

Patient-reported outcome measures for life participation in kidney transplantation: a systematic review

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Abstract

Background: For many patients with end-stage kidney disease, transplantation improves survival and quality of life compared to dialysis. However, complications and side-effects in kidney transplant recipients can limit their ability to participate in activities of daily living including work, study and recreational activities; which remains to be adequately assessed.

Methods: We searched MEDLINE, Embase, PsycINFO, and CINAHL to July 2018 for all studies that reported life participation in kidney transplant recipients. Instruments measuring life participation were identified and reviewed for characteristics, psychometric properties and content.

Results: In total, 227 studies were included: 19 (8%) randomized trials, 17 (7%) non-randomized trials and 191 (85%) observational studies. Across these studies, we identified 28 different measures that were used to assess life participation. The most frequently used instrument was the 36-Item Short Form Health Survey (SF-36) (155 studies) followed by Kidney Disease Quality of Life-Short Form (KDQOL-SF) (36 studies) and EuroQol-5D (EQ-5D) (12 studies). Twelve (43%) measures specifically assessed aspects of life participation (e.g. physical activities, disability assessment, functioning, daily activities of living), while 16 (57%) assessed other constructs (e.g. quality of life and psychological well-being) that included questions on life participation. Validation data to support the use of these measures in kidney transplant recipients were available for only six measures. Seventeen (63%) measures assess both obligatory (e.g. eating) and non-obligatory (e.g. recreational activities) dimensions of life participation, while 10 (37%) assess only one dimension. Specific activities within each dimension also vary across different measures.

Conclusions: Most patient-reported outcome measures for life participation used in kidney transplant recipients are not designed specifically to assess this outcome, have limited validation data, and vary widely in the dimensions of life participation assessed. A well-validated measure to improve the consistency and

accuracy of measuring life participation in research may inform strategies for transplant recipients to be better able to engage in their life activities.

Introduction

For many patients with end-stage kidney disease, kidney transplantation is expected to offer better survival and quality of life compared with dialysis. However, kidney transplant recipients are at risk of graft rejection, life-threatening comorbidities including cardiovascular disease, diabetes, infection, and debilitating side effects of immunosuppression¹⁻³. These side-effects and complications can severely impair the ability to participate in their daily, social and recreational activities in kidney transplant recipients⁴⁻⁶, and the rates of unemployment remain high in this population^{7,8}. They can experience disappointment and frustration with role limitations due to transplant-related physical and emotional problems, which can diminish overall outcomes after transplantation⁹.

Life participation has been identified as a critically important outcome among kidney transplant recipients, caregivers, and health professionals, and is defined as the ability to participate in meaningful activities of daily living including work, study, and social recreational activities¹⁰⁻¹². Terms such as ‘social participation’¹³, ‘social function’¹⁴, and ‘activities of daily living’¹⁵, have also been used to capture concepts of life participation in this population. Yet, the evidence to inform strategies to maximize life participation in kidney transplant recipients remains limited as it is reported infrequently in research, using measures that may not be valid for this population.

The aim of this study was to identify the characteristics, psychometric properties, and content of the outcome measures used to assess life participation in kidney transplant population. This may inform the selection or development of a psychometrically robust measure suitable for use in research to improve this outcome for kidney transplant recipients.

Methods

Selection criteria

An initial search for randomized trials reporting life participation in kidney transplant patients yielded only a few studies and measures. Therefore, we expanded our search to include all randomized, non-randomized trials and observational studies that included an assessment of life participation in adult kidney transplant recipients (aged 18 years and older). Studies that included a measure of constructs other than life participation (e.g. health status, physical activity, quality of life) were eligible if there was at least one or question specific to life participation. Abstract-only citations were included only if we were able to extract relevant data (characteristic, psychometric properties and content) about the measure used for life participation. We excluded studies only assessing physical mobility or patient satisfaction of their perceived ability to participate in activities as these are distinct and separate constructs to life participation.

Study sources and measures

The search strategies are provided in Table S1. We conducted searches in MEDLINE, Embase, PsycINFO, and CINAHL from database inception to July, 2018 (to be updated). Reference lists of relevant studies were also searched. One author (AJ) screened the results based on titles and abstracts, and excluded those that did not meet the inclusion criteria. The full texts of potentially relevant articles were assessed for eligibility. A second investigator (AR) reviewed the titles, abstracts, and full texts. Any disagreement was resolved through discussions until consensus was reached. All measures that included at least one question on life participation were included.

Data extraction and analysis

We extracted the following characteristics from each study: publication year, sample size, country, type of intervention (if applicable) and the measure used.

To summarize characteristics for the measures identified, two authors (AJ, JC) referred to the source study and searched for the full measure and validation work where available to extract the following information: number of studies that used the measure, response format, number of items, recall period, cost of license to use the measure, language and completion time, content, psychometric data in kidney transplant recipients. Where the completion time was not available, it was estimated based on the number and length of the items.

Content dimensions of life participation

Life participation has previously been conceptualized as having two dimensions – obligatory and non-obligatory (leisure) activities^{16,17}. We examined the content using this framework and categorized measures as assessing obligatory activities crucial for survival (e.g. working, eating, buying groceries) and/or non-obligatory activities (e.g. going on a holiday and meeting friends).

Assessment of psychometric properties

As recommended by COnsensus-based Standards of health Measurement Instruments-Core outcome measures in Effectiveness Trials (COSMIN-COMET)¹⁸, we aimed to examine the available evidence for psychometric properties (content validity, reliability including internal consistency and test re-test, responsiveness, structural validity, measurement error, criterion validity and cross-cultural validity known groups validity) of measures identified in the main search.

Results

Characteristics of studies

We included 227 studies involving a total of 48,089 participants across 40 countries. Of these, 19 (8%) were randomized trials, 17 (7%) were non-randomized trials, and 191 (84%) observational studies. The search results can be found in Figure 1. The study characteristics are shown in Tables S2 and S3.

Characteristics of the measures

Across the 227 studies, 28 different measures were used to measure life participation. Six (21%) were developed specifically for use in kidney transplant recipients, 1 (4%) for patients with all stages of chronic kidney disease (including kidney transplantation) and 21 (75%) were for general (or other) populations. Twelve (43%) measures were designed specifically to assess ability to participate in activities (e.g. physical activities, disability assessment, functioning, daily activities of living), whereas 16 (57%) measures were designed to assess a broader construct (e.g. psychological well-being, quality of life, health status) with a subscale or selected questions on life participation. The SF-36 was the most frequently used measure (155 studies), followed by KDQOL (36 studies), and EQ-5D (12 studies). Eighteen measures were used in only one study.

The number of items in each measure varied from eight to 105 items. The time taken for completion ranged from two to 30 minutes. The recall period ranged from the day of assessment to two years. Most measures asked patients to recall their current ability to participate in activities, or over the past four weeks. The cost of the measures ranged from \$0 to \$5000 USD. Detailed characteristics and frequency of use for the measures of life participation are provided in Table 1.

Psychometric properties

Of the 28 measures, only six were validated in the kidney transplant population. A summary of the psychometric data for each measure is provided in Table 2. All of these six measures were assessed as a global measure of quality of life, and there is no data available for the specific subscale or questions on life participation. The validation data or psychometric properties assessed for the measures were highly variable. The Kidney Disease Quality of Life demonstrated moderate to strong negative correlations with scores indicating psychological distress, and showed good known group validity through comparison with old and young patients. While internal consistency was good, test-retest reliability was lacking in some dimensions. The EuroQol-5D has good discriminant validity when assessed in general population and transplant recipients, as well as good concurrent validity when compared to SF-36. The End-Stage Renal Disease Symptom Check List – Transplant Module was developed with good content validity where symptoms present in more than 20% of patients were chosen. Good concurrent validity was seen when compared to SF-36 and test-retest reliability was reasonable at 12 months. The Renal Transplant Quality of Life questionnaire was developed with substantial efforts to ensure good content validity, construct validity and has demonstrated good concurrent validity when compared to SF-36 and known group validity comparing transplant recipients who were hospitalized in the last 12 months and those who were not. We were unable to retrieve the validation data for The Quality of Life Kidney Transplantations Recipients Questionnaire in English. We were unable to find validation data specific to questions about the ability to participate in daily activities in any of these measures.

Content of measures

Eighteen (64%) measures assessed both obligatory and non-obligatory dimensions of life participation, while 10 (37%) assess only one dimension. Some questions in the measures were more specific in asking about activities such as washing themselves, buying groceries, bicycling, whereas other questions were more general in assessing the ability to do ‘things you want to accomplish’. Specific activities within each

dimension also varied across different measures. Details of activities assessed in each measure is given in Table 3.

Discussion

Life participation is a critically important outcome for kidney transplant recipients, signifying success of the transplant in restoring ability to do the meaningful activities of daily living. Yet, this outcome is infrequently reported and inconsistently assessed with a range of different measures. Of the 227 studies reporting life participation, 28 different measures were used to assess this outcome. These measures varied in content, length, response scale, recall period, cost and available psychometric data. More than half of the measures are embedded life participation questions in broader constructs such as quality of life. Across the measures used, 13 included questions about participation in specific activities ranging from eating to travelling on holidays. Number of items in each measure ranged from eight to 105. The recall period for measures varied from current (or overall) to as long as 2 years.

Furthermore, studies that have evaluated the psychometric properties of measures used to assess life participation in kidney transplant recipients are sparse. Only six measures have been assessed for psychometric robustness in this population. As such, the suitability of these measures remains uncertain because psychometric properties such as content validity, responsiveness and reliability may not necessarily transfer across populations due to differences in condition, treatment and symptoms^{19,20}. In the few measures that have been validated in the kidney transplantation population, the types of psychometric properties assessed are inconsistent and limited. Of note, there were no validation data available for the specific subscale or question for life participation.

Life participation is infrequently assessed as a distinct or specific construct in across the stages of chronic kidney disease and other settings including cancer, where it is typically considered as a part of quality of life^{21,22}. In the field of rehabilitation, however, life participation has been well recognized to signify a

positive pathway of recovery from disablement – due to a health condition, disease or treatment – to enablement²³, ultimately leading to gains in quality of life. Accurate measures of life participation may provide more systematic information about a patient’s capacity and functioning in domains of life that are meaningful for them. This reiterates the need to focus on life participation as a separate and distinct construct that reflects physical, psychological and social wellbeing.

Patient-Reported Outcome Measure Information System (PROMIS) have developed questionnaires and an item bank for assessing concepts similar to life participation²⁴. The ‘Ability to Participate in Social Roles and Activities’ questionnaire assesses an individual’s ability to engage in family, leisure, social and obligatory activities. The item bank contains questions assessing this outcome that are calibrated onto the same measurement scale to ensure reliable, valid and easily interpretable measurement of life participation. The questionnaire and item bank were developed using rigorous methods before being made available to the public, and demonstrates substantial psychometric robustness in patients with other chronic conditions such as cancer²⁵. Although this has not yet used or validated in the kidney transplantation population, the PROMIS measure may potentially be a suitable measure for life participation in this population.

The Standardized Outcomes in Nephrology – Kidney Transplant (SONG-Tx) Initiative identified life participation as the most important patient reported outcome for kidney transplant patients based on consensus among patients, caregivers and health professionals^{10,11}. Efforts are underway to establish a standardized, validated patient-reported outcome measure designed specifically to assess life-participation in kidney transplant recipients. In a recent SONG-Tx workshop on establishing a core outcome measure for life participation, patients described having to adjust to a new normal to resume their life activities after transplant. The term ‘life’ was necessarily subjective in that it meant something different for each patient. They emphasized the importance in being able participate in the meaningful activities that constitute ‘life’¹². Further work will involve piloting and validating potential measures including the Ability to Participate in Social Roles and Activities questionnaire developed by PROMIS.

A well-validated, standardized measure for life participation will ensure that aspects of life participation that are important and relevant to stakeholders including kidney transplant recipients are being measured. It will also help to reduce reporting bias, and enable comparison of interventions across different trials. Thus, such a measure is critical for development and evaluation of effective interventions. Also, a standardized measure can be used to monitor change in ability to participate in life activities for patients over time to inform clinical practice. Ultimately, a standardized outcome measure for life participation may help to fully achieve the benefits of transplantation hoped for, in enabling kidney transplant recipients to fulfil their goals and roles in their daily living.

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Table 1. Characteristics of measures used to assess life participation in kidney transplant recipients

Measure	Response format	Number of items	Recall	Cost	Completion Time ^a	Specific to CKD or transplantation	Language	Frequency of use (number of studies)
SF-36	Yes/no, 3-/5-/6-point Likert	11	Current, Past 4 weeks	Annual license fee upon request	<10 mins	No	170 languages and dialects including English, Chinese, Arabic, German, Dutch	155
KDQOL-SF	Yes/no, 3-/5-/6-/10-point Likert, open ended response	96	Current, Past 4 weeks	Free	~ 16 mins	Yes (CKD)	More than 10 languages and dialects including English, Chinese, Korean	36
EQ-5D	'Indicate which statements best describe...', VAS	16	Current	Licensing fee based on quote	<5 mins	No	130 languages including English and Chinese	12
SF-12	Yes/no, 3-/5-/6-point Likert	12	Current, Past 4 weeks	License fee upon request	~ 2-3 mins	No	148 languages and dialects including English, Chinese, Arabic	9
WHOQOL-BREF	Yes/no, 5-point Likert/ open ended responses	26	Current/ Past 2 weeks	Free with Inquisit Lab or Inquisit Web license	~ 5 mins	No	More than 40 languages including English, Chinese	7
ESRDSCS-TM ^b	5-point Likert	43	NA	Contact author	~ 9 mins	Yes (Tx)	German, English, Norwegian, Slovak, Spanish, Turkish	5
HUI-III	5-/6-point Likert	8	Current	\$5,000 USD for initial base package of manual and one version of questionnaire, \$2,500 for each of the next five versions	~ 3 - 5 mins	No	Different versions available 40 languages including	5

							English, Afrikaans, Spanish, Chinese, Korean (HUI version 3 may not be available in all 40 languages, contact Health Utilities Inc.)	
PGWBI	6-point Likert	22	Past month	300 € per study (funded academic research) Free for not funded academic users.	< 5 mins	No	English, Ukrainian, Turkish, Czech, Bulgarian	2
EORTC-QLQ-C30	4-point Likert	30	Past week	License fee for non-academic use depends on number of patients	~ 6mins	No	More than 100 languages including English, Chinese, Iranian	2
Fernandez Questionnaire ^b	NA	15	NA	Contact author	~ 5 mins	No	Spanish	2
WAI	Yes/no, 3-/5-/6-/10-point Likert, own opinion and physician's diagnosis	24	Current, Past 12 months, Past 2 years	Contact author	~ 5 mins	No	24 languages including English, Finnish, Swedish,	1
WHOQOL-100	'Tick next to those that apply to you', open ended response, 5-point Linkert	105	Current, Past 2 weeks	NA	~ 30 mins	No	More than 20 languages including English, Chinese	1
GHQ-28	Yes/no , % better/worse than usual	28	Recent	Licensing fee based on quote	~ 5 mins	No	38 languages including English, Spanish	1
ICF	5-point Likert scale	84	NA	NA	~17 mins	No	NA	1
ReTransQol (French)	6-point Likert	45	In general	Contact author	~10 mins	Yes (Tx)	French	1
The Participation Scale	4-point Likert	18	Current	NA	< 5 mins	No	7 languages including English	1

IPAQ	Yes/no, time spent on activities	27	Recent, last 7 days	NA	~ 5 mins	No	English, French, Korean, Spanish, Vietnamese	1
NEADL	Yes/no	45	Current	Free	< 10 mins	No	English, Turkish	1
GPPAQ	4-point Likert, 'Please mark one box only'	11	Past week	NA	< 3 mins	No	English	1
DASI	Yes/no	12	Current	NA	< 3 mins	No	English	1
HSQ2.0	3-/5-/6-point Likert	12	Current, Past 4 weeks	NA	< 3 mins	No	English	1
DHPQ	3-point Likert	17	Current, Past week	License fee upon request	~5 mins	No	English, French	1
The Quality of Life Kidney Transplantation Recipients Questionnaire ^b	NA	34	NA	NA	~ 7 mins	Yes (Tx)	Chinese	1
WHODAS 2.0	Number of days /5-point Likert	39	Past 30 days	Licensing fee upon request	~ 8 mins	No	47 languages including English and Chinese	1
USER-Participation	5/6-point Likert	32	In general	NA	~7 mins	No	English	1
Author-developed measures (for own study, non-validated)								
De Baere 2010 ^b	NA	NA	NA	Contact author	NA	Yes (Tx – liver, kidney, heart, lung)	Dutch	1
Goals Questionnaire (De Vries 2017) ^b	5-point Likert	39	Current	Contact author	~8 mins	Yes (Tx)	Dutch	1
Chen 2014 ^b	NA	NA	NA	Contact author	NA	Yes (Tx)	Taiwanese	1

^awhere data on completion time was unavailable, authors estimated based on ~12 seconds per item; ^bCould not retrieve full measure; CKD, chronic kidney disease; Tx, transplantation

SF-36; 36-Item Short Form Health Survey, KDQOL-SF; Kidney Disease Quality of Life-Short Form, EQ-5D; EuroQol-5D, SF-12; 12-Item Short Form Health Survey, WHOQOL-BREF; Generic World Health Organization Quality of Life, ESRD-SCL-TM; End-stage renal disease symptom checklist-transplantation module, HUI-III ; Health Utility Inc-III, PGWBI; Psychological General Well-Being Index, EORTC-QLQ-C30; European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire, WAI; Work Ability Index, WHOQOL-100; World Health Organization Quality of Life-100, GHQ-28; General Health Questionnaire-28, ICF; International Classification of Functioning, Disabilities, and Health, ReTransQol; Renal Transplant Quality of Life , IPAQ; International Physical Activity Questionnaire, NEADL; Nottingham Extended Activities of Daily Living, GPPAQ; GP Physical Activities Questionnaire, DASI; Duke Activity Status Index, HSQ2.0; Health Status Questionnaire 2.0, DHPQ; Duke Health Profile Questionnaire, WHODAS 2.0; World Health Organization Disability Assessment Schedule 2.0, USER-Participation; Utrecht Scale for Evaluation of Rehabilitation-Participation

Table 2. Dimensions of life participation assessed by each measure

Instrument	Obligatory	Non-obligatory	Types of activities
SF-36	•	•	Moving a table, pushing a vacuum cleaner, bowling, playing golf, running, lifting heavy objects, carrying groceries
KDQOL-SF	•		Groceries, work
EQ-5D	•	•	Washing, dressing oneself, leisure activities, housework, family, work or study
SF-12	•	•	Moving a table, pushing a vacuum cleaner, bowling, playing golf
WHOQOL-BREF	•		Things you need to do
ESRDSCS-TM	•		Daily activities (washing, dressing)
HUI-III	•		Self-care (eating, bathing, dressing, using the toilet independently/normally for age)
PGWBI	•	•	Things you have to do, things you like to do
EORTC QLQ-C30	•	•	Eating, dressing, washing, work, daily activities, hobbies, leisure time activities, family life, social activities
Fernandez Questionnaire ^a	•		Normal daily activities
WAI	•		Regular daily activities
WHOQOL-100	•		Daily activities, work
GHQ	•		Normal day-to-day activities
ICF	•	•	Participation in general tasks and demands, self-care (washing, caring for body parts, getting dressed, eating, health), domestic life (groceries, services, preparing meals, cleaning, washing clothes, dishes), community, social and civic life (recreation and leisure, religion and spirituality, political life and citizenship)
ReTransQol	•	•	Housework, 'things', hobbies/leisure activities
The Participation Scale	•	•	Household work, participation in festivals, travels, recreational and social activities
IPAQ	•	•	Work activities, household work (house maintenance e.g. shoveling snow, chopping wood, gardening, cleaning), recreation, sport, leisure activities (exercise for leisure e.g. swimming, aerobics, double tennis, bicycling)
NEADL	•	•	Work, vacations
GPPAQ	•	•	Housework, physical exercise, leisure
DASI	•	•	Housework, recreational activities
HSQ 2.0	•	•	Groceries, social activities
DHPQ		•	Social, religious, recreational activities
The Quality of Life Kidney Transplantation Recipients Questionnaire (Chinese) ^a		•	Social function
WHODAS 2.0	•	•	Self-care (washing, dressing, eating, independence), life activities (household tasks/responsibilities), work/school, participation in society (community activities e.g. festivities, religious or other activities)

USER Participation	•	•	Paid work, unpaid work (volunteering for a society, community center, at school or any other voluntary activities), education (training courses taken in the context of paid work or help you obtain paid work), household duties (cooking, cleaning, shopping, caring/supervising children, gardening), sports/physical exercise (gym, cycling, tennis), going out (eating out, visiting a café, cinema, concert), day trips/outdoor activities (shopping, events, beach, church, mosque), leisure activities at home (crafts, needlework, reading, puzzles, playing computer games), visiting family/friends
Author-developed measure (for own study, non-validated)			
De Baere 2010	•	•	Paid job, social participation (volunteer, active member of a club)
De Vries 2017 ^a	•	•	Eat/drink, enjoy life, help others, exercise, go out, go on vacation, arrange time schedule, obligations towards others
Chen 2014	•	•	Social function (leisure activity, paid work)

^aFull measure unavailable

SF-36; 36-Item Short Form Health Survey, KDQOL-SF; Kidney Disease Quality of Life-Short Form, EQ-5D; EuroQol-5D, SF-12; 12-Item Short Form Health Survey, WHOQOL-BREF; Generic World Health Organization Quality of Life, ESRDSCL-TM; End-stage renal disease symptom checklist-transplantation module, HUI-III ; Health Utility Inc.-III, PGWBI; Psychological General Well-Being Index, EORTC-QLQ-C30; European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire, WAI; Work Ability Index, WHOQOL-100; World Health Organization Quality of Life-100, GHQ-28; General Health Questionnaire-28, ICF; International Classification of Functioning, Disabilities, and Health, ReTransQol; Renal Transplant Quality of Life , IPAQ; International Physical Activity Questionnaire, NEADL; Nottingham Extended Activities of Daily Living, GPPAQ; GP Physical Activities Questionnaire, DASI; Duke Activity Status Index, HSQ2.0; Health Status Questionnaire 2.0, DHPQ; Duke Health Profile Questionnaire, WHODAS 2.0; World Health Organization Disability Assessment Schedule 2.0, USER-Participation; Utrecht Scale for Evaluation of Rehabilitation-Participation

Table 3. Psychometric properties of measures that have been used to assess life participation in kidney transplant recipients

Measure	Validity ^a	Reliability ^b
SF-36 ²⁶	<u>Construct validity</u> : factor analysis identified 8 factors with eigen values ranging from 10.1 to 1.0, which explains 66.6% of the variance	<u>Internal consistency</u> : the 36 items on the survey resulted in a value for Cronbach's α statistic equal to 0.91 (95% CI: 0.89-0.92) and in all of the domains the value for this coefficient ranged 0.70-0.92
KDQOL-SF ²⁷	<u>Concurrent validity</u> : significant moderate to strong negative correlations between most of the KDQOL-SF domains and the CES-D scores (higher scores on the CES-D scale reflect more psychological distress) <u>Known group validity</u> : older patients had substantially worse scores along the generic QoL domains reflecting physical function [59 ± 3 vs. 83 ± 4 (mean \pm S.E.M.), for the oldest vs. youngest (highest vs. lowest) tertile, respectively; $P < .001$] in the "work" subscale, where the younger group had better scores [31 ± 4 vs. 53 ± 4 (mean \pm S.E.M.), for the oldest vs. youngest tertile, respectively; $P < .001$]	<u>Test-retest</u> : correlation was above .60 for 7 out of 11 kidney disease-targeted domains and for 7 out of 8 of the generic dimensions. Low correlation for 'quality of social interactions', 'cognitive function', 'staff encouragement', 'general health perception' and 'patient satisfaction' <u>Internal consistency</u> : alpha values ranging between .71 (social function) and .92 (bodily pain) for SF-36 domains, above .70 for all except three of the disease-specific subscales.
EQ-5D ²⁸	<u>Construct validity</u> : Convergent: EQ-5D compared to mobility, older patients have both lower mobility and EQ-5D index scores in comparison to younger patients <u>Discriminant validity</u> : significant difference between the frequency of reported problems by patients and the general public found for all dimensions including EQ-5D index scores except self-care. <u>Concurrent validity</u> : spearman rank correlation coefficients between the EQ-5D index scores and the SF-36 domain range from 0.41 to 0.68. The correlations with all other domains of the SF-36 are also significant on the 1% significance level.	N/A
ESRD-SCL-TM ²⁹	<u>Content validity</u> : symptoms present in >20% of patients were chosen for content <u>Concurrent validity</u> : expected correlations between dimensions of ESRD-SCL and SF-36	<u>Internal consistency</u> : Cronbach α =0.76-0.85 <u>Test-retest</u> : moderate correlation between first and second assessment (12 months after)
ReTransQoI ³⁰	<u>Content validity</u> : items generated from content analysis of 24 recorded interviews with kidney transplant recipients, discussed comprehensiveness and acceptability with nephrologists, methodologists and patients <u>Construct validity</u> : factor analysis identified a structure of five factors accounting for 46.3% of the total variance <u>Concurrent validity</u> : moderate to strong positive correlations (>0.6) with similar dimensions of SF-36 (physical function, vitality, emotional well-being; $p < 0.001$) <u>Known group validity</u> : kidney transplant recipients hospitalized during the past 12 months reported significantly lower scores on physical health compared to those who were not (51.9 ± 18.8 vs. 63.9 ± 17.9 , $p < 0.01$), and those hospitalized for transplant complications had significantly lower scores on physical ($51.8 \pm$	<u>Internal consistency</u> : Cronbach α =0.70-0.86

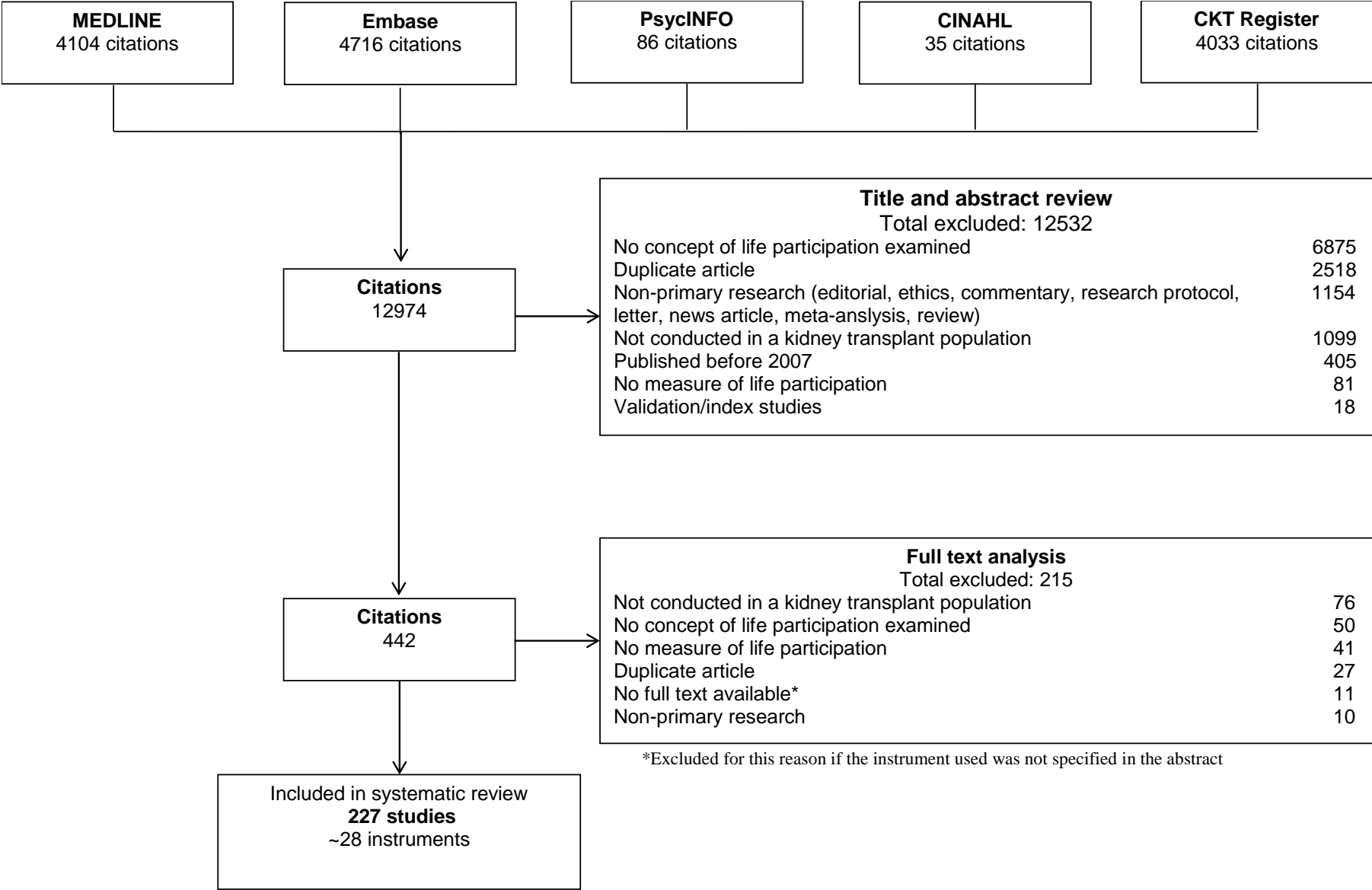
	18.8 vs. 69.96 ± 10.2 , $p < 0.01$) and mental health dimensions (60.7 ± 12.2 vs. 65.9 ± 10.2 , $p < 0.01$). Significant negative correlation between BMI and physical health ($r = -0.258$, $p < 0.05$)	
The Quality of Life Kidney Transplantation Recipients Questionnaire (Chinese) ^c	N/A	N/A

^aFrom initial development study, ^bReliability of the life participation questions (whole measure if life participation-specific, life participant subscale if generic) from initial development study, internal consistency is measured by Cronbach's alpha unless otherwise stated, ^cValidation study unavailable in full/English
SF-36; 36-Item Short Form Health Survey, KDQOL-SF; Kidney Disease Quality of Life-Short Form, EQ-5D; EuroQol-5D, ESRDSCL-TM; End-stage renal disease symptom checklist-transplantation module

Figure legend

Figure 1. Search results

Figure 1. Search results



Supplementary files

Table S1. Search strategies

Table S2. Characteristics of randomized studies

Table S3. Characteristics of non-randomized and descriptive studies

Table S1. Search strategies

To be added

Table S2. Characteristics of randomized studies

Study	N	Country	Intervention	Measure Used
Aasebo 2005	124(124)	Norway	Effects of lisinopril and nifedipine in hypertensive renal transplant recipients	SF-36
Anderson 2011	207(207)	USA	Comparison of alemtuzumab with rabbit antithymocyte globulin induction for KTA and SKP	SF-36
Chisholm-Burns 2011	71(71)	USA	Intervention group RTRs received the behavioral contract intervention administered by a clinical pharmacist at baseline and every 3 months post study enrollment; control group RTRs received usual care	SF-12 v2
Dobbels 2014	666(666)	Belgium	2 randomized clinical trials (BENEFIT and BENEFIT-EXT) of belatacept vs. cyclosporine	SF-36
Greenwood 2015	60(60)	UK	Effect of moderate-intensity aerobic or resistance training on vascular health	SF-36
Hedayati 2017	64(64)	Iran	Randomized double-blind clinical trial - two groups: the first received expressive emotion intervention and the second received fact recording education as the control group	General health questionnaire (GHQ-28)
Liu 2016	156(156)	China	Randomized to standard-dose cyclosporine A (CsA), mycophenolate mofetil, and corticosteroids or daclizumab induction, mycophenolate mofetil, and corticosteroids with a low dose of CsA, tacrolimus (Low-Tac), or sirolimus	SF-36
Loftus-Farren 2012	51(51)	USA	5-7 cm mini incision (MI) or the standard Gibson incision (SGI)	SF-36
Mahrova 2012	21(21)	Czech Republic	Regular exercise and nutrition intervention	KDQOL-SF
Musgrave 2013	200(200)	USA	randomized to receive rabbit anti-thymocyte globulin or an IL-2 receptor antagonist in	SF-36

			addition to Fk, MMF, and corticosteroids	
Oppenheimer 2009	156(156)	Spain	Different low-Toxicity Immunosuppressive Regimens	SF-36
Palanisamy 2015	111(111)	USA	All patients received either rabbit antithymocyte globulin (rATG) or interleukin 2 receptor antagonists (IL-2RA) in addition to tacrolimus (FK), mycophenolate mofetil (MMF), and corticosteroids in a randomized fashion	SF-36
Riess 2014	31(31)	Canada	Effects of 12 weeks of supervised endurance and strength training versus usual care	SF-36
Russ 2007	430(430)	Australia	Elimination of cyclosporine in sirolimus-treated kidney transplant patients	SF-36
Shehata 2009	134(134)	UK	Effect of conversion from mycophenolate mofetil to enteric- coated mycophenolate sodium on maximum tolerated dose and gastrointestinal symptoms	SF-36
Tzvetanov 2014	17(17)	USA	Physical Rehabilitation	SF-36 v2
Walker 2007	21(21)	Australia	Conversion of cyclosporine to tacrolimus	SF-36

Table S3. Characteristics of non-randomized and descriptive studies

Non-randomized studies				
Study	N	Country	Intervention	Measure Used
Andres 2009	134(134)	Spain	Effect of conversion from mycophenolate mofetil (MMF) to enteric-coated mycophenolate sodium (EC-MPS)	PGWBI
Bloom 2011	66(66)	USA	Effect of darbepoetin alfa administered subcutaneously on hemoglobin	SF-36
Calia 2011	78(78)	Italy	Effects of switching from twice-daily to once-daily tacrolimus formulation	PGWBI
Cure 2008	7(7)	USA	Allogenic islet transplantation as part of a pilot IAK trial (Study ID: 2000/0329)	Health status Questionnaire (HSQ 2.0)
Dobbels 2011 ^a	NA	USA	2 randomized clinical trials (BENEFIT and BENEFIT-EXT) of belatacept vs. cyclosporine	SF-36 v2
Hoda 2010	16(16)	Germany	Pelvic reconstructive surgery	SF-36
Kawada 2009	26(26)	Japan	administration of recombinant human erythropoietin (rHuEPO-ad)	SF-36
Liu 2014	194(194)	China	effects of psychosocial factors and behaviors correlated to three major coping strategies on health-related quality of life (HRQOL)	SF-36 v2
Luthman 2011	31(31)	Sweden	Physiotherapist supervised physical exercise	SF-36
Masajtis-Zagajewska 2014	40(25)	Poland	Physical activity program	SF-36, International Physical Activity Questionnaire
Mazzoni 2014	317(118)	Italy	Sport Activity	SF-36
Prasad 2010	231(231)	Canada	Effect of cyclosporine or tacrolimus as a long-term immunosuppressive agent	SF-12
Romano 2010	8(8)	Italy	Effects of exercise on renal transplant recipients (RTRs)	SF-36
Totti 2014	22(11)	Italy	Playing football	SF-36
Villeneuve 2015	370(370)	France	Adherence to immunosuppressants	SF-36

			(IS) estimated with the four-item Morisky medication (MMS-4) scales	
Weigand 2012	32(32)	Germany	Pelvic reconstructive surgery	SF-36
Zhirnova 2014	87(57)	Russia	Physical rehabilitation	SF-36
Descriptive studies				
Aasebo 2009	2491(131)	Norway	NA	SF-36
Abachi 2015	200(200)	Turkey	NA	KDQOL-SF
Alavi 2009	163(100)	Iran	NA	The Nottingham Extended ADL scale, the Duke Health Profile questionnaire
Alkatheri 2015	305(151)	Saudi Arabia	NA	WHOQOL-BREF
Altunoglu 2014	157(47)	Turkey	NA	SF-36
Alvares 2012	3036(627)	Brazil	NA	SF-36
Alvarez-Rangel 2015	278(278)	Mexico	NA	SF-36
Amro 2016	110(110)	Norway	NA	KDQOL-SF
Antonopoulos 2015	1432(1432)	Brazil	NA	SF-36
Apostolou 2007	85(20)	Greece	NA	SF-36
Ay 2015	141(47)	Turkey	NA	SF-36
Ayav 2016	355(355)	France	NA	SF-36
Azevedo 2012	83(83)	Portugal	NA	SF-36
Baguelin-Pinaud 2009 ^a	NA	France	NA	SF-36
Balaska 2015	121(121)	Greece	NA	KDQOL-SF
Basok 2009	106(20)	Turkey	NA	SF-36
Beauger 2015	NA	France	NA	SF-36, KDQOL, RTQ
Beauger 2016	334(334)	France	NA	SF-36
Bernarda Logar 2015	58(58)	Slovenia	NA	SF-36, ESRDSCL-TM
Bernsmeier 2016	443(271)	Germany	NA	EORTC-QLQ-C30
Bohlke 2009	272(272)	Brazil	NA	SF-36
Bozek-Pajak 2012	49(KTx-27, SPK-22)	Poland	NA	KDQOL-SF
Bozek-Pajak 2016	53(KTx-26, SPK-27)	Poland	NA	KDQOL-SF
Butt 2011	314(314)	USA	NA	SF-12
Buyukkaragoz 2016	13(12)	Turkey	NA	SF-36
Cader 2013	39(39)	Malaysia	NA	SF-36
Calia 2015	43(43)	Italy	NA	SF-36
Calia 2017	40(40)	Italy	Na	SF-36
Canche-Arenas 2011	30(30)	Mexico		Fernandez Questionnaire
Carvalho 2012	28(14)	Brazil	NA	Sf-36
Chakkerla 2011 ^a	NA	USA	NA	ESRDSCL-TM, SF-36

Chan 2013	106(106)	UK	NA	SF-36
Chan 2014	55(55)	UK	NA	SF-36
Chen 2014	101(101)	Taiwan	NA	Social function (leisure activity, paid work)
Chisholm-Burns 2012	75(75)	USA	NA	SF-12 v2
Chkhotua 2011	340(48)	Georgia	NA	SF-36
Colak 2013	41(41)	Turkey	NA	SF-36
Colak 2015	77(77)	Turkey	NA	SF-36
Cornella 2008	52(52)	Italy	NA	SF-36
Costa 2014	147(147)	Brazil	NA	SF-36
Costa-Requena 2014	72(72)	Spain	NA	KDQOL-SF
Costa-Requena 2017	124(124)	Spain	NA	KDQOL-SF
Curcani 2011	42(42)	Turkey	NA	SF-36
Czyzewski 2014	117(47)	Poland	NA	SF-36, KDQOL-SF
De Baere 2010	383(126)	Belgium	NA	Own questionnaire
De Groot 2013	535(535)	Netherlands	NA	SF-36, USER-Participation
De Pasquale 2011	70(70)	Italy	NA	SF-36
De Pasquale 2014	120(120)	Italy	NA	SF-36
De Vries 2017	220(220)	Netherlands	NA	Own questionnaire
Del Carmen Rodriguez 2014	47(47)	Spain	NA	SF-36
Dobbels 2014	1209(1209)	Belgium	NA	SF-36
Dukes 2013	200(200)	USA	NA	EQ-5D, HUI-III, SF-36, KDQOL-36
Ekberg 2007	4232(4232)	Sweden	NA	SF-36
Esposito 2017	132(132)	Italy	NA	KDQOL-SF
Fernandez-Jimenez 2013	5881(30)	Spain	NA	SF-36
Ferrario 2014	150(50)	Italy	NA	International Classification of Functioning, Disabilities and Health (ICF)
Forbes 2016	505(505)	USA	NA	SF-36
Forbes 2016	1201(1201)	USA	NA	SF-36
Forster 2009	35(17)	USA	NA	SF-36
Fructuoso 2011	111(30)	Portugal	NA	SF-36, KDQOL-SF
Gentile 2013	1061(1061)	France	NA	RTQ, SF-36
Gibbons 2016	179(179) ^b	UK	NA	EQ-5D
Goetzmann 2008	131(35)	Switzerland	NA	SF-36
Goetzmann 2012	121(31)	Germany	NA	SF-36
Gomes 2013	49(22)	Brazil	NA	SF-36
Griva 2009	262(117)	UK	NA	SF-36

Griva 2013	347(347)	Singapore	NA	SF-36
Gungor 2012	198(198)	Turkey	NA	SF-36
Guo 2008	120(60)	China	NA	WHOQOL-BREF
Han 2008	92(46)	China	NA	SF-36
Herczeg 2010	833(833)	Hungary	NA	KDQOL-SF
Hernandez Sanchez 2016	37(16)	Spain	NA	SF-36
Hossain 2014	80(40)	Bangladesh	NA	KDQOL-SF
Hou 2009	240(120)	China	NA	SF-36
Iqbal 2016	120(40)	Bangladesh	NA	KDQOL-SF
Isla Pera 2009	69(69) ^b	Spain	NA	SF-36
Jana 2014	105(105)	India	NA	WHOQOL-BREF
Joshi 2013	60(30)	India	NA	KDQOL-SF
Junchotikul 2015	232(232)	Thailand	NA	WHOQOL-BREF, EQ5D
Kachuee 2007	125(125)	Iran	NA	SF-36
Khedmat 2007	316(246)	Iran	NA	SF-36
Kim 2016	105(105)	South Korea	NA	SF-36
Knap 2010	164(164)	Slovenia	NA	SF-36
Kontodimopoulos 2008	874(167)	Greece	NA	SF-36
Kontodimopoulos 2009	874(167)	Greece	NA	SF-36
Kostro 2016	69(69)	Poland	NA	KDQOL-SF
Kugler 2013	354(165)	Germany	NA	SF-36
Kuhn 2014	350(350) ^b	Germany	NA	SF-36
Kusleikaite 2007	61(61)	Lithuania	NA	SF-36
Lee 2012	560(36)	Brunei	NA	WHOQOL-BREF
Lewis 2014	931(698)	UK	NA	SF-36
Li 2017	2216(512)	UK	NA	EQ-5D
Lim 2014	175(175)	Korea	NA	KDQOL-SF, SF-36
Liu 2008	138(138)	USA	NA	SF-36
Liu 2015	204(204)	USA	NA	SF-36
Lopes 2013	80(35)	Portugal	NA	SF-36
Lorenz 2017	140(140)	USA	NA	SF-36
Loza-Concha 2011	58(58)	Peru	NA	SF-36
Maglakelidze 2010	330(48)	Georgia	NA	SF-36
Mahrova 2011	67(67)	Czech Republic	NA	KDQOL-SF
Man-ki 2015	105(105)	South Korea	NA	SF-36
Martins 2015	126(126) ^b	Portugal	NA	EQ-5D
Mendonca 2015	63(63)	Brazil	NA	WHOQOL-BREF
Miehalke 2011	90(90)	Germany	NA	SF-36
Mokarram Hossain 2015	80(40)	Bangladesh	NA	KDQOL-SF
Molnar 2007	785(785)	Hungary	NA	KDQOL-SF

Molnar 2011	879(879)	Hungary	NA	KDQOL-SF
Myint 2012	194(194)	Australia	NA	KDQOL-SF
Nagaraja 2015	497(54)	UK	NA	SF-36
Neri 2009	266(266)	USA	NA	EQ5D, HUI-III, KDQOL-SF, SF-12
Neri 2010	442(442)	UK	NA	EQ-5D
Neri 2011	311(311)	Italy	NA	EQ-5D, HUI-III, KDQOL-SF, SF-12
Neri 2012	200(200)	Italy	NA	EQ-5D, HUI-III
Neri 2012	184(184)	UK	NA	EQ-5D, HUI-III, SF-12, KDQOL-SF
Noohi 2007	162(162)	Iran	NA	SF-36
Norby 2014	38(38)	Norway	NA	SF-36
Nourbala 2007	374(205)	Iran	NA	SF-36
Nyumura 2014	93(41) ^b	Japan	NA	SF-36
Ong 2011	457(192)	Singapore	NA	SF-36
Ortega 2009	156(126)	Spain	NA	SF-36
Otalvaro 2007 ^a	NA	Spain	NA	WHOQOL-100
Painter 2012	77(20)	USA	NA	KDQOL
Panuccio 2017	224(133)	Italy	NA	SF-36 v2
Peddi 2010	90(90)	USA	NA	SF-36
Perez 2008	94(38)	Spain	NA	EORTC-QLQ-C30
Perez 2008	28(28)	Spain	NA	SF-36, EQ-5D, ESRDSCL-TM
Pistorio 2015	30(30)	Italy	NA	SF-36
Pollice 2010	157(30)	Italy	NA	SF-36
Prihodova 2010	177(177)	Slovakia	NA	SF-36
Prihodova 2014	151(151)	Slovakia	NA	SF-36, ESRDSCL-TM
Prihodova 2015	331(331)	Slovakia	NA	SF-36, the Participation Scale
Purnomo 2016	80(40)	Indonesia	NA	KDQOL-SF
Qazi 2011	10(10)	USA	NA	SF-36
Ravagnani 2007	17(17)	Brazil	NA	SF-36
Rodriguez 2008	107(44)	Spain	NA	SF-36, EQ-5D
Rogan 2015	253(81)	UK	NA	SF-36
Rosenberger 2010	124(62)	Slovakia	NA	SF-36
Rouphael 2015	1694(1694)	USA	NA	SF-36
Russcher 2015	46(23)	Netherlands	NA	SF-36
Sangalli 2014	336(336)	Italy	NA	Work Ability Index (WAI)
Sapkota 2013	119(57)	Nepal	NA	WHOQOL-BREF
Saracino 2008	230(128)	Italy	NA	SF-36
Sarris 2008	212(212)	Greece	NA	SF-36
Sarris 2008	407(407)	Greece	NA	SF-36
Sayin 2007	186(20)	Turkey	NA	SF-36
Shrestha 2010	95(57)	UK	NA	SF-36

Shur 2016	271(271)	UK	NA	GP Physical Activity Questionnaire (GPPAQ), Duke Activity Status Index (DASI)
Smith 2010	37(37) ^b	Australia	NA	SF-36
Speyer 2014	2909(2909)	Netherlands	NA	SF-36
Srifuengfung 2017	217(217)	Thailand	NA	WHODAS 2.0
Stomer 2013	76(38)	Norway	NA	SF-36
Stonnington 2016	31(4)	USA	NA	SF-36
Sundararajan 2016	20(20)	Australia	NA	SF-36
Suzuki 2008	11(6)	Japan	NA	SF-36
Suzuki 2010	14(14)	Japan	NA	SF-36
Suzuki 2012	16(16)	Japan	NA	SF-36
Suzuki 2012	91(91)	Japan	NA	SF-36
Tabbakh 2015	253(253)	UK	NA	SF-12
Tai 2010	8(8)	China	NA	SF-36
Taskintuna 2009	149(69)	Turkey	NA	SF-36
Tavallaii 2007	117(117)	Iran	NA	SF-36
Tavallaii 2009	242(242)	Iran	NA	SF-36
Tchan 2011	54(2)	Australia	NA	SF-36
Tel 2010	54(54)	Turkey	NA	SF-36
Tjaden 2014	89(73)	Netherlands	NA	SF-36
Tozzi 2012	66(66)	Italy	NA	SF-36
Turanyi 2010	100(100)	Hungary	NA	KDQOL-SF
Ujszaszi 2012	100(100)	Hungary	NA	KDQOL-SF
Uwechue 2011	508(322)	UK	NA	SF-36
Van Der Mei 2007	61(61)	Netherlands	NA	ESRDSCS-TM
Van Der Mei 2011	34(34)	Netherlands	NA	SF-36
Villeneuve 2014	297(297)	France	NA	SF-36
Virzi 2007	96(48)	Italy	NA	SF-36
Von Der Lippe 2014	6013(110)	Norway	NA	KDQOL-SF, SF-36
Von Der Lippe 2014	110(110)	Norway	NA	KDQOL-SF
Von Der Lippe 2016	142(142)	Norway	NA	KDQOL-SF
Walczak 2012	100(100)	USA	NA	SF-36
Wang 2014	150(150)	China	NA	SF-36
Weber 2014	1694(1694)	USA	NA	SF-36
Wei 2013	88(88)	Taiwan	NA	SF-36
Weng 2010	150(150)	Taiwan	NA	SF-36
White 2010	172(172)	Ireland	NA	WHOQOL-BREF
Wong 2010	173(68)	Australia	NA	EQ-5D
Yatkin 2010	66(33)	Turkey	NA	SF-36

Yavuz 2013	150(53)	Turkey	NA	SF-36
Zaman 2013	2718(1460)	USA	NA	EQ-5D
Zheng 2014	338(169)	China	NA	SF-36
Zhao 2017	250(250)	China	NA	The Quality of Life Kidney Transplantation Recipients Questionnaire
Ziaja 2009	38(38) ^b	Poland	NA	KDQOL-SF
Zimmermann 2016	241(241)	Germany	NA	SF-12
Zoller 2010	841(841)	UK	NA	KDQOL-SF

^aAbstract only, sample size not stated in the abstract; ^bSample size includes pancreas-kidney patients