

Lung transplant recipients' experiences of and attitudes towards self-management

Recommendations*

- Health care professionals should provide patients with support in establishing new routines, modifying their health beliefs and their sense of responsibility in order to enhance their self-management following lung transplantation. **(Grade B)**
- Health care professionals should prepare potential lung transplant recipients for both the positive and negative aspects of receiving a lung transplant within preoperative education and counseling. **(Grade A)**
- Lung transplant recipients require postoperative and ongoing counseling, and psychological and social support should be provided. **(Grade A)**

* Please refer to: [JBI's Grades of Recommendation](#)

Information source

This Best Practice Information Sheet (BPIS) is a summary of evidence derived from a systematic review published in 2024 in *JBI Evidence Synthesis*.¹

Background

Lung transplantation is an established treatment for patients with end-stage lung diseases such as chronic obstructive pulmonary disease, cystic fibrosis, and pulmonary fibrosis. It substantially improves quality of life, especially in the domains of physical health and function. However, it is not a cure for end-stage lung diseases, and lung transplant recipients need to adapt to and follow complex self-management tasks to prevent complications, such as graft rejection or infections. These tasks comprise adherence to a lifelong medical regimen, including medication-taking; self-monitoring of lung function and signs and symptoms of complications; and maintaining a healthy lifestyle, which requires abstinence from harmful substances, attending medical appointments, refraining from smoking, eating healthily, exercising, and avoiding exposure to the sun. Hence, similar to other groups of patients with chronic illness, lung transplant recipients need to possess and execute a set of skills, including action-taking, decision-making, problem-solving, resource-finding and utilization, as well as establishing partnerships with health care providers.

Although lung transplant recipients are aware of the need and importance of self-management, there is a gap between their knowledge and their individual health-related behaviors.

Research has shown that for recipients of solid organ transplants, adherence to self-management tasks depends on personal experiences and attitudes rather than on non-modifiable factors, such as gender, age, or ethnicity. A positive, optimistic attitude to life and illness in general was also shown to be an important part of managing everyday life after lung and heart transplantation.

Objectives

The purpose of this BPIS is to present the best available evidence of lung transplant recipients' experiences and attitudes towards self-management to assist health care providers to better understand the challenges their patients face, potentially resulting in more patient-centered education and an increase in lung transplant recipients' self-management abilities.

Phenomenon of interest

The phenomenon of interest is the experiences and attitudes of lung transplant recipients towards self-management.

Quality of the research

Ten papers, using different qualitative research approaches that all conducted interviews to gather data, were included in the review. The methodological quality of the included studies was assessed independently by 2 reviewers using the JBI appraisal checklist for qualitative research. The quality of most included studies was moderate to high with a score of 7 to 9 on a 10-item scale. One study received a score of 3 due to various methodological ambiguities. All studies were included in the review.

Findings

The included studies were conducted across North America and Central/Northern Europe. The 137 findings (114 unequivocal and 23 credible) were aggregated into 19 categories and 4 synthesized findings.

Synthesized finding 1: Changes in routines, beliefs, and sense of responsibility are essential for better adaptation and self-management after lung transplantation

This synthesized finding was based on 50 findings across 6 categories. Lung transplant recipients play a pivotal role when it comes to adapting to being a transplant recipient. This may involve fundamental changes in daily routines in order to follow the guidance required to maintain the best possible health status. Following this guidance, however, may prove difficult and may also challenge one's sense of independence.

I will do what I have to; getting better and getting home is my job.

Actually, I know very well what I'm expected to do. Doing it, that's something else.

Synthesized finding 2: Life after transplantation is characterized by both positive and negative feelings and experiences

Forty-seven findings formed the 6 categories that led to this synthesized finding. Many lung transplant recipients only realize post-operatively that transplantation can bring a significant improvement in quality of life, but that it is not a cure for their chronic disease. Transplant recipients have positive experiences, such as a renewed joy for life; however, negative feelings, such as an awareness of never being free from disease or facing a limited life expectancy, may also be experienced.

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.

I have no shortness of breath and I feel like a 20-year-old again.

Synthesized finding 3: Better adjustment and self-management after a lung transplant require dealing with one's own feelings and beliefs

This synthesized finding was based on 25 findings across 3 categories. Adjustment to having experienced a life-threatening condition and transplantation may require new approaches to deal with one's emotions and focus in life. In this regard, holding certain beliefs may also play a role in the adaptation process.

Physically, I am in good condition. However, when I was allowed to leave the hospital, suddenly I found myself suffering from a number of fears. I had great difficulties structuring and organizing my daily life. I quickly felt distressed and overwhelmed doing things that used to be easy for me. My wife worked full-time and could not be with me all day. I was not able to cope with the situation at home and felt like I was going crazy. So I let myself be hospitalized again.

Synthesized finding 4: After transplantation, engaging with relatives, friends, medical team, and donors is essential to improve experiences and adapt to being a transplant recipient

Fifteen findings formed the 4 categories that led to synthesized finding 4. Other people play a very important role in life after a lung transplant. This concerns not only relatives, friends, and the medical team, but also the donors, to whom many lung transplant recipients feel deeply indebted.

But she (a daughter) has been extremely supportive without even being aware of it... that I needed her and there was a reason to fight.

I feel obliged to take care of the matter, mainly out of respect for the donor, but also for the transplant team.

Conclusions

Lung transplant recipients perceive themselves to be at the core of self-management, which requires fundamental changes in lifestyle, beliefs, and assumptions around responsibility. These changes may be perceived positively and be embraced as a part of lung transplants' post-transplant persona but may also be perceived on a continuum ranging from being challenging to being an invasion of one's individual life.

Life after transplantation is characterized by a high degree of ambiguity, since it may not deliver total health and well-being as anticipated by many transplant recipients. This means that lung transplant recipients often simultaneously experience a significant improvement in quality of life and a variety of new physical and/or emotional challenges, including the realization that there is no prospect of ever being free of disease. Therefore, psychosocial support is an essential aspect of life after lung transplantation. Emotional challenges may not only relate to fear regarding graft failure but also to processing and making the most of a regained joy in life. These emotional challenges may have both positive and negative connotations, adding to the state of ambiguity described. Likewise, engagement with others is crucial. This not only refers to the recipients' social networks but may also extend to the medical team as well as a sense of indebtedness and commitment to the deceased lung donor.

Implications for practice

The findings from this review provide a deeper understanding of the challenges associated with executing complex self-management tasks on a lifelong daily basis. Lung transplant recipients need comprehensive support, including preoperative education and counseling that address both the positive and negative aspects of the procedure. This support should extend postoperatively, with ongoing psychological, social, and self-management guidance to help recipients adjust their health beliefs, establish new routines, and take on a sense of responsibility for their well-being.

POPULATION

Adults (≥ 18 years) who had received a lung transplant regardless of the underlying disease and length of time since transplant

PHENOMENON OF INTEREST

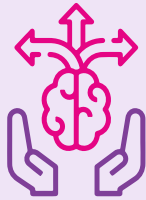
Experiences and attitudes of lung transplant recipients towards self-management

SETTING

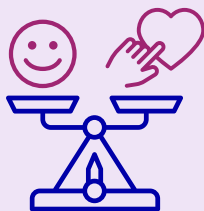
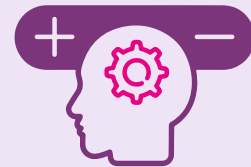
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SYNTHESIZED FINDINGS

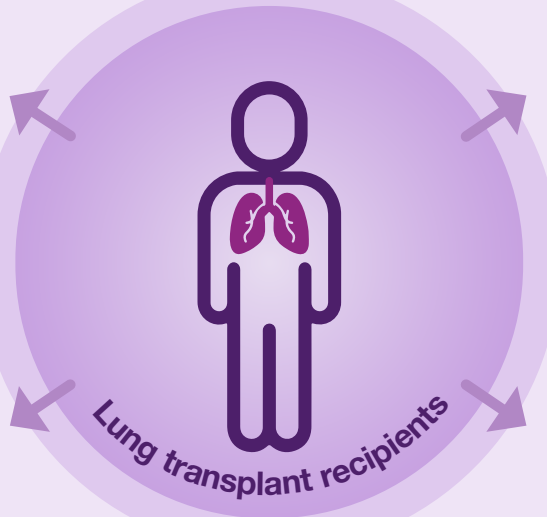
► Changes in routines, beliefs, and sense of responsibility are essential for better adaptation and self-management after lung transplantation



► Life after transplantation is characterized by both positive and negative feelings and experiences



► Better adjustment and self-management after a lung transplant require dealing with one's own feelings and beliefs



► After transplantation, engaging with relatives, friends, medical team and donors is essential to improve experiences and adapt to being a transplant recipient

RECOMMENDATIONS FOR PRACTICE

► Health care professionals should provide patients with support in establishing new routines, modifying their health beliefs and their sense of responsibility in order to enhance their self-management following lung transplantation. **(Grade B)**

► Health care professionals should prepare potential lung transplant recipients for both the positive and negative aspects of receiving a lung transplant within preoperative education and counseling. **(Grade A)**

► Lung transplant recipients require postoperative and ongoing counseling, and psychological and social support should be provided. **(Grade A)**

References

1. Rebafka A, Bennett C, Dunn C, Roche D, Hawker C, Edwards D. Lung transplant recipients' experiences of and attitudes towards self-management: a qualitative systematic review. *JBI Evid Synth.* 2024; 22(9):1656-714.

Summary writers

Anne Rebafka^{1,2,3}

Clare Bennett¹

Deborah Edwards¹

Vincent Pearson⁴

1 The Wales Centre for Evidence Based Care: A JBI Centre of Excellence, Cardiff University, Cardiff, UK

2 Center for Medicine, Medical Center, University Freiburg, Freiburg, Germany

3 Institute of Nursing Science, Faculty of Medicine, University of Freiburg, Freiburg, Germany

4 JBI, School of Public Health, The University of Adelaide, Adelaide, SA, Australia

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JBI, Faculty of Health and Medical Sciences, The University of Adelaide SA 5006, AUSTRALIA

Email: jbi@adelaide.edu.au | <https://jbi.global>