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Defining Novel Health-Related Quality of Life Domains in Lung Transplantation: A Qualitative Analysis

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Abstract

Purpose—Health-related quality of life (HRQL) domains vary across disease conditions and are determined by standards, values, and priorities internal to patients. Although the clinical goals of lung transplantation are to improve patient survival *and* HRQL, what defines HRQL in lung transplantation is unknown. Employing a qualitative approach, we aimed to identify HRQL domains important in lung transplantation.

Methods—We conducted semi-structured interviews in purposefully sampled lung transplant recipients (n=8) representing a spectrum of ages, gender, indications for transplantation, and time since transplantation as well as health-care practitioners representing a spectrum of practitioner types (n=9). Grounded Theory was used to identify HRQL domains important in lung transplantation, building on but going beyond domains already defined in the SF-36, the most commonly used instrument in this population.

Results—In addition to confirming the relevance of the eight SF-36 domains, we identified 11 novel HRQL domains. Palliation of respiratory symptoms was identified as important. After transplant surgery, new HRQL domains emerged including: distressing symptoms spanning multiple organ systems; worry about infection and acute rejection; treatment burden; and depression. Further, patients identified challenges to intimacy, changes in social relationships, and

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problems with cognitive functioning. Saliiently, worry about limited life expectancy was pervasive and impaired life planning.

Conclusions—We found that HRQL in lung transplantation is defined by both generic and transplant-specific domains. Delineating and refining these domains can inform efforts to improve clinical outcomes and HRQL measurement in lung transplantation.

Keywords

lung transplantation; disability; patient centered outcomes; health-related quality of life; qualitative methods

Introduction

Over the last three decades, lung transplantation has emerged as an effective therapeutic option for advanced lung disease.[1] The primary clinical goals are to extend survival and improve health-related quality of life (HRQL).[2] Indeed, some consider lung transplantation for palliation of symptoms and HRQL improvement, even when extended survival is not assured.

Because many likely determinants of HRQL are unique to lung transplantation, better delineating its condition-specific domains is critical in informing patient-centered outcomes. Prior to transplant, respiratory limitations could be expected to dominate HRQL. After transplant, however, immunosuppressants may cause myopathy, diabetes, renal insufficiency, infections, and cancer, all non-respiratory specific complications.[3] Lung transplant recipients are also prescribed up to 30+ medications varying in frequencies and routes of administration, which require extensive time and focus. Lung allograft monitoring, laboratory checks, and clinic visits limit participation in non-health related activities, especially for those who live far from the transplant center. Further, the financial burden is considerable, including costs not directly related to health care. Thus, HRQL domains important in lung transplantation may not be represented in existing generic measures or those developed for other conditions.

HRQL is generally understood to be a multidimensional construct comprised of major health-related areas of life (domains) considered important to a particular patient group.[4, 5] For quantitative instruments designed to measure HRQL, content validity assesses the degree to which the instrument measures what is important to the group in question.[6] The importance of establishing content validity is underscored by agencies including the Federal Drug Administration and Patient Centered Outcomes Research Institute who emphasize that establishing content validity is fundamental to measuring HRQL.[7, 8] Although more than twenty instruments have been used to study HRQL in lung transplantation, no study has systematically evaluated their content validity.[9]

Given its clinical importance in the field, we sought to understand how HRQL is perceived in lung transplantation. Understanding this perception may provide clinicians with a more comprehensive appreciation of the issues their patients deem important and inform potential clinical interventions. Further, identifying the constituent domains of HRQL considered

relevant for patients undergoing lung transplantation may serve as foundational work for efforts to refine the quantitative measurement. We had two specific aims for this study. First, we sought to assess whether the domains represented in the Medical Outcomes Study Short Form-36 (SF-36), the most frequently administered HRQL measure in lung transplantation, were relevant.[9-11] Second, we aimed to determine if there were additional HRQL domains important to lung transplant recipients that are not captured by the SF-36. We anticipated the SF-36 would not be comprehensive as an HRQL assessment tool for this condition.

We sought to characterize condition-specific HRQL in lung transplantation through semi-structured interviews and utilizing qualitative modes of inquiry. Since this is the first study to probe deeply into the question ‘What defines HRQL in lung transplantation?’ qualitative methods offer the strongest research design.[7, 12, 13] By using such methods, we could avoid the constraints of any single pre-existing, closed-item HRQL instrument, while at the same time probing areas relevant to the established domains of the SF-36.

Methods

We employed Grounded Theory informed by the constructivist perspective as our primary study method.[14] This method acknowledges that researchers are not naïve to the topic under investigation; rather, they possess clinical and content expertise that may inform the entire research process from the formulation of the research question through data analysis.

Participant Selection

To achieve a breadth and depth of perspectives that would not have been possible by interviewing one group alone, we used purposeful sampling to recruit both lung transplant recipients and their health-care practitioners at a single center, consistent with previous approaches.[15, 16] We sampled patients spanning the adult age spectrum, including men and women, representing common (e.g., cystic fibrosis, pulmonary fibrosis, chronic obstructive pulmonary disease) and less common indications (e.g., connective tissue disease-related interstitial lung disease) and time since transplant surgery. Practitioners sampled included physicians, post-transplant nurse coordinators, pharmacists, and social workers. This approach attempts to ensure a spectrum of perspectives are represented.[17] Non-English speakers were excluded due to limitations of requiring interviewers with fluency in multiple languages. Those too ill to complete a one-hour seated interview were also excluded. The principal investigator (PI) reviewed clinic schedules to identify subjects meeting selection criteria. For the practitioner (non-patient) group, selection targeted those who work closely with lung transplant recipients across disciplines including physicians, nurse coordinators, social workers, and pharmacists.

Potential subjects were first sent a recruitment letter followed by a telephone call or in-person meeting to provide additional information, answer questions about the study, and establish an interview meeting time. The study was approved by the UCSF Committee on Human Research.

Data collection

The PI (JPS) and a research coordinator trained in qualitative interviewing led one-on-one, semi-structured interviews. All interviews occurred in a private academic office separate from buildings where clinical care was provided to facilitate the discussion of potentially sensitive topics. Interview guides were developed by experts in clinical lung transplantation (JPS), psychometrics and instrument development (JPS,[18] PPK,[18, 19] ALS[10, 20]), and qualitative methods (JPS, MKS, PPK). The guides were also informed by literature review and clinical knowledge. Interviews were audio-recorded and lasted approximately one-hour. To begin, the study purpose was explained, informed consent obtained, and participants reviewed the item content of the SF-36. Next, perspectives on the meaning of HRQL in lung transplantation were explored through semi-structured questions and follow-up probes, as necessary. Using Grounded Theory methods, interview guides were reviewed and revised throughout the study process.[21] Interviews were transcribed verbatim and uploaded into a qualitative software program to facilitate textual analysis and coding (Dedoose, *Los Angeles CA*).

Analytic Approach

Employing constant comparison, data collection and analysis proceeded concurrently.[15, 22] Sequential data analysis was performed in which data gathered from interviews were used to develop and test emerging hypotheses and cross-validate findings from previous sessions.[17, 22, 23] Significant statements or phrases pertaining to HRQL were extracted and categorized into clusters representing recurring ideas.

Given that one study aim was to determine the relevance of the SF-36 in lung transplantation, a template of its eight health domains was established *a priori*. Recurring ideas thematically represented by the SF-36 were assigned to the relevant domain of that instrument. Unique clusters of ideas emerging from the interviews that did not match any of the eight SF-36 domains were assigned a new domain. Domains were compared with previous coding and modified, as necessary. Data were reviewed independently by two investigators (JPS, JC) trained in this analytic approach. Throughout the study process, the two investigators met to discuss and reconcile coding, terms, and domains. Other investigators (MKS, ALS) were available to adjudicate coding and analysis, when necessary.

Subject accrual continued until saturation was achieved.[15, 22] Saturation is defined as the point at which no new information is identified through additional interviews and analysis and is a standard approach to selecting sample size in qualitative studies.[21, 24]

Results

Consistent with prior work, saturation was reached after 17 subjects (8 patients and 9 practitioners).[25-27] The patient group was 38% female, median age 55 (range 29–69) and interviewed between 3–25 months after transplant surgery. The practitioner group was 78% female, median age 38 (range 33–47) with 2–14 years of transplant experience (Table 1).

Above all, patients identified being alive to participate in life activities as critically important to their HRQL. One patient noted:

Patient 9014: I am so grateful and I am healthy...I plan to find the donor's family and show my appreciation to them too because I wouldn't be here. I wouldn't have the quality of life I have now or the quality of life I've been gifted down the road...I am lodging these [complaints], but they are so miniscule to the whole picture...they don't even hit the radar screen as far as the whole thing.

As expected, all the domains represented in the SF-36 were considered relevant (see Appendix for illustrative quotes). Importantly, we also identified 11 novel HRQL domains not already defined in the SF-36 that were important to lung transplant recipients (Figure 1). Definitions and illustrative quotes for these transplant-specific domains follow below; Table 2 summarizes these domains and provides additional quotes that reflect their conceptual breadth. These novel domains demonstrate that a broad range of factors—physical, emotional, spiritual, and existential—defines HRQL in lung transplantation.

1. Symptoms impacted by transplant surgery or the side effects of medications

Patients uniformly emphasized the importance of the palliation of respiratory symptoms and liberation from supplemental oxygen achieved by lung transplantation. A patient remarked:

Patient 9013: There's not a backpack, there's not cannula, you're not hypoxic, you're not dizzy anymore...I'm getting the oxygen that I need and that oversees everything.

Emergent extra-pulmonary symptoms involving multiple organ systems, however, were pervasive and distressing. Symptoms were commonly attributed to medication side effects and included neurological effects such as tremors or neuropathy; leg muscle weakness; gastrointestinal symptoms including difficulty swallowing, reflux, nausea, and diarrhea; skin changes, including easy bruising and photosensitivity; insomnia; and chest and incisional pain. A practitioner lamented how many of these adverse effects were related to medications that could not be stopped:

Provider 9004: There are a lot of negative side-effects to these drugs. And sometimes we are not able to stop that. We identify this medication as the [problem]--like they are either having severe nausea, vomiting, or they are having hallucinations, or memory loss and things like that, or peripheral edema that's so significant they can't fit their feet into their shoes. And we [know] and they know...it's linked to the medication yet they don't have the control to stop it or we're not allowing them to stop the medications because the benefits outweigh the [risks].

2. Transplant-Related Health Outlook: uncertain future health hinders life planning

Patients were keenly aware that approximately 50% of lung transplant recipients die within 5-6 years after surgery.[1] The reality of a limited life expectancy and fear of chronic allograft rejection influenced decisions on whether to pursue activities that require years to complete. A practitioner recalled:

Provider 9009: She [a patient] was ten years out and she was doing well... younger, pulmonary hypertension. And she said, 'You know, I don't really know what to do now. I wasn't supposed to live this long, and now I am trying to reassess things.'

Younger patients struggled with whether to return to school, marry, or start a family. Others nearer retirement age decided that returning to work was no longer a priority.

3. *Transplant-related Health Distress: emotional distress caused by health concerns/ issues*

The constancy of allograft care and new symptoms after transplant caused considerable emotional distress. Patients were reminded daily that they are never free from disease or the need to take numerous medications. Many struggled with interpreting the importance of new subtle signs or symptoms. A patient reflected this struggle:

Patient 9011: So it is kind of hard for me to gauge if I am really sick or not. I don't want to be sitting at home for two weeks thinking nothing is going on and it is. But at the same time I don't want to be calling off the hook...driving everybody nuts, driving myself nuts when there's nothing going on... there's no 'normal' for me to follow.

The intense allograft monitoring requirements also contributed to fear and anxiety. A practitioner remarked:

Provider 9009: There's also this kind of other factor, which is this idea that they're still sick. There's this kind of self-perception that accompanies constant follow-up, long-term follow-up as kind of never being out of the window, that they're always in some danger...many patients are nervous, anxious, waiting for the other shoe to drop, in terms of follow-up. I think a lot of them are really terrified of bad news, and this really preoccupies them.

4. Risk of and vulnerability to transplant-related illnesses

Patients understood they were always vulnerable to infection *and* acute rejection. Early worries about infection were pervasive and, for some, the risk remained a dominant concern even later in therapy. A patient recalled his struggle to balance his susceptibility to infection and his relationship with his wife:

Patient 9013: [My wife] being a teacher...we were going to hose her off before she came in the house every day from work...she routinely sanitizes her hands before she gets in the car to come home...we just kind of keep separated.

While patients appreciated the risk for acute rejection, few expressed worry as they felt there was little they could do to mitigate it aside from taking their medications as prescribed.

5. *Cognitive Limitations: reduced ability to perform mental processes*

Patients encountered problems with forgetfulness, reasoning, confusion and maintaining focus. They attributed this to medications; practitioners also raised the possibility that intra-operative events including the use of cardiopulmonary bypass and anesthetic agents might contribute. A practitioner noted:

Provider 9002: I've had a patient [who]...swears that her memory is just not the same as it was pre-transplant...when she tried to go back to working she couldn't remember [customers'] faces and she was so embarrassed that she had to stop working.

6. Depression

Depressive symptoms were particularly common and were affected by many factors including medications and limitations on intimacy, socializing, working, and physical functioning. A practitioner noted:

Provider 9003: There is quite a bit of depression...there's some medications that can physiologically cause some depression, the disappointment that they feel in themselves as far as not being as vital as they want to be, financial issues make them depressed, there can be sexual issues that make them depressed...Some of them just want to travel right away, they want to go back to being very social and they find that they have to limit themselves. If they want to be successful at transplant, in order to survive you have to look at yourself in this situation as a patient first and as a person second.

7. Intimacy: challenges to physical and emotional closeness

Early after transplant, patients expressed concerns that physical intimacy could harm their surgical site or lung allograft itself. A patient recalled,

Patient 9013: [My wife] was afraid...There was less touching and feeling and such things just because she...didn't want to hurt anything.

Later, libido and performance limitations for both men and women emerged that were commonly attributed to medication side effects. Changes in body image resulting from the surgery or prednisone also negatively impacted physical intimacy.

8. Social Relationships change in self-identity and transplant-related experiences alters relationships with others

Patients' perception of their identities became partly defined by their status as lung transplant recipients. This perception impacted friendships and the ability to relate to others around shared experiences or outlooks on life. A patient discussed how transplant impacted his friendships:

Patient 9011: If you're not careful you can make everything about 'me', and I think there was a little time where that happened...what I want is to be actually functioning with other human beings...I didn't want my entire life to become this bloody surgery.

For others, overcoming adversity engendered a new capacity to support and relate to others. A patient related:

Patient 9012: I tell people, "Oh, I had a transplant," and they're, "Oh my God, are you OK? I am so sorry for you." I was like, "Dude, don't be sorry, be happy for me, it's awesome, you know, it's really cool."...when anyone else with CF or someone

else [is] getting a transplant and they figure that out and can talk to me, it's a really powerful and uplifting thing to be able to be there.

All patients acknowledged the burden experienced by their caregivers. Expressions of gratitude were common. A patient recalled,

Patient 9007: On the relationship front, [my wife] was there for me. She took care of me [for] two years...when I was sick... slept in the hospital beds and weird stuff for me... so I asked her to marry me.

Patients also expressed feelings of guilt that so much of their caregiver's life had become occupied by caring for them. In some cases, the stress resulted in dissolution of relationships as a practitioner noted:

Provider 9009: In support group even now they talk about how their marriage was saved by transplant. Or their marriage is no longer because of transplant.

9. Body Image: the effects of surgery and medications on perceived physical appearance

Immunosuppressants, particularly corticosteroids, caused distressing changes in physical appearance including hair loss/gain, weight gain, and skin fragility. These changes in body image impacted patients' sense of identity, sensuality, and self-confidence. A practitioner noted:

Provider 9042: There's lots of skin changes: bruising, losing their hair...people look physically different after transplant...that does impact some people... as far as anxiety or depression related to their body changing.

10. Treatment burden: the impact of medications, testing, and allograft monitoring on daily life and finances

Most patients found the requirement to spend six weeks living near the transplant center after surgery difficult, but approached it as a discrete event. They identified that the care requirements in the 6-9 months after transplant was both a time consuming and psychological burden in their daily lives. A patient early after transplant noted:

Patient 9014: When you have all these tests it's like you're in a maze...

Even after the first several months when the intensity of testing and follow-up care and number of medications prescribed decreased substantially, some patients continued to struggle with the daily requirements of allograft maintenance. A patient reported:

Patient 9011: On another level... the day-to-day living is the hardest part... waking up every morning and think, "Oh, here we go again." It's constant. It's constant. It's relentless, it doesn't stop.

In addition to the time consuming and psychological burden of transplant aftercare, financial costs engendered stress in patients and their families. The most common source of stress was medication costs. A practitioner pointed out,

Provider 9002: Even though people have good insurance, it can be more of a financial burden than people are aware...sometimes to the detriment [of] that

person's health. They can't get here for visits; they can't focus on their own healthcare because of financial burdens. Sometimes it's the transportation, housing costs [of living near the transplant center for 6 weeks after surgery], a lot of times it is the medications.

Depending on the insurance plan offered by a *potential* employer, these costs determined whether patients could resume working and afford to lose their existing disability benefits. Although unusual, practitioners recalled some patients who liquidated assets, including their homes, to afford the transplant procedure and required aftercare.

11. Spirituality and transcendence: transplantation is a transformative experience

Nearly all patients found the lung transplant process to be a positive transformative experience and time of substantial spiritual growth. Religious or non-denominational faith carried many through the waiting period and surgery and helped them to interpret issues that arose after transplant. Patients were acutely aware that they perceived the world and prioritized areas in their life differently than before transplant. A patient reflected,

Patient 9013: One thing is that I never thought about... as much as when I was dead and then recovering and ...all of a sudden you realize, especially when you see your family who are just wide-eyed and crying, you realize how important this whole system of life is. Without the transplant that wouldn't have happened...it's an awakening

Discussion

This qualitative study provides novel insights into the experiences and perspectives that define HRQL among lung transplant recipients. It was only through using an inductive qualitative approach that we were able to identify the health domains considered important in this condition.

Patients consistently reported that lung transplantation markedly improved their overall HRQL. This improvement was driven by factors such as survival, palliation of dyspnea, freedom from supplemental oxygen, and a return to physical functioning. Less obvious intuitively, many interviewees also considered the transplant process to be a positive transformative experience, providing them a greater appreciation of and refocusing on life priorities.

We also found, however, that lung transplantation negatively impacted several domains of HRQL. Worry about interpreting the importance of new symptoms or signs, chronic allograft rejection, and limited anticipated life expectancy was pervasive. These persistent worries impacted decision-making ranging from straightforward day-to-day issues such as whether to exercise vigorously to major life decisions such as whether to begin a family or return to work. Previous work has shown immunosuppressant-related symptoms are associated with distress, poorer HRQL, and adherence.[28-30] Complicating this was an unexpected finding that constituted a discrete domain of HRQL: self-perceived deficits in cognitive functioning. We also found depressive symptoms were common, consistent with prior observations.[31]

Biological, social, behavioral, economic, and health-system factors all were important in perceived HRQL. Lung transplantation impacted how patients related to friends, family members, and co-workers; in some cases, relationships were deeply enriched whereas others struggled with a sense of isolation and inability to relate to others. Patients expressed both profound gratitude and guilt for the commitment made to their aftercare by caregivers. These feelings compounded their struggle with emotional and/or physical intimacy with their spouse/partner. Our findings extend prior work linking transplant recipient-caregiver relationships with adherence to transplant-specific self-care and caregiver (not patient) HRQL to lung transplant recipient mortality.[32-34] Finally, it is noteworthy that the financial costs of transplant were an ongoing source of worry that extended far beyond the immediate operative period. This economic burden limited participation in recreational activities (e.g., taking vacations), return to salaried employment (for fear of losing disability benefits), and even being able to afford medical care for other family members. These findings are consistent with work demonstrating lower SES is associated with poorer adherence [33] and foreshortened survival [35] in lung transplantation.

This is the first study designed to identify the specific domains that constitute HRQL in lung transplantation. Of the domains we identified as novel in lung transplantation, some are relevant to and described in other chronic health conditions. Others appear to be more unique to lung transplantation. For example, among other domains, patients coping with advanced cancer experience worry about the future, barriers to physical and emotional intimacy, bothersome symptoms from the malignancy itself, and symptoms and cognitive limitations from systemic chemotherapy.[36-41] These shared domains offer insights into the shared experiences of people living with disease and potentially identify opportunities for adapting interventions developed for other conditions. The specifics that underpin these general domains, however, may be unique to lung transplant recipients as they are for individual types of cancer (e.g., breast versus brain). Thus, understanding the lung transplant recipient experience or the efficacy of an intervention adapted from other conditions will depend on careful identification of lung transplant specific HRQL determinants.

Notably, the intensity with which some of these shared domains affect HRQL is likely to be distinct in lung transplant recipients. The proximity of death before and after lung transplantation contributes to the profound perception of transplant as a spiritual and transcendent experience. Indeed, patients are only listed for transplant when their expected 1-2 year survival without transplant falls below 50% [42] and many are listed whose life expectancy is weeks to months.[43] Patients are also counseled that one in five patients die within the first-year after lung transplantation and nearly half by five-years.[1] Of those who survive, half will have developed chronic lung rejection by five-years.[1] Domains that are more unique to lung transplantation are those that reflect the immunosuppressant-related infections, cancer, and side-effects; allograft rejection; and process of integrating breathing with lungs from another individual into one's self-identity.

Although the domains identified were common across lung transplant recipients and practitioners, this study was limited to a single center and patients who were evaluated within the first two years of lung transplantation. Thus, despite using purposeful sampling to achieve diverse perspectives and continuing recruitment until we achieved saturation,

several factors may affect transferability.[44] Regional or cultural effects may have impacted our findings. Within the multidisciplinary practitioner group, it is possible that a “group perspective” on what is important in lung transplant or the relatively young age of the team members impacted the domains identified. Further, a focus on specific subgroups of patients such as by disease indication, age category, or gender, may have yielded different findings or identified domains important to some, but not all, subgroups. The domains identified by long-term survivors may also be different from those identified by patients closer to transplant surgery who require substantially more intense immunosuppression and may simultaneously be dealing with peri-operative complications and the newness of their experience as a lung transplant recipient. While possible, should subgroup specific domains be identified, they would, by definition, be only applicable to that subgroup. Lastly, given the goals of this study, the conceptual framework of the study focused on identifying and characterizing HRQL domains. Future work should be directed towards addressing these limitations including presenting narratives that depict the entire patient experience.

While not explicitly a limitation, qualitative research is not intended to test hypotheses, but to generate hypotheses by bringing to light factors that would not likely be uncovered by administering previously validated, structured, close-ended questionnaires. Thus, our study did not test the degree to which HRQL was quantitatively impacted within the novel domains identified. Lastly, we evaluated a lung transplant population and our findings may not be relevant to other solid organ transplant populations. Similar experiences in treatment regimens, health outlook, and vulnerability to infection and rejection (among others), however, raise the possibility that they may be.

Our findings lay a foundation for future studies focused on policy and research efforts. Although patients and clinicians emphasize the importance of HRQL, U.S. organ allocation policy gauges “transplant-benefit” by survival alone.[43] It is accepted clinically, however, that some patients would exchange *quantity* of life for *quality* of life. Calls are therefore increasing for the incorporation of patient-reported outcomes (PROs)[45], such as HRQL, into policy decision-making to better reflect these clinical goals.[9, 46-48] As was shown in lung volume reduction surgery for emphysema, accounting for HRQL may identify a “net benefit”, even when extended survival is not clear.[49] If PROs are to be combined with survival to more holistically determine transplant efficacy is essential that the PRO measure what is relevant to the lung transplant population (e.g., content validity).[7, 8, 21, 50, 51]

Our findings show that HRQL assessment through generic instruments alone (e.g., SF-36) misses important domains in lung transplantation. Therefore, comprehensive HRQL assessment in lung transplantation would likely require multi-instrument batteries or a novel instrument that addresses these newly identified important transplant-specific domains. Our findings reveal promising directions and insights that may contribute to efforts develop a more comprehensive measure that captures the domains most meaningful to lung transplant recipients. Indeed, qualitative approaches are generally considered a foundational step in the multi-step process of quantitative patient-reported outcome instrument development.[21, 51]

Taken together, our findings provide novel insights into the domains of HRQL that are important to lung transplant recipients. It is abundantly clear that HRQL after lung

transplantation encompasses much more for patients than respiratory complaints and physical functioning. For clinicians, these data shed light on issues relevant to their patients' sense of well-being that have immediate clinical implications. Attention should be directed at symptoms and the common psychological, social, and financial problems encountered by patients following lung transplantation. Previous interventional studies have been small in scope but lend credence to the potential viability of such strategies.[52, 53] This approach is also consistent with the comprehensive cancer staged-intervention "survivorship programs" recommended by the Institute of Medicine.[54, 55] Only through understanding how our patients perceive their HRQL can we hope to realize the aims of lung transplantation in a truly holistic sense.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

HRQL	Health-related quality of life
SF-36	36-item Short Form Health Survey
PI	Principal Investigator
PROs	Patient-reported outcomes

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Lung Transplant Specific Domains:

Symptoms: problems impacted by surgery or side effects of medications

Transplant-related health outlook: uncertain future health hinders life planning

Transplant-related health distress: emotional distress caused by health concerns/issues

Risk of transplant-related illnesses: risk of infection and allograft rejection due to immunosuppression

Cognitive limitations: reduced ability to perform mental processes

Depressive symptoms

Intimacy: challenges to physical and emotional closeness

Social relationships: change in self-identity and transplant-related experiences impact relationships with others

Treatment burden: the impact of medications, testing, monitoring of the allograft on daily life and finances

Body image: medication and surgery effects on perceived physical appearance

Spirituality and transcendence: lung transplantation is a transformative experience

SF-36 Domains:

Physical functioning: Limitations in physical activities due to health

Role Physical: Problems with work or other daily activities as a result of physical health

Bodily Pain: Pain severity and its interference with normal work

General Health: Self-evaluation of current health, resistance to illness and future health

Vitality: Amount of time felt tired and energetic

Social Functioning: Physical health or emotional problems interfere with normal social activities

Role Emotional: Problems with work or other daily activities as a result of emotional problems

Mental Health: Amount of time felt emotional distress (nervous, down in the dumps) and well-being (peaceful, happy, calm)

Figure 1.
Summary of novel lung transplant and SF-36 HRQL domains and definitions

Table 1

Participant Demographics

Patient Group (n = 8)	
Age, years	52 (29-69)
Female	3 (38%)
Race/Ethnicity	
Non-Latino White	7 (87.5%)
Hispanic/Latino	1 (12.5%)
Time since transplant surgery, months	10 (3-25)
Indication for lung transplantation	
Idiopathic pulmonary fibrosis	3 (37.5%)
Chronic obstructive pulmonary disease	1 (12.5%)
Hypersensitivity pneumonitis	1 (12.5%)
Pulmonary fibrosis	1 (12.5%)
Cystic fibrosis	1 (12.5%)
Scleroderma	1 (12.5%)
Bilateral lung transplantation	7 (87.5%)
Practitioner Group (n = 9)	
Age, years	38 (33-47)
Female	7 (78%)
Years of experience in lung transplantation	10 (2-15)
Specialty	
Physician	3 (33%)
Post-transplant nurse coordinator	2 (22%)
Pharmacist	2 (22%)
Social worker	2 (22%)

Data presented as median (range) or n (%)

Table 2

Novel Lung Transplant HRQL Domains with Additional Participant Quotes

HRQL Domain	Quote
<p>Symptoms: problems impacted by surgery or side effects of medications</p> <ul style="list-style-type: none"> • Extra-pulmonary symptoms including • Neurological- tremors, neuropathy • Skin photosensitivity • Gastrointestinal: aspiration, nausea, diarrhea • Renal dysfunction or failure • Insomnia • Edema • Muscle weakness • Improved respiratory symptoms 	<p>Patient 9012: I have noticed that it's way harder for me to build muscle.</p> <p>Patient 9012: Before, I was always in the sun, always had my shirt off, and I never wore sunscreen, I hate sunscreen. That's the one thing that bugs me. Basically my solution so far has just been to stay out of the sun, I just don't go to the river, I don't hang out at the river. And I love sitting in the sun because it makes me happy.</p> <p>Practitioner 9004: I [asked] 'How is everything going as far as the medication?' He [said], 'Well, the drugs are causing me to have skin cancer, and the [voriconazole] you guys had me on, I was unable to walk. And I keep on having infections.'</p> <p>Practitioner 9004: Some patients just understand [side effects] as the consequences of the drugs, and ...they say, 'I am alive and so I can deal with the sequelae of the drugs.' But other patients [say], 'If I would have known this, that these problems would occur post-transplant, I don't know if I would have done this.'</p> <p>Practitioner 9003: You hear about insomnia all the time, and it's not always medications. Also, a lot of early satiety and just nausea immediately after eating ...Loss of appetite. Terrible appetite problems... Bloating, the stomach bloating, not digesting their food well, heartburn, nausea, diarrhea...So a lot of GI issues. The diarrhea you hear about from at least half of the people at one time or another.</p> <p>Practitioner 9008: [Patients] individually come up to you saying, 'This is nothing, I can breathe...I don't care if I have to carry around pills, it's not carrying around a tank, or being able to walk around without getting short of breath.'</p>
<p>Transplant-Related Health Outlook: uncertain future health hinders life planning</p> <ul style="list-style-type: none"> • Limited life expectancy and possible chronic rejection hinders ability to plan for the future 	<p>Patient 9013: Life's good at the present, right? But - if you look to the future... grasping or hoping or whatever...it's a futile attempt because there's not much you can do about the future</p> <p>Patient 9011: Well, it's just the unknown. You know, I don't think there's a day goes by where I don't think, how much longer do I have to live? I mean, I just turned 50 two months ago and so that's a concern.</p> <p>Patient 9015: When I was in evaluation, they give you the sheet of paper that says 'rates of survival' and you see the one year, 95%, that's very hopeful. But then you see the number, I think it was five years drops to like 60-something, it was like...oh, that's only five years. I focused on that and I always feel that as technology's moving forward, these statistics are based on what's come before. And in the next five years there may be huge advances that may project these numbers way out. So I just always pull back and I'm trying to stay more in the present.</p> <p>Practitioner 9002: How do they view the future, how far ahead in the future do they think? ...Young people, they were in the process of getting a degree... Do they continue, do they finish that degree? Is it worth doing that? What kind of career do they develop? What kind of family do they start or develop? All these things are impacted by having a lung transplant, and they are never free of that.</p> <p>Practitioner 9009: Transplant patients...feel like [death] is more concrete...there's not this kind of open-endedness about it, they always think the end is going to happen, because [they] know that [lung transplant] isn't a permanent solution. It is difficult for them to make long-term plans because they just don't really think they are going to live that long.</p>
<p>Transplant-related health distress: emotional distress caused by health concerns/issues</p> <ul style="list-style-type: none"> • Fear and worry that transplant will not 'work', including fear of eventual death and other complications/ health issues • Worry about misinterpreting symptoms or signs • Never free from disease or its treatment 	<p>Patient 9015: I ... try not to go there too often mentally, but there's always a chance this might not work... that little gray area where there might be rejection and suddenly everything would be different. So there always is that kind of fear, but I try not to go there too often. I just kind of stay... in the present, and know that I am feeling good ... I can't look too far forward.</p> <p>Patient 9011: I feel guilty because people ... say, 'You're alive.' I say, 'I know I'm alive... I'm not saying I'm not grateful to be alive, I am so grateful to be alive.' But at the same time it is hard, just hard, you know, every day... And if it can be better, I'm human, I would like it to be better.</p> <p>Patient 9006: I was scared off my ass on that [infection]...you think about it when you wake up. You go to bed and you think about it. Then you need a Valium or something to knock you out because you'll just keep -- your mind will just keep going.</p>
<p>Risk of transplant-related illnesses: risk of infection and allograft rejection due to immunosuppression</p>	<p>Patient 9007: I try not to go to places that are too crowded... I am protecting myself from other people.</p> <p>Patient 9013: One thing that's kind of tough is that you are told to be careful about all this stuff because of your immune system and lack thereof... that's really the cloud over your head.</p> <p>Patient 9013: My goal is to... stay within the boundaries. There's a sterility that... is induced into you when you're here [the lung transplant program]. You're going to be in a bubble [and] it takes some time to realize really what you can do.</p> <p>Practitioner 9021: Some patients...want...total control and so it pushes the wife away or just pushes people away. One patient, the children would not get the flu shots, so he changed all the locks on his house, so he basically locked the rest of the family out of the house.</p>
<p>Cognitive limitations: reduced ability to perform mental processes</p> <ul style="list-style-type: none"> • Forgetfulness 	<p>Patient 9010: I used to be very good with numbers, you know, I could remember people's telephone numbers, addresses, and everything else, and I just kind of lost a little bit of that. I used to be able to do mathematics in my head very easily... it seems like I slowed down a little bit on that.</p>

HRQL Domain	Quote
<ul style="list-style-type: none"> • Difficulty reasoning • Confusion • Trouble maintaining focus 	<p>Patient 9012: I'm a little bit more out of it now... My brain's just a little different... it just kind of messes with your head a tiny bit ... It seems worse... [my wife] always comments on it, like I'm forgetful</p> <p>Patient 9015: I feel that sometimes now I don't have that same focus that I did once...I have to be more cognizant of like really trying to focus on remembering...I get distracted</p> <p>Practitioner 9004: I hear patients' families say like, "He's ... not as sharp as he was, when he was well." ...It happens a lot, they are just not as sharp.</p> <p>Practitioner 9004: [Lung transplant patients] don't retain the information well, they are not able to process complex thoughts as much, have a hard time doing simple math and so it becomes a challenge for us to teach them and then for them to do the medications.</p>
<p><u>Depressive symptoms</u></p>	<p>Patient 9011: So psychologically it has been hard trying to find a baseline for me where I feel that I'm ok up here [points to his head] without worrying about stuff going on because there's no black and white for me.</p> <p>Practitioner 9002: We definitely see this period of depression they get. It is not necessarily right in the acute phase when they are so focused on getting better. It is almost when they are starting to feel better but then they go through...a pretty intense depression. Sometimes it is survivor guilt: "Why did I get to survive and the person whose lungs I got died?"</p> <p>Practitioner 9003: He just did not know what to do with himself. Physically he was enjoying fantastic health, but he was the most down person, and he just could not -- I mean -- he just was listless. He'd come in and we'd be like, 'Oh, OK, what have you been doing?' Tell me about what has been going on with you.' Just chit-chat to get him ready for his procedure. And he just was always very flat -- I mean he really wanted this transplant. He had this stellar set of lungs and he always just looked perfect. But he just literally was not prepared to live, that has stuck with me.</p>
<p><u>Intimacy: challenges to physical and emotional closeness</u></p> <ul style="list-style-type: none"> • Worry about physical injury • Medications impact libido and performance • Changes in body composition impacts perceived attractiveness • Transplant-related stress impacts emotional closeness 	<p>Patient 9011: I haven't had any sex since the surgery. [Patient was 8 months post-transplant]</p> <p>Practitioner 9009: He's on Prednisone, he's eating all the time, he's puffy...his body has changed in a way such that not only is he physically recovering and therefore afraid of being intimate with his wife... he's afraid of picking up his grandkids and... having that kind of emotional closeness.</p> <p>Practitioner 9002: In terms of intimacy sometimes going through such a period of intense stress brings people together and sometimes it draws them apart.</p> <p>Practitioner 9004: They feel better, so they would like to be more intimate with their partner, but then... the males are unable to perform... and as far as females, some of the medications can...[cause] a lot of discomfort with sexual intercourse, so this has come up as an issue post-transplant.</p> <p>Practitioner 9009: [Lack of intimacy is] more so a physical issue and their relationship to their own body... I have heard of patients feeling like they're a little bit afraid of having sex after transplant... they don't want to harm themselves in some way that they may not even be aware of, but more so it's this change in body and self-perception of their body.</p>
<p><u>Social relationships: change in self-identity and transplant-related experiences impact relationships with others</u></p> <ul style="list-style-type: none"> • Perceived caregiver sacrifice (appreciation, guilt for being a burden) • Sense of abandonment by friends • Perceived by others primarily as a transplant recipient • Overcoming adversity engenders desire to support and inspire others 	<p>Patient 9015: The support I have received from my friends and family ...it's overwhelming in the sense that people have been so caring and supportive through this process, there's no way to ever thank people enough.</p> <p>Patient 9012: It was through my transplant that a lot of my friends kind of revealed themselves as either true friends...or not.</p> <p>Patient 9015: Immediately I start talking about transplant to her. But it was the oddest thing because her cousin was a liver transplant... So here we are then talking about transplant. And it was just like this very surprising conversation we had, it was a great bond.</p> <p>Practitioner 9001: There is an idea... or a hope that the caregiver perhaps was going to be relieved some of their duties, and then when [the patient] has a complicated course that necessitates continued care beyond what we were thinking was going to be required, that's an impact on the caregiver and of course the patient feels bad. 'Now I went through this transplant and you are still burdened.'</p> <p>Practitioner 9009: They, by virtue of being a transplant recipient, are put in a position of total powerlessness, and they have to trust their caregiver to see them through that emotionally and to manage their medications, to help let them know that they're not actually going crazy when they're on Prednisone. It's that kind of support and care and feedback that really only a caregiver can provide, when you have that intimate relationship with a spouse or a child or a family member.</p> <p>Practitioner 9001: [Patients] have gone through a really transformative life event ...When... you are questioned about your transplant, I think some people may feel it is difficult to be understood because there's a whole history and a story that's difficult to explain to people in casual social context.</p>
<p><u>Treatment burden: the impact of medications, testing, monitoring of the allograft on daily life and finances</u></p> <ul style="list-style-type: none"> • Taking oral, inhaled, or IV medications requires extensive time and mental energy • Medications are a daily reminder of mortality risk • Allograft monitoring requires lab, imaging, bronchoscopy, and clinic evaluations involving time and travel to the transplant center 	<p>Patient 9013: It's not just heart/lung, I've got a kidney guy, I've got... the liver guy, and... I've got these different orders... I would like to see [nurses] ... and the other doctors get together and say, 'Hey -- Let's do this. ... so that I can go with one and it would be taken care of.'</p> <p>Patient 9007: Stay vigilant, because [the treatment regimen] is not going to go away, this is what we have got to deal with... This is a must. You really can't question it. You just gotta adapt to it.</p> <p>Patient 9007: The way I feel now...is a good quality of life. Although I gotta take medications and attend meetings and appointments and all this, but that's nothing, you know?</p> <p>Patient 9011: Last year just from living up here [near the transplant center] and being up here... we just have to cut back.</p> <p>Practitioner 9009: She's just so tired of taking [medications]... she has this task that she does every day that reminds her ... she has this responsibility and that she's also never quite safe.</p> <p>Practitioner 9004: There's multiple levels of problems with the medication. One is just pill burden, the sheer amount, and the frequency of the medications... the stress of always having to remember them. We ... put a ton of emphasis on compliance... with that pressure comes a lot of</p>

HRQL Domain	Quote
<ul style="list-style-type: none"> • Treatments defined by care team impact self-efficacy • Financial costs of residing near the transplant center after surgery • Financial costs of medications impacts resource allocation • Insurance type impacts sense of security 	<p>psychological stress of, 'I can't miss them and if I miss them I am going to die'... Diabetes is huge as a problem...and if they get put on insulin...I am asking them to... inject themselves in public and monitor their sugars.</p> <p>Practitioner 9003: At the drop of a hat [transplant providers will] say, "Well, you have to come back [to UCSF]" ... They don't anticipate having to come in a lot and make those types of time and financial sacrifices to be able to get here.</p> <p>Practitioner 9042: We just saw a patient recently who basically... [is] kind of bankrupting themselves in order to get the lung transplant... we definitely have people who do that and spend all of their liquid assets in getting a transplant so that they can continue to live, so it really impacts not just them but their whole family... And we've had people decide not to do the transplant because they don't want that financial burden on their family.</p> <p>Practitioner 9009: I am thinking of one patient in particular who is just very fixated on this idea of living on SDI -- disability -- forever, and how it's not enough... she just flat out doesn't want to [work]...there's... that fear of, 'How am I going to manage all these appointments and what if I get sick again', because that's what she's known is getting sick again always, so... why even try to work.</p> <p>Patient 9014: I'm still not healed...the scars are not going to be where anybody can see them...I'm never going to wear a two-piece suit.</p> <p>Patient 9019: I am gaining a little bit more weight, for some reason I'm constantly hungry lately, and they increased my Prednisone, my God, just can't eat enough, it seems like...I don't like gaining weight.</p> <p>Practitioner 9005: The impacts of having a big thoracic surgery, they get edema, swollen above the chest, I think people... feel disfigured from their transplant. We had a young woman who needed breast augmentation... [She] felt insecure about the way she looked after her surgery.</p> <p>Practitioner 9042: Everyone holds different importance into how they present themselves...some of these changes make a person feel like they don't look healthy.</p>
<p>Spirituality and transcendence: lung transplantation is a transformative experience</p> <ul style="list-style-type: none"> • Overcoming death and achieving new potential for life redefines priorities and sense of self • Spirituality helps patients through transplant or is rediscovered after • Integrating donor organ into sense of self can be difficult 	<p>Patient 9012: Without [cystic fibrosis and lung transplant], I wouldn't have my understanding and awareness of my own mortality, and that to me has been a big catalyst in my spiritual growth. And that, in turn, affects my music, and the lyrics in that...people are really moved and touched by the positive messages in it.</p> <p>Patient 9007: You gotta think positive about other people... it will really be good to give back to society in the same way that it was given to me. Because money didn't save my life. The person that donated the lungs for me saved my life. I mean, this is something you can't go to the supermarket and buy.</p> <p>Patient 9015: I just reflected on what has happened quickly and I thought, I am going to be a better person for this, the profound change that's happened in my life. It's really stuck with me, and I think that I do try to be kinder to people... I think I do have a more Zen kind of way of looking at the world since transplant.</p> <p>Patient 9012: I just don't worry about things, I have very strong faith, and I really live my life and I have fun and I help people...And even if I did die tomorrow, I would be totally cool with that...I pretty much eradicated my whole, entire fear of dying through that aspect.</p> <p>Practitioner 9009: Patients that do have this...marked shift in their self-identity as transplant recipients, as being part of this larger community... they internalize this new sense of identity and in turn can in many ways demonstrate greater ownership over their care. And for them, I find that their quality of life really improves.</p>