

Understanding the lived experiences of quality of life in solid organ transplant recipients: a systematic review of qualitative research

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Background

In 2022, 157,494 patients received a solid organ transplant, worldwide^[1]. Following transplantation, recipients may live for long periods; for example, liver recipients have 95% one-year survival and 81% 10-year survival while comparable figures for heart recipients are 84% and 61%^[2]. It is, therefore, important to understand how quality of life (QoL) is experienced in solid organ transplant recipients, following transplantation.

Although transplant recipients may experience improvements in QoL, compared to pre-transplant^[3], we know from systematic reviews of quantitative research that QoL is poor across several dimensions, in comparison to general population controls^[4,5]. Transplant recipients may experience psychological distress (e.g. concerns about future health)^[6,7], physical changes (e.g. weight gain)^[8], and social (e.g. social restrictions due to risk of infection) and role challenges (e.g. inability to work)^[9]. The extent of this impact may be influenced, or vary, by side-effects of immunosuppressant medications^[10], the specific organ received^[11] (e.g. pulmonary symptoms for lung patients^[12]; nausea or appetite loss for kidney patients^[13]), or sociodemographic factors (e.g. age, ethnicity)^[14].

In transplant research, QoL is most commonly measured using generic patient-reported outcome measures (PROMs), such as SF-36^[15,16]; these measures may not be sensitive to the specific QoL outcomes relevant to solid organ transplant recipients (e.g. fear of graft rejection). When selecting a PROM for use in research or clinical practice, it is crucial to consider whether it has good content validity, with content (i.e., the areas/topics covered by the measure) that is relevant and meaningful to the target population^[17]. A recent systematic review identified 26 condition- and transplant-specific QoL PROMs validated in solid organ transplant recipients^[18]; while this presents potential alternatives to generic QoL PROMs, the quality of their content validity was criticised; in general, this was because of insufficient patient involvement in PROM development (e.g. failing to ask transplant recipients about the relevance and comprehensiveness of PROM items). This emphasises the importance of, and need for, rigorous qualitative research to underpin PROM development and ensure content is relevant and meaningful, and comprehensively captures what is important to solid organ transplant recipients, regarding their QoL.

The potential for qualitative research to inform clinical and policy decision making in transplantation has previously been outlined; being used, for example, to facilitate successful intervention implementation^[19]. Hence, a qualitative understanding of how transplant recipients experience QoL could be of value to inform future PROM development and selection. Systematic reviews of qualitative research offer comprehensive understandings of social phenomena^[20]. Such reviews have been conducted across several areas of transplantation, but often with a narrow focus on specific experiences (e.g. medicine-taking^[10], identity disclosure with donor families^[21]) or specific organs received (e.g. heart^[22], kidney^[23]). Where existing reviews have pertinence to QoL experiences, Yang et al.^[24] explored post-operative difficulties in organ transplant recipients but was limited by its search strategy and sought to combine qualitative and quantitative evidence, while Stubber et al.^[25] explored heart and lung recipients' overall experiences across pre- and post-transplantation, without specific focus on different aspects of QoL. There is, therefore, an important gap for a systematic review that would provide a comprehensive understanding of the lived experiences of QoL in transplant recipients across all solid organs.

Aim

This systematic review of qualitative research will aim to comprehensively understand the lived experiences of QoL in solid organ transplant recipients, to inform future development of transplant-specific QoL PROMs.

Objectives

1. Identify and synthesise existing qualitative research reporting the lived experiences of QoL in solid organ transplant recipients.
2. Examine the breadth of QoL outcomes described within the lived experiences of solid organ transplant recipients.

Design

This systematic review of qualitative research will be registered with the Prospective Register for Systematic Reviews (PROSPERO), and reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework^[26].

We have used the SPIDER framework^[27] to inform our search strategy and eligibility criteria: Sample (adult solid organ transplant recipients); Phenomenon of Interest (quality of life); Design (qualitative methods, e.g. interviews, focus groups); Evaluation (lived experiences); Research type (qualitative research).

Throughout paper selection, data abstraction, appraisal of transparency of reporting, and data synthesis, the reviewers will resolve any disagreements through discussion, involving a third reviewer where necessary.

Eligibility criteria

Inclusion criteria

A paper will be eligible if: (1) it is an original peer-reviewed article, available in English; (2) it reports the findings of qualitative research; (3) it elicits the lived experiences of people who received a solid organ (heart, lung, liver, kidney, pancreas, intestine) transplant as an adult (aged ≥ 18 years); (4) the reported lived experiences are relevant to overall, single, or multiple dimensions of QoL. We will use what is captured in existing studies to help us define what we mean by QoL for this population; this will be guided by a well-established definition of QoL, namely *“the state of wellbeing that is a composite of two components: the ability to perform everyday activities that reflect physical, psychological, and social well-being; and patient satisfaction with levels of functioning and control of the disease”*^[28].

Exclusion criteria

A paper will be excluded if: (1) it is a conference abstract, book chapter or doctoral thesis; (2) it only reports the findings of quantitative research; (3) the qualitative data is elicited from free-text questionnaire responses; (4) it elicits the lived experiences of paediatric transplant recipients (aged < 18 years) or adults who received their transplant as a paediatric patient; (5) the transplant recipient’s experiences are described by someone else (e.g. family-member); (6) the participants have not yet received a transplanted organ; (7) the lived experiences are related to a specific intervention (e.g. mobile health intervention to enhance medication adherence). To ensure the review remains explicitly focused on the post-transplant lived experiences of transplant recipients, we will not consider: (1) multi-methods studies where there is very limited detail of the qualitative methods and/or data; (2) studies where the sample included transplant recipients and others (e.g. donors, candidates, family-members, healthcare professionals); (3) studies reporting on both pre- and post-transplant lived experiences.

Search strategy

Searches will be conducted from inception on the following five bibliographic databases: MEDLINE (OVID), Embase (OVID), CINAHL (EBSCO), PsycINFO (OVID), and Scopus. Our search strategy will encompass three key concepts, namely: organ transplant, quality of life, qualitative.

Previously published search strategies for solid organ transplant recipients on lived experiences in other contexts (e.g. medicine-taking)^[10,25], and quantitative reviews of QoL^[5,29], will inform the development of search terms. To formulate a combination of appropriate medical subject headings and keywords, we will consult with an experienced information specialist; final search terms will be tailored in line with the specific subject headings used by each database. To retrieve any additional papers for inclusion, we will hand-search the reference lists and forward citations of eligible papers and relevant systematic reviews.

Paper selection

Paper selection will follow a two-stage process. Firstly, titles and abstracts of papers identified through the bibliographic database searches, will be independently screened by two blinded reviewers, using Rayyan software. Any paper referring to the lived experiences of (an aspect of) QoL in solid organ transplant recipients will be retained for full-text screening. If a full-text is not readily available, we will use an inter-library loan, or request it from the corresponding author.

Two reviewers will then screen the full-texts against the eligibility criteria. Any paper excluded during full-text screening will be given a coded exclusion reason to ensure transparency when completing the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram^[30].

Data abstraction

Data abstraction will be conducted by one reviewer and, for accuracy, checked by a second reviewer. To facilitate this, we will create and pilot a structured form, and refine as needed. If multiple included papers report different findings from the same study, this will be treated as a single study (sample) in the synthesis (although sample characteristics may be derived from multiple papers). Corresponding authors of included papers will be contacted if we need to request relevant missing information; we will permit a three-week response time, after which, the available published material will inform data abstraction decisions.

We will abstract the following data: study setting; study aim; sample characteristics (sample size, organ(s) received, sex, age, ethnicity, socio-economic status, employment status, rurality, time since transplant, co-morbid conditions); study design; sampling method; data generation method (example question framing); data analysis strategy; author-reported key findings (e.g. themes).

We will summarise the sample characteristics to document the level of diversity within, and across, the samples of included qualitative research. Following data synthesis (process outlined below), we will count how many

included papers report findings related to each QoL dimension, and the number of QoL dimensions reported within the findings of each included paper.

Appraisal of transparency of reporting

To appraise the reporting of each included paper, we will use an amended version of the widely used Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist^[31]; this will be completed by one reviewer and checked by a second reviewer. The COREQ checklist considers three dimensions, namely: research team and reflexivity; study design; and analysis and findings. Example items include “How were participants selected?” and “What was the duration of the interviews or focus groups?”. We will count the number of included papers that report each item, and the number of items reported by each included paper. We are conscious of the potentially reductionist nature of checklists for qualitative research, including concerns regarding their credibility^[32]; thus, appraisal will not be used to “measure” study quality, rather highlight where there is variability, and potential room for improvement, in the reporting of qualitative research.

Data synthesis

In accordance with the RETREAT criteria for selecting a qualitative evidence synthesis approach^[33], our review question, timescale, resources, expertise, and purpose, warrant the use of thematic synthesis^[34]. We will conduct the thematic synthesis within a framework approach. Firstly, we will import the results text and participant quotations from each included paper into NVivo for storing, coding, and searching of the qualitative data. One reviewer will then conduct line-by-line coding and inductively identify the specific QoL outcomes (e.g. fear of graft rejection) experienced by solid organ transplant recipients. A second reviewer will independently conduct line-by-line coding on a sub-sample of the included papers, to ensure rigour and consistency in the specific QoL outcomes identified. Following this, the review team will meet to discuss and reach consensus on how each specific QoL outcome deductively maps to a framework of nine QoL dimensions (e.g. physical, emotional, social functioning) used in a systematic review of transplant-specific QoL PROMs^[18]; for example, fear of graft rejection would be mapped to, and presented within, emotional functioning. Throughout data synthesis we will remain open to the possibility of adding more QoL dimensions to this framework. Overall, this will help inform relevant and meaningful content in future QoL PROM development for solid organ transplant recipients.

Dissemination plans

This systematic review of qualitative research will be published in a relevant peer-reviewed journal, and presented at relevant (inter)national conferences.

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