

Evaluation of health literacy in lung transplant candidates

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Study Highlights

Objective: A patient’s ability to make informed decisions during the pretransplant evaluation phase largely depends on their understanding of the information provided by clinicians. Health literacy’s role in renal, cardiac, and liver transplant is well-described, yet its impact in lung transplant was unknown. This study’s purpose was to identify the prevalence of health literacy and associated risk factors for marginal/inadequate health literacy in this population.

Methods: This is a single-center, prospective pilot study of adult patients undergoing lung transplant evaluation between 2022 and 2024. Participants completed a pre-transplant education class and an internal assessment covering key concepts. The Brief Health Literacy Screening (BRIEF) tool was used to assess health literacy, which categorized it by score as adequate, marginal, or inadequate.

Results: Of the 30 participants, 77% had adequate health literacy, while 23% had marginal/inadequate. Education beyond high school was associated with adequate health literacy, and all participants that received a lung transplant had adequate health literacy. The pre-transplant education assessment and BRIEF scores were moderately correlated.

Conclusions: Nearly one quarter of candidates had limited health literacy, and only those with adequate health literacy were ultimately transplanted, suggesting a link between literacy and likelihood of undergoing transplantation.

Table 2 Health literacy

Variable	All (N=30)
Median Health literacy score [IQR]	18 [17–20]
Health literacy status, n (%)	
Adequate (Score > 16)	23 (77)
Marginal (Score between 13 and 15)	3 (10)
Inadequate (Score less than 13)	4 (13)
Listed for transplant, n (%)	16 (53)
Died on waitlist (n=16), n (%)	1 (6)
Transplanted, n (%)	11 (37)
Median time on wait list ((n=11), days [IQR]	42 [20.5 - 133]
Died on waitlist (n=11), n (%)	1 (9)

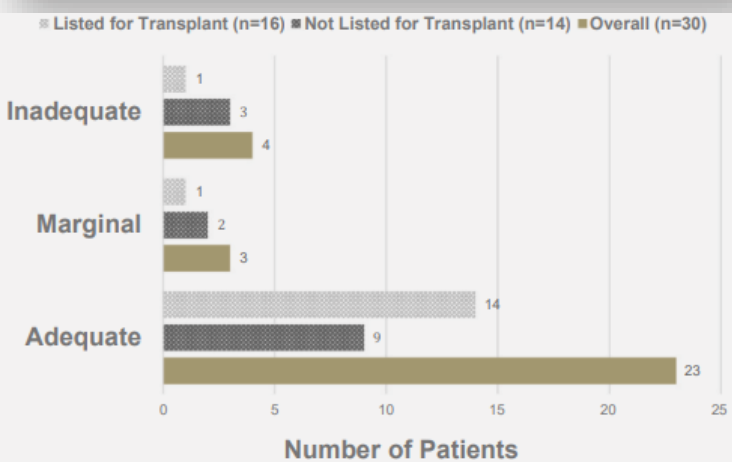


Figure 1 Association of health literacy with transplant listing, overall (n=30).

Reviewer’s Comments

- This is the first study to assess health literacy specifically in lung transplant candidates.
- The findings suggest that health literacy likely influences transplant listing and outcomes.
- Education level beyond high school appears to be a key determinant in adequate health literacy.
- This study identified a health literacy gap in the lung transplant candidate population, suggesting the importance of addressing this disparity to support equitable care and improve outcomes.
- This study underscores the need for tailored educational content to support any health literacy status.

Limitations

- This study’s small sample size (n=30) and single center design limits its generalizability.
- The predominately white, educated participant sample may not represent the broader population demographic.
- Voluntary participation for the BRIEF survey may introduce bias.
- No longitudinal follow-up to assess how health literacy impacts long-term transplant outcomes.

Reasons for donor heart offer refusal in the United States: Results from 14,132 transplant clinician surveys in the Donor Heart Study

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Study Highlights

Objective: This study discusses the nationwide shortage of donor organs suitable for heart transplantation and examines cases where organs are deemed unsuitable to identify any common trends or reasoning why, unrelated to the donor organs.

Methods: Between 2015 and 2020, the Donor Heart Study (DHS) collected data from 4,333 adult individuals in the U.S. who were considered potential heart donors. For each donor, transplant centers that declined the organ were asked to specify their reason for doing so. The study analyzed how frequently 18 different non-donor-related refusal reasons were cited and examined whether these reasons varied depending on whether the offer occurred on a weekday or during the weekend.

Results: The study analyzed 14,132 surveys, each linked to a declined organ offer from one of 3,083 donors. In about 24% of the cases, the reason for turning down the heart wasn't related to the donor. However, some reasons, such as a center already considering another offer, or the donor being too far away from the transplant center, became noticeably more common after 2018. The study also found that certain donor related reasons, such as heart abnormalities or risky behaviors, were more likely to be cited on weekends. These weekend trends weren't explained by any clear differences in the donors themselves.

Conclusion: About one in four declined heart offers are turned down for reasons unrelated to the donor. The study found that some refusal reasons are more common on weekends suggesting that donor evaluations are subjective and dependent upon the provider reviewing the organ offer.

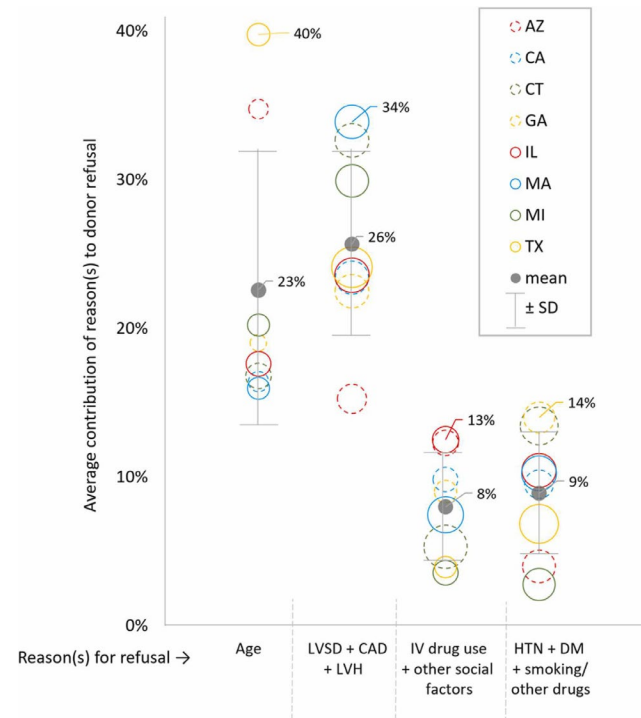


Figure 4: Geographic variation in selected reasons for donor heart offer refusal and objective donor characteristics. Shown are the average contribution of selected reasons (and combinations of reasons) for offer refusal by OPO, across all 2,222 potential donors for whom any donor-specific reason was cited. OPOs are labeled here using the abbreviation of the state in which they are headquartered; OPOs and these states are listed in Methods. The prevalence of selected donor characteristics by OPO is proportional to the diameter of each point; these donor characteristics include (by column, from left to right): (1) age ≥ 50 years; (2) LVSD, CAD, and/or LVH; (3) social risk factors; and (4) hypertension, diabetes mellitus, and/or smoking (each defined in Methods). CAD, coronary artery disease; DM, diabetes mellitus; HTN, hypertension; IV, intravenous; LVH, left ventricular hypertrophy; LVSD, left ventricular systolic dysfunction; OPO, organ procurement organization.

Reviewer's Comments

- This study took on the issue of nationwide shortage of donors for heart transplant and identified key influences that were donor-unrelated.
- The study suggests a bias in decision making on the weekends, "the weekend effect," noting an increase in donor-related organ refusals on these days.
- These findings implicate the need for standardized criteria for organ acceptance and suggest further exploration within individual transplant centers' policies and training.

Limitations

- The study focused on the generalized "weekend factor" but did not identify potential contributory factors such as staffing levels or resource availability that could play into this trend noted on the weekend.
- Although the study did establish that 24.3% of heart transplant offer refusals were due to donor-unrelated reasons, there was limited exploration into recipient-specific factors, such as urgency status, which could influence decision making heavily.

Lived experiences for individuals with cystic fibrosis who have undergone lung transplantation: a qualitative study

Skogeland U, de Monestrol I, Pincikova T, Godskesen T. *BMC Nursing* 2025 Feb;24:127. | DOI: doi.org/10.1186/s12912-025-02774-x

Study Highlights

Objective: Although prior studies have explored the support and information needs following lung transplantation from various patient perspectives, this study focuses specifically on the distinct experiences and challenges that people with cystic fibrosis encounter before and after receiving a lung transplant.

Methods: This qualitative study included 23 participants with cystic fibrosis who had undergone lung transplantation. Researchers conducted individual semi-structured interviews and analyzed the data using an inductive content analysis approach.

Results: Participants described a range of physical and emotional difficulties such as exhaustion, anxiety, and depression. While waiting for a transplant many of the participants felt isolated and experienced feelings of guilt. After the transplant, they felt relief but simultaneously faced intense pain and the challenge of adapting to a new life. Many participants also called for more open and timelier communication with healthcare providers, as well as better emotional support throughout the transplant journey, particularly when it came to preparing for pain and addressing mental health issues like anxiety and depression.

Conclusion: This study highlights the serious physical and emotional difficulties that people with cystic fibrosis encounter throughout the lung transplant process. This study suggests that focusing on providing psychological support, managing pain effectively after surgery, and introducing palliative care early on may help enhance the overall patient experience. This study also emphasized that nurses have a key role in this effort by promoting clear communication, helping patients understand their medication routines, and overall supporting a more holistic approach to care.

Table 1 Interview guide

• How long did you wait for lung transplantation?

- Can you describe how you decided to undergo transplantation?
- Could you share your overall experiences during the waiting period?
- What were the most challenging aspects for you?
- How do you perceive your family's or relative's experiences during this time?
- What kind of information were you provided with while waiting?
- What support did you need while waiting for a lung transplantation?
- Did you perceive any aspects that health care professionals may not have fully considered in your care, such as cultural, religious, or life philosophy factors?
- How do you feel about taking immunosuppressive medications daily?
- Is there anything else you want to discuss that we have not discussed?

Table 2 A representative example of the interview analysis process

Meaning unit	Con-densed meaning unit	Code	Subcategory	Cat-ego-ry
I was focused on being transplanted. My goal was to be transplanted and given a second chance. I trusted the surgeons, and they were allowed to do what they wanted if I was transplanted with new lungs.	I would be trans-planted and given a second chance for a new life	Puts trust in the hands of surgeons for a second chance	A second chance but with new challenges	Re-born with new lungs

Reviewer's Comments

- This study focuses on the unique CF population who have undergone lung transplantation and offers valuable insight to their individual experiences.
- These findings emphasize the critical role of nursing and allied health professionals in the care of the complex post-lung transplant patient.

Limitations

- Although the study offers an in-depth qualitative review of individual patients, it is a single-country study with a small sample size (23 patients). There is also an absence of detailed demographic data in the study, which begs the question of representativeness of the sample.
- Given that the study was completed using retrospective interviews, the qualitative data may be influenced by memory biases/limitations.