Systematic review on the involvement and engagement of patients as advisers for the organisation of organ transplantation services

Zhi Qu, Carina Oedingen, Tim Bartling, Christian Krauth, Harald Schrem

ABSTRACT

Objectives This systematic review aims to derive practical lessons from publications on patient involvement and engagement in the organisation of organ transplantation services.

Design This systematic review was conducted according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses. Inclusion criteria for the analysis of publications in English cited in the databases PubMed and Web of Science until 6 December 2022 required that patients participated as advisers in the organisation of organ transplantation services. Quality assessment was performed using the Guidance for Reporting Involvement of Patients and the Public (GRIPP) 2 small form and the Critical Appraisal Skills Programme (CASP) tool for the assessment of the risks of bias.

Results Deployed search strings identified 2263 records resulting in a total of 11 articles. The aims and strategies, deployed methods, observed effects, observed barriers and proposed improvements for the future varied vastly. All reported that well-developed programmes involving and engaging patients at an organisational level provide additional benefits for patients and foster patient-centred care. Lessons learnt included: (1) to empower patients, the information provided to them should be individualised to prioritise their needs; (2) financial as well as organisational resources are important to successfully implement patient involvement and engagement; (3) systematic feedback from patients in organisational structures to health providers is required to improve clinical workflows and (4) the consideration of ethical issues and the relationship between investigators and participating patients should be clarified and reported.

Conclusions Actionable management recommendations could be derived. The quantitative impact on clinical outcome and economic clinical process improvements remains to be investigated. Study quality can be improved using the GRIPP 2 guidance and the CASP tool.

PROSPERO registration number CRD42022186467.

BACKGROUND

Involving and engaging patients on the organisational and management level of healthcare may help to ensure that patients’ needs and concerns are clearly understood and appropriately prioritised. Studies on primary care, acute care, oncology care and mental health services demonstrated benefits for healthcare providers and patients gained by actively involving and engaging patients in gathering information, sharing experiences and joint decision-making.

Patient involvement and engagement is a concept that involves patients in decision-making about their care and giving them choice and control over the healthcare services they receive. A substantial lack of understanding in regard to the interpretation of related terms such as patient engagement, patient empowerment and patient-centred care has recently been described. As a result, confusion and misunderstandings prevail in the perception of the implications of this term. This situation provides major hurdles for the successful establishment of best practices and evidence-based approaches for patients’ involvement and engagement as advisers in the organisation of organ transplantation services and other medical services.

The National Health Service in the UK has provided the following practical definition including all relevant stakeholder

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The deployed analytical framework can also be used as a strategic tool for the introduction of patient involvement and engagement in the organisation of organ transplantation services.

⇒ Although a large number of studies on patient involvement and engagement were identified with the initial search strategy, only a small number of identified articles could be identified that focused on patient involvement and engagement in the organisation of organ transplantation services.

⇒ Negative effects of patient involvement and engagement may be less likely reported in the literature due to publication bias.
perspectives: ‘Patient and public engagement is active participation of patients, carers, community representatives, community groups and the public in how services and policy are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the ongoing process of developing and sustaining constructive relationships, building strong, active partnerships and holding a meaningful dialogue with stakeholders’. Currently, the concept of patient involvement and engagement in healthcare is not standard practice for most healthcare organisations. In this systematic review, we focus on patients as advisors for programme design and clinical process improvement within the organisation of organ transplantation services.

Organ transplantation is an ethically challenging field and very cost intensive. Therefore, representative voices of patients should be included in the process of policy-making as well as in the organisation and management of organ transplantation services in a transparent and systematic way with the goal to optimise clinical processes and healthcare resource allocation. Such an approach may provide a very powerful asset for a more effective and efficient management of services mainly by the inclusion of relevant and unique insights from transplant patients. This could be realised for example by including patient representatives in relevant advisory committees and/or management boards of the transplant centre in official roles. Moreover, integration of involved and engaged patients in transplant organisations may greatly improve transparency and public understanding and could thus promote societal acceptance of and trust in national transplantation systems. Increased patient-centredness with improved service quality and transparency might improve public readiness to altruistic organ donation for transplantation, which would help to reduce the currently increasing scarcity of suitable donor organs.9–11

The importance, benefits and potentials of patient involvement and engagement in the organisation of transplantation services, as well as its effects on transplantation practice have not been investigated in a systematic manner so far. Therefore, the aim of this systematic review is to evaluate published reports and studies on this topic with the focus on goals, roles of patients, involved stages of transplantation, deployed measures and methods of implementation, barriers to implementation, and observed process benefits and outcome improvements. This review aims to derive practical lessons learnt from the published literature that may be useful for the improvement of transplantation services.

**METHODS**

This systematic review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (see online supplemental appendix 1)12 and has been registered in the PROSPERO database (registration code: CRD42022186467).

**Literature search**

A predefined literature search strategy was used to identify articles of potential interest. The term ‘patient involvement and engagement’ was based on the definition as published by the National Health Services in the UK8 and also used as a MeSH term for the search string in PubMed, while the search string for Web of Science was adapted accordingly (online supplemental appendices 2 and 3). The literature search included all publications cited in PubMed or Web of Science until 6 December 2022 deploying predefined inclusion and exclusion criteria in order to generate a highly sensitive overview of relevant publications. Furthermore, the reference lists of relevant studies identified in the literature search process were also screened in order to find additional studies. Moreover, further potential studies of interest were identified by hand search via Google Scholar to increase the sensitivity of the search.

**Inclusion criteria**

Inclusion criteria for the analysis of publications required that patients participated in transplantation practice at an organisational level as advisers or advisory committee members with the goal to participate in programme design, clinical process and outcome improvement and/or joint decision-making at the organisational level.

**Exclusion criteria**

Publications that were not published in English were eliminated. As implied by the literature search date, publications published after 6 December 2022 could not be analysed. Furthermore, surveys that collected data on patients’ attitudes and studies that focused on new methods for patient reported outcome evaluation were also excluded as well as systematic reviews, meta-analyses, abstracts-only, commentaries and letters.

**Data extraction**

After deduplication of search results, title screening was carried out based on the above mentioned predefined inclusion and exclusion criteria. The next steps were taken in a sensitive approach, which means that if one or both reviewers (ZQ and CO) found the article to be relevant, it was included for further analysis. Abstract as well as full text screening was performed to further exclude ineligible studies. All data were extracted using a standardised form that was developed prior to analysis as proposed by the PRISMA statement.12 Relevant information identified in finally analysed publications was systematically extracted according to a predefined structure as described by the column headings of table 1 and summarised independently by two authors (ZQ and CO). In cases of inconsistent judgements, a third reviewer (TB) was asked to evaluate and his decision on the inclusion or exclusion of any article was discussed within the research group. After reaching consensus, the results were summarised in table 1.
### Table 1: Characteristics and results of systematically reviewed articles

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Country</th>
<th>Population</th>
<th>Methods</th>
<th>Outcome</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Franco et al&lt;sup&gt;45&lt;/sup&gt;</td>
<td>1996</td>
<td>USA</td>
<td>Solid organ transplant patients</td>
<td>Planning process with a Patient and Care Partner Advisory Board to stimulate their input to the Steering Committee on plans of the design and operation of the cooperative care and education programmes.</td>
<td>The patient educational programme focusing on cooperative care evolved and their perspectives were provided for the new Cooperative Care Centre.</td>
<td>The strengths of current programmes will be the foundation for designing, implementing and evaluating innovative educational strategies.</td>
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<tr>
<td>Rosaasen et al&lt;sup&gt;46&lt;/sup&gt;</td>
<td>2018</td>
<td>Canada</td>
<td>Kidney patients, healthcare providers</td>
<td>Codevelopment and testing of an educational intervention.</td>
<td>A set of six educational videos, ranging in length from 3 to 24 min, was created.</td>
<td>Patient involvement significantly influenced the development of a video series about kidney transplantation.</td>
</tr>
<tr>
<td>Sullivan et al&lt;sup&gt;47&lt;/sup&gt;</td>
<td>2018</td>
<td>USA</td>
<td>Kidney patients</td>
<td>Renal transplant recipients received formal training as peer educators, met with in-centre haemodialysis patients, and provided tailored education and assistance; questionnaires for the navigators to learn about their experiences.</td>
<td>Practical comments about programmatic or implementation observations of the navigators were obtained, and affective comments that reflected a shared experience among the navigators and patients were identified.</td>
<td>Kidney transplant recipients trained as patient navigators, offered support during the transplant process, and provided an added-benefit to complement routine dialysis and nephrology care.</td>
</tr>
<tr>
<td>Squires et al&lt;sup&gt;48&lt;/sup&gt;</td>
<td>2019</td>
<td>USA</td>
<td>Paediatric liver transplant institutions, technology innovators and patients</td>
<td>Meeting and pre-meeting surveys were circulated to both centre representatives and patient/family representatives to identify common themes and challenges.</td>
<td>Medication, transition to adult providers, psychosocial support, general aspects of care, educational and social networking tools, and improvements in quality of life were identified for future improvement.</td>
<td>Demonstrating generalisability and value in a resource-constrained environment and establishment of community-healthcare team reciprocity are crucial.</td>
</tr>
<tr>
<td>Gomis-Pastor et al&lt;sup&gt;49&lt;/sup&gt;</td>
<td>2020</td>
<td>Spain</td>
<td>Heart transplant recipients, patient associations, health providers, stakeholders</td>
<td>Implementation strategy study for a technology-based behavioural intervention model, patient–provider interactions, and comprehensive clinical care combining a literature review, several surveys, interviews, and focus groups.</td>
<td>Implementation of the new behavioural intervention model (mHeart system) and the experience gained during the implementation.</td>
<td>Involvement of an interdisciplinary team, patients, and several experts as well as a patient-centred design was essential for the successful implementation; Key recommendations for a successful implementation.</td>
</tr>
<tr>
<td>Healey et al&lt;sup&gt;50&lt;/sup&gt;</td>
<td>2020</td>
<td>Canada</td>
<td>Donation and transplantation professionals and patient partners</td>
<td>Description of the process used to create patient partner engagement resulting in premeeting education, in-meeting expert support, full participation and permission to step back and postmeeting debriefing.</td>
<td>Medical, legal and ethical framework for heart donation after cardiocirculatory death and transplantation were established.</td>
<td>Patient engagement allows the fostering and sharing of mutual benefits and for a strong consensus-building process, well-planned strategy to involve patient partners is important, impactful and central to the process.</td>
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<tr>
<th>Study</th>
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<th>Country</th>
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<th>Methods</th>
<th>Outcome</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Seljeld et al</td>
<td>2020</td>
<td>Norway</td>
<td>Renal transplant recipients, non-functioning</td>
<td>Content and software development and design of a digital patient–provider</td>
<td>(1) Making symptoms and challenges visible, (2) Mastering a new life and</td>
<td>The new digital tool has the potential to support shared decision making</td>
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<td>pituitary adenoma patients, healthcare</td>
<td>provider communication tool using a combination of interviews with patients,</td>
<td>(3) Digital opportunities for follow-up, theme 1 and 2 gave input for</td>
<td>for patients and can provide opportunities for interactions and</td>
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<td>practitioners</td>
<td>patients, focus groups with healthcare providers and workshops with both.</td>
<td>content development and theme 3 provided ideas for the software</td>
<td>communications, to explore the usability and potential effects.</td>
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<td>development.</td>
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<td>Andersen et al</td>
<td>2021</td>
<td>Norway</td>
<td>Kidney patients and nurses</td>
<td>Implementation of an health literacy intervention using explorative</td>
<td>Patients’ and nurses’ experiences gained during the implementation.</td>
<td>Findings indicated both positive and negative experiences with the new</td>
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<td></td>
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<td>qualitative designs to explore</td>
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<td>intervention, three main themes were identified.</td>
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<td>patients’ and nurses’ experiences of the feasibility and acceptability of</td>
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<td>the intervention.</td>
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<tr>
<td>Schaffhausen et</td>
<td>2021</td>
<td>USA</td>
<td>Liver patients, caregivers/ families and</td>
<td>Design of a decision support tool for organ offer decisions using</td>
<td>Themes related to the offer process, repetition and timing of education</td>
<td>Information specific to offer decisions is needed, the new tool can</td>
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<td>al</td>
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<td>providers</td>
<td>interviews and focus groups to identify relevant themes for this new tool.</td>
<td>and standardisation and tailoring of content were identified and were</td>
<td>improve patient well-being during an organ offer, reduce the resources</td>
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<td>used to develop and test a public, interactive tool to prepare for an</td>
<td>required, and improve the utilisation of the donor pool and help</td>
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<td>real organ offer.</td>
<td>providers.</td>
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<tr>
<td>Coe et al</td>
<td>2021</td>
<td>USA</td>
<td>Medical students and liver or kidney transplant</td>
<td>Creating of a pilot programme of non-medical interactions using a</td>
<td>Appreciation of the opportunity to share patients’ personal experience</td>
<td>Virtual student-patient interactions are a useful approach to engage</td>
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<td>recipients or kidney donors</td>
<td>virtual meeting between students and patients on phone or video</td>
<td>to improve students’ communication skills, and development of knowledge,</td>
<td>patients and a unique way to teach medical students resulting in</td>
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<td></td>
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<td>interface, interviews and focus groups were conducted to explore their</td>
<td>attitudes and independent management of a patient encounter.</td>
<td>curricular changes and a new introductory lecture on the principles of</td>
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<td>experiences.</td>
<td></td>
<td>organ transplantation.</td>
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<tr>
<td>Jansen et al</td>
<td>2021</td>
<td>EU countries</td>
<td>Organ recipients and wait-listed patients</td>
<td>Surveys, educational activities and patient learning work stream.</td>
<td>Platform for mutual understanding, learning and a collaborative</td>
<td>Patient’s need should be clearly defined and incorporated, the joint</td>
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<td></td>
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<td>partnership was established (policy change).</td>
<td>initiative give patients opportunities for a continuing effective</td>
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<td>engagement and involvement.</td>
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*This study belongs to the Starzl Network for Excellence in Paediatric Transplantation (see also Perito et al).*
Development of an analytical framework for the analysis
An initial literature review was conducted using a scoping rapid review process to identify existing concepts for patient involvement and engagement in healthcare. Overall, 29 conceptual publications on patient involvement and engagement in the organisation of different healthcare services and settings were identified and structured accordingly (see online supplemental appendix 4). These publications were used for the development of the analytical framework (figure 1) which was later used for the subsequent systematic review of articles on patient involvement and engagement in the organisation of transplantation services (table 1). The theoretical basis for the creation of a comparative matrix that was used to extract relevant categories and items from all systematically reviewed articles was based on these conceptual publications. Following this approach, these articles were classified and categorised for further analysis in subsequent steps (online supplemental appendix 5).

Patient and public involvement
Neither patients nor the public were directly involved in the process of the creation of this manuscript. The plan of disseminating the current review involves direct dissemination to patient representatives and advisory committee members and the press to ensure that this research is communicated widely to all relevant stakeholders.

RESULTS
Search and selection results for systematic review
The electronic database search strategy yielded a total of 2263 non-duplicate records, further 2 articles were identified by hand search. Of these, 2142 were excluded after title screening based on the predefined inclusion and exclusion criteria. Eighty-six articles were further excluded after abstract screening. Of the remaining 37 articles, 11 could finally be identified as suitable for the systematic review based on full-text screening (figure 2).

Characteristics and results of systematically reviewed articles
The publication years of the 11 systematically reviewed articles ranged from 1996 to 2021. These articles originated from various countries, with most of them coming from the USA (n=5) and Norway (n=2). Among these, patient involvement and engagement in the organisation of organ transplant services was analysed in context with the support of clinical experts (n=5), nurses (n=2) and other healthcare providers (n=2). Medical students were also involved as professionals in one study (table 1).
The methods used to involve and engage patients included the codevelopment of a peer education programme (n=6) or a communication tool (n=1), or the participation in representative or advisory groups or user panels in patient or steering committees (n=5) and a mix of different methods (n=1) (table 1). Only two articles described several methods to involve and engage patients.

All articles described that well-developed programmes, which involve and engage patients in the organisation of transplant services, provide benefits for patients and foster patient-centredness. However, none of these articles investigated the impact on clinical outcomes such as increased quality of life or improved coping with disease or focused on an ongoing process to involve and engage patients as required by the definition of the National Health Services.

Compared with 29 conceptual publications on patient involvement and engagement in different healthcare services and settings, the 11 articles on patient involvement and engagement in the organisation of transplantation services focused predominantly on process goals of patient involvement and engagement such as enhancing existing services or the development of new services, but rarely on outcome goals (online supplemental appendix 5). Only three reported clinical outcome goals were improvements in health status as well as increase in quality of life, while aspects such as increase in service utilisation, satisfaction with services as well as improvements in coping with the disease were not the aims. Furthermore, none of these articles involved and engaged patients at the stage of dissemination and communication (online supplemental appendix 5).

Some systematically reviewed articles investigated aspects that have not been described in the conceptual publications on patient involvement and engagement in other, different healthcare services. Examples of such aspects include dynamic changes in patients’ conditions and perspectives, emotional sensitivities in regard to discussions on deceased organ donation, inadequate or inconsistent information for patients, lack of digital system interoperability and financial barriers for institutions to implement patient involvement and engagement in the organisation of transplantation services, while financial barriers for patients were not
identified as an important barrier to such an implementation according to the conceptual publications (online supplemental appendix 5).

Systematically reviewed articles revealed that patients and their relatives/partners were usually involved and engaged in various ways in the organisation of transplant services for patients on the waiting list for transplantation, or in the organisation of transplant services for patients in the long-term follow-up period after transplantation or in both phases. All of these articles supposed that clinical transplant services would benefit from active patient involvement and engagement with different goals. The most commonly expressed goal in these articles was the improvement of existing services.

In most articles, patients were assigned the following roles: Involvement in the design of focus group discussions to explore patient experiences with transplant services, or in discussions prior to and following transplantation to evaluate transplant service development. The reported approaches to patient involvement and engagement were coproduction, collaboration and consultation. Most of the articles focused on patient involvement and engagement activities in the stages of the design and planning of transplantation services. The most commonly expected mechanism was the support of the interaction between patients and their healthcare providers aiming to address patients’ needs.

Notably, inadequate or inconsistent information for patients was identified as most frequent barrier. Other articles identified barriers to the involvement and engagement of patients in the organisation and management of transplant care included dynamic changes in patients’ conditions and perspectives, high emotional sensitivity to discussions on deceased organ donation, financial barriers for the institution, barriers due to lack of time or support for practitioners and lack of system interoperability (the property of systems and medical records to exchange data). All these aspects were not identified through the conceptual publications indicating the specific characteristics of the transplant field.

The most frequently proposed strategies to facilitate or to improve patients’ involvement and engagement in the organisation of transplant services were better support for practitioners, adding new modes of communication between practitioners and patients, and more or clearer information for patients. For a summary of details, see online supplemental appendix 5.

Quality assessment of systematically reviewed articles revealed that no technical report on training or on supporting information for the patients and their relatives or partners who have been involved and engaged in the organisation of transplant services was reported. None of them reported patient involvement and engagement in the plain summary or abstract according to the criteria of current recommendations in GRIPP 2. The results of the assessment of the reporting quality using the GRIPP 2 short form are summarised in table 2. The results of the risk of bias assessment using the CASP tool are summarised in online supplemental appendix 6.

DISCUSSION

This systematic review shows that the goals of active patient involvement and engagement in the organisation of transplant services mainly include the improvement of patient education and the development of new

| Table 2 | Quality assessment of the reporting of systematically reviewed articles on patient involvement and engagement in the organisation of transplantation services based on the GRIPP 2 short form |
|-----------------|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Study           | Report the aim of the study     | Provide a clear description of the methods used for PPI in the study | Report the results of PPI in the study, including both positive and negative outcomes | Comment on the extent to which PPI influenced the study overall | Comment critically on the study, reflecting on the things that went well and those that did not |
| Franco et al    | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Rosaaesen et al | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Sullivan et al  | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Squires et al   | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Gomis-Pastor et al | ✓                       | ✓               | ✓               | ✓               | ✓               |
| Healey et al    | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Seljelid et al  | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Andersen et al  | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Schaffhausen et al | ✓                       | ✓               | ✓               | ✓               | ✓               |
| Coe et al       | ✓                               | ✓               | ✓               | ✓               | ✓               |
| Jansen et al    | ✓                               | ✓               | ✓               | ✓               | ✓               |

GRIPP 2, Guidance for Reporting Involvement of Patients and the Public; PPI, patient and public involvement.
services, while enhancing existing transplant services was the most common goal. We think that further management goals should also include increased transparency of processes to increase trust in transplantation and in the transplantation system with the goal to achieve more public support for transplantation in times of increasing scarcity of suitable donor organs.

Appropriate approaches to patient involvement and engagement such as coproduction, collaboration and consultation can facilitate meaningful patient engagement and involvement in transplant programme design, development and enhancement as well as in process improvement projects. This could be found in the systematically reviewed articles, for example, for the codevelopment of a peer education programme, the participation in advisory groups or in steering committees, and for a mix of different methods. Patients can provide unique perspectives for the design of focus group discussions and for the exploration of patient experiences with transplant services. Patients should be involved in discussions to evaluate transplant service development. Such contributions can be valuable for the improvement of patient-centredness and for the elimination of waste in dysfunctional or suboptimal clinical service processes, which are important management goals. The improved delivery of healthcare services by fostering patient-centredness with reduced waste of resources could lead to more efficient resource allocation increasingly strained healthcare systems across the globe. This may also improve workforce satisfaction by reducing strain on already overburdened clinical staff. Further studies on patient involvement and engagement should therefore analyse potential quantitative evidence for process improvements, for example, improved cost-effectiveness, quantified reduced waste, shortened process time, improved process reliability, as well as improved clinical outcomes such as improved quality of life and patient survival. This may be supported by deploying Lean Six Sigma methodology for process optimisation in future studies on patient involvement and engagement.

The methods summarised in this review cover a set of powerful tools for strong leadership action with high levels of transparency in the management of transplant centres and transplant institutions. These methods create and foster a deeper mutual understanding between patients and their transplant institution and thus enable better and more informed service processes. It appears that all stages of transplant care and all types of organ transplants can be improved by suitable deployment of patient involvement and engagement.

The analytical framework which has been developed for the purpose of this systematic review (figure 1) could also be used as a concise strategic guide for patients’ involvement and engagement in the organisation of transplant services. However, such a strategic approach to transplant centre management requires strong leadership decisions and support as well as experience in change management. This becomes obvious when internal resistance to change by powerful and established decision-makers surfaces in addition to the reported and thus expected barriers to patient involvement and engagement such as dynamic changes in patients’ conditions and perspectives, high emotional sensitivity to discussions on deceased organ donation and lack of system interoperability. As this review shows, these challenges should be weighed against the above mentioned potential benefits.

The systematically reviewed articles did not aim at some goals such as an increase in the usage of services or improved satisfaction with services while these goals were aimed at in the conceptual publications from other healthcare fields for example cancer screening. None of them reported the effects of patient involvement and engagement on the dissemination and communication of transplant services while conceptual publications mentioned such effects in the context of other medical fields (online supplemental appendix 5). Financial barriers for patients as a commonly mentioned barrier has not been reported, while risk of tokenism and barriers due to the lack of support for practitioners also have not been reported while these aspects have been reported as issues in other medical fields (online supplemental appendix 5). So far only conceptual publications from other medical fields did suggest the clarification of roles, the rationale and the responsibility of patients and the enhancement of access to involvement in order to improve patient involvement and engagement. We believe that future studies and projects that focus on patient involvement and engagement in the organisation of transplantation services can benefit from considering all of these aspects. This may maximise the utility of future studies by using the lessons learnt in other medical fields. We could not identify any reason why these aspects could not be examined, introduced or discussed for the improvement of patient involvement and engagement in the organisation of transplantation services.

Patient involvement and engagement navigated by nurses in cancer care could be shown to significantly improve the outcome of care as well as access to care, continuity of care and clinical efficiencies. Such an approach to a codesign together with patients may lead to better clinical processes also in transplant care while it could improve mutual learning, the sharing of knowledge and the development of new competencies.

Different formats and types of patient involvement and engagement such as in temporary project-related taskforces versus longer-term membership in a management board and their effects have not been compared yet. From a management perspective the deployment of different types of patient involvement and engagement at different levels of the organisation is a strategic question that could be answered using our analytical framework depicted in figure 1.

As the common stages of patient involvement and engagement are setting the priorities for patients, the
Although studies on other organs or tissues were not identified, which is likely due to the smaller volume of publications on these topics, for example, in the contexts of intestine transplantation or vascularised composite tissue transplantation. We believe that it is important to incorporate the perspectives of patients in these contexts as well which will be more challenging due to lower case numbers of such transplantations, and the current lack of published experiences with patient involvement and engagement in the organisation of such transplantation services.

There were several limitations to this review. Although a large number of studies on patient involvement and engagement were identified with the initial search strategy, only a small number of identified articles could be identified that focused on patient involvement and engagement in the organisation of organ transplantation services. Furthermore, negative effects of patient involvement and engagement may be less likely reported due to publication bias. To identify this bias, we used the GRIPP 2 checklist for reporting quality improvements in systematically reviewed articles and recommend the adherence to this checklist in future research on this topic.

CONCLUSIONS

We derived from this systematic review the following recommendations for future projects on patient involvement and engagement in the organisation of transplant services:

► To empower patients, the information provided to them should be individualised to prioritise their needs.
► Both financial and organisational resources are important to successfully implement patient involvement and engagement at least partially.
► Communication should always be seen as a two-way street, because feedback to health providers is required to improve clinical workflows.
► Medical staff should be enabled by the provision of resources (eg, working time, training, financial resources) to improve clinical processes effectively by the involvement and engagement of patients.
► Active and consistent leadership within the organisation and system is required to overcome resistance to change while active participation of patients as coinitiators of improvement should be invited officially by the institution.
► Ideally, successful projects should analyse the impact on the improvement performance parameters of clinical processes and clinical outcomes of transplantation such as graft survival, patient survival and the improvement of patients’ quality of life.
► Furthermore, these projects should be focused on a longer-term period to avoid short and time-consuming projects.

The systematically reviewed articles showed that published projects with patient involvement and engagement in the organisation of transplantation services are still localised activities and small and time-limited projects. These programmes were also described in one publication as time-consuming and energy-intensive while the impact on patient care can be marginal. In order to avoid such an unwanted situation, it is highly relevant that patient involvement and engagement activities are integrated and aligned with an overall strategic approach to improve the organisation in which it operates. We believe that this requires active and consistent leadership within the organisation and system, supportive managers to be involved and encouraged active participation of patients as coinitiators of improvement.

The lack of consideration of ethical issues in three systematically reviewed articles and the lack of consideration of the role of the relationship between researchers and participants in almost all of these articles showed how the quality of studies in this area could and should be improved in the future (online supplemental appendix 6). Further improvements may be achieved by closely following the GRIPP 2 guideline (table 2).

It is noteworthy that one included study addressed the unique challenges in the paediatric transplant area due to limited resources, a relatively small number of cases, and the need to measure unique but significant factors, such as medication adherence, recipient health and development, and readiness for transitioning to adult care providers, which were ignored by the transplant community for a long time. Furthermore, the patients’ perspectives may be hard to integrate because many paediatric patients who require organ transplants are of very young ages and will need be represented by their parents’ voice. In addition, determining the role of paediatric centres in quality initiatives is complicated by factors such as whether they are standalone facilities, part of an adult-focused programme, or integrated within a larger hospital quality programme. However, the establishment of the Starzl Network for Excellence in Paediatric Transplantation, which aims to incorporate the patient voice at the onset of any improvement project, may significantly contribute to the continuous improvement of transplant practice with integration of emerging technologies with evidence-based patient-centred outcomes and translate evidence into practice in the future.
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