



University of Groningen

Self-reported health status after solid-organ transplantation

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DOI:
[10.33612/diss.144702130](https://doi.org/10.33612/diss.144702130)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2020

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Shahabeddin Parizi, A. (2020). *Self-reported health status after solid-organ transplantation: The development and application of an innovative assessment method*. University of Groningen. <https://doi.org/10.33612/diss.144702130>

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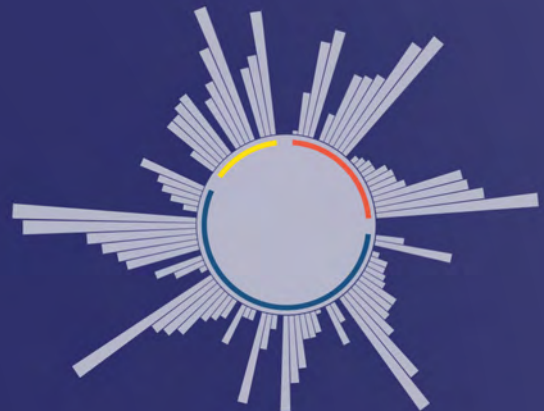
CHAPTER 4



A scoping review of key health items in self-report instruments used among solid-organ transplant recipients

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Patient. 2019;12:171-181.



Abstract

The overall aim of this scoping review of the literature is twofold: (1) to provide an overview of all instruments that have been used to assess health-related quality of life (HRQoL) after solid-organ transplantation; and (2) to provide a list of health items they include to support future studies on the development of a new generation HRQoL instrument. All studies that had administered any form of HRQoL instrument to post-transplant solid-organ recipients were identified in a comprehensive search of PubMed (MEDLINE), Embase, and Web of Science, with a cut-off date of May 2018. The search used various combinations of the following keywords: lung, heart, liver, kidney, or pancreas transplantation; quality of life; well-being; patient-reported outcome; instrument; questionnaire; and health survey. In total, 8013 distinct publications were identified and 1218 of these were selected for review. Among the instruments applied, 53 measured generic, 51 organ-specific, 271 domain-specific, and 43 transplant-specific HRQoL. A total of 78 distinct health items grouped into 16 sub-domains were identified and depicted in a graphical representation. The majority of the publications did not report a logical rationale for the choice of specific HRQoL instrument. The most commonly used types of instruments were generic health instruments, followed by domain-specific instruments. Despite the availability of transplant-specific instruments, few studies applied these types of instruments. Based on the 78 items, further research is planned to develop a patient-centered, transplant-specific HRQoL instrument that is concise, easy to apply (mobile application), and specifically related to the health issues of solid-organ recipients.

Introduction

With respect to the considerable improvements in clinical outcomes in the field of solid-organ transplantation (i.e., lung, heart, liver, kidney, and pancreas), there is growing awareness of post-transplant perceived health status or health-related quality of life (HRQoL) [1-4]. Today, the main objectives of organ transplantation include extension of survival, decrease in the level of disability, and improvement of HRQoL [5].

HRQoL is a multi-dimensional concept that refers to the overall impact of health aspects on an individual's quality of life [6, 7]. More specifically, HRQoL embraces physical symptoms, functional status, psychological states, and social relationships. Together these constitute the domains of the World Health Organization's (WHO) definition of health [7-10].

Before transplantation, a patient's HRQoL is significantly reduced due to clinical dysfunction of the failing organ and psychosocial distress. Shortly after transplantation, a significant increase in HRQoL is observed [11, 12]. However, life-long, immunosuppressive regimens are necessary to prevent organ rejection, and chronic exposure to these medications is associated with complications that adversely affect the HRQoL of solid-organ transplant recipients [13-15]. Previous studies have emphasized that a considerable proportion of patients are more concerned about HRQoL than about survival [16, 17].

Numerous instruments are available to measure HRQoL of transplant patients. Here, 'instrument' refers to any form of self-report questionnaire and rating scale that is used to measure any aspect of an individual's HRQoL. Most reviews of post-transplant HRQoL studies have focused on frequently used instruments in only one or two organ types, so they may have omitted some less well-known instruments. Recent systematic reviews of the literature on HRQoL in lung, liver, kidney, and pancreas transplant patients have revealed that the most common instruments are the 36-Item Short Form Survey (SF-36) and the EQ-5D [4, 18-22]. These two instruments have proven to be beneficial in measuring the health status and outcomes associated with healthcare interventions [23]. However, these are generic instruments and thus do not contain health items that are specifically relevant to post-transplant patients.

With increased attention being paid to the concept of HRQoL among transplant patients, targeted measurement of HRQoL is becoming more important. An appropriate transplant-specific (Tx-specific) instrument should cover the full spectrum of HRQoL and assess both general and transplant-specific health issues of patients. Additionally, although many existing HRQoL instruments measure the intensity or frequency of complaints, they lack the ability to measure the impact of these complaints on the health status experienced by patients [24-26]. To measure the latter, specially designed instruments are necessary, derived from methodologies that include the preferences of patients. Special judgmental tasks (e.g., ordering a set of health states or paired comparisons between different health state descriptions) are a central element in such instruments [7, 27]. Embedding patients' preferences into health-outcome instruments is becoming increasingly important, due to the increasing attention being paid to patient-centered healthcare [28-31].

Some generic preference-based HRQoL instruments, for example, the HUI-3 and EQ-5D, are available. However, their content is not focused on the specific health issues of transplant patients, and the selection of the health items in these instruments is

mainly based on expert opinion [24, 31]. Moreover, the determination of the importance of the various health items, which consist of a value-judgment task, is based on a representative community sample [32-35]. Recently, a novel preference-based method has been introduced, which makes it possible for patients themselves to make the value judgements [34, 36]. Therefore, we see a need for a preference-based, patient-centered, transplant-specific HRQoL instrument.

The first step in developing a patient-centered HRQoL instrument for transplant patients is to extract relevant health items from existing instruments [37, 38]. Therefore, we conducted a scoping review of the literature to provide an overview of all instruments that have been used to assess HRQoL after transplantation in major solid-organ recipients. Our aim was to find all studies that evaluated any aspects of HRQoL in post-transplant patients and subsequently to identify all instruments and health items used. This study is not directed to the psychometric properties of the instruments or concerned with recommending the best instruments available.

Methods

Study design and literature search strategy

A scoping literature review was conducted to extract all HRQoL instruments that had been administered to major solid-organ transplant recipients. This was not a systematic review, but rather aimed at acquiring adequate information about existing HRQoL instruments to establish a basis for formulating relevant items. To identify relevant studies, the three major electronic databases, namely PubMed (MEDLINE), Embase, and Web of Science, were searched to May 2018. To ensure we included all self-reported instruments that have thus far been applied, different combinations of broad keywords and MeSH terms were formulated to cover three domains: (1) solid-organ transplantation, i.e. lung, heart, liver, kidney, or pancreas transplantation; (2) quality of life, i.e., quality of life itself, well-being, or patient-reported outcome; and (3) instruments, i.e., questionnaire or health survey. The search strategy was discussed with four experts on epidemiological and transplant studies (PK, EB, KV, and SB) to finalize the list of keywords (Figure 1).

Identification of relevant literature and eligibility criteria

We included all original publications in English if they met the following criteria: (1) human studies in which the participants had been transplanted with at least one of the five major solid organs and were ≥ 18 years old at the time of the study; (2) studies that evaluated symptoms, physical functioning, psychological distress, or social relationships in terms of health outcomes; and (3) studies that used any form of HRQoL instrument.

The finalized list of keywords was then used to select potentially eligible articles for title and abstract review. Because our aim was to include all studies that assessed HRQoL in the post-transplant population, we only excluded publications that clearly did not meet the inclusion criteria, and retained all other references for full text review. If there was any doubt, the full article was retrieved and the methods section was read to check selection criteria. Studies were excluded if they were restricted to donors, organ transplant candidates, pediatric transplant recipients, and family or relatives of the patient. Case studies, editorials, letters to the editor, meta-analyses, systematic reviews, and books were also all excluded from the review. Subsequently, the full text of each eligible paper was reviewed to identify studies that met the inclusion criteria. In addition,

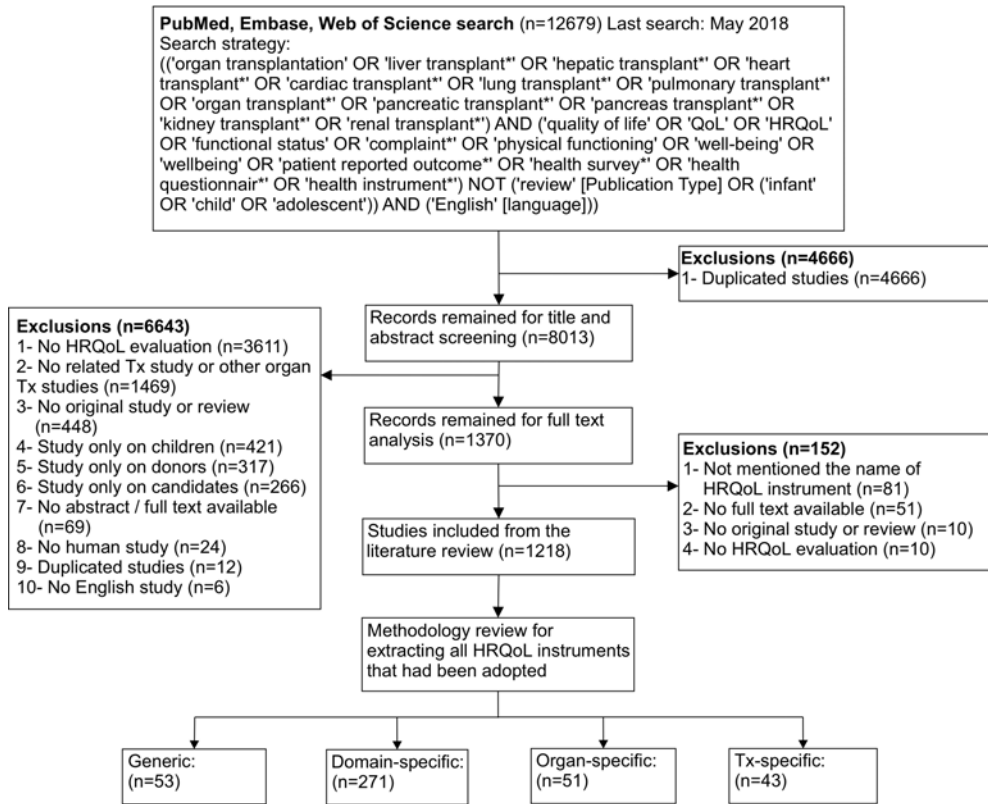


Figure 1. Studies inclusion process.

if studies included both adult and pediatric participants, the instruments applied were listed in our results (i.e., the number of instruments may be greater than the number of publications, and some pediatric-specific instruments are shown in the results).

Health items extraction

We checked the names of the extracted instruments in the different studies to identify the standard unique name for each instrument. In the next step, the names and the items of the extracted instruments were reviewed. Thus, for each instrument, we identified the intended type and dimensions of HRQoL that were assessed (e.g., general health, disease burden, social aspects, etc.). Based on the concepts underpinning the items, we then divided the instruments into four groups: generic (overall) HRQoL; domain-specific HRQoL; disease/organ-specific HRQoL; and transplant-specific HRQoL.

The transplant-specific HRQoL instruments were reviewed by two authors (AS and KV) and health items were extracted. In this stage, all items were listed regardless of whether they belonged to the concept of HRQoL. If a health item occurred in multiple instruments, the most frequent or shortest phrase was selected for the inventory. In the meetings with all authors, health items were categorized into three broad domains of health: physical, psychological, and social. Items that were clearly irrelevant to the measurement of HRQoL (e.g., religion or income level) were eliminated.

The main aim of this study is to provide an informative pool of items for the development of a new HRQoL instrument. To display the items in a clear and organized way, a technique called HealthFan© was used [24]. All health items included were arranged in a diagram and were classified under three higher order major domains (physical, mental, and social) to create a clear and concise overview. The sub-domains were graphically presented under each major domain, thereby listing the health items in a systematic way.

Results

Based on the search strategy, we identified 4381 articles in PubMed, 5066 in Embase, and 3232 in Web of Science, of which 1218 met the inclusion criteria (Figure 1). There were 120 related titles (most published before 2000) for which we did not find the full text, and, therefore, were unable to extract data from them. Furthermore, the names of the HRQoL instruments applied were not mentioned in 81 articles. The majority of the publications assessed kidney recipients (525 articles), followed by liver (340 articles), heart (196 articles), lung (131 articles), and pancreas recipients (20 articles). We also included 138 articles that consisted of two or more different groups of solid-organ recipients. We identified 418 distinct instruments that were divided into four groups: generic HRQoL; domain-specific HRQoL; disease/organ-specific HRQoL; and transplant-specific HRQoL.

Instruments and outcome measures

Generic (overall) HRQoL instruments

Generic instruments assess global aspects of health status and are thus potentially suitable for a wide range of patient groups. This literature review found that the majority of solid-organ transplantation studies applied generic HRQoL instruments. The 36-Item Short Form Survey (SF-36) is by far the most frequently used generic instrument in post-transplant HRQoL studies, followed by the Karnofsky Performance Status Scale (KPS), and the Sickness Impact Profile (SIP) (Table 1). The complete list of generic HRQoL instruments is available in Appendix 1.

Domain-specific HRQoL instruments

Domain-specific instruments measure one particular aspect of health, such as life satisfaction or social functioning. Contrary to generic or organ-specific instruments that cover broad aspects of health, these instruments assess a particular dimension of health in detail. Instruments that assess depressive and/or anxiety symptoms were the most frequently applied domain-specific HRQoL instruments in transplantation studies. Moreover, because insomnia is one of the most frequently reported side effects of immunosuppressive medications [42], sleep quality assessment was frequent in our findings. Social support and life satisfaction instruments were the third most frequently applied domain-specific HRQoL instruments in transplantation studies (Table 1). The complete list of domain-specific HRQoL instruments is available in Appendix 2.

Disease/organ-specific HRQoL instruments

These instruments are designed to measure the patient's perceptions of a specific health problem in a particular organ or disease (e.g., respiratory symptoms,

Table 1. Characteristics of the top three prominent administered generic and domain-specific HRQoL instruments

Name of the instrument	Type of instrument	Number of items	Domains	Year	Frequency
36-Item Short Form Survey (SF-36) [39]	Generic	36	Vitality Physical functioning Bodily pain General health perceptions Physical role functioning Emotional role functioning Social role functioning Mental health	1992	460
Karnofsky Performance Status Scale (KPS) [40]	Generic	11	Performance status	1948	78
Sickness Impact Profile (SIP) [41]	Generic	136	Physical items (ambulation, mobility, and body care/movement) Psychosocial items (social interaction; communication; alertness behavior; emotional behavior; home management; eating; sleep/rest; recreation and pastimes; and work)	1981	75
Hospital Anxiety and Depression Scale (HADS) [43]	Anxiety and depression-targeted	14	Mood Interest in activities Anxiety Panic symptoms	1983	107
Pittsburgh Sleep Quality Index (PSQI) [44]	Sleep-targeted	19	Subjective sleep quality Sleep latency Sleep duration Habitual sleep efficiency Sleep disturbances Use of sleep medication Daytime dysfunction	1988	26
Social Support Questionnaire (F-SozU) [45]	Social functioning-targeted	54	Emotional support Affiliation support Instrumental support Social integration Satisfaction with the received support	1989	13

gastrointestinal symptoms, heart failure, etc.). The Kidney Disease Quality of Life Short Form (KDQOL-SF) is the most commonly applied organ-specific HRQoL instrument in solid-organ transplant patients. Table 2 introduces the characteristics of the most frequently applied kidney-, liver-, lung-, pancreas-, and heart-targeted HRQoL instruments. The complete list of disease/organ-specific HRQoL instruments is available in Appendix 3.

Table 2. Characteristics of the top five prominent administered organ- and transplant-specific HRQoL instruments

Name of the instrument	Type of instrument	Number of item	Domains	Year	Frequency
Kidney Disease Quality of Life Short Form (KDQOL-SF) [46]	Kidney-targeted	79	8 SF-36 domains Symptoms/problems Effects of kidney disease Burden of kidney disease Work status Cognitive function Quality of social interaction Sexual function Sleep Social support Staff encouragement Patient satisfaction	1994	38
Liver Disease Quality of Life instrument (LDQOL) [47]	Liver-targeted	111	8 SF-36 domains Symptoms of liver disease Effects of liver disease Concentration Memory Sexual functioning Sexual problems Sleep Loneliness Hopelessness Quality of social interaction Health distress Stigma of liver disease	2000	18
St. George's Respiratory Questionnaire (SGRQ) [48]	Lung-targeted	50	Symptom (illness status such as cough, sputum production, and dyspnea) Activity (activities that cause breathlessness and activities limited by breathlessness) Impact (social functioning and psychological disturbances resulting from airways disease)	1991	17
Diabetes Quality of Life questionnaire (DQOL) [49]	Pancreas-targeted	62	Core items (satisfaction; impact; diabetes worry; and social/vocational worry) Auxiliary questions about adolescent patients (schooling experience and family relationships)	1988	14
Minnesota Living with Heart Failure Questionnaire (MLHFQ) [50]	Heart-targeted	21	Physical functioning Emotional functioning	1987	5

Key health items in solid-organ transplantation

Table 2. (Continued).

Name of the instrument	Type of instrument	Number of item	Domains	Year	Frequency
End-Stage Renal Disease Symptom Checklist-Transplantation Module (ESRD-SCLTM) [51]	Kidney Tx-targeted	43	Limited physical capacity Limited cognitive capacity Transplantation-associated psychological distress Cardiac and renal dysfunction Side effects of corticosteroids Increased growth of gum and hair	1999	20
Kidney Transplant Questionnaire (KTQ) [52]	Kidney Tx-targeted	25	Physical symptoms Uncertainty/fear Fatigue Appearance Emotions	1993	17
Modified Transplant Symptom Occurrence and Symptom Distress Scale (MTSOSD) [53,54]	All organs Tx-targeted	59	Symptom occurrence (cognitive component) exclusively related to the side effects of the immunosuppressant Symptom distress (emotional component) exclusively related to the side effects of the immunosuppressant	1985	17
Transplant Effects Questionnaire (TxEQ) [55,56]	All organs Tx-targeted	23	Worry about the transplant Guilt regarding donor Disclosure Adherence Responsibility	2002	16
Heart Transplant Symptom Checklist [57]	Heart Tx-targeted	92	Cardiopulmonary symptoms Gastrointestinal symptoms Genitourinary symptoms Dermatological symptoms Neuromuscular symptoms Psychological symptoms	1992	14

Transplant-specific HRQoL instruments

Transplant-specific instruments were developed to evaluate certain aspects of the health status of patients who receive a graft, such as physical symptoms or medication side effects. Many of these tools are modified modules of disease-specific instruments that contain items pertaining to the transplantation setting and can be used for recipients of a particular kind of organ. A few instruments were designed for transplants of any type and have been used in studies that include various transplanted organs. Table 2 briefly describes the characteristics of the most frequently applied transplant-specific HRQoL instruments. The complete list of transplant-specific HRQoL instruments is available in Appendix 4.

Health items

To obtain an overview of the health domains that are currently assessed by transplant-specific instruments, an inventory was made of the health items in these instruments. In total, 576 items were extracted (full list available on request from the author). After elimination of the irrelevant items and merging repetitions and items that assess similar concepts, 78 distinct health items remained for development by our HealthFan tool. Items that assessed physical symptoms were commonly repeated in different transplant-specific instruments (Figure 2).

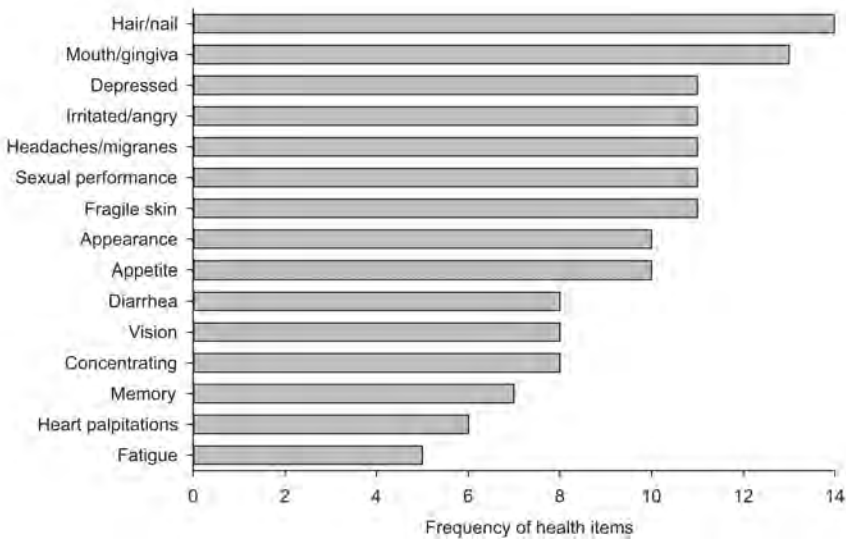


Figure 2. Frequency of health items with most repetitions in available transplant-specific HRQoL instruments.

These 78 health items were classified into three broad domains (colored areas): physical, mental, and social (Figure 3). To provide a visual overview, health items were subdivided into 16 sub-domains (filled-in dots). The class of physical items was subdivided into belly, body heat, chest, eating, energy, pain, physical, respiratory, senses, and skin. The class of mental items was subdivided into cognition, feelings, and worries. The class of social items was subdivided into activities, autonomy, and relationships.

Discussion

Ever since the concept of HRQoL was introduced, it has been a challenge to define and measure it [58]. There is no single instrument that can be construed as the gold standard for measuring HRQoL in different populations, particularly when they are heterogeneous. One of the aims of this paper was to identify all HRQoL instruments that have been applied thus far among solid-organ transplant patients. On the basis of this review, we compiled a complete list of all HRQoL instruments that have been developed or applied to date in the field of solid-organ transplantation as well as a comprehensive list of health items. We discovered that different studies sometimes refer to a particular instrument by

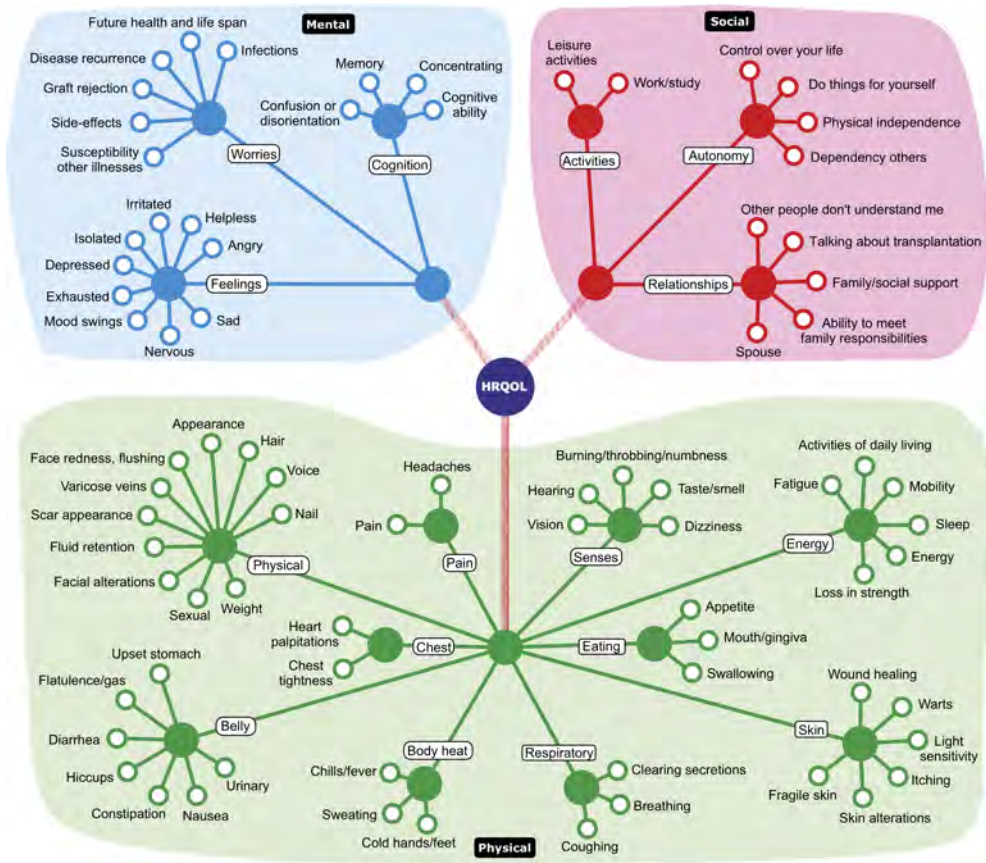


Figure 3. Selected extracted health items organized into physical, mental, and social domains (HealthFan).

different names. We carefully selected the most generally known name corresponding to each instrument. Additionally, we developed a helpful scheme to depict relevant health items.

This review revealed that the majority of publications did not provide a logical rationale for the choice of the HRQoL instrument. Additionally, 81 publications did not mention the name or the reference for the HRQoL instruments that were applied. Moreover, the validity of some of the HRQoL instruments seems questionable, as the studies did not cite a source that described the development and validation procedure. The overview of instruments that we presented in this study will be useful in the process of instrument selection in future studies, and is conducive to credible findings.

The health assessment instruments most commonly reported in the literature were generic measures, and among these the SF-36 was particularly frequent. These generic instruments have a rich history of assessing psychometric properties and performing validation studies in general populations and many patient groups. Their wide application also enables researchers to compare results from transplant patients with the general population. However, these instruments were not developed specifically for transplant patients. Consequently, they do not capture the most salient health domains

of organ recipients. Using generic instruments alongside transplant-specific instruments would make the results more comparable. Together they could detect the unanticipated positive or negative effects of transplantation that are not covered by specific instruments. However, relying solely on generic instruments may be insufficient to discover clinically relevant changes in post-transplant patients [59].

Domain-specific instruments, especially those measuring psychological symptoms, were the second most commonly used instruments. The literature has emphasized the importance of assessing psychological issues, due to their high prevalence and their enormous impact on the health status of transplant patients [60-63]. Moreover, as found in this review, the items of some very frequently used transplant-specific HRQoL instruments (e.g., TxEQ, Heart Transplant Symptom Checklist, and Heart Transplant Stressor Scale) are restricted to the psychological domain of HRQoL. Although domain-specific instruments provide detailed data on their target domain, they do not give a global sum score that can be interpreted for all domains of HRQoL. We expect that the list of selected health items of domain-specific instruments in the HRQoL studies of post-transplant patients will be very informative.

Disease- or organ-specific HRQoL instruments were the third most frequently applied instruments in studies in transplant patients. These include items that focus on a particular disease or organ. Therefore, in theory, they provide more accurate estimates of HRQoL, with higher consistency and reliability for their target population (i.e., recipients of a specific type of organ). However, the content of these instruments also has certain shortfalls. For example, all of the instruments that we described in the results section were designed to measure HRQoL in patients who were suffering from chronic disease of that organ (i.e., before transplantation) and were therefore not, or less, applicable after transplantation. Additionally, it is difficult to interpret the results of organ-specific instruments in heterogeneous patient groups who received different organs. We suggest that the application of organ-specific instruments should be limited to the transplant candidates, since the health issues are usually substantially different after transplantation [3, 15, 64, 65].

Our review revealed that despite the availability of transplant-specific instruments, only a few studies have applied these types of instruments to measure HRQoL. This low level of application, which has also been observed in some previous reviews [3, 4, 18-20, 66-70], might be explained in several ways. First, transplant-specific instruments are relatively new, meaning that many longitudinal studies started data collection before transplant-specific instruments were available. Second, by applying generic or domain-specific instruments, researchers can compare their results with characteristics of various other populations, whereas transplant-specific instruments restrict the comparability across studies. Third, most transplant-specific instruments (e.g., ESRD-SCLTM, which includes 43 items, or the MTSOSD, which includes 59 items) comprise more items compared to most generic instruments (e.g., EQ-5D, which includes 5 items, or the SF-36, which includes 36 items), which makes them lengthy and thus less desirable for clinical studies, especially those that require repeated measurements.

We consider that the current transplant-specific instruments have more potential than generic HRQoL instruments for use in post-transplant research. However, given the fact that the content of the available instruments is largely determined by experts rather

than patients, it is currently unclear whether the health items included in these instruments are relevant from the perspective of the patients. In addition, the current instruments are not preference-based, meaning the health items are not weighted to generate a single value that expresses the overall quality of the patient's health condition. This makes the results more complicated to interpret and also not suitable for use in cost utility studies to support decision makers. Therefore, it might be necessary to develop one, or even a set of, targeted HRQoL measurement instruments for solid-organ recipients. The development strategy for such a future instrument must take into account the input of patients at all steps, including: (1) item generation based on review of the literature and patient input; (2) item selection; (3) value judgment on the items. Regarding the increasing use of smartphones and touchscreens, new HRQoL instruments might be devised as mobile applications, which would make them more convenient for patients to use and researchers to apply.

This review had a very broad search strategy which ensured that we included all articles that evaluated HRQoL after solid-organ transplantation. We carefully assessed the selection of eligible studies and provided the complete list of HRQoL instruments in our results. The HealthFan listed the health items in a systematic way. In our next study, this graphical arrangement of the health items available will be used to present the items to post-transplant patients in order to select or add items they consider most important. We believe that in this way patients will have a prominent role in the process of developing a generic transplant health-outcome instrument.

Our review has some limitations, which should be mentioned. The inclusion of only English-language publications might limit the results to those instruments that have appeared in an English version. However, we did include non-English instruments if they were published in an English-language article. Another possible limitation is the exclusion of studies that had only assessed pre-transplant or pediatric patients. For our purposes, however, these two groups are not comparable with adult post-transplant patients. Post-transplant issues (e.g., immunosuppressive side effects) do not pertain to pre-transplant patients, while adult issues (e.g., partner relationships and employability) cannot be compared with childhood issues.

In summary, we emphasize the need to develop a preference-based, transplant-specific HRQoL instrument that is easy to apply and that targets the health issues of solid-organ recipients. The current set of key health items that was collected in this study is a valuable outcome that will be used in the next developmental phase. In the following step, patients' opinions will be included through focus group meetings, and an online survey will be carried out to derive the content for a new patient-centered, transplant-specific instrument.

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Appendix

Appendix 1: Alphabetic list of all applied generic HRQoL instruments

12-Item Short Form Survey (SF-12)
36-Item Short Form Survey (SF-36)
8-Item Short Form Survey (SF-8)
Achenbach System of Empirically Based Assessment (ASEBA) Adult Behavior Checklist
Achenbach System of Empirically Based Assessment (ASEBA) Adult Self-Report
Atkinson Life Satisfaction Scale (ALSS)
Austin Quality of Life Scale (AUSQUAL)
CDC HRQOL-14 Measure
Child Health and Illness Profile-Adolescent Edition (CHIP-AE)
Child Health Questionnaire-Child Form 87 (CHQ-CF87)
Child Health Questionnaire-Parent Form 50 (CHQ-PF50)
Computer-Based Health Evaluation System Software (CHES)
Delighted-Terrible (D-T) Scale (By Andrews FM. & Withey SB. 1976)
DISABKIDS Chronic Generic Module (DCGM-37)
Duke Health Profile (DUKE)
European Organization for Research and Treatment of Cancer QOL questionnaire-C30 (EORTC QLQ30)
EuroQOL-5D (EQ-5D)
Functional Independence Measure (FIM)
Functional Limitations Profile (FLP)
General Health Questionnaire (GHQ)
General Quality of Life Inventory (GQOLI-74)
Generic 15D instrument
Health Measurement Questionnaire (HMQ)
Health Status Questionnaire (HSQ 2.0)
Health Utility Index-Mark II and III (HUI-2/3)
Illness Effects Questionnaire (IEQ)
Illness Intrusiveness Rating Scale (IIRS)
International Classification of Functioning, Disabilities and Health Questionnaire (ICF)
Karnofsky Performance Scale (KPS)
KIDSCREEN-27
LEIPAD Quality of Life questionnaire
McMaster Health Index Questionnaire (MHIQ)
Medical Outcomes Study (MOS 20)
Munich Quality of Life Dimensions List (MLDL)
Nottingham Health Profile (NHP)
One-item General Quality of Life (GenQOL)
Patient-Centered Outcomes Questionnaire (PCOQ)
Patient-Reported Outcomes Measurement Information System Health Assessment Questionnaire (PROMIS HAQ)
PatientsLikeMe Quality of Life Scale (PLMQOL)
Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0)
Perceived State of Health Questionnaire (PSH)

Profile of Quality of Life Related to Health (PICAUIRES)
Quality of Life Index (QLI)
Quality of Life Profile for the Chronically Ill (PLC)
Quality of Life Scale (QOLS)
Rotterdam Symptom Checklist (RSCL)
Schedule for the Evaluation of Individual Quality of Life (SEIQoL)
Short-Form Six-Dimension (SF-6D)
Sickness Impact Profile (SIP)
Spitzer Quality of Life Index (SQLI)
Visual Analog Scale (VAS)
World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)
World Health Organization Quality of Life Scale (WHOQOL-BREF)

Appendix 2: Alphanumeric list of all applied domain-specific HRQoL instruments

Acceptance of Illness Scale (AIS)
ACQ Busyness Scale
Activities of Daily Living Index (ADL)
Adult Self-Image Scale (ASIS)
Affect Balance Scale (ABS)
Affective Neuroscience Personality Scales (ANPS)
Alcohol Problems Questionnaire (APQ)
Alcohol Use Disorder Identification Test (AUDIT)
Anamnestic Comparative Self-Assessment Scale (ACSA)
Antonovsky's Sense of Coherence (SOC)
Arizona Sexual Experiences Scale (ASEX)
Athens Insomnia Scale (AIS)
Attachment Style Questionnaire (ASQ-40)
Baecke Habitual Physical Activity Questionnaire
Barriers and Motivators Questionnaire
Barthel Activities of Daily Living Index (ADL)
Basic Hope Inventory (BHI-12)
Basic Nordic Sleep Questionnaire (BNSQ)
Basic Personality Inventory (BPI)
Basic Psychological Need Satisfaction Scales
Beck Anxiety Inventory (BAI)
Beck Depression Inventory (BDI)
Beck Hopelessness Scale (BHS)
Beck Scale for Suicide Ideation (BSI)
Behavioral Regulation in Exercise Questionnaire-2 (BREQ-2)
Beliefs about Medicines Questionnaire (BMQ)
Bender Visual Motor Gestalt Test (Bender-Gestalt Test)
Berlin Questionnaire for Sleep Apnea
Berliner Stimmungs Fragebogen (BSF)
Bickel and Hanson's Perceived Self-Care Agency Questionnaire (PSCAQ)
Blessed-Dementia Scale (BLS-D)
Body Cathexis-Self Cathexis Scale (BCSC)

Body Image Questionnaire (BIQ)
Brief Cognitive Status Examination (BCSE)
Brief COPE
Brief Michigan Alcoholism Screening Test (bMAST)
Brief Pain Inventory (BPI)
Brief Symptom Inventory (BSI)
Burnout Measure (BM)
Campbell Well-Being Scale
Cantril's Self-Anchoring Striving Scale (Ladder)
Caregiver Burden Scale (CBS)
Center for Adherence Support Evaluation (CASE) Adherence Index
Center for Epidemiologic Studies Depression Scale (CES-D)
Center for Marital and Sexual Health Sexual Functioning Questionnaire (CMASH SFQ)
Checklist Individual Strength (CIS)
Children's Depression Inventory (CDI)
Chinese Coping Scale (CCS)
Chinese Mood Health Questionnaire
Clinical Global Impressions (CGI)
Cognitive Appraisal of Health Scale (CAHS)
Cognitive Failures Questionnaire (CFQ)
Cognitive Performance Test (Syndrom-Kurztest - SKT)
Composite International Diagnostic Interview (CIDI)
Connor-Davidson Resilience Scale (CD-RISC)
Control Attitudes Scale (CAS)
Cook–Medley Hostility Scale (Ho)
Coopersmith Self-Esteem Inventory
Coping Inventory for Stressful Situations (CISS)
Coping Responses Inventory (CRI)
Coping Strategy Indicator (CSI)
Coping With Serious Illness Battery (CSIB)
Davidson Trauma Scale (DTS)
DeMeester Reflux Questionnaire
Depression, Anxiety and Stress Scale (DASS-21)
Derogatis Sexual Functioning Inventory (DSFI)
Desirability of Control Scale (DC)
Dresden Body Image Inventory (DKB-35)
Duke Activity Status Index (DASI)
Duke University Religion Index (DUREL)
Duke-UNC Functional Social Support Questionnaire (FSSQ)
Dyadic Adjustment Scale (DAS)
Dysregulation Inventory (DI)
Edmonton Symptom Assessment System (ESAS)
Empowerment Scale
Epworth Sleepiness Scale (ESS)
Essen Trauma Inventory (ETI)
Eysenck Personality Questionnaire (EPQ)

Family APGAR Questionnaire
Family Assessment Measure III (FAM III)
Family Crisis Oriented Personal Evaluation Scale (F-COPES)
Family Environment Scale (FES)
Family Impact Questionnaire
Fatigue Impact Scale (FIS)
Fatigue Severity Scale (FSS)
Fatigue Symptom Inventory (FSI)
Female Sexual Distress Scale (FSDS)
Female Sexual Function Index (FSFI)
Fleming Self-Esteem Scale
Freiburg Complaint List (Freiburger Beschwerdenliste FBL-R)
Freiburg Questionnaire of Coping With Illness (FQCI)
Fried Frailty Phenotype (FFP)
Functional Assessment of Chronic Illness Therapy (FACIT)
Functional Living Index-Cancer (FLIC)
General Coping Questionnaire (GCQ)
General Self-Efficacy Scale (GSE)
Generalized Anxiety Disorder 7-item Scale (GAD-7)
Geriatric Depression Scale (GDS)
Giessen Subjective Complaints List (GSCL)
Global Assessment of Relational Functioning Scale (GARF)
Global Severity Index (GSI)
Goal Orientation Index (GOI)
Godin Leisure Time Exercise Questionnaire (GLTEQ)
Hamburg Pain Adjective List (HPAL)
Hamilton Anxiety Rating Scale (HAM-A)
Hamilton Depression Rating Scale (HAM-D)
Health Behaviour Inventory (HBI)
Healthcare Provider Support Survey (By Lin SY. 2011 - HPS)
Health-Promoting Lifestyle Profile (HPLP)
Herth Hope Index (HHI)
Hopkins Symptom Checklist (HSCL)
Hospital Anxiety and Depression Scale (HADS)
Human Figure Drawing Test (HFD)
Illness Perceptions Questionnaire (IPQ)
Impact of Events Scale (IES)
Index of Illness-Related Concerns
Index of Well-Being (IWB)
Insomnia Severity Index (ISI)
Instrumental Activities of Daily Living Scale (IADL)
INTERMED
International Physical Activity Questionnaire (IPAQ)
Interpersonal Support Evaluation List (ISEL)
Intimate Relationship Scale (IRS)
Inventory of Socially Supportive Behavior (ISSB)

Jalowiec Coping Scale (JCS)
Kellner's Symptom Questionnaire (SQ)
Kessler Psychological Distress Scale (K10)
Krantz Health Opinion Survey (KHOS)
Leeds Self-assessment of Anxiety (SAA) Specific Scale
Leeds Self-assessment of Depression (SAD) Specific Scale
Life Attitudes Profile (LAP)
Life Orientation Test (LOT)
Life Satisfaction (Fragebogen zur Lebenszufriedenheit - FLZ)
Life Satisfaction Index (LSI)
Lipp Stress Symptom Inventory (LSSI)
Locke-Wallace Marital Adjustment Test (LWMAT)
Long Term Medication-Behavior Self-Efficacy Scale (LTMBS)
Lubben Social Network Scale (LSNS)
McGill Pain Questionnaire
Medical Coping Modes Questionnaire (MCMQ)
Medication Experience Scale for Immunosuppressants (MESI)
Mehrdimensionaler Stimmungsfragebogen (MSF)
Mental Adjustment to Cancer Scale (MAC)
Mental Health Inventory (MHI)
Milan Overall Dementia Assessment (MODA)
Mindful Attention Awareness Scale (MAAS)
Mini-Mental State Examination (MMSE)
Minnesota Leisure Time Physical Activity Questionnaire (MILTPAQ)
Minnesota Multiphasic Personality Inventory (MMPI)
Mishel Uncertainty in Illness Scale-Adult version (MUIS-A)
Montreal Cognitive Assessment (MoCA)
Morisky Medication Adherence Scale (MMAS)
Multidimensional Fatigue Inventory (MFI-20)
Multidimensional Health Locus of Control Scale (MHLC)
Multidimensional Scale of Perceived Social Support (MSPSS)
Multiple Affect Adjective Checklist (MAACL)
National Adult Reading Test (NART)
NEO Five-Factor Inventory (NEO-FFI)
Neuropsychological Impairment Scale (NIS)
Nottingham Extended Activities of Daily Living Scale (NEADL)
Numeric Pain Rating Scale (NPRS)
On Your Own Feet Self-Efficacy Scale (OYOF-SES)
Optimism-Pessimism Scale (PSM)
Orthostatic Grading Scale (OGS)
Overall Treatment Effect Scale (OTE)
Pain-O-Meter (POM)
Palliative Performance Scale (PPS)
Participation Scale
Patient Global Impression Scales (PGI)
Patient Health Questionnaire (PHQ)

Patient Satisfaction Questionnaire Short-form (PSQ-18)
Perceived Health Competence Scale (PHCS)
Perceived Social Support Scale (PSSS)
Perceived Stress Scale (PSS)
Perception of Self-Care Agency (PSCA)
PERI Life Events Scale
Personal Resource Questionnaire (PRQ)
Physical Activity Scale for the Elderly (PASE)
Physical Symptom Distress Scale (By Chiou CP. 1998 - PSDS)
Pittsburgh Sleep Quality Index (PSQI)
Positive And Negative Affect Schedule (PANAS)
Positive Symptom Distress Index (PSDI)
Positive Symptom Total (PST)
Posttraumatic Growth Inventory (PTGI)
Posttraumatic Self-rating Scale (PTSD-SS)
Posttraumatic Stress Syndrome 10-Questions Inventory (PTSS-10)
Profile of Mood States (POMS)
Psychiatric Symptom Index (PSI)
Psychological General Well-Being Index (PGWB)
Psychosocial Adjustment to Illness Scale (PAIS)
Psychosocial Assessment of Candidates for Transplantation (PACT)
Purpose in Life Test (PIL)
Quality of Life Inventory (QOLI)
Quality of Well-Being Scale (QWB)
Questionnaire on Everyday Living (ALLTAG)
Quick Inventory of Depressive Symptomatology (QIDS)
Reflux Symptom Index (RSI)
Regulatory Emotional Self-Efficacy Scale (RESE)
Reintegration to Normal Living Index (RNLI)
Relationship and Sexuality Scale
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)
Resilience Scale (RS)
Revised UCLA Loneliness Scale
Rivermead Behavioural Memory Test (RBMT)
Rosenberg Self-Esteem Scale (RSES)
Rotterdam Transition Profile (RTP)
Ryff's Psychological Well-Being Scales (PWB)
Ryle Marital Pattern Test (MPT)
Satisfaction Profile (SAT-P)
Satisfaction With Life Scale (SWLS)
Scale for Suicidal Ideation (SSI)
Scale of Personal Religiousness
Schwab-Gilleard Depressive Scale (SGDS)
Self-Efficacy for Managing Chronic Disease
Self-Rating Inventory for Posttraumatic Stress Disorder (SRIP)
Self-Regulation Questionnaire (SRQ)

Self-Reported Medication-Taking Scale (SMTS)
Sense of Mastery Scale
Seven-Day Physical Activity Recall Questionnaire (PAR)
Severity of Alcohol Dependence Questionnaire (SADQ)
Sexual Concerns Questionnaire (SCQ)
Sexual History Form (SHF)
Sexualmedizinischer Fragebogen bei Chronischen Erkrankungen (SFCE)
Shame and Guilt Inventory (SAGI)
Shanan Sentence Completion Technique (SSCT)
Sheehan Disability Scale (SDS)
Short Physical Performance Battery (SPPB)
Short Physical Performance Battery (SPPB)
Short QUestionnaire to ASsess Health-enhancing physical activity (SQUASH)
Sleep Disturbance Questionnaire (By Irvibe J. 1993)
Sleep, Energy, and Appetite Scale (SEAS)
Snaith-Hamilton Pleasure Scale (SHAPS)
Social Embedding Questionnaire (SEB)
Social Provisions Scale
Social Reintegration Questionnaire
Social Resources and Social Supports Questionnaire (By Myers HF. 1996)
Social Support Appraisals Scale (SSA)
Social Support Index (SSI)
Social Support List Discrepancies (SSL-D)
Social Support Network Inventory
Social Support Questionnaire (F-SozU)
Social Support Questionnaire (SSQ)
Social Support Scale (MOS-SSS)
Social Well-being Scale (SWBS)
State-Trait Anxiety Inventory (STAI)
Subjective Fatigue Checklist (By Pearson P. & Byars G. 1956)
Subjective Global Assessment (SGA)
Survey of Recent Life Experiences (SRLE)
Survey of Sleep (SOS)
Symptom Checklist-90 (SCL-90)
Symptom Distress Scale (SDS)
Symptom Experience Report (SER)
Tampa Scale for Kinesiophobia (TSK)
Toronto Alexithymia Scale (TAS-20)
Trauma and Life Events Self-Report Inventory (TLESI)
Treatment Satisfaction Questionnaire for Medication (TSQM)
Trier Inventory for the Assessment of Chronic Stress (TICS)
Utrecht Coping List (UCL)
Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation)
Valued Life Activities Disability and Accommodations Scale (VLA)
Van Dream Anxiety Scale (VDAS)
Ways of Coping Scale (WOCS)

Wechsler Memory Scale (WMS)
Work Ability Index (WAI)
Work Performance Index (WPI)
Work Productivity and Activity Impairment-General Health Questionnaire (WPAI:GH)
Xiao Social Support Interview (By Xiao RC. 1989)
Zerssen's Mood-Scale (Bf-S)
Zung Self-Rating Anxiety Scale (SAS)
Zung Self-Rating Depression Scale (SDS)

Appendix 3: Alphabetic list of all applied disease/organ-specific HRQoL instruments

Airway Questionnaire 20 (AQ 20)
Androgen Deficiency in the Aging Male Questionnaire (ADAM)
Cardiac Depression Scale (CDS)
Cardiac Symptoms Inventory (By Irvibe J. 1993)
Carolinas Comfort Scale (CCS)
Chronic Liver Disease Questionnaire (CLDQ)
Chronic Respiratory Questionnaire (CRQ)
Colorectal-Anal Distress Inventory 8 (CRADI-8)
Cushing Quality of Life Questionnaire (Cushing QoL)
Cystic Fibrosis Quality of Life Questionnaire (CFQoL)
Dermatology Life Quality Index (DLQI)
Diabetes Distress Sclae (DDS)
Diabetes Quality of Life Measure (DQOL)
End Stage Renal Disease Physical Symptom Scale (By Parfrey PS. 1989)
European Heart Failure Self-care Behaviour Scale (EHFScBS)
Expanded Disability Status Scale (EDSS)
Functional Assessment of Cancer Therapy-General (FACT-G)
Gastrointestinal Quality of Life Index (GIQLI)
Gastrointestinal Symptom Rating Scale (GSRS)
Heart Failure Symptom Checklist
HeartQoL
Hemodialysis Stressor Scale (HSS)
Hepatic Encephalopathy Score (PHES)
Hornheide Screening Instrument (HSI)
Hypoglycemia Fear Survey (HFS)
International Index of Erectile Function (IIEF)
International Prostate Symptom Score (IPSS)
Johns Hopkins Restless Legs Severity Scale (JHRLSS)
Kansas City Cardiomyopathy Questionnaire (KCCQ)
Kidney Disease Quality of Life Short form (KDQOL-SF)
Lequesne Index of Severity for Osteoarthritis of the Hip (LISOH)
Liver Disease Quality of Life Questionnaire (LDQOL)
Liver Disease Symptom Index (LDSI)
Liver Frailty Index (LFI)
Medical Research Council (MRG) Dyspnoea Scale

Menopause-Specific Quality of Life (MENQOL)
Minnesota Living with Heart Failure Questionnaire (MLHFQ)
Modification of Diet in Renal Disease (MDRD)
Oral Health Impact Profile (OHIP)
Pelvic Organ Prolapse Distress Inventory 6 (POPDI-6)
Problem Areas In Diabetes Scale (PAID)
Pulmonary-specific Quality of Life Scale (PQLS)
Quality of life for Primary Biliary Cirrhosis (PBC-40)
Quality of Life Index Cardiac Version
Quality of Life Index-Dialysis Version
Quality of Life Questionnaire In Osteoporosis (QUALIOST)
Restless Legs Syndrome Quality of Life Questionnaire (RLSQoL)
Skindex-16
St George's Respiratory Questionnaire (SGRQ)
Standardized Outcomes in Nephrology-Children and Adolescents (SONG-Kids)
University of California San Diego Shortness of Breath Questionnaire (UCSD)

Appendix 4: Alphabetic list of all applied transplant-specific HRQoL instruments

Assessment of Problems with the Heart Transplant Regimen
Basel Assessment of Adherence to Immunosuppressive Medication Scale (BAASIS)
Battelle Heart Transplant Recipient Questionnaire
Chinese Symptom Experience Questionnaire (By Lin YH. - CSE)
Cincinnati Transplant Questionnaire (CTQ)
Effects of Transplant on Daily Life
End Stage Renal Disease Symptom Checklist-Transplantation Module (ESRD-SCLTM)
Heart Transplant Intervention Scale
Heart Transplant Rating Question Form
Heart Transplant Stressor Scale
Heart Transplant Symptom Checklist
Immunoglobulin Therapy After Liver Transplantation Questionnaire (ITaLi-Q)
Immunosuppressant Therapy Adherence Scale (ITAS)
Immunosuppressant Therapy Barrier Scale (ITBS)
Impact of Gastrointestinal Symptoms on Quality Of Life (SIGIT-QoL)
Kidney Transplant Health Promotion Behavior Survey (By Lin SY. 2011 - KTHPB)
Kidney Transplant Questionnaire (KTQ)
Kidney Transplant Recipient Stressor Scale (KTRSS)
Kidney Transplantation Adaptation Assessment Scale (KTAAS)
Kidney Transplantation Self-Care Behavior Scale (By Weng LC. 2008)
Kidney Transplantation Self-Care Self-Efficacy Scale (by Weng LC)
Kidney Transplantation Self-Management Scale (By Weng LC. 2008)
Memphis Survey
Modified Transplant Symptom Occurrence and Symptom Distress Scale (MTSOSD)
Multidimensional Adherence Questionnaire for Liver Transplanted Patients (MAQ)
National Institute of Diabetes and Digestive and Kidney Disease Transplantation Quality of Life Questionnaire (NIDDK QOL)
Organ Transplant Symptom and Well-being Instrument (OTSWI)

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Pediatric Liver Transplant Quality of Life (PeLTQL)
Pediatric Quality of Life Inventory 3.0 (PedsQL 3.0) - Transplant Module
Perceived Threat of the Risk of Graft Rejection Questionnaire (PTGR)
Positive Effects of Transplant Scale (PETS)
post-Liver Transplant Quality of Life Questionnaire (pLTQ)
Quality of Life Index-Liver Transplant Version (QLI-LT)
Quality of Life Index-Transplantation Version
Questionnaire for Lung Transplant Patients (QLTP)
ReTransQoI (RTQ)
Transplant Care Index (TCI)
Transplant Effects Questionnaire (TxEQ)
Transplant Recipient Questionnaire (Gozdowska J, 2016 - KBpP)
Transplant Symptom Frequency and Symptom Distress Scale
Transplant Symptom Inventory (By Lanuza DM. 2012 - TSI)
Transplantation Evaluation Rating Scale (TERS)
Transplant-Related Stressors Scale

