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ORIGINAL CONTRIBUTION

Quality of Life Outcomes and Associated Symptoms Reported by Lung Transplant Recipients Amidst COVID-19 Pandemic: Applying a Novel Assessment Tool

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ABSTRACT

Background. There are 2 main aims of lung transplantation for people with end-stage lung disease: (1) to extend life and (2) to improve its quality. Much consideration is given to how to support the longevity and functioning of the allograft, though less robust studies have been done on the quality of the recipients' lives. With an interest in providing compassionate and holistic patient-centered care, it is vital that the treatment providers accurately understand their patients' lived experience. This study aimed to describe the health-related quality of life experiences of lung transplant recipients. An interest was held for where patients may struggle, thus informing where support might be needed to achieve the best possible outcomes.

Methods. This single-center study used a validated Lung Transplant Quality of Life questionnaire, which was sent in autumn of 2020 to all of the lung transplant recipients (n = 581) under the care of Columbia University Irving Medical Center (New York, NY).

Results. "Anxiety/Depression" had the highest concentration of struggle responses, followed closely by "Pulmonary Symptoms" and "Neuromuscular Symptoms." "Neuromuscular Problems" and "Sexual Problems" had the highest percentage of struggle responses. As the struggles increased, the overall quality of life rating dropped proportionately. There was no correlation between the overall quality of life and graft dysfunction, age, or time out from transplant date. All of the domains held an average rating of "Satisfactory," except "Treatment Burden," which was rated as "Favorable." Those ratings dropped for the cohort of patients who died during the study period.

Conclusions. With the goal of providing comprehensive care at the forefront of transplant priorities, we found the newly developed questionnaire invaluable in targeting areas for quality improvements, mostly notably respecting recipient mental health.

LUNG transplantation is the only treatment option for patients with end-stage lung failure, with the goal being the prolongation of life and an improvement in the quality of life [1].

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Naturally, the providers care to understand and support their patients' lived experience. Toward that end, a body of literature pertaining to lung recipients' quality of life has grown over time, though the reports have often used a multitude of varied tools, making it difficult to make meaningful comparisons or to see a complete picture. Existing instruments evaluate lung function, mood or affect, and medical outcomes [2–4]. Until recently, none of the evaluative instruments available held the capacity to capture health related quality of life (HR-QoL) in a holistic fashion and from the perspective of the patient. Singer et al recently developed and validated the Lung Transplant-QoL (LT-QoL) questionnaire, a novel tool thoughtfully designed to capture all of the domains of QoL, which lung transplant recipients have previously deemed as relevant, with presentation to the transplant community in 2019 [5]. Our original aim was to explore the extent to which anxiety and depression were experienced by our patients. We hypothesized that far more lung transplant recipients struggle with issues of mental health than was appreciated. The LT-QoL became the instrument of choice, as it afforded the ability to see beyond anxiety/depression as silo considerations and evaluate for other aspects of patient experience as well. We aimed to discover which domains patients struggled with most. Herein we described the findings after administering the LT-QoL questionnaire to our lung transplant population.

MATERIALS AND METHODS

This was a single-center study at the New York-Presbyterian Hospital/Columbia University Irving Medical Center Lung Transplant Program (New York, NY). The study was approved by our Institutional Review Board.

The scope of the study involved surveying patient experience by administering a recently validated LT-QoL instrument. The survey was composed of 60 questions that were organized into 10 domains. We were able to examine more thoroughly how it might have been interconnected with the other 9 domains of QoL (“Pulmonary Symptoms,” “Gastrointestinal Symptoms,” “Neuromuscular Problems,” “Treatment Burden,” “Worry About Future Health,” “Cognitive Limitations,” “Health Distress,” “Sexual Problems,” and “General QoL”) and relevant variables, such as age, time from transplant, and presence of graft dysfunction. In accordance with design intentions for the instrument, we analyzed the participants' responses along the domains identified and obtained an average rating for each. All of the questions used a 5-point Likert scale, which was recoded for uniformity (1-Favorable, 2-Satisfactory, 3-Tolerable, 4-Challenging, 5-Worrisome). We explored the dataset for which domains had the highest percentage of struggle response. Using the independent variables of patient age, time from transplant and graft dysfunction, we assessed for association with the domains. Graft dysfunction was defined by chronic lung allograft dysfunction (CLAD) stage ≥ 1 [6].

We focused on the experience of struggle by turning our attention to all of the scoring indicative of such (responses of 4 or 5). This allowed us to observe where struggle was distributed across the domains. We looked for associations between domains of struggle and all of the other domains, and with graft function, time from transplant, and age. We envisioned this analysis revealing the trailheads into which further screening, assessment and possible treatment interventions might be applied for the purposes of quality improvement.

Descriptive statistics were also used, revealing the relative frequency, and an average rating, of the patient ratings for each of the 10 domains.

Spearman correlation was applied, in an inquiry of the possible associations between each domain and overall QoL, which was measured by 2 statements: “I am able to enjoy life” and “I am content with the quality of my life right now.” After getting a broad view of our participants' QoL experiences, we returned our attention to the original research questions, which held an interest in knowing as much as possible about where struggle was experienced. To do so, we created dichotomous groupings of “struggle” and “no struggle” for our data set, with the former being identified by the presence of a 4 or 5 rating of any of the 60 items, which meant “no struggle” included all of the other scores. The struggle count was identified as the number of times a patient experienced a rating of 4 or 5. For instance, 155 participants reported only 1 instance of struggle, whereas 1 patient reported 45 (out of 60).

Next, we separated the 155 participants who struggled into 2 groups by using the median struggle count [3] as the cut off, and thereafter analyzing the upper half. Regression analysis was used to determine if a greater frequency of negative outcomes was associated with the overall experience of QoL. It was again applied in examining the relationship between the upper half of struggling patients with graft dysfunction, time from transplant, and age. Based on what we discovered about where areas of struggle were most concentrated, we then looked to see if those domains were associated with any others, thereby getting a sense for how various aspects of QoL are interrelated.

During the study period, 14 of our respondents died and so we evaluated them as a cohort for descriptive trends.

RESULTS

The LT-QoL survey was distributed via electronic medical record to all lung transplant recipients ($n = 581$) under the care of Columbia University's Irving Medical Center's Lung Transplant Program. The LT-QoL survey was converted to Qualtrics for ease in data collection and storage. The survey distribution occurred in September and October of 2020, 6 months into the COVID-19 pandemic. Of the surveys sent, there were 230 respondents. There were 32 largely incomplete surveys that were omitted from the data analysis, leaving us with a cohort of 198 (34%). The respondents were all adults (aged ≥ 18), and who spoke English and Spanish (Table 1). The majority of respondents were white, with an average age of 63 years and an average time from transplant of 7 years (+/- 6).

In addressing our question of the degree to which lung recipients experienced mental health challenges, we did find that the highest preponderance of struggle, on average, was within the domain of “Anxiety/Depression.” This was followed fairly closely by “Pulmonary Symptoms,” “Neuromuscular Symptoms,” and “Sex Problems.” We cross-correlated “Anxiety/Depression” with all of the other domains and found strong to very strong associations. The domain it was most strongly correlated with was “Health Distress.” There was no association between “Anxiety/Depression” and graft dysfunction, time from transplant, or respondent age. We found that 43 respondents had no struggle at all, whereas 155 (78%) had ≥ 1 instance. The median number of times in which a respondent indicated struggle (out of 60) was 3. The upper quartile of struggle began with 8 instances, as reported by 8 respondents, and increased to 45, as reported by 1 respondent (Fig 1). We analyzed whether severity of struggle (struggle count) was correlated with overall QoL experience (domain 10). We found those who experienced

Table 1. Cohort Demographics and Clinical Characteristics (n = 198)

Demographics	N = 198
Age (y)	
Mean	63
STD	± 13
Race	
Black or African American	17 (8.59%)
Native American or Alaskan	2 (1.01%)
Other Combinations Not Described	6 (3.03%)
White	156 (78.79%)
Declined to Report	10 (5.05%)
Missing	7 (3.54%)
Time from transplant (y)	
Mean	7
STD	± 6
Dx at Transplant	
Group A (obstructive lung disease)	26 (14%)
Group B (pulmonary hypertension)	10 (5%)
Group C (suppurative lung disease)	38 (20%)
Group D (pulmonary fibrosis)	114 (61%)
Chronic lung allograft dysfunction (Stage ≥1)	
Yes	50 (25.25%)
No	148 (74.75%)

Dx, diagnosis; STD, standard deviation

more struggles had a worse QoL outcome than those with experience less struggles.

In looking at the broad descriptions from the data set, we saw an average QoL outcome of “Favorable.” The percentage of each rating (1-5) is as follows: 55% = Favorable (1), 22% = Satisfactory (2), 13% = Tolerable (3), 6% = Challenging

Table 2. Average Score, by Domain (Overall Cohort)

Domain	Score, Overall (n = 198)	Score, Deceased (n = 14)
1. Pulmonary Symptoms	Satisfactory (1.59)	Tolerable (2.56)
2. GI Symptoms	Satisfactory (1.59)	Satisfactory (1.80)
3. Neuromuscular	Satisfactory (2.27)	Satisfactory (2.27)
4. Treatment Burden	Favorable (1.40)	Satisfactory (1.81)
5. Worry About Future Health	Satisfactory (2.18)	Tolerable (2.87)
6. Anxiety/Depression	Satisfactory (1.76)	Satisfactory (2.01)
7. Cognitive Limitations	Satisfactory (1.57)	Satisfactory (1.74)
8. Health Distress	Satisfactory (1.80)	Tolerable (2.50)
9. Sexual Problems	Satisfactory (2.24)	Satisfactory (2.28)
10. General QoL	Satisfactory (1.94)	Satisfactory (2.25)

GI, gastrointestinal; QoL, quality of life.

(4), and 4% = Worrisome (5). We then narrowed our focus to the mean score of each domain, finding all to rate “Satisfactory” (in rounding to nearest whole number), except for the domain of “Treatment Burden,” which was rated “Favorable” (Table 2). We also reviewed the score distribution, tabulating the frequency for each domain (Fig 2). This offered a different perspective of struggle than what was reported just prior, in terms of where it was most heavily concentrated. We found that neuromuscular and sexual problems shared the highest frequency of struggle, with just over 20% scored as such. “Pulmonary Symptoms” and “Worry About Future Health” were domains of the next most experienced struggles (~14%). There was a correlation between the sexual problems and age, though not with graft dysfunction. When looking at the question whether our

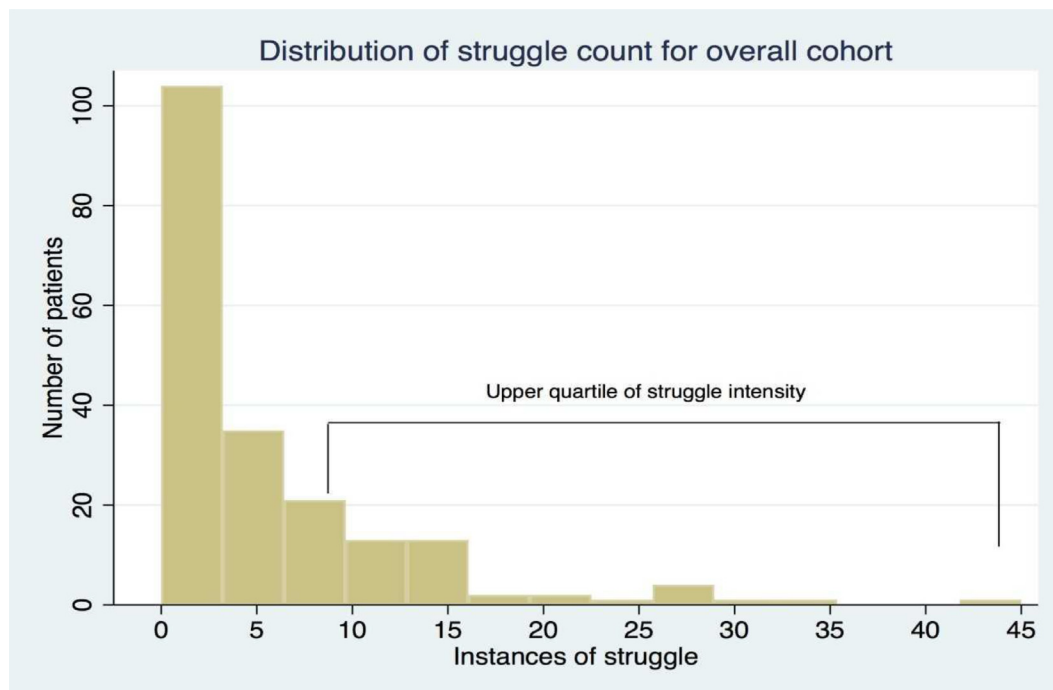


Fig 1. Distribution of respondent quality of life struggle count (n = 198). QoL, quality of life.

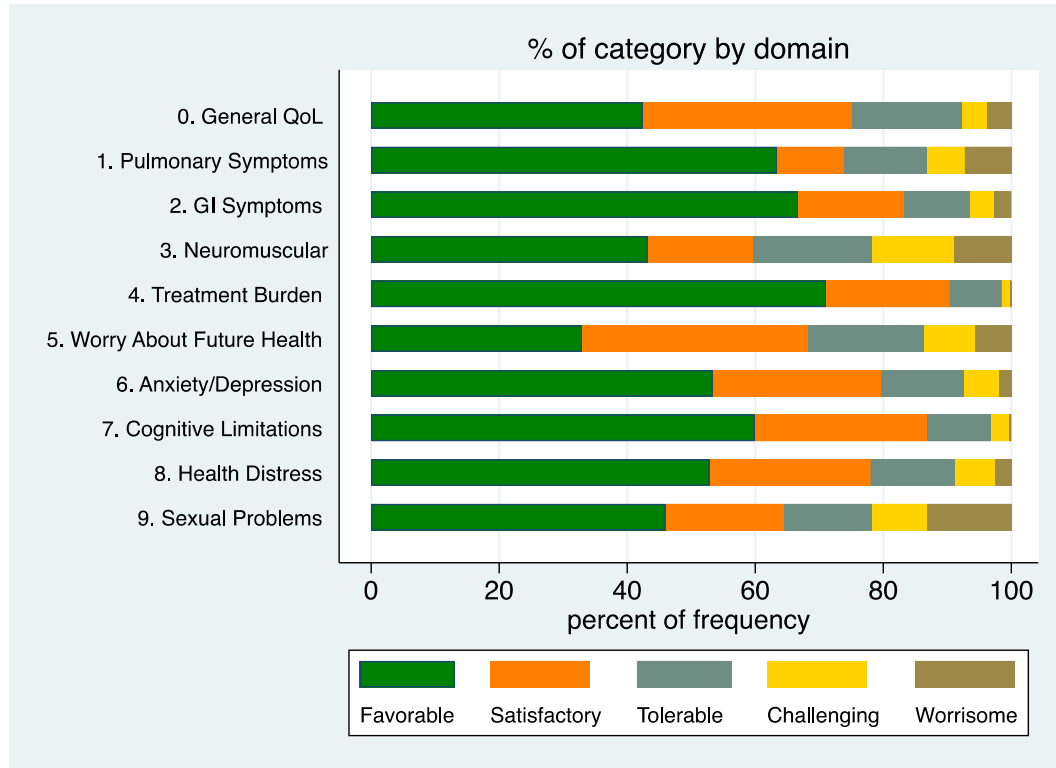


Fig 2. Rating percentages, by domain. Overall cohort (n = 198). GI, gastrointestinal; QoL, quality of life.

respondents were content with their overall QoL, a third found it to be tolerable or worse (Fig 3).

During the survey period, 14 of our respondents died. In this subset of patients, we found that every domain had a worse average rating than the overall cohort and 4 dropped a full rank, those being “Treatment burden” (decreased to “Satisfactory”) and “Pulmonary Symptoms,” “Worry About Future Health,” and “Health Distress (decreased to “Tolerable”)” (Table 2). In looking at the composite scores for struggle, there were 5 domains in which at $\geq 25\%$ of our now deceased respondents experienced struggle. Those domains are “Worry About Future Health,” “Neuromuscular Symptoms,” “Pulmonary Symptoms,” “Health Distress,” and “Sexual Problems” (Fig 4).

For the deceased cohort, we found the median struggle count was 6, which is double that of the overall cohort. The upper quartile of struggle for the deceased cohort began at a count of 14, whereas the upper quartile for the overall population began at 8. Of the 14 patients, 2 received palliative care consultation and 1 received hospice services. The patient with home hospice had a “redo” lung transplant and began receiving services 2 weeks prior to death. The patients receiving palliative care consultation were under intensive care unit care and the services were initiated in tandem with palliative extubation.

DISCUSSION

Within the transplant community, there is a mounting emphasis in looking at the clinical outcome metrics in an increasingly holistic

way when evaluating program performance [1]. Our study kept abreast with these expanding visions by virtue of originating from a patient-centered perspective. In looking at the data through dual lenses of frequency and concentration of struggle, we saw 4 domains of interest: “Anxiety/Depression,” “Pulmonary Symptoms,” “Neuromuscular Problems,” and “Sexual Problems.”

Anxiety and depression were the prominent areas of struggle for our patients, and these domains have been well explored within the transplant literature. We know these psychiatric experiences are associated with morbidity and mortality for lung recipients. Negative effects have an association with worse survival after transplantation, with depression more than doubling the risk of post-transplant mortality. This impact of depression is independent from its relationship to nonadherence to immunosuppressant regimen, with the latter also influencing mortality. New onset of both depression and anxiety, specifically panic attacks, have also been found within the first 2 years after lung transplant to a noteworthy degree [7–13].

The association of anxiety and depression with health distress is new information, which has offered a more textured understanding of experience. Due to the stigma around mental health issues, the patients may be less forthcoming with their struggles; however, when approached from the vantage of health distress, such discussion may feel more comfortable. Normalizing and validating emotional and psychological experiences that run in tandem with a complex, and at times traumatic, medical event could promote a sense of safety in discussing these often privately kept matters. The low rates of treatment-seeking for

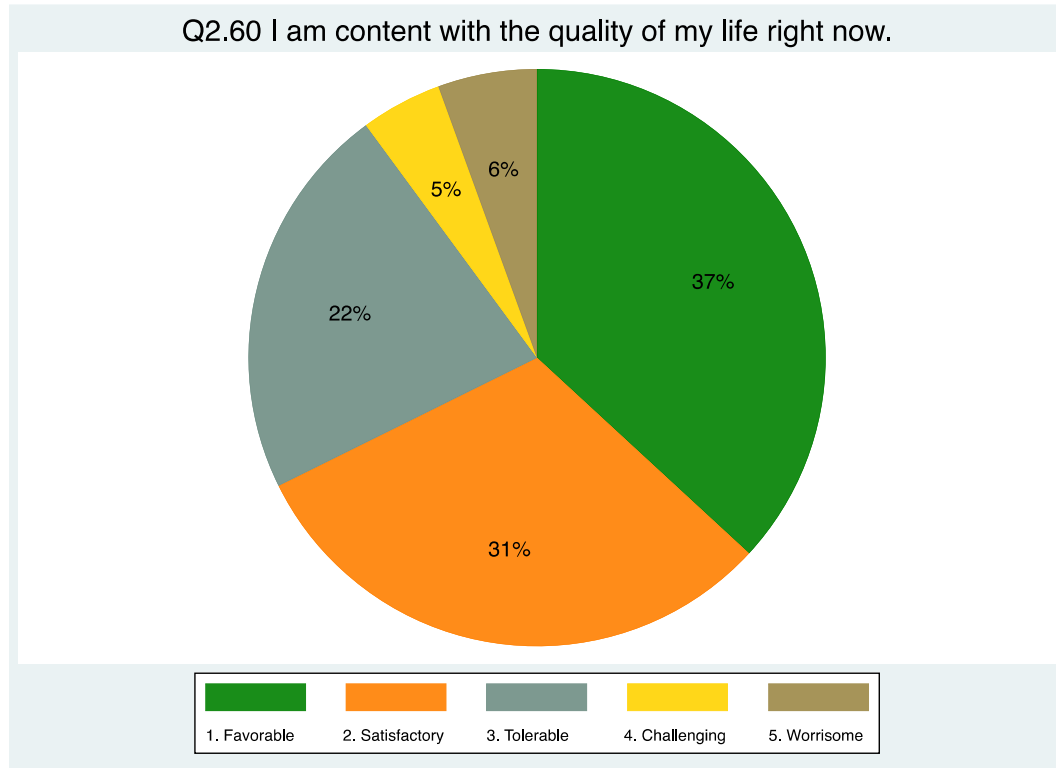


Fig 3. Rating response to contentment with quality of life.

mental health conditions among transplant recipients add further impetus for treatment providers to be proactive in elucidating struggles with mood. The problems with mood are treatable problems. Given the strong to very strong correlations we saw between “Anxiety/Depression” and all other QoL domains, supporting mental health has the potential to shift the entirety of one’s QoL experience through the reduction of distress and elevation of well-being. We see mental health support imbedded within other disciplines of medicine, oncology being a forerunner, and how we might move toward supporting of lung recipients in this way as well feels vital.

The lack of correlation between “Anxiety/Depression” and graft dysfunction deviates from the outcome reported for the cohort of patients with whom the instrument was validated [5]. An original hypothesis of ours was that there would be an increase in mood challenges with the onset of graft dysfunction. The circumstances of a CLAD diagnosis, and its progressive staging of severity, does involve a different psychological confrontation with mortality than pretransplant, when the hope inherent in transplant was present. It is possible we did not see a linkage between mood and graft dysfunction because of the eco-systemic influences at play at the time. The global pandemic, societal and racial reckoning, and a divisive political climate may have confounded our results [14,15]. Because this survey was completed in early autumn of 2020, a review of the literature pertinent to mental health and the COVID-19 pandemic was conducted. It was found that chronic diseases were risk factors for anxiety during COVID-19 and that comorbid

physical symptoms experienced the month preceding the arrival of COVID-19 were significantly associated with depression. This has lent credence to the possibility of the pandemic impacting QoL experiences, particularly as pertaining to mental health.

The LT-QoL survey allowed us to know for the first time that sexual problems were a common experience our lung recipients dealt with, yet it remains a markedly underdeveloped area of study in the field of transplantation. One single-center study reported 32% of liver recipients had de novo sexual dysfunction and felt it was caused by immunosuppression [16]. Sexual health may be a sensitive topic for patients to address in visits for a variety of reasons. However, improvements to sexual health have the potential to provide not only enjoyment, but to foster emotional connection and intimacy as well. For many patients, sexual life becomes sidelined due to the debilitating nature of end-stage lung disease. Lung transplant affords the opportunity to reclaim an aspect of their life that enhances well-being in the physical, emotional, and potentially spiritual senses. Like mood problems, sexual problems are treatable.

To see our respondents’ outcomes regarding neuromuscular problems came as no surprise, as we also knew that calcineurin inhibitors, vital to maintaining the longevity of graft function, could have neurotoxic effects that may be difficult to live with [17]. A new consideration for us was the degree to which this side effect was bothersome to our patients. To have shaky hands—the question in this domain holding greatest struggle—pales in comparison to death, which would be the outcome in the absence of calcineurin inhibitors. The same could be true for struggles with

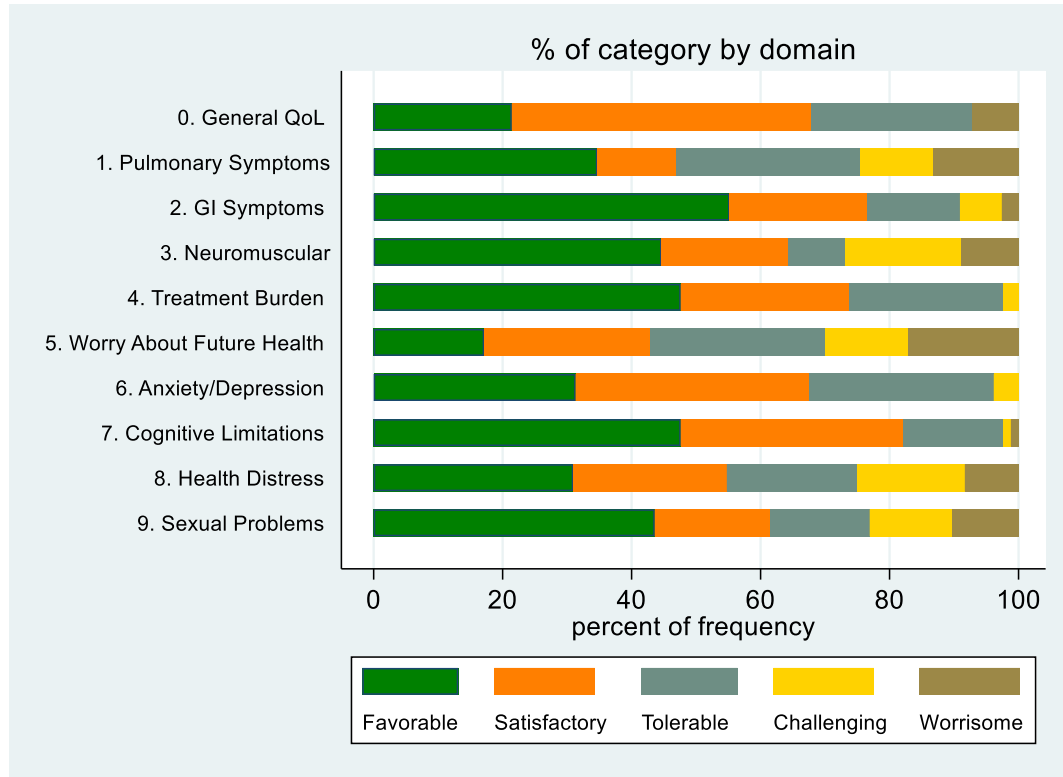


Fig 4. Response percentages, by domain. Deceased cohort (n = 14). GI, gastrointestinal; QoL, quality of life.

pulmonary symptoms, where having a cough proved to be the most bothersome outcome. There is a degree of acceptance for various symptoms that are part and parcel of the lung recipient's journey and yet this should not shut the door on the consideration of how to improve management in these areas.

Lastly, although the deceased cohort (n = 14) was too small to generalize or analyze for correlations, we did see a nearly doubled experience of struggle for the patients, in both intensity and number of domains. In addition to "Neuromuscular Problems" and "Sexual Problems" remaining as domains that were high in struggle, we saw the addition of "Pulmonary Symptoms," "Worry About Future Health," and "Health Distresses" as holding equally high, or higher, degrees of struggle (Fig 5). Despite being inconclusive, these results did spark curiosity about how we can best support patients at end-of-life. Recent studies by Nolley et al have inspired deeper consideration of the relationship between palliative care and lung transplant [18,19]. Our small collection of results pointed to the potential for further integration of work with our partners in palliative care to help improve QoL experiences throughout the transplant journey, including in the approach toward end-of-life [20].

Limitations

There were limitations inherent in the results of our study. First, we were missing data from nearly two-thirds of the patients the

LT-QoL was sent to, with 351 patients omitting a response. There was potential of self-selection bias at play in the results reported here, which were largely reflective of an elderly white demographic, and lacked substantial diversity in the patient sample. Because QoL was defined as "an individual's perception of their position in life, within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns," it was unclear if our data was reflective of the larger body of lung transplant recipient experience [21]. It was also possible that some of our patients who reported struggle had those same challenges before transplant. Longitudinal studies will need to be conducted with the administration of the LT-QoL survey to pretransplant patients and include following the evolution of QoL over time, through transplant and beyond. Lastly, our assessment for association of anxiety and depression with graft dysfunction was limited by not having the staging data in regard to the severity of CLAD diagnosis.

Again, the influence of a pandemic and the sociopolitical climate at the time of our study may also have skewed the reporting of our participants' QoL experiences. This survey was distributed and collected about 6 months after the first COVID-19 case landed in our hospital, in March of 2020. Our cohort of respondents were uniquely vulnerable. There were no COVID-19 vaccines yet available, likely compounding anxiety. The summer of 2020 was charged with political

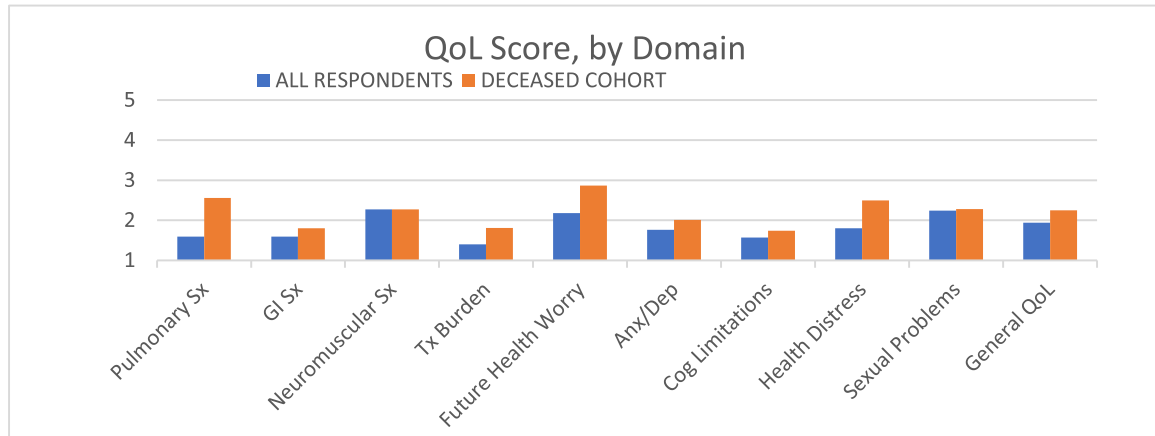


Fig 5. Comparison of scores between overall cohort and the deceased. GI, gastrointestinal; QoL, quality of life; Sx, symptoms; Tx, treatment; Anx/Dep, anxiety/depression.

unrest and frequent protests, calling for societal and racial reckonings. Despite these possible confounders, we felt compelled to know how our patients were, especially in light of the aforementioned circumstances.

CONCLUSIONS

In conclusion, the LT-QoL proved to be an excellent instrument for extracting useful information about how lung recipients experience their outcomes. The data we collected through its administration allowed us to analyze those outcomes from the macro to the granular level. The results provided our program baseline metrics from which future QoL work will branch out, while also capturing data from a historically significant time and for a population of people uniquely vulnerable to the threat of COVID-19. We were reassured to see that, on average, the respondents were satisfied with their quality of life outcomes. For those who struggled, we appreciated receiving clear information about where that was felt most strongly, which was notably with anxiety/depression, neuromuscular symptoms, pulmonary symptoms, and sexual problems. This helped us see where to shift the dial toward the direction of improvement. We were also curious to see how the further integration of work with our partners in palliative care might continue to evolve [22].

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REFERENCES

[1] United Network of Organ Sharing (UNOS). Working collaboratively to enhance system performance and improve transplant program monitoring metrics, <https://unos.org/news/improvement/>

[collaboratively-enhance-performance-improve-transplant-metrics/](#); 2021 [accessed 13.11.21].

[2] Stacel T, Jaworska I, Zawadzki F, et al. Assessment of quality of life among patients after lung transplantation: a single-center study. *Transplant Proc* 2020;52:2165–72.

[3] Tikkanen JM, Cypel M, Machuca TN, et al. Functional outcomes and quality of life after normothermic ex vivo lung perfusion lung transplantation. *J Heart Lung Transplant* 2015;34:547–56.

[4] Limbos MM, Joyce DP, Chan CK, et al. Psychological functioning and quality of life in lung transplant candidates and recipients. *Chest* 2000;118:408–16.

[5] Singer JP, Soong A, Chen J, et al. Development and preliminary validation of the lung transplant quality of life (LT-QOL) survey. *Am J Respir Crit Care Med* 2019;199:1008–19.

[6] Verleden GM, Glanville AR, Lease ED, et al. Chronic lung allograft dysfunction: definition, diagnostic criteria, and approaches to treatment—a consensus report from the Pulmonary Council of the ISHLT. *J Heart Lung Transplant* 2019;38:493–503.

[7] Dew MA, Rosenberger EM, Myaskovsky L, et al. Depression and anxiety as risk factors for morbidity and mortality after organ transplantation: a systematic review and meta-analysis. *Transplantation* 2015;100:988–1003.

[8] Dew MA, DiMartini AF. Psychological disorders and distress after adult cardiothoracic transplantation. *J Cardiovasc Nurs* 2005;20(5 Suppl):S51–66.

[9] Courtwright AM, Salomon S, Lehmann LS, et al. The effect of pretransplant depression and anxiety on survival following lung transplant: a meta-analysis. *Psychosomatics* 2016;57:238–45.

[10] Smith PJ, Blumenthal JA, Trulock EP, et al. Psychosocial predictors of mortality following lung transplantation. *Am J Transplant* 2016;16:271–7.

[11] Rosenberger EM, DiMartini AF, DeVito Dabbs AJ, et al. Psychiatric predictors of long-term transplant-related outcomes in lung transplant recipients. *Transplantation* 2016;100:239–47.

[12] Dew MA, DiMartini AF, DeVito Dabbs AJ, et al. Onset and risk factors for anxiety and depression during the first 2 years after lung transplantation. *Gen Hosp Psychiatry* 2012;34:127–38.

[13] Chu MC, Smith PJ, Reynolds JM, et al. Depression, immunosuppressant levels, and clinical outcomes in postlung transplant recipients. *Int J Psychiatry Med* 2020;55:421–36.

[14] Cénat JM, Blais-Rochette C, Kokou-Kpolou CK, et al. Prevalence of symptoms of depression, anxiety, insomnia, posttraumatic stress disorder, and psychological distress among populations affected by the COVID-19 pandemic: a systematic review and meta-analysis. *Psychiatry Res* 2021;295:113599.

- [15] Hossain MM, Tasnim S, Sultana A, et al. Epidemiology of mental health problems in COVID-19: a review. *F1000Res* 2020;9:636.
- [16] Ho JK, Ko HH, Schaeffer DF, et al. Sexual health after orthotopic liver transplantation. *Liver Transpl* 2006;12:1478–84.
- [17] Bechstein WO. Neurotoxicity of calcineurin inhibitors: impact and clinical management. *Transpl Int* 2000;13:313–26.
- [18] Nolley E, Fleck J, Kavalieratos D, et al. Lung transplant pulmonologists' views of specialty palliative care for lung transplant recipients. *J Palliat Med* 2020;23:619–26.
- [19] Nolley EP, DeSensi R, Nouraie M, et al. Characteristics, trends, and predictors of specialty palliative care utilization after lung transplantation. *J Palliat Med* 2019;22:1092–8.
- [20] Patel AA, Ryan GW, Tisnado D, et al. Deficits in advance care planning for patients with decompensated cirrhosis at liver transplant centers. *JAMA Intern Med* 2021;181:652–60.
- [21] World Health Organization. WHOQOL: Measuring Quality of Life, <https://www.who.int/tools/whoqol/>; 2012. [accessed 08.02.22].
- [22] Aversa M, Chowdhury NA, Tomlinson G, et al. Preoperative expectations for health-related quality of life after lung transplant. *Clin Transplant* 2018;32:e13394.