



ORIGINAL CLINICAL SCIENCE

A systematic review of health-related quality of life and psychological outcomes after lung transplantation

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social functioning

BACKGROUND: Lung transplantation (LTx) aims to reduce physical disability and mental distress, extend survival, and improve health-related quality of life (HRQoL). In this systematic review we aimed to: (1) augment evidence regarding measures to assess HRQoL and psychological outcomes after LTx; and (2) summarize HRQoL and psychological outcomes after LTx.

METHODS: Validated and standardized instruments with well-known psychometric properties used for assessing HRQoL and psychological outcomes after LTx were identified by means of comprehensive literature searches of PsychINFO and Medline/PubMed, up through March 2014, using the following search terms in various combinations: lung transplantation; physical functioning; symptom experience; mental health; anxiety; depression; distress; social functioning; life satisfaction; and health-related quality of life.

RESULTS: The search strategy identified 371 titles and abstracts. Of these, 279 were retrieved for further assessment and 63 articles selected for final review. Thirty-nine studies were found for HRQoL, 15 for physical functioning, 5 for mental health and 4 for social functioning. A total of 50 psychometric instruments were encountered.

CONCLUSIONS: Considerable heterogeneity exists in methodology, operational concepts and applied outcome measures in the existing literature on HRQoL and psychological outcomes after LTx. Nevertheless, the studies generally point to significant improvements in both mental health and HRQoL post-transplant. Further research is warranted utilizing consistent outcome measures, including LTx-specific measures and longitudinal study designs.

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Among the multiple aims of lung transplantation (LTx), the most important are to reduce disability, extend survival and improve health-related quality of life (HRQoL).¹⁻³ Traditionally, patient survival has been the primary LTx

outcome measured. With improved survival rates, however, post-transplant HRQoL has become an important component of any evaluation of benefits. Furthermore, LTx patients within different diagnostic groups do not necessarily experience the same survival benefits or exhibit the same post-transplant trajectories.⁴ Therefore, it is clinically important to assess post-operative HRQoL and mental health, as well as to identify those patients at risk for poor post-transplant outcomes.

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In transplant medicine, a variety of assessment instruments have been suggested, although there is no standard inventory to formally evaluate health-related quality of life (HRQoL) or psychological outcomes after lung transplants. An overview of existing self-report diagnostic instruments would assist researchers and clinicians in choosing the most appropriate psychometric instruments for assessing post-transplant outcomes in lung transplant populations. However, as yet, only a small number of investigators have evaluated the relative merits of specific outcome screening instruments after organ transplantation of any kind.^{5–9} A comprehensive systematic review was presented by Singer et al, who thematically assessed published studies of HRQoL in LTx patients. However, scientific articles on mental and psychosocial health of LTx recipients were not considered in their report. To address this knowledge gap, in this study we systematically focus on published empirical studies of HRQoL and psychological outcomes among adult lung transplant recipients. According to the definition of health, which was mandated by the World Health Organization as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity,”¹⁰ we directed our analyses toward the 3 HRQoL domains, namely physical functioning, mental health and social functioning. We considered this multidimensional approach essential for adequate evaluation of the post-operative clinical management of adult LTx recipients. Moreover, these 3 HRQoL domains have generally been considered when investigating post-operative outcomes after solid-organ transplantation.^{5,11,12}

The overall purposes of this systematic review were to: (1) determine which validated self-report instruments are being used to assess HRQoL and psychological outcomes after LTx; (2) explore the study designs adopted for the eligible studies; (3) review outcomes among those instruments that have been utilized most frequently; and (4) provide recommendations for selecting appropriate outcome measures.

Methods

By systematic literature review, validated and standardized outcome measures with well-known psychometric properties were identified that had been applied to evaluate HRQoL and psychological outcomes after LTx. Data extraction and the study review process were conducted following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).¹³ In accordance with these guidelines, our systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO; Registration No. CRD42013006204).

Search strategy

A comprehensive literature search was performed to identify scientific studies that included at least 1 measure of HRQoL and/or psychological outcome after LTx. For purposes of this review, physical functioning was defined in terms of the level of physical activity in daily life, symptom experiences (pain) and the physical side effects of immunosuppressant medication. Mental health was considered the patient's levels of anxiety, depression and/or psychological distress; and social functioning was characterized

in terms of the patient's quality of relationships, social support and level of life satisfaction. A systematic search of electronic databases, including PsychINFO and Medline/PubMed, was conducted from inception to March 2014. Keywords used for the search included: lung transplantation; physical functioning; symptom experience; mental health; anxiety; depression; distress; social functioning; life satisfaction; and health-related quality of life.

Eligibility criteria

English- and German-language studies were eligible if they examined any form of HRQoL or psychological outcome of LTx recipients, in terms of physical functioning, psychological functioning and/or social functioning, using standardized validated instruments. Considered for inclusion were also studies on pre vs post comparisons of LTx patients. Only studies involving patients who were adults (≥ 18 years old) at the time of LTx were included. Studies were excluded if they involved solely LTx candidates (i.e., patients referred for LTx), pediatric lung transplant recipients or recipients of additional solid-organ transplants, such as stem cells, bone marrow, liver, kidney, heart or heart–lung. Moreover, systematic reviews, meta-analyses, qualitative studies and case-study investigations were excluded, as were unpublished manuscripts, master's or doctoral theses, books and book chapters, studies for which only abstracts were available, and studies for which data collection methods were not adequately reported.

Data selection and extraction

The first stage of article selection was based on titles and abstracts. Full-text articles were obtained for all abstracts meeting the inclusion criteria for further evaluation, and for articles that could not be rejected with certainty. The reference lists of studies meeting the eligibility criteria were screened for additional relevant studies that may have been missed by our electronic searches. Two researchers (A.S. and M.T.) independently evaluated the selection of eligible articles following inclusion and exclusion criteria. In cases of disagreement, consensus was achieved by discussion. The process of study selection is outlined in Figure 1. The evaluation of data was processed by means of qualitative description. Results are summarized in tables and presented in a narrative form.

Results

The search strategy identified 371 titles and abstracts. Of these, 279 were retrieved for further assessment and 63 selected for inclusion in the final review. All eligible articles were published between 1994 and 2013.

Study characteristics

Study designs used in the 63 eligible studies were not always reported clearly. The majority of the articles (54%) used a cross-sectional study design that predominantly assessed LTx patients 12 months post-operatively or later (68%). The duration of follow-up ranged from 6 months to 8.5 years post-transplant. The average sample size across all studies was 80.1 (range 10 to 287) participants. Examination of the studies that described participants' age ranges revealed an average participant age of 46.1 years (age range

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