung transplant trades one set of medical problems for another, psychosocial aspects adjust after transplant as well.

The early stages of recovery require intensive caregiver requirements, and the designation of a caregiver is a criteria for lung transplant eligibility (Bright & Craven, 1990; Hertz, 2001; Kurz & Cavanaugh, 2001). According to Kurz & Cavanaugh (2001) the caregiver is usually a spouse, and it is the couple, not just the patient, that adapts to the problems of life after transplant. A frequent refrain from caregivers/spouses and transplant recipients is that they did not feel prepared for, or were shocked by, the intensity of the medical regimen and roller coaster of medical crisis' they would experience after surgery (Bright & Craven, 1990; Dew, et al., 2002; Festle, 2002; Kurz & Cavanaugh, 2001; Olbrisch, et. al., 2002).

Nevertheless, lung transplant recipients scored significantly better than candidates in studies that used self-rating scales to measure anxiety, depression, current state of health, and quality of life (Festle, 2002). The author acknowledges bias in these studies – data is missing from those post-operatives who are in poor health (and unable to take surveys) or have died. However, Festle's QOL qualitative study of oral history interviews still reinforced these conclusions. A constant theme of these interviews was that recipients felt an exceptional sense of gratitude.

“When asked about the current quality of their lives, the answer transplant recipients gave was usually a relative one, in direct comparison to how they had been doing before the transplant” (Festle, 2002, p.74). Most contrasted their pre- and post-operative lives in their answers. This is reflected elsewhere in Micheal Randolph's Second Wind website entry: “This first year anniversary of a lung transplant, of which I almost did not survive, fills my soul, my body, my very being, with feelings of gratitude, joy and thanksgiving that are some times

overwhelming, indescribable, unbelievable. It has been a phenomenal year” (Randolph, M., 2002, paragraph 1).

Even those with serious, continuing health problems in Festle’s interviews (2002) said the transplant was worthwhile, and that their QOL is better than before the surgery. Perhaps this is because, despite the problems, the transplant gives people a marked improvement in their ability to breathe. In addition, all recipients interviewed knew that they had no chance other than a transplant in order to live. Festle acknowledges that because of their gratitude for getting a transplant, recipients may minimize the extent of their problems. Limbos, Chan & Kesten (1997) mention that when people are faced with near death situations, postevent QOL improves dramatically. Given the high death rate on the waiting list, the alternative (any time alive with transplantation) is considered quality time.

Their gratitude extended to the donor and their families. Recipients experience mixed feelings of joy and relief, as well as sadness and anguish that their life came from the loss of another’s – which weighed heavily on their minds. Depending on transplant center policy and the donor family’s wishes, some recipients have the option of writing to the donor family. One recipient said he tried to write the letter for six and a half years: “How do you thank somebody for giving you your life? I’ve sat down ten times to write this letter, and I get very emotional and it’s too hard for me to write” (Festle, 2002, p. 79). Another recipient expressed his sadness and frustration that, because the donor’s family did not want to hear from recipients, he was unable to say thank you.

An interesting phenomenon regarding receiving another person’s organs is demonstrated in Claire Sylvia’s book, “Change of Heart.” After a heart-lung transplant, she experienced changes in food cravings and her behavior, even the way she walked. Although she wasn’t told

her donor's name, she says it was revealed to her in a dream. Her transplant coordinator confirmed the name was correct, and later, when meeting with her donor's family, she discovered that her posttransplant food cravings and behaviors reflected those of her donor. Sylvia's explanation was that cells have memory, so her body now contained the characteristics and personality of her donor. Although the evidence is anecdotal, other transplant patients have had similar experiences (Rosen, 1997).

Recipients express a desire to express their gratitude for their transplant in tangible ways. Events honoring donor families, especially the Transplant Olympics (Festle, 2002; Sims M., 2002; Sims R., 2002) are mentioned as significant. Others indicate having a "sense of purpose" and a desire to "pass along the gift" and that "I've been given so much that I want to give something back" (Festle, 2002, p. 80).

According to Dew, et al. (2002), recipients and their families say it took longer than they expected to recover physically and emotionally from the transplant surgery and to adapt to the routine of medications and side effects. However, evidence suggests that posttransplant psychological adjustment may be less difficult for patients who wait for long periods. The list of psychosocial issues common to all organ transplant recipients are: coping with medical complications; psychological side effects of immunosuppressive drugs; managing a complex medical regimen of drugs, tests, diet, exercise and lifestyle restrictions; altering self-perceptions (less illness-focused); acceptance/dealing with someone's loss of life when they regained his/hers; coping with financial issues (Depending on whether or not insurance is adequate to cover costs for treatment and medications, medical coverage can be a source of stress or comfort. [Kurz & Cavanaugh, 2001]). Olbrisch, et al. (2002) also mentions fear of organ rejection and infection as a main posttransplant stressor.

Unfortunately, psychological side effects of immunosuppressants include mood swings, sleep disorders, cognitive dysfunction, and hallucinations; and these side effects can mimic serious neuropsychiatric conditions. Laura Rothenberg's memoir (*Breathing for a Living*, 2003) relays her struggle with severe anxiety attacks accompanied by uncontrollable shaking which required medical treatment. For months, her psychiatrist told her that she was experiencing post traumatic stress disorder (PTSD). However, when one of her immunosuppressant medications was changed, the anxiety attacks subsided. In general, the symptoms of these side effects tend to diminish over time, and there are newer drugs to help reduce these side effects (Olbrisch, et. al., 2002).

Clinically significant depression and anxiety disorders are more frequent during the first posttransplant year for lung transplantation. Post traumatic stress disorder is second to depression in prevalence for first year transplant survivors (Dew, et al., 2002; Olbrisch, et. al., 2002). One QOL study showed that, although overall QOL scores improved following transplant, women lung transplant recipients continued to have significant impairments, including those regarding sexuality and body satisfaction (Limbos, et al., 1997).

Evidence suggests that early intervention may deter the influence of psychological problems on the person's health and well being in subsequent years. Also, early posttransplant psychological distress levels may influence medical compliance (Dew, et al., 2002), which tends to be demonstrated better early in recovery than later along (Olbrisch, et. al., 2002).

In general, according to Dew, et al. (2002), psychological stress lessens as time goes on and people incorporate the transplant experience into their lives. However, "the development of new medical complications and loss of graft function may provoke psychosocial distress and even precipitate psychiatric disorders" (Dew, et al., 2002, p. 10). Unfortunately, psychosocial

issues in “the long-term years after transplantation have received relatively little attention” (Dew, et al., 2002, p. 12). The importance of the transplant center continuing to maintain communication with the recipient and timely interventions with the recipient (by Internet if necessary) – as well as the need to identify appropriate interventions – is stressed. According to Limbos, et. al (1997), it is important to investigate the psychosocial impacts of lung transplantation to identify areas to target in the posttransplant period that may allow for an improved QOL. Since psychologic distress increases the likelihood of perceived physical limitations, timely identification and treatment of distress may help maximize QOL after lung transplantation (Dabbs, et al., 2003; Dew, et al., 2002).

Long Range Outlook

Status. Only heart-lung transplant has lower survival rate at three years (43%) than the lung-only transplant: 59% at three years, 46% at five years. By comparison, heart-alone transplant survival at three years is 77% (UNOS, 2003). However, a University of Wisconsin study showed that lung graft survival (with good function) was only 29% after two years in male donors-to-female recipients, compared with survival rates from 60-87% in all other patients (Key & Lindgren, 1999). Graft failure is usually associated with death of the recipient due to respiratory failure. This study’s findings appear to be unique to lung transplantation.

Long term survival is limited by the development of obliterative bronchiolitis, also known as chronic rejection (Smith, S., 2002; Wunsch, 1999). It is generally irreversible (Hertz, 2001). White patients experienced lower death rates and times to transplant than patients of other races on the lung waiting list. In 2001, the annual death rates per 1,000 patient years were 130, 147 and 214 for white, African American and Asian patients, respectively (UNOS).

Outcomes and range of recovery can vary. Some recipients do not survive the surgery; other recipients have recovered to run marathons and engage in competitive bicycle racing (August & Faltermayer, 1996; Stanghelle, Koss, Bjortuft, & Geiran, 2000). *Women's Health Weekly* (2002) states that successful pregnancy is possible, although lung transplant recipients are considered the highest risk group of transplant recipients. Most lung transplant centers advocate waiting two years after the surgery.

Medical Advances. Medical breakthroughs continue to improve survival rates, and the literature is full of recent advancements in procedures, medications and health care, including the use of living donors in some conditions (Barclay, 2003; Grady, 2002; Henderson, 2000; Hertz, 2001; Ko, 2001; Key & Lindgren, 1999, Smith, S., 2002; Stewart & Patterson, 2001). Another breakthrough is relaxed criteria for donor standards (*Blood Weekly*, 2003; Whiting, et al., 2003). The formation of a national collaborative, the Organ Donation Breakthrough Collaborative, will test best practices in increasing donor consent rates, and a national campaign to increase minority donations (UNOS news releases at <http://www.optn.org/news/>) should contribute to the availability of organs. Surgeons at the University of Pittsburgh Medical Center have developed an unconventional post-transplant protocol that uses significantly less antirejection drugs. The result is much less risk for complications/side effects associated with high levels of immunosuppression, which is common in lung recipients (*Immunotherapy Weekly*, 2003; Waldholz, 2003). As survival rates improve, it is expected that the number of lung transplant survivors in rehabilitation will increase.

Employment

Employment is an important aspect of the reestablishment of a transplant recipient's identity, self-esteem and quality of life (Olbrisch, et. al., 2002; Carter, Winsett, Rager &

Hathaway, 2000). However, even with physical rehabilitation, which can be a long and grueling process, recipients may face functional limitations and medical restrictions in their activities.

Recent studies have demonstrated that although more than 62% of all transplant patients are able to resume work within 9-12 months posttransplant, less than 50% are returning to work.

Unemployment nationally among all transplant recipients is roughly 80% (Carter et al., 2000).

Although the Ochsner Transplant Clinic in New Orleans claims that half of all their lung transplant recipients have returns to gainful employment,

(http://www.ochsner.org/transplant/lung_evaluation.html), there is no supporting documentation or mention of a return-to-work program. From a cursory review of lung transplant center's Web sites, it appears that the medical centers' primary method of addressing post-transplant employment is to provide a description of state Rehabilitation Services and the Americans with Disabilities Act as a referral to resources. An excellent example is the USC Web site:

<http://www.usctransplant.org/lung/rehabilitation.html>.

An exception is the Vanderbilt Medical Center, which has a Return-to-Work program directed by a Certified Vocational Evaluator. Working in coordination with the State Division of Rehabilitation Services, the program offers a range of free services from career interest testing to job retraining. The Transplant Return-to-Work program is designed to find solutions to the low employment rates among transplant patients. Since its inception, the program has had over 400 referrals, 300 participants, and 125 participants have returned to previous employers or found new jobs through the program. Others have become involved in career retraining through Tennessee State Rehabilitation Services (<http://www.mc.vanderbilt.edu/transplant/transvoc.htm>).

This author was only able to discover two references in the literature that specifically address lung transplant recipient's return-to-work (Festle, 2002; Paris, et. al, 1998). The Paris

study found that 38% of lung transplant recipients who were medically able to work remained unemployed. Only 22% of 99 recipients were employed after transplant, 29% were disabled and 10% were retired. Festle's summary is that "despite improvements in QOL and function, only a small percentage of lung transplant recipients returned to work" (p.71). Given the deconditioning and deteriorating health associated with sitting on a long waiting list prior to surgery, extensive complications associated with lung transplant surgery, and limited life expectancy, it is likely that lung transplant recipients' employment rates would be at least the same, if not lower, than other recipients. During a conversation with Dr. Marshall Hertz, Director of the lung transplant program at Fairview University Medical Center in Minneapolis, (personal communication January 19, 2004), his observation was that most recipients choose not to work, although he remarked he didn't know why.

The first year post-transplant has the potential for medical crises, and well as many clinic visits, physical therapy, etc., making it difficult to incorporate medical and work schedules. Recipients who have been out of work for long periods will tend to have difficulty in returning to work. Depending on the work environment, return to work may pose potential health risks to lung transplant recipients (Couture, 2001). Potential barriers for all organ recipients' return to work include: a change in the recipient's life priorities, hiring discrimination on the basis of medical history, poor economic conditions, health insurance availability or restrictive cost, limited education or work skills, or the recipient's perception that these obstacles are insurmountable (Carter, et al., 2000; Couture, 2001). Also, "remaining on disability after the transplant would have been acceptable to all recipients because of their lack of knowledge about how to re-enter the workforce" (Carter, p. 207).

The solution proposed in the Carter et al. (2000) study was to incorporate an employment specialist on staff at a kidney/liver/pancreas transplant center as a liaison to the state Vocational Rehabilitation (VR) department. The employment specialist provides expertise on the unique problems organ transplant recipients face, while the VR counselor serves as the guide through the landscape of a sometimes confusing process. Another benefit of adding an advocate for employment to the transplant center is a “shift in the thinking and approach to care from the sick role to one of rehabilitation and from reactive to proactive” (Carter, et al., 2000, p. 206). This change in attitude is intended to assist in empowering transplant recipients to feel as if they can truly resume a normal life. Study findings showed that since the employment specialist era, posttransplant employment rates improved significantly for recipients who were both employed and unemployed prior to surgery. Adding an employment specialist to the transplant center appears to provide a bridge for the transition from being a patient into vocational rehabilitation: “The employment program has allowed us to think beyond the disease to recovery” (Carter, et al., p. 207).

Uniqueness of Lung Transplant

Organ Transplant Commonalties

Lung transplantation has much in common with other solid organ transplantation: gravely deteriorating health; evaluation of eligibility for surgery; waiting for organ donation/match; someone almost always has to die; anxiety and depression; major surgery, hospitalization and rehabilitation; and the need to take immunosuppressant medications for the remainder of one’s life.

Issues unique to lung transplantation

Medical: Supplemental oxygen is usually required 24 hours a day for pre-operative persons; the wait is extremely long (only heart-lung median wait is longer at 934 days; heart-only is 307 days [UNOS, 2003]); poor odds of getting a lung in time; the sensitivity and viability of the organ; the high percentage of medical risks involved, including high risk of infection; and limited life expectancy compared to other transplants.

Psychosocial: Anxiety is highest in this population followed by PTSD and depression. End-stage lung disease, and lung disease, in particular, may have an etiologic relationship to anxiety disorders such as panic disorder.

Ethical: Because of severe organ shortage, the first-come, first-served policy extends the waiting list to the point that the majority of candidates, regardless of how critically ill they are, may never get a transplant. Eligibility determination is becoming increasingly controversial.

Vocational: The primary uniqueness here is the lack of data. What little data exists suggests that employment rates may be at least equal to, if not lower than, other transplant recipients' rates. Also, it is possible that employment may not be a high priority in this population.

CHAPTER 4: SUMMARY & CONCLUSIONS

Summary

The literature in this review begins to tell of the arduous, harrowing, painful, exhilarating, traumatic, life-and-death experience of lung transplant recipients.

The majority of lung transplantation literature is geared towards and addresses the medical crisis/triage aspect of keeping patients alive and psychologically capable – and understandably so, given the risks involved, inherent stressors and limited life expectancy. However, there is very little qualitative research regarding lung transplant recipients, and there is an even more obvious lack of research on the subject of employment (quantitative and qualitative) in this population. What research exists demonstrates that, despite a myriad of complications, lung transplant recipients report an improvement in their quality of life after surgery. However, it appears that the majority of recipients do not return to work, even if medically capable. Psychosocial issues are seen as significantly impacting this population, and the importance of addressing these issues as soon as they arise in order to maximize quality of life posttransplant is stressed repeatedly in the literature.

There is very little discussion of lung transplant recipient's posttransplant values, priorities, and perspectives regarding employment in the literature reviewed. Most of the literature that was qualitative in nature and/or discussed employment was anecdotal, memoir-type material. Any conclusions on employment issues can only be inferred at this point.

Conclusions

Some of the possibilities for the lack of research may be: This is a relatively new field and the primary focus is on medical issues and survival, recipients have relatively low survival rates and limited life expectancy, 57% of recipients from 2001-2003 were ages 50-64 and are

nearing retirement age, and accessing the medical community to administer surveys is difficult. However, there are people who survive surgery, and even if it is for only three to five years, they deserve the best rehabilitative services we can provide. Therefore, the more information gathered, and the more we learn and understand about the individual's experience, the better equipped medical and rehabilitation providers are to provide quality care and services.

The majority of lung transplantation research is medically based, and although it is necessary and informative, it is only the beginning. Gaining a full appreciation for what these people have endured and what this experience means to them is an important part of the landscape for rehabilitation. Therefore, there is a need for research to supplement the medical data with more qualitative, psychosocial quality of life studies that incorporate the aspect of vocational rehabilitation – it is sorely missing.

For this author, the medical background lays an essential foundation of knowledge for serving this population. However, it is the qualitative, anecdotal material that proved to be the most personally compelling – for this is what infuses humanity into the statistics. In conclusion, here is a poem written by Laura Rothenberg's friend, Diane Sawyer, regarding Laura's double lung transplant surgery:

The transplant was an education (like a crash course in medical school).

It was hope and prayer all braided into one.

It was joy, then a whiplash of worry.

Finally, feeling like a parachute opened on a free fall.

And most of all, it was Laura, full bravery, full passion, full poetry.

It was a reminder that life doesn't let us choose. But oh how it lets us love.

(Rothenberg, 2003, p. 216)

CHAPTER 5: RECOMMENDATIONS FOR FUTURE RESEARCH

Employment Statistics

There is a serious lack of, and need for, employment statistics data for lung transplant recipients. One research study from 1998 is simply not enough information.

Qualitative Research

Qualitative research attempts to understand the world from the subjects' point of view, to unfold the meaning of people's experiences (Kvale, 1996). According to Meg Sewell's online text, (2001), qualitative interviewing is most useful for exploring individual differences between participants' experiences and outcomes, and evaluating programs that are seen as dynamic or evolving. The primary advantages of using qualitative interviewing (open-ended questions) are:

- Allows the participant to describe what is meaningful to him or her using his or her own words rather than being restricted to predetermined categories; thus participants may feel more relaxed and candid,
- Provides high credibility and face validity; results "ring true" to participants and make intuitive sense to lay audiences (Sewell, p. 3).

There is not much qualitative research on lung transplant recipients. There is none that specifically investigates transplant recipient's posttransplant values, priorities, and perspectives regarding employment. As survival rates continue to improve, qualitative research will be an important factor in this evolving field, and will benefit professionals in health care and rehabilitation – as well as the individuals with their family and friends.

Suggested survey

The following suggested survey (see Appendix A) for lung transplant recipients is a semi-structured interview that would collect primarily qualitative data. The survey intent is to

elicit responses that accurately represent the person's point of view about their experience of surviving lung transplant. The survey is a combination of qualitative and quantitative data.

The nature of the data is expected to provide a more in-depth understanding of the experience of those who have survived lung transplant surgery than what currently exists. A primary intent is to capture the person's posttransplant values, priorities, and perspectives regarding employment.

Some examples of the open-ended interview questions: "How has your lung condition impacted your life?" "How have your life priorities and values shifted or changed since your surgery?" "What do you see as your barriers to employment?"

Some questions require responses on a Likert-type scale rating. The Likert scale can be modified to provide more specific replies to questions such as, "Where does employment fit into your priorities? – Very Important/Somewhat Important/Not Very Important/Not Important at All." The purpose for reducing the range of responses on the scale is to avoid the tendency of respondents to gravitate toward the center (middle response), thus encouraging respondents to make a decisive response one way or the other. Ideally, this modification will provide more "truthful" and valid data.

In addition, some closed-ended questions will be asked. Examples of closed-ended questions are: "Are you unemployed/employed full time/employed part time?" "If you are unemployed, do you think it's likely you will be employed?" "If you are unemployed, do you wish to be employed?" and, "If you had to do it all over again, would you make the same decision to undergo the transplant surgery?"

It is also suggested that care providers complete a short, open-ended survey (See Appendix B) that addresses some of the same themes from the patient's surveys; e.g., "What do

you see as the most critical issues facing people posttransplant?” “In your opinion, what is the vocational outlook for people with postoperative transplant?”

Return to Work Programs

It is recommended that a study be conducted of all lung transplant medical centers to see which incorporate Return-to-Work programs (such as the Vanderbilt Medical Center), and perform an in-depth analysis of those that do exist in order to yield a “best practices” summary of the most successful programs. Ideally, this in-depth research would then yield a pilot program that could be adapted to other transplant centers in conjunction with local Departments of Rehabilitation Services.

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Appendix A

Lung Transplant Recipient Survey

Gender (Check or "X" one):

- Male
 Female

Please indicate the Age range that applies:

- 18-34
 35-49
 50-64
 Over 65

Please indicate your Race/Ethnicity: _____

Employment Status (Check or "X" one):

- Unemployed
 Employed Part Time
 Employed Full Time

Disability Status (Please indicate the one that best applies):

- I currently qualify for disability benefits
 I do NOT qualify for disability benefits
 I have applied for disability benefits and am awaiting a response
 Don't know

How are your medical costs being paid?

- Self (no insurance coverage)
 Private insurance
 Public (Medicare/Medicaid)

If your medical coverage is through private insurance, is it:

- Provided by Employer
 Spouse or partner's family coverage

What are your estimated OUT OF POCKET expenses (what you pay) per year?

Do you have any comments about your medical coverage?

How long were you on the waiting list for a transplant? _____

How long ago was your surgery? _____

Check one:

- One lung

Both lungs

How has your lung condition impacted your life?

Vocationally:

Emotionally:

Socially:

Accessibility issues:

Have your life priorities and values shifted or changed since your surgery?

Yes

No

If so, what has changed and how?

What is most important to you now?

Where does employment fit into your priorities?

Very Important

Somewhat Important

Not Very Important

Not Important at All

Please list your top three most critical needs:

FIRST critical need:

How well do you think this is being addressed?

Very Well

Well

Hardly

Ignored

SECOND critical need:

How well do you think this is being addressed?

Very Well

Well

Hardly

Ignored

THIRD critical need:

How well do you think this is being addressed?

Very Well

Well

Hardly

Ignored

What is the most helpful service you are receiving now with regard to your lung condition?

Who do you see as your primary sources of support? (Some examples are spouse, family, friends, other transplant recipients and their families, your faith community, medical staff or anyone that you find helpful.)

Who is your primary caregiver at present?

- Spouse/partner
 Family member (Please indicate relationship - mother, brother, etc.)

Other (please indicate)

If you are unemployed, do you think it's likely you will be employed?

- Yes
 No

If you are unemployed, do you wish to be employed?

- Yes
 No

Did you receive any vocational services or vocational counseling from the transplant center?

- Yes
 No

Have you sought help for finding employment from state vocational rehabilitation services?

- Yes, and I am receiving services
 Yes, but I did not qualify for services
 No

If you could get free help for finding employment, would you?

- Yes
 No

What do you see as your barriers to employment?

What are your limitations?

What are your possibilities?

If you had to do it all over again, would you make the same decision to undergo lung transplant surgery?

What other comments do you have?

Appendix B

Care Provider for Lung Transplant recipient

Your Position/Title: _____

Length of time in transplant field: _____

What do you see as the most critical issues facing people with post-operative lung transplant?

In your opinion, what is the vocational outlook for people with post-operative lung transplant?

Does your transplant center provide vocational counseling or services of any kind?

If Yes, please explain:

What are the limitations for persons with post-operative lung transplant?

What are the possibilities for persons with post-operative lung transplant?

What other comments do you have?