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Breaking barriers, personalizing pathways: psychological health and self-management of people with chronic kidney disease

Cardol, C.K.

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Chapter 5

The Personalized Priority and Progress Questionnaire (PPPQ): A personalized instrument for quality of life and self-management for use in clinical trials and practice

Judith Tommel*, Cinderella K. Cardol*, Andrea W.M. Evers, Rianne Stuivenberg, Sandra van Dijk, and Henriët van Middendorp

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*Shared first authorship

Abstract

Background

The aim of this study was to develop and validate a brief personalized instrument that (1) defines patients' priorities for improvement, (2) measures progress in prioritized quality of life (QoL) and self-management outcomes, and (3) is applicable in both clinical practice and clinical trials.

Methods

The instrument was developed based on literature on personalized assessment and patient priorities, feedback by clinicians, and six cognitive interviews with patients with chronic kidney disease. The resulting questionnaire, the Personalized Priority and Progress Questionnaire (PPPQ), contains a baseline and follow-op measurement. The baseline measurement assesses functioning on QoL (eight items) and self-management (five items). The final item evaluates patients' priorities for improvement. The follow-up measurement assesses progress in QoL and self-management. A personalized progress score can be calculated indicating the amount of progress on the QoL or self-management domain that is prioritized by the individual patient. Psychometric properties of the PPPQ were evaluated among patients with chronic kidney disease (n=121) and patients with kidney failure treated with dialysis (n=22).

Results

The PPPQ showed to be a feasible instrument that is easy and quick to complete. With regard to the construct validity, small to large correlations were found between the items and existing validated questionnaires measuring related constructs.

Conclusions

The PPPQ proved to be a feasible and valid instrument. The PPPQ could be a useful tool both in clinical practice (e.g., to identify priorities and tailor treatment) and clinical trials (e.g., to evaluate the effectiveness of personalized interventions).

Keywords Personalized outcome; Patient-centered care; Patient priorities; Quality of life; Self-management; Chronic disease

Introduction

Every patient is unique. Patients do not only vary in functioning, but also in preferences, goals, and values and all have unique personal situations.[1,2] Therefore, it is argued that intervention research should not only focus on mean levels of biological and clinical functioning, but should incorporate these individual differences and priorities.[3,4] As found by several studies on patients with chronic kidney disease (CKD), patients expressed a clear need for such a holistic approach to care that includes all aspects of a person's health and wellbeing, including quality of life (QoL) and the self-management behaviors they need to adopt (e.g., engage in physical activity, dietary changes, taking medication, stopping with smoking).[2,5] Moving away from a 'mechanistic' focus on laboratory results and focusing on patients' actual wellbeing instead, is thought to be key for patient-centered care (PCC).[5] PCC is defined as providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.[6] Several studies found positive associations of PCC with enhanced QoL, wellbeing, patient satisfaction, perceived quality of care, and self-management.[7-9] PCC was also shown to relate to improved clinical outcomes, for example reductions in pain, blood pressure, complications, and hospitalization.[8] Qualitative research showed that patients highly value the principles of PCC: patients want to be taken seriously and treated by competent and empathic clinicians who consider each patient's unique situation, needs, and wishes.[10]

This implies that instead of evaluating one-size-fits-all interventions to find an effect in "the average patient", the focus should be on identifying and offering the best intervention for *every individual patient.*[11] Conform the PCC principles, this calls for (1) personalized interventions and (2) personalized outcome variables in order to properly evaluate the effectiveness of personalized interventions while doing justice to the individual patient's unique treatment trajectory.[3,4,11]

As personalized interventions imply individual differences in the focus of treatment, using only standard generic outcome measures to evaluate their effectiveness will not suffice. Multiple questionnaires would be necessary to evaluate the different treatment goals, which could significantly harm the power of these studies since only the data of subgroups that worked on similar treatment goals can be used.[4] Moreover, standard generic measures will invalidate the personalized character of the intervention by clouding patients' results with scores on health domains that may be unimportant to them and that were not the focus of their treatment.[3,4,11,12] Adding personalized assessments, however, enables researchers to evaluate whether the invention is not only clinically, but also personally relevant to patients (i.e., personal utility).[13] Such personalized assessment would allow for general conclusions

on the effectiveness of a treatment, while taking each patient's unique treatment trajectory into account. This feature makes personalized outcome measures highly valuable in research settings.

Next to research settings, personalized assessment can be of great value in clinical practice. Since personalized assessments help to clarify patients' needs and priorities, they would be a valuable asset in shared decision-making.[12] In shared decision-making, patients have an active role in selecting treatment and care plans that match their preferences, which is a crucial element of PCC. Another application of personalized assessments is that they could help to define personally-relevant treatment goals, which form the basis of personalized treatment.[12] Subsequently, personalized outcomes can be used to monitor patient functioning over time.[12] Although incorporating patient priorities in decision-making and interventions is highly valued,[6] patient priorities are usually not routinely assessed or recorded in medical records, making them not explicitly visible and thereby unlikely to be discussed.[14] A personalized instrument or tool that assesses priorities would be helpful to make patient priorities explicitly visible in clinical practice.

However, adequate practical tools for use in either clinical practice or clinical trials are sparse. A review focusing on patients with multiple comorbid conditions found several studies on tools that measure priorities or preferences, but all tools lacked an assessment of the effect on health outcomes that are prioritized by patients themselves.[14] Other than these tools, the McMaster Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR)[15] does offer the possibility to assess change in areas of functioning that actually matter to patients. This questionnaire, however, requires trained interviewers and has complex scoring, which limits its feasibility in clinical care and clinical trials.[16] Similarly, scales with a focus on goal setting such as Goal Attainment Scaling (GAS),[17] the Patient Goal Priority Questionnaire (PGPQ),[18] and Self-Identified Goal Assessment (SIGA)[19] can be highly valuable as a way to help patients prioritize their needs for improvement, but have the same limitation of being time-consuming and requiring a trained interviewer or therapist to help patients in setting realistic goals.[20]

The aim of the current study is to develop and validate a brief personalized instrument that (1) defines patients' top priorities for improvement, (2) measures changes in patient functioning on QoL and self-management outcomes that are prioritized by the patient, and (3) is applicable in both clinical practice and clinical trials. This newly developed instrument includes a variety of QoL areas (e.g., physical health, mental health, social functioning, and daily activities) and self-management behaviors, and is a generic and easily adjustable questionnaire that is applicable to diverse populations of patients with (chronic) somatic

conditions. To illustrate this, this study evaluates the psychometric properties of the instrument in two different chronic kidney disease (CKD) samples. If this instrument proves to be a feasible and valid instrument, this brief, personalized tool can be used to easily identify, prioritize, and monitor individual problems and progress over time.

Methods

Study Population

Questionnaire Development

In the developmental phase of the questionnaire, cognitive interviews were conducted to evaluate the feasibility, comprehensibility, readability, and relevance of the items. Using purposeful sampling, four patients with CKD not on dialysis and two patients with kidney failure treated with dialysis were recruited from the Leiden University Medical Center. The interviews were conducted in March 2018.

Questionnaire Evaluation

To evaluate the psychometric properties of the questionnaire, datasets of two multicenter randomized controlled trials (RCT) were used. Both trials evaluated the effectiveness of a personalized e-health intervention in chronic somatic populations, with one trial focusing on patients with CKD not on dialysis (the E-GOAL study)[21] and the other focusing on patients with kidney failure treated with dialysis (the E-HELD study).[22]

Recruitment of patients with CKD for the E-GOAL study took place from April 2018 through March 2020. Patients were recruited from academic hospitals (Leiden University Medical Center, Leiden; Radboud university medical center, Nijmegen; University Medical Center Groningen, Groningen) and a non-academic hospital (Haaglanden Medical Center, The Hague) in the Netherlands. To determine eligibility for participating in the RCT, patients completed screening questionnaires on depressive and anxiety symptoms as well as problems with adherence to self-management recommendations. Adult patients with CKD with an eGFR of 20-89 ml/min/1.73 m^2 under treatment by an internist-nephrologist were invited to participate when their screening questionnaire results showed that they had at least mild depressive or anxiety symptoms and that they failed to meet at least one of the nephrology guidelines for self-management.[23]

Recruitment of patients on dialysis for the E-HELD study took place from February 2019 through October 2021. Patients were recruited from academic hospitals (Radboud university medical center, Nijmegen; Leiden University Medical Center, Leiden), non-academic hospitals (VieCuri Medical Centre, Venlo; Bernhoven Hospital, Uden), and

dialysis centers (Ravenstein Dialysis Centre, Ravenstein; Dialysis Center Groningen, Groningen) in the Netherlands. To determine eligibility, patients completed a screening questionnaire on adjustment problems including questionnaires on QoL, fatigue, itch, depression, and anxiety. Adult patients with an eGFR <15 ml/min/1.73 m^2 that were treated with hemodialysis or peritoneal dialysis for at least three months were invited to participate when they presented adjustment problems as shown by the screening questionnaire (i.e., low QoL or symptoms of fatigue, itch, depression, or anxiety). Since this intervention did not focus on self-management, adherence to self-management recommendations was not assessed.

Exclusion criteria for both studies were: having an age of <18 years; having >10% renal function loss over the last year, serious comorbid physical (life expectancy <12 months) or psychiatric conditions, recent major stressful life events unrelated to CKD or kidney failure, cognitive problems that would interfere with participating in the study, receiving psychological treatment, having received a kidney transplant <1 year ago or a scheduled kidney transplant within the upcoming 12 months, not being fluent in Dutch language, pregnancy, and not having access to a computer or internet. Additionally, the E-GOAL study excluded patients who had an anticipated need for dialysis work-up within the time frame of the study and patients who had a systolic blood pressure <95 mmHg not responding to withdrawal or antihypertensives.

Ethical approval was obtained from the Medical Ethical Committee Leiden-Den Haag-Delft, with reference numbers P17.172 (E-GOAL) and P18.013 (E-HELD). The procedures used in both studies were in line with the principles of the Declaration of Helsinki.

Item Generation

The topics assessed by the questionnaire items were based on expertise within the research team and literature on frequently reported symptoms and patient priorities in the CKD and dialysis population.[2,24-27] The structure of the questionnaire, including the items in which patients are asked to prioritize individual problems, is based on relevant elements from existing personalized measurements and questionnaires on goal setting.[15-19] The resulting items were judged on comprehensibility and relevance by medical psychologists and nephrologists and were revised accordingly.

Cognitive Interviews

Subsequently, six cognitive interviews were conducted with patients with CKD and kidney failure to evaluate the feasibility, comprehensibility, readability, and relevance of the items

according to patients. The interviewers, JT and CKC, made use of the *think-aloud* approach and *verbal probing techniques* to gain insight in the response process of patients answering the questionnaire.[28] In the think-aloud approach, the interviewees are asked to vocalize their thoughts while answering the items on the questionnaire. Verbal probing techniques that were used included comprehension/interpretation probes (e.g., explaining terms in own words), paraphrasing (e.g., repeating the question in own words), recall probes (e.g., remembering QoL three months ago), specific probes (e.g., 'What do you think this questionnaire aims to measure?'), and general probes (e.g., 'How did you arrive at that answer?'; 'Was that easy or hard to answer?').[28] Based on the results of the cognitive interviews, minor textual revisions were made and the questionnaire was finalized.

Personalized Priority and Progress Questionnaire (PPPQ)

The resulting questionnaire, called the Personalized Priority and Progress Questionnaire (PPPQ), consists of a baseline and follow-up measurement:

Baseline measurement. The goal of the baseline measurement is to assess personal priorities for improvement, both in QoL areas and self-management behaviors.

- QoL: The baseline measurement starts by assessing whether patients experience limitations in several QoL areas in the past two weeks using eight items (fatigue, pain, itch, anxiety, depression, social environment, daily activities, and dependency), with the possibility to omit any item that may not be relevant in a particular population. Items are scored on a 5-point Likert scale (1 = not at all, 5 = extremely). An example item is "To what extent have you experienced limitations in the area of fatigue or sleep problems?".
- Self-management: Self-management behaviors are assessed by five items (medication adherence, healthy diet, physical activity, weight maintenance, and non-smoking) using 5-point Likert scales (1 = not at all, 5 = extremely well). An example item is "To what extent have you managed to always take your medication as prescribed?".
- Prioritize: Patients are asked to select the areas of QoL they prioritize for improvement and would actively commit to over the coming period by making a top 2. Also with regard to self-management, patients select the areas they prioritize for improvement and would actively commit to in the upcoming period by making a top 2.

Progress measurement. The goal of the follow-up measurement is to assess the amount of progress in QoL or self-management behavior compared to the baseline measurement, especially progress on the areas selected as personal priorities at baseline.

- QoL: Patients are asked to indicate whether they feel that their experienced limitations in the QoL areas changed (worsened, remained the same, or improved) since the baseline measurement. The items are answered using a 7-point Likert scale (-3 = many more, 0 = remained the same, +3 = much fewer). Higher scores indicate less limitations and, thus, improved functioning. An example item is: "Compared to the last time I completed this questionnaire, I now experience more/fewer limitations in the area of fatigue or sleep problems".
- Self-management: Patients are asked to indicate whether they feel that their self-management behaviors changed (worsened, remained the same, or improved) since the baseline measurement. The items are answered using a 7-point Likert scale (-3 = much less well, 0 = equally well, +3 = much better), with higher scores indicating improved self-management behavior. An example item is: "Compared to the last time I completed this questionnaire, I have managed less well/better to always take my medication as prescribed".
- Prioritize: Patients are asked to indicate if they tried to improve anything in any of these QoL or self-management areas over the recent period. Patients can select a maximum of two QoL areas and two self-management behaviors. If they worked on another area, they can select the option 'other'. If they did not work on any of the QoL areas or self-management behaviors, they can select the option 'not applicable'.

Progress score. The progress score indicates the amount of progress (i.e., change) on the QoL or self-management domain that is prioritized by the individual patient. This score consists of the isolated scores on the progress items that represent the areas that were selected as priorities at baseline. For example, when fatigue was selected as priority at baseline, the score on the progress item on fatigue will be used for the calculation. Ultimately, this will result in one single score that includes all personally meaningful changes.

The original Dutch version of the PPPQ was translated in English using the forward-backward method.[29] This multistep approach included the following steps: (1) the original Dutch version was translated into English by a professional translator, bilingual in English and Dutch; (2) the English version was translated back to Dutch by a native Dutch speaker; (3) the translations were reviewed by the developers of the questionnaire; and (4) the developers and the translators reached consensus and decided upon the final English version. The complete, English version of the PPPQ is enclosed in Supplementary File 1: PPPQ_EN. The Dutch version is enclosed in Supplementary File 2: PPPQ_NL.

Measures

Patient Characteristics

Information on socio-demographic and clinical characteristics (age, sex, education level, marital status, and comorbidity) was collected using self-administered questionnaires.

In addition to the PPPQ, several existing validated measures were administered in order to evaluate the construct validity of the PPPQ.

Areas of QoL

Fatigue and sleep. The Shortened Fatigue Questionnaire (SFQ)[30] was used to assess fatigue. The SFQ is a 4-item shortened version of the Checklist Individual Strength.[30] Higher scores indicate more fatigue. To assess sleeping problems, the 9-item Sleep Problem Index of the Medical Outcomes Study (MOS) Sleep Scale[31] was used, with higher scores indicating more sleeping problems. Energy was measured by the subscale energy of the RAND Short Form-36 Health Status Inventory (RAND SF-36).[32] This subscale consists of four items, with higher scores indicating more energy. Scores on the RAND SF-36 are shown as *T*-scores (Hays norm-based scoring algorithm; $M = 50$, $SD = 10$ in the general population).[32]

Pain. The subscale pain of the RAND SF-36[32] was used to assess pain. This subscale contains two items, with higher scores indicating less pain.

Itch. A subscale of the Impact of Chronic Skin Disease on Daily Life (ISDL)[33] was used to measure itch. This scale contains four items. Higher scores indicate more itch.

Anxiety symptoms and worrying. The Generalized Anxiety Disorder 7-item Scale (GAD-7)[34] was used to assess anxiety symptoms, with higher scores indicating a higher level of anxiety symptoms. The Penn State Worry Questionnaire (PSWQ)[35] was used to measure worrying. The PSWQ contains 16 items, with higher scores indicating a stronger tendency to worry.

Depressive symptoms. The Patient Health Questionnaire depression scale (PHQ-9)[36] was used to measure depressive symptoms. Higher scores indicate a higher level of depressive symptoms.

Social environment. The 2-item subscale social functioning of the RAND SF-36[32] was used to assess social functioning, with higher scores indicating better social functioning. Additionally, the subscales perceived support (five items), actual support (three items), and mutual visiting (two items) of the Inventory for Social Reliance (ISR)[37] were administered. Higher scores on the ISR indicate better social functioning.

Daily activities. To measure limitations in daily activities, the subscale role limitations due to physical problems of the RAND SF-36[32] was administered. This subscale contains four items, with higher scores indicating fewer limitations.

Self-Management Behavior

Self-management. The Partners in Health Scale (PiH)[38] was used to assess chronic condition self-management knowledge and behaviors. The PiH consists of 12 items. Higher scores indicate better self-management.

Medication adherence. To assess medication adherence the Simplified Medication Adherence Questionnaire (SMAQ)[39] was used. The SMAQ contains six items, with higher scores indicating better medication adherence.

Dietary adherence. Dietary adherence was operationalized as keeping a healthy diet in accordance with the CKD guidelines or individual prescriptions as perceived by patients themselves. It was assessed using two questions: "In the past week, how often have you kept a healthy diet?" with scores on a 5-point scale from "never" to "always", and "In the past week, how well do you believe you have kept a healthy diet?" on a 1-10 rating scale from "very badly" to "very well". A categorical or nonlinear principal components analysis[40] was done to combine the two ordinal items, in order to obtain a single summary variable (*z*-score) for dietary adherence. Higher scores indicate better dietary adherence.

Physical activity. The Short Questionnaire to Assess Health-enhancing physical activity (SQUASH)[41] was used to assess physical activity. In the SQUASH, respondents indicate how many days per week, average minutes per day, and at which intensity they practice commuting, leisure time, and household activities, and activities at work or school. Total scores were calculated of weekly moderate-to-high intensity physical activity in minutes. Higher scores indicate more physical activity.

Smoking behavior. Patients could indicate whether they currently smoke (on a daily or nondaily basis) or not, in dichotomous answer categories (yes/no). Subsequently, patients could indicate how much tobacco they smoke on a daily basis. Higher scores indicate more tobacco use.

Weight maintenance. Weight maintenance was assessed by body mass index (BMI),[42] by calculating the ratio of body weight (kg) and the square of height (m). Scores <18.5 indicate underweight, scores of 18.5-24.9 indicate normal weight, and scores ≥25 indicate overweight with scores ≥30 indicating obesity.[42]

Statistical Analyses

It is important to note that the PPPQ does not intend to measure a single underlying concept—the PPPQ measures different QoL areas and self-management behaviors—and, therefore, homogeneity of the items is not assumed. Consequently, no factor analysis was performed; we did examine the internal consistency of the functioning and self-management items of the PPPQ to explore possible associations between the individual items.[43,44]

Descriptives were calculated of the patient characteristics, the PPPQ, and related constructs as measured by existing validated measurements. We calculated the means and standard deviations (*SD*s) of the baseline and progress measurement and of all the individual items of the PPPQ. The means and *SD*s were separately calculated for the QoL items and the self-management items. The internal consistency was calculated for the PPPQ QoL and self-management items and the measurements of related constructs, with Cronbach's alphas between .70 and .95 as an indicator of good internal consistency.[43] Additionally, exploratory intercorrelations between the PPPQ items were calculated to detect possible associations between the individual items.

In order to examine item characteristics of the PPPQ items, the presence of floor and ceiling effects was evaluated using the descriptives of the PPPQ items. Floor or ceiling effects were considered to be present if more than 15% of the patients achieved the lowest or highest possible score.[43]

To examine the construct validity of the PPPQ, correlations were calculated between the PPPQ items and existing validated measurements assessing similar constructs. The baseline items of the PPPQ were correlated with their related constructs as assessed at baseline. Since the follow-up measurement assesses progress (i.e., change) in QoL or self-management behavior, we calculated change scores of the measurements (mean score at follow-up subtracted by mean score at baseline) and used these in the correlation analyses with the PPPQ progress items to ensure a proper comparison. As result of the heterogeneity of the PPPQ items, all correlational analyses were performed on item level. For example, the PPPQ item on fatigue was correlated with fatigue scales (e.g., SFQ) and the PPPQ item on patients' social environment was correlated with social functioning scales (e.g., ISR). Due to the small number of patients in the dialysis sample (E-HELD study), the magnitude of the association was deemed more informative than its statistical significance (*p*-values), with correlation coefficients above .10, .30, and .50 being interpreted as small, moderate, and large.[45]

For the calculations focusing on the QoL items we used both the CKD and dialysis sample. For calculations focusing on the self-management items we only used the CKD sample: The trial that included patients treated with dialysis did not focus on self-management and, therefore, the PPPQ self-management items and other measures focusing on self-management behavior were not administered. The item on dependency was not added in the CKD sample, since the trial that included CKD patients did not focus on dependency.

Results

Questionnaire Development

Feasibility PPPQ

Six patients completed the PPPQ as part of the cognitive interviews and gave feedback on the answering process. None of the patients reported difficulties with comprehending or answering the questionnaire. The questions on limitations in QoL and on self-management behavior were clear and easy to understand. The item on depression, for example, was explained as "Feeling down, don't feel like doing anything, lying on the couch'' and the item on medication adherence as "Taking medication as told: when, at what time, how many, and at how many times during the day". The areas that were listed under limitations in QoL and self-management were thought to be relevant for patients with a kidney disease. Additionally, patients had no trouble selecting areas as personal priorities: "Select what keeps you occupied, what is the thing you would most like to get rid of what comes with your disease"; "What are the most important areas to me, what keeps me busy, what I would like to improve". Patients completed the questionnaire quickly, in 2-4 minutes.

Questionnaire Evaluation

Patient Characteristics

Of the 2240 eligible patients with CKD not on dialysis, 460 patients completed screening questionnaires (20.5%). Based on the screening results, 146 patients were eligible for randomization based on the presence of at least mild depressive or anxiety symptoms and failing to meet at least one of the nephrology guidelines for self-management outcomes. Of these patients, 121 (82.9%) were included in the trial.

Of the 195 eligible patients with kidney failure treated with dialysis, 59 completed the screening questionnaires (30.3%). Based on the screening results, 46 were eligible for randomization based on the presence of adjustment problems. Of these patients, 35 (76.1%) were included in the trial. Twenty-two of them completed the assessments that are needed

for the current study's analyses (NB these analyses are not the focus of the main research questions of the E-HELD study). Patient characteristics are shown in Table 1.

Table 1. Patient characteristics

		CKD patients (*N* = 121)	Dialysis patients (*N* = 22)
Age,	Mean (*SD*)	55.95 (13.87)	65.50 (11.68)
	Median	57.31	67.00
	Range	25.77–81.59	46.00–83.00
Male sex		56.7%	54.5%
Education level,	Lower	52.9%	45.5%
	Higher	46.3%	54.5%
	Unknown	0.8%	-
Marital status, with partner		73.6%	95.5%
Comorbidity		69.4%	86.4%
	Hypertension	39.7%	50.0%
	Heart disease	19.0%	40.9%
	Diabetes	16.5%	31.8%
	Gastrointestinal disease	9.1%	27.3%
	Lung disease	6.6%	18.2%
	Cancer	5.8%	9.1%
Physical quality of life (PCS, RAND SF-36)		35.97 (8.64)	34.18 (7.14)
Mental quality of life (MCS, RAND SF-36)		39.81 (8.68)	44.18 (9.22)

Notes: Lower education includes primary, pre-vocational, and vocational education; higher education includes advanced secondary and tertiary education. Abbreviations: CKD, chronic kidney disease; SD, standard deviation; PCS, physical component summary; RAND SF-36, RAND Short Form-36 Health Status Inventory; MCS, mental component summary.

Descriptives PPPQ and Other Measurements

Descriptives of the sum scores of the PPPQ baseline and progress items and the measurements of related constructs as measured at baseline and follow-up can be found in Table 2. The internal consistency of the QoL items was $\alpha = .74$ (CKD sample) and $\alpha = .60$ (dialysis sample) at baseline. The progress items showed an internal consistency of $\alpha = .88$ (CKD sample) and $\alpha = .80$ (dialysis sample). In the CKD sample, the self-management items showed an internal consistency of $\alpha = .42$ (baseline items) and $\alpha = .69$ (progress items). Results of exploratory intercorrelations between the PPPQ items can be found in Supplementary File 3: Intercorrelations.

Table 2. Descriptives of the Personalized Priority and Progress Questionnaire (PPPQ) and measures of related constructs

	CKD patients (*N* = 121)				Dialysis patients (*N* = 22)			
	Baseline		Follow-up[a]		Baseline		Follow-up[b]	
	Mean (*SD*)	α	Mean (*SD*)	α	Mean (*SD*)	α	Mean (*SD*)	α
PPPQ QoL items[c]	2.15 (0.63)	.74	0.42 (0.91)	.88	1.94 (0.43)	.60	0.27 (0.82)	.80
PPPQ self-management items[c]	3.56 (0.58)	.42	0.28 (0.74)	.69	-	-	-	-
Fatigue (SFQ)	18.98 (5.16)	.85	17.10 (5.94)	.89	20.59 (5.47)	.87	19.54 (5.75)	.86
Sleeping problems (Sleep Problem Index II, MOS Sleep scale)	40.63 (15.89)	.81	36.16 (15.90)	.81	-	-	-	-
Energy (Energy scale, RAND SF-36)	42.29 (6.41)	.63	44.31 (7.70)	.76	44.77 (8.92)	.82	41.91 (7.19)	.67
Pain (subscale RAND SF-36)	44.26 (9.60)	.73	46.33 (9.82)	.74	47.64 (11.17)	.76	47.23 (10.16)	.66
Itch (ISDL)	-	-	-	-	7.05 (2.89)	.88	6.87 (2.44)	.80
Anxiety (GAD-7)	5.49 (3.78)	.81	3.95 (3.16)	.81	2.36 (1.92)	.68	2.55 (2.44)	.72
Worrying (PSWQ)	44.79 (10.94)	.91	42.01 (11.33)	.91	-	-	-	-
Depression (PHQ-9)	7.91 (3.33)	.54	5.76 (3.78)	.74	5.73 (3.67)	.77	7.14 (4.39)	.79
Social functioning (subscale RAND SF-36)	39.07 (9.67)	.68	42.24 (10.50)	.79	39.68 (9.78)	.56	35.68 (10.47)	.78
Perceived emotional support (ISR)	14.47 (3.52)	.82	14.89 (3.47)	.82	15.68 (3.71)	.81	15.82 (3.58)	.88
Actual emotional support (ISR)	7.25 (2.00)	.77	7.22 (1.84)	.72	6.36 (2.24)	.81	6.05 (2.01)	.80
Mutual visiting (ISR)	5.35 (1.42)	.74	5.35 (1.26)	.64	5.18 (1.53)	.84	4.81 (1.62)	.53
Role limitations due to physical problems (subscale RAND SF-36)	36.18 (11.44)	.82	40.77 (11.80)	.81	30.73 (9.40)	.88	33.05 (10.40)	.84
Self-management (PiH)	80.04 (9.63)	.78	82.74 (9.27)	.81	-	-	-	-
Medication adherence (SMAQ)	5.16 (1.05)	n/a	5.25 (0.95)	n/a	-	-	-	-
Dietary adherence	0.00 (0.93)	n/a	0.35 (0.76)	n/a	-	-	-	-
Physical activity, hrs. per week (SQUASH)	17.10 (16.04)	n/a	15.54 (15.52)	n/a	-	-	-	-
BMI	27.38 (5.33)	n/a	27.16 (5.35)	n/a	-	-	-	-
Smoking, %	9.1	n/a	8.3	n/a	-	-	-	-
Amount of tobacco per day, units	0.80 (3.31)	n/a	0.50 (2.75)	n/a	-	-	-	-

Notes: Mean and standard deviations shown as mean (*SD*); internal consistency: Cronbach's α; Follow-up[a]: 3-months follow-up; Follow-up[b]: 6-months follow-up; PPPQ QoL/self-management items[c]: average sum scores, the items differ per assessment point, i.e. the baseline measurement assessed the baseline items and the follow-up measurement assessed the progress items. Abbreviations: CKD, chronic kidney disease; SD, standard deviation; QoL, quality of life; SFQ, Shortened Fatigue Questionnaire (SFQ); MOS Sleep Scale, Medical Outcomes Study Sleep Scale; RAND SF-36, RAND Short Form-36 Health Status Inventory; ISDL, Impact of Chronic Skin Disease on Daily Life; GAD-7, Generalized Anxiety Disorder 7-item Scale; PSWQ, Penn State Worry Questionnaire; PHQ-9, Patient Health Questionnaire depression scale; ISR, Inventory for Social Reliance; PiH, Partners in Health Scale; SMAQ, Simplified Medication Adherence Questionnaire; SQUASH, Short Questionnaire to Assess Health-enhancing physical activity; BMI, body mass index.

Item Characteristics PPPQ and Floor or Ceiling Effects

QoL items. Item characteristics of the PPPQ QoL items as measured in the CKD and dialysis sample are shown in Table 3. Regarding the baseline items, mean item scores ranged from 1.61 (itch) to 3.15 (fatigue) in the CKD sample. All items covered the full range from 1 to 5, except for the item on depression, where none of the patients selected the option "very much". Floor effects were found for the items on pain, itch, anxiety, depression, social environment, and daily activities. No ceiling effects were detected. In the dialysis sample, the mean of the baseline items ranged from 1.55 (anxiety and depression) to 2.86 (fatigue). The item on fatigue was the only one covering the full range from 1 to 5. The items on itch, social environment, daily activities, and dependency ranged from 1 to 4; the items on pain and depression ranged from 1 to 3; and the item on anxiety ranged from 1 to 2. Floor effects were found for all items except for the item on fatigue. No ceiling effects were detected.

Regarding the progress items, mean item scores ranged from 0.21 (fatigue) to 0.62 (depression) in the CKD sample. All items covered the full range from -3 to 3, except for the itch item that ranged from -2 to 3, indicating that none of the patients selected the option "much worse". No floor or ceiling effects were detected. In the dialysis sample, the mean of the progress items ranged from -0.45 (fatigue) to 0.59 (anxiety and depression). The item on dependency was the only one covering the full scale from -3 to 3. The fatigue item ranged from -3 to 2, indicating that none of the patients selected the option "much better"; the items on pain, anxiety, depression, and the social environment ranged from -2 to 3; and the item on itch ranged from -1 to 3. No floor effects were found. Ceiling effects were detected for anxiety and depression.

Self-management items. Item characteristics of the PPPQ self-management items as measured in the CKD sample are shown in Table 3. Regarding the baseline items, mean item scores ranged from 2.64 (weight maintenance) to 4.52 (non-smoking). All items covered the full range from 1 to 5, except for the medication adherence item that ranged from 2 to 5, indicating that none of the patients selected the option 'not at all'. A floor effect was found for the item on weight maintenance. Ceiling effects were found for the items on medication adherence and non-smoking.

Concerning the progress items, mean scores ranged from 0.17 (weight maintenance) to 0.45 (non-smoking). The healthy diet and non-smoking item covered the full range from -3 to 3. The items on medication adherence, physical activity, and weight maintenance ranged from -2 to 3, indicating that none of the patients selected the option "much worse". No floor or ceiling effects were detected.

Table 3. Characteristics of the Personalized Priority and Progress Questionnaire (PPPQ) items

	Baseline								Follow-up							
	CKD patients (*N* = 121)				Dialysis patients (*N* = 22)				CKD patients (*N* = 121)				Dialysis patients (*N* = 22)			
Item	Mean (*SD*)	Floor (%)	Ceiling (%)	Range	Mean (*SD*)	Floor (%)	Ceiling (%)	Range	Mean (*SD*)	Floor (%)	Ceiling (%)	Range	Mean (*SD*)	Floor (%)	Ceiling (%)	Range
QoL																
Fatigue	3.15 (1.12)	5.0	13.2	1 – 5	2.86 (1.04)	4.5	9.1	1 – 5	0.21 (1.14)	0.8	2.5	-3 – 3	-0.45 (1.18)	4.5	0	-3 – 2
Pain	2.08 (1.05)	36.4	0.8	1 – 5	1.82 (0.85)	45.5	0	1 – 3	0.32 (1.21)	1.7	8.3	-3 – 3	0.27 (1.07)	0	4.5	-2 – 3
Itch	1.61 (0.93)	62.0	0.8	1 – 5	2.05 (0.72)	18.2	0	1 – 4	0.56 (1.25)	0	13.2	-2 – 3	0.45 (1.10)	0	4.5	-1 – 3
Anxiety	2.02 (0.91)	30.6	0.8	1 – 5	1.55 (0.51)	45.5	0	1 – 2	0.57 (1.25)	0.8	8.3	-3 – 3	0.59 (1.44)	0	18.2	-2 – 3
Depression	1.79 (0.87)	43.8	0	1 – 4	1.55 (0.60)	50.0	0	1 – 3	0.62 (1.29)	0.8	9.9	-3 – 3	0.59 (1.47)	0	18.2	-2 – 3
Social environment	1.90 (0.96)	39.7	3.3	1 – 5	1.59 (0.96)	63.6	0	1 – 4	0.33 (1.15)	0.8	5.8	-3 – 3	0.41 (1.30)	0	13.6	-2 – 3
Daily activities	2.50 (1.14)	19.8	5.8	1 – 5	2.27 (0.99)	18.2	0	1 – 4	0.32 (1.14)	1.7	5.0	-3 – 3	0.36 (1.09)	0	4.5	-1 – 3
Dependency	-	-	-	-	1.86 (0.89)	40.9	0	1 – 4	-	-	-	-	-0.09 (1.34)	4.5	4.5	-3 – 3
Self-management																
Medication adherence	4.45 (0.77)	0	58.7	2 – 5	-	-	-	-	0.23 (0.78)	0	4.1	-2 – 3	-	-	-	-
Healthy diet	3.39 (0.90)	1.7	8.3	1 – 5	-	-	-	-	0.29 (1.04)	0.8	3.3	-3 – 3	-	-	-	-
Physical activity	2.82 (1.04)	9.9	4.1	1 – 5	-	-	-	-	0.29 (1.21)	0	5.8	-2 – 3	-	-	-	-
Weight maintenance	2.64 (1.23)	20.7	7.4	1 – 5	-	-	-	-	0.17 (1.16)	0	4.1	-2 – 3	-	-	-	-
Non-smoking	4.52 (1.24)	9.9	85.1	1 – 5	-	-	-	-	0.45 (1.29)	2.5	14.9	-3 – 3	-	-	-	-

Notes: Follow-up measures for the CKD and dialysis population took place at, respectively, 3- and 6-months follow-up. Abbreviations: CKD, chronic kidney disease; SD, standard deviation; QoL, quality of life.

Construct Validity PPPQ

QoL items. The results regarding the construct validity of the baseline QoL items of the PPPQ can be found in Table 4. In the CKD sample, all baseline items correlated at least moderately with validated questionnaires measuring related constructs, with correlations varying from $r = .38$ to $r = .68$, except for the social environment item that did not show a meaningful correlation with perceived and actual emotional support and mutual visiting (ISR; r-values $\leq$ -.10). In the dialysis sample, insignificant or small correlations were found between the social environment item and actual emotional support and mutual visiting (ISR); between the daily activities item and role limitations due to physical problems (RAND SF-36); and between the dependency item and perceived and emotional support and mutual visiting (ISR; r-values $\leq$ -.22). All other baseline items correlated at least moderately with their related constructs, with correlations varying from $r = -.31$ to $r = .70$.

The results regarding the construct validity of the QoL progress items of the PPPQ can be found in Table 5. In the CKD sample, insignificant or small correlations were found between the items pain, anxiety, social environment, and daily activities and change in their related construct as measured by validated questionnaires(r-values $\leq .21$). All other progress items showed at least moderate correlations with questionnaires measuring related constructs, with correlations varying from $r = .30$ to $r = .36$. In the dialysis sample, insignificant or small correlations were found between the PPPQ progress item on pain and change in pain (RAND SF-36); between the anxiety item and change in anxiety (GAD-7); between the depression item and change in depression (PHQ-9); between the social environment item and change in social functioning (RAND SF-36), actual emotional support (ISR), and mutual visiting (ISR); between the daily activities item and change in role limitations due to physical problems (RAND SF-36); and between the dependency item and change in perceived emotional support (ISR), with r-values $\leq .27$. All other PPPQ progress items showed moderate correlations with their related constructs as measured by validated questionnaires, with correlations varying from $r = .30$ to $r = -.43$.

Self-management items. The results regarding the construct validity of the baseline self-management items of the PPPQ can be found in Table 6. In the CKD sample, all baseline items showed at least moderate correlations with questionnaires measuring related constructs, with correlations varying from $r = .43$ to $r = -.66$, except for the physical activity item that only showed a small correlation with hours of physical activity per week ($r = .23$). Additionally, small correlations between the PPPQ self-management items and self-management were found (r-values $\leq .27$).

Table 4. Construct validity of baseline quality of life items of the Personalized Priority and Progress Questionnaire (PPPQ) and related constructs (Pearson correlations)

		Fatigue	Pain	Itch	Anxiety	Depression	Social environment	Daily activities	Dependency
Fatigue (SFQ)	CKD: Dialysis:	.47** .41	-	-	-	-	-	-	-
Sleeping problems (Sleep Problem Index II, MOS Sleep scale)	CKD: Dialysis:	.42** -	-	-	-	-	-	-	-
Energy (subscale, RAND SF-36)	CKD: Dialysis:	-.42** -.43*	-	-	-	-	-	-	-
Pain (subscale RAND SF-36)	CKD: Dialysis:	-	-.68** -.70*	-	-	-	-	-	-
Itch (ISDL)	CKD: Dialysis:	-	-	- .68**	-	-	-	-	-
Anxiety (GAD-7)	CKD: Dialysis:	-	-	-	.67** .32	-	-	-	-
Worrying (PSWQ)	CKD: Dialysis:	-	-	-	.55** -	-	-	-	-
Depression (PHQ-9)	CKD: Dialysis:	-	-	-	-	.46** .70**	-	-	-
Social functioning (subscale RAND SF-36)	CKD: Dialysis:	-	-	-	-	-	-.38** -.44**	-	- -.35
Perceived emotional support (ISR)	CKD: Dialysis:	-	-	-	-	-	-.09 -.31	-	- .13
Actual emotional support (ISR)	CKD: Dialysis:	-	-	-	-	-	-.02 -.22	-	- .002
Mutual visiting (ISR)	CKD: Dialysis:	-	-	-	-	-	-.10 -.21	-	- -.16
Role limitations due to physical problems (subscale RAND SF-36)	CKD: Dialysis:	-	-	-	-	-	-	-.42** -.003	-

*$p<.05$; **$p<.01$; CKD patients ($N = 121$); Dialysis patients ($N = 22$). Abbreviations: CKD, chronic kidney disease; SFQ, Shortened Fatigue Questionnaire; MOS Sleep Scale, Medical Outcomes Study Sleep Scale; RAND SF-36, RAND Short Form-36 Health Status Inventory; ISDL, Impact of Chronic Skin Disease on Daily Life; GAD-7, Generalized Anxiety Disorder 7-item Scale; PSWQ, Penn State Worry Questionnaire; PHQ-9, Patient Health Questionnaire depression scale; ISR, Inventory for Social Reliance.

Table 5. Construct validity of quality of life items of the Personalized Priority and Progress Questionnaire (PPPQ) and change scores (Pearson correlations)

		Fatigue	Pain	Itch	Anxiety	Depression	Social environment	Daily activities	Dependency
Fatigue (SFQ)	CKD: Dialysis:	-.36** -.39	-	-	-	-	-	-	-
Sleeping problems (Sleep Problem Index II, MOS Sleep scale)	CKD: Dialysis:	-.30** -	-	-	-	-	-	-	-
Energy (subscale, RAND SF-36)	CKD: Dialysis:	.36** .39	-	-	-	-	-	-	-
Pain (subscale RAND SF-36)	CKD: Dialysis:	-	.14 .05	-	-	-	-	-	-
Itch (IHDL)	CKD: Dialysis:	-	-	- -.43*	-	-	-	-	-
Anxiety (GAD-7)	CKD: Dialysis:	-	-	-	-.21* -.15	-	-	-	-
Worrying (PSWQ)	CKD: Dialysis:	-	-	-	-.11 -	-	-	-	-
Depression (PHQ-9)	CKD: Dialysis:	-	-	-	-	-.35** -.04	-	-	-
Social functioning (subscale RAND SF-36)	CKD: Dialysis:	-	-	-	-	-	.14 .13	-	- .30
Perceived emotional support (ISR)	CKD: Dialysis:	-	-	-	-	-	.03 -.41	-	- .27
Actual emotional support (ISR)	CKD: Dialysis:	-	-	-	-	-	-.03 -.20	-	- -.32
Mutual visiting (ISR)	CKD: Dialysis:	-	-	-	-	-	.004 .20	-	- -.30
Role limitations due to physical problems (subscale RAND SF-36)	CKD: Dialysis:	-	-	-	-	-	-	.21* -.06	-

*$p<.05$; **$p<.01$; CKD patients ($N = 121$); Dialysis patients ($N = 22$). Abbreviations: CKD, chronic kidney disease; SFQ, Shortened Fatigue Questionnaire; MOS Sleep Scale, Medical Outcomes Study Sleep Scale; RAND SF-36, RAND Short Form-36 Health Status Inventory; ISDL, Impact of Chronic Skin Disease on Daily Life; GAD-7, Generalized Anxiety Disorder 7-item Scale; PSWQ, Penn State Worry Questionnaire; PHQ-9, Patient Health Questionnaire depression scale; ISR, Inventory for Social Reliance.

Table 6. Construct validity of the baseline self-management items of the Personalized Priority and Progress Questionnaire (PPPQ) (Pearson correlation) in a CKD sample (Pearson correlation)

	Medication adherence	Healthy diet	Physical activity	Weight maintenance	Non-smoking
Self-management (PiH)	.19*	.27**	.23*	.22*	.25**
Medication adherence (SMAQ)	.44**	-	-	-	-
Dietary adherence	-	.61**	-	-	-
Physical activity, hrs per week (SQUASH)	-	-	.23*	-	-
Physical activity, days per week minimally 30 mins			.43**		
BMI	-	-	-	-.63**	-
Amount of tobacco per day					-.66**

*p<.05; **p<.01, N = 121, CKD patients. Abbreviations: CKD, chronic kidney disease; PiH, Partners in Health Scale; SMAQ, Simplified Medication Adherence Questionnaire; SQUASH, Short Questionnaire to Assess Health-enhancing physical activity; BMI, body mass index.

The results regarding the construct validity of the self-management progress items of the PPPQ can be found in Table 7. The progress in physical activity (r = .40) and weight maintenance items (r = .31) showed moderate correlations with change in self-management. The other progress items showed small correlations with their related constructs and change in self-management (r-values $\leq$ .29).

Table 7. Construct validity of self-management progress items of the Personalized Priority and Progress Questionnaire (PPPQ) and change scores of measurements assessing similar constructs (Pearson correlations) in a CKD sample

	Medication adherence	Healthy diet	Physical activity	Weight maintenance	Non-smoking
Self-management (PiH)	.09	.26**	.40**	.31**	-.02
Medication adherence (SMAQ)	.15	-	-	-	-
Dietary adherence	-	.29**	-	-	-
Physical activity, hrs per week (SQUASH)	-	-	-.12	-	-
Physical activity, days per week minimally 30 mins			.18		
BMI	-	-	-	-.18	-
Amount of tobacco per day					-.25**

**p<.01, N = 121, CKD patients. Change scores of the measurements assessing similar constructs were calculated by subtracting the mean score at baseline from the mean score at follow-up. Abbreviations: CKD, chronic kidney disease; PiH, Partners in Health Scale; SMAQ, Simplified Medication Adherence Questionnaire; SQUASH, Short Questionnaire to Assess Health-enhancing physical activity; BMI, body mass index.

Discussion

The aim of this study was to develop a brief personalized instrument that (1) defines patients' priorities for improvement, (2) measures change in functioning on QoL and self-management outcomes that are prioritized by the individual patient, and (3) is applicable in both clinical practice and clinical trials. The resulting questionnaire, the PPPQ, includes a baseline and a follow-up measurement. The baseline measurement assesses personal priorities for improvement, both in QoL and self-management. The follow-up measurement assesses the amount of self-perceived progress in QoL or self-management compared to the baseline measurement. Based on these results, a progress score can be calculated indicating the amount of progress on the area of QoL or self-management that is prioritized by the individual patient. The PPPQ was completed in two samples–a sample of patients with CKD and a sample of patients with kidney failure treated with dialysis–and subsequently evaluated on its psychometric properties. The PPPQ showed to be a valid and feasible instrument that is easy and quick to complete. This indicates that the PPPQ could be a valuable tool to easily identify, prioritize, and monitor individual QoL and self-management problems over time, both in clinical practice and clinical trials.

The PPPQ showed to have good construct validity. With regard to the baseline items, moderate to large correlations were found between all items and validated questionnaires measuring related constructs. Only the scales measuring emotional support and mutual visiting did not show significant correlations with the PPPQ items on social functioning and dependency. Possibly, this social support questionnaire (ISR) was not a good choice to determine the construct validity of these items. Social support is, after all, a different construct that is not necessarily related to social functioning and dependency.[46,47]

The correlations between the progress items and questionnaires measuring related constructs were somewhat smaller than the correlations of the baseline items. Possibly, this is the result of different ways of determining progress (i.e., change). In the PPPQ progress items, patients make their own comparison of their current versus their previous functioning, while for the measurements of related constructs we calculated change by subtracting the baseline score from the follow-up score. Possibly, patients' self-perceived comparison of their current and previous functioning is influenced by 'response shift'. This phenomenon involves changing internal standards, values and the conceptualization of QoL as part of adaptation to disease.[48] In both samples, no associations were found between the progress items on pain and daily activities and their related constructs. Additionally, in the CKD sample, no correlations were found between the social environment item and scales on social functioning or social support. In the dialysis sample, no correlations were found

between the progress items on anxiety and depression and the anxiety and depression scales. The latter could have been the result of the fact that almost none of the dialysis patients reported symptoms of anxiety or depression, which diminishes potential changes in these areas that could be picked up by the progress part of the PPPQ (i.e., floor effect).[43] Due to differences in the eligibility screening, all CKD patients reported at least mild symptoms of anxiety or depression. In this sample, we did find significant associations between the progress anxiety and depression items and their related constructs. Based on these results, the construct validity of the baseline measurement was positively evaluated. Regarding the progress items, the correlations were slightly too small.

Since the PPPQ includes items on several domains of QoL and self-management—instead of measuring one single concept—we did not necessarily expect high Cronbach's alpha's of the QoL and self-management items.[43,44] Nevertheless, the internal consistency of the QoL items was surprisingly good. The self-management items showed lower Cronbach's alphas, possibly because they are less related in terms of content. Weight maintenance, for example, is not necessarily related to medication adherence.

Several floor and ceiling effects were detected for the baseline items. Particularly in the dialysis sample, several items did not cover the full range, which probably results from the small sample size. Beyond that, floor and ceiling effects are dependent upon the population.[49] The fact that, for example, 85% answered "very well" on the question "To what extent do you succeed in stopping with smoking?" demonstrates that not all areas are experienced as problematic in this sample. Normally, floor and ceiling effects would decrease the responsiveness of a questionnaire: they make it difficult to detect an intervention effect in participants who score on the lower levels of the scale before the start of an intervention.[49] Since the PPPQ is a personalized scale that specifically addresses changes in the areas patients do find important, this will not be a problem. Besides, the progress score is based on the scores of the progress items and these items rarely showed any floor or ceiling effects.

Strengths and Limitations

It is increasingly recognized that a one-size-fits all approach to health care falls short to the complexity and diversity of individual patients. Shifting to a personalized approach (i.e., PCC) helps to better understand individual patient needs.[7-9,50] For PCC to succeed, adequate tools that promote personalization are required.[4] We believe the specific functionalities of the PPPQ, of isolating personally meaningful areas and using these scores as an outcome measure (i.e., progress score), could make this instrument a valuable tool in PCC. While

there are instruments that assess patient priorities, it is precisely the effect on QoL and self-management outcomes that are valued by patients themselves that is lacking in current instruments.[14] An additional strength is the high flexibility in which the PPPQ items can be adapted to match diverse populations. It is, for example, possible to only administer the QoL items—as illustrated by the dialysis sample in this study—or only the self-management items. The possibility of adding or omitting items is illustrated by the dependency item that was added only in the dialysis sample since patients have indicated dependency on others to be a major problem in this specific population.[2] Another strength is the ease and speed in which this questionnaire can be completed by patients without needing assistance, as shown by the cognitive interviews. This low burden is a great advantage compared to existing personalized instruments that are usually time-consuming and require trained interviewers or therapists.[16]

A limitation of this study is the relatively small sample size, especially regarding the dialysis sample. Therefore, when interpreting the results in this sample, we decided to focus more on the magnitude than on the significance of the associations. For a more robust examination of the validity of the PPPQ, larger samples of patients with diverse medical conditions would be advised. Another limitation is the lack of a gold standard that measures personalized health outcomes that are prioritized by patients.[20] Consequently, instead of using a similar personalized instrument to compare the PPPQ to, we had to select different questionnaires for each item to evaluate the construct validity.

Implications

The PPPQ could be of use in both clinical and research settings. See Box 1. for an overview of the applicability of the PPPQ. In clinical settings, the PPPQ could be used as a brief tool to evaluate patients' priorities and to keep track of patients' functioning. In this sense, the PPPQ could be used to evaluate patients' functioning in general–similar to QOL questionnaires–but also to specifically zoom in on the areas of QoL and self-management that patients themselves find important. The PPPQ could be completed on a routine basis and the results can be discussed during consultations between clinicians and patients. In this way, the PPPQ results can form the starting point of a discussion on patient priorities and shared decision-making to decide on a personalized treatment plan. Patients usually find it difficult to discuss their priorities, especially if this is not explicitly asked by clinicians,[51,52] and clinicians may find it difficult to know what to ask for to each patient and lack the time to discuss all potential QoL areas or self-management behaviors. The PPPQ could lower this

threshold by making it easier for patients to discuss their particular difficulties and needs. Thereby, patient-clinician communication can be facilitated.[53,54]

Box 1. Implications of the Personalized Priority and Progress Questionnaire (PPPQ) in clinical and research settings

Clinical settings	Research settings
- Identify patient priorities	- Evaluate personalized interventions by using the progress score
- Use as conversation starter for a talk on patient priorities and patient needs	- Add or remove items to match the specific needs of the study population
- Use to support shared decision-making and tailor treatment based on results	- Use both the QoL and self-management items or only the QoL or self-management items to match the specific research questions
- Monitor patients' QoL and adherence to self-management behaviors	- All implications listed under clinical settings are applicable in intervention studies as well

Abbreviations: QoL, quality of life.

In research settings, the PPPQ is an ideal tool to evaluate the effectiveness of personalized interventions. In personalized interventions, treatment goals vary per participant. Some participants may work on improving their coping skills with regard to fatigue, while others work on improving their social relationships. When evaluating personalized treatments using general health outcomes, the outcome will be clouded by scores on areas that may be unimportant to patients and, therefore, the personalized character will be lost.[3,4,11,12] Additionally, multiple questionnaires would be necessary to evaluate the different treatment goals (e.g., questionnaires on fatigue and social relationships), with the consequence of decreased power, since only part of the participants worked on fatigue or social relationships.[4] Ideally, researchers would have one overall score that justifies the personalized character of the intervention. We believe the progress score of the PPPQ could be that score. By using the progress score, scores on personally meaningful areas will be isolated and this will result in one single score that researchers can use in their analyses. When determining this progress score, researchers can use the priorities as selected at baseline or the areas patients indicated to have actively worked on at follow-up. The latter option can be useful if there is indication of switched treatment goals over the course of the study. Additionally, this option can be used as a check question to find out whether patients

in the control condition spontaneously worked on their health. For trials with waiting list or care as usual control conditions, we advise to use the priorities as selected at baseline. This strategy is in line with existing personalized measurements such as the MACTAR and the GAS[15,16] that advice patients to set goals prior to randomization which enables researchers to apply the same calculations to both the control and the intervention condition.[15,16,55]

Conclusions

To identify and monitor patient priorities over time, the PPPQ was developed. The PPPQ can be used in both clinical and research settings and proved to be a valid questionnaire that patients can easily complete without needing assistance. The PPPQ is a personalized scale that specifically addresses changes in the areas prioritized by patients themselves. Using the results of the PPPQ, a progress score can be calculated. This score is based on the isolated areas that are personally meaningful to the individual patient and thus not blurred by areas that may be unimportant to them. This great benefit makes the PPPQ a suitable instrument to evaluate personalized interventions in which patients work on different treatment goals. In clinical settings, the PPPQ could be used as a quick and easy tool to evaluate patients' priorities and to monitor their functioning. With these characteristics, the PPPQ could aid in delivering high-quality care that is tailored to the unique needs and priorities of every individual patient.

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Supplementary File 1

Personalized Priority and Progress Questionnaire (PPPQ) - English

Quality of life

1. <u>Baseline: Score for current functioning – general</u>

The following questions are about limitations that people may experience **due to their kidney disease**. Think about the past 2 weeks. Please indicate to what extent you have experienced **limitations in the following areas**.

GENERAL To what extent have you experienced limitations in the area of…	*Not at all*	*Slightly*	*Moderately*	*Considerably*	*Extremely*
a. ...fatigue or sleep problems?	1	2	3	4	5
b. ...pain?	1	2	3	4	5
c. ...itching?	1	2	3	4	5
d. ...tension, anxiety, or worrying?	1	2	3	44	55
e. ...low mood or feeling down?	1	2	3	4	5
f. ...your social environment (e.g., communication about your needs or wishes, asking for or receiving support)?	1	2	3	4	5
g. ...daily activities (e.g., work, hobbies, or social activities)?	1	2	3	4	5
h. ...dependence on others?	1	2	3	4	5

2. <u>Baseline: Setting priorities - general</u>

Choose the top two areas related to your perceived limitations that you would **most like** to improve, and that you plan to work on actively over the coming period. Rank these in order of relevance, where priority 1 is the most relevant, and priority 2 the next most relevant.

Limitations in the area of...

1. fatigue or sleep problems
2. pain
3. itching
4. tension, anxiety, or worrying
5. low mood or feeling down
6. social environment
7. daily activities
8. dependence
9. other (please state):

Priority 1: _____

Priority 2: _____

3. <u>Follow-up measurement: Score for self-perceived progress – general</u>

The following questions are about limitations that people may experience **due to their kidney disease**. For the statements below, please indicate whether, compared to the last time you completed these questionnaires, you now experience more or fewer **limitations**, or whether your situation has remained the same. It is not a problem if you do not remember exactly what you entered the last time: a rough estimate will do.

GENERAL

Compared to the last time I completed this questionnaire, I now experience more/fewer limitations in the area of...	*Many more*	*More*	*Slightly more*	*Remained the same*	*Slightly fewer*	*Fewer*	*Much fewer*
a. fatigue or sleep problems.	-3	-2	-1	0	1	2	3
b. pain.	-3	-2	-1	0	1	2	3
c. itching.	-3	-2	-1	0	1	2	3
d. tension, anxiety, or worrying.	-3	-2	-1	0	1	2	3
e. low mood or feeling down.	-3	-2	-1	0	1	2	3
f. social environment (e.g., communication about your needs or wishes, asking for or receiving support).	-3	-2	-1	0	1	2	3
g. daily activities (e.g., work, hobbies, or social activities).	-3	-2	-1	0	1	2	3
h. dependence on others.	-3	-2	-1	0	1	2	3

4. <u>Follow-up measurement: Areas actively worked on – general</u>

Have you tried to improve anything in any of these areas over the recent period?

If so, please choose up to two areas below that you have actively tried to improve recently. Rank these two areas, where number 1 is the area you have worked on most, and number 2 the area you have worked on slightly less.

If you have not actively worked on any of these areas, choose "not applicable".

Limitations relating to..

1. fatigue or sleep problems
2. pain
3. itching
4. tension, anxiety, or worrying
5. low mood or feeling down
6. social environment
7. daily activities
8. dependence
9. other (please state):
10. not applicable

Area 1: I worked on limitations in the area of _____

Area 2: I worked on limitations in the area of _____

Self-management

1. **Baseline: Score for current functioning - self-management**

   The following questions are about self-management. Think about the past 2 weeks. Please indicate to what extent you have successfully managed to maintain a healthy lifestyle in the following areas.

SELF-MANAGEMENT To what extent have you managed...	*Not at all*	*Slightly*	*Reasonably well*	*Well*	*Extremely well*
a. ...to always take your medication as prescribed?	1	2	3	4	5
b. ...to eat healthily?	1	2	3	4	5
c. ...to engage in enough physical activity?	1	2	3	4	5
d. ...to maintain a healthy body weight?	1	2	3	4	5
e. ...to not smoke?	1	2	3	4	5

2. **Baseline: Setting priorities - self-management**

   Choose the top two areas related to your current self-management that you would **most like** to improve, and that you plan to work on actively over the coming period? Rank these in order of relevance, where priority 1 is the most relevant, and priority 2 the next most relevant.

   Self-management in the area of...

   1. taking medication
   2. healthy eating
   3. sufficient physical activity
   4. healthy body weight
   5. not smoking
   6. other (please state):

Priority 1: _____

Priority 2: _____

3. <u>Follow-up measurement: Score for self-perceived progress - self-management</u>

For the following statements about your current self-management, please indicate whether you have managed more or less successfully than the last time to carry out or maintain the behavior in question, or whether your situation has remained the same. It is not a problem if you do not remember exactly what you entered the last time: a rough estimate will do.

SELF-MANAGEMENT Compared to the last time I completed this questionnaire, I have managed less well / better ...	*Much less well*	*Less well*	*Slightly less well*	*Equally well*	*Slightly better*	*Better*	*Much better*
1. to always take my medication as prescribed.	-3	-2	-1	0	1	2	3
2. to eat healthily.	-3	-2	-1	0	1	2	3
3. to engage in enough physical activity.	-3	-2	-1	0	1	2	3
4. to maintain a healthy body weight.	-3	-2	-1	0	1	2	3
5. to not smoke.	-3	-2	-1	0	1	2	3

4. <u>Posttest measurement: Areas actively worked on - self-management</u>

Have you tried to improve anything in any of these areas over the recent period?
If so, please choose up to two areas below that you have actively tried to improve recently. Rank these two areas, where number 1 is the area you have worked on most, and number 2 the area you have worked on slightly less.

If you have not actively worked on any of these areas, choose "not applicable".

Self-management in the area of...

1. taking medication
2. healthy eating
3. sufficient physical activity
4. healthy body weight
5. not smoking
6. other (please state):
7. not applicable

Area 1: I worked on my self-management in the area of _____
Area 2: I worked on my self-management in the area of _____

Supplementary File 2

Personalized Priority and Progress Questionnaire (PPPQ) - Dutch

Kwaliteit van leven

1. <u>Baseline: Scoren huidig functioneren – algemeen</u>

Onderstaande vragen gaan over beperkingen die mensen **door hun nieraandoening** kunnen ervaren. Denk aan de afgelopen 2 weken. Geef aan in hoeverre u **beperkingen ervaart op de volgende gebieden**.

ALGEMEEN

In welke mate ervaart u beperkingen op het gebied van…	*Helemaal niet*	*Enigszins*	*Nogal*	*Veel*	*Heel erg veel*
a. …vermoeidheid of slaapproblemen?	1	2	3	4	5
b. …pijn?	1	2	3	4	5
c. …jeuk?	1	2	3	4	5
d. …spanning, angst of bezorgdheid?	1 1	2 2	3 3	4	5
e. …een sombere of neerslachtige stemming?	1	2	3	4	5
f. …uw sociale omgeving (bijv. communicatie over uw behoeften of wensen, het vragen of ontvangen van steun)?	1	2	3	4	5
g. …dagelijkse activiteiten (bijv. bij werk, hobby's of sociale activiteiten)?	1	2	3	4	5
h. …afhankelijkheid van anderen?	1	2	3	4	5

2. <u>Baseline: Prioriteiten stellen – algemeen</u>

Maak een top 2 van gebieden die te maken hebben met uw ervaren beperkingen, die u het **liefst** zou willen verbeteren en waarop u zich actief wilt inzetten de komende tijd. Hierbij vindt u prioriteit 1 het meest relevant en prioriteit 2 iets minder relevant van de twee gebieden die u kiest.

Beperkingen op het gebied van…

1. vermoeidheid of slaapproblemen
2. pijn
3. jeuk
4. spanning, angst of bezorgdheid
5. sombere of neerslachtige stemming
6. sociale omgeving
7. dagelijkse activiteiten
8. afhankelijkheid
9. anders, namelijk …

Prioriteit 1: _____

Prioriteit 2: _____

3. <u>Nameting: Scoren zelfwaargenomen verandering – algemeen</u>

Onderstaande vragen gaan over beperkingen die mensen **door hun nieraandoening** kunnen ervaren. Geef voor onderstaande stellingen aan of u ten opzichte van de vorige keer dat u deze vragenlijsten invulde meer of minder **beperkingen** ervaart, of dat uw situatie gelijk gebleven is. Het is niet erg als u niet meer precies weet wat u toen heeft ingevuld, een globale inschatting is voldoende.

ALGEMEEN

In vergelijking met de vorige keer dat ik deze vragenlijst invulde ervaar ik meer/minder beperkingen op het gebied van…	*Veel meer*	*Meer*	*Een beetje meer*	*Gelijk gebleven*	*Een beetje minder*	*Minder*	*Veel minder*
a. vermoeidheid of slaapproblemen.	-3	-2	-1	0	1	2	3
b. pijn.	-3	-2	-1	0	1	2	3
c. jeuk.	-3	-2	-1	0	1	2	3
d. spanning, angst of bezorgdheid.	-3	-2	-1	0	1	2	3
e. een sombere of neerslachtige stemming.	-3	-2	-1	0	1	2	3
f. mijn sociale omgeving (bijv. communicatie over mijn behoeften of wensen, het vragen of ontvangen van steun).	-3	-2	-1	0	1	2	3
g. dagelijkse activiteiten (bijv. bij werk, hobby's of sociale activiteiten).	-3	-2	-1	0	1	2	3
h. afhankelijkheid van anderen.	-3	-2	-1	0	1	2	3

4. <u>Nameting: Gebieden waar actief aan gewerkt is – algemeen</u>

Heeft u in de afgelopen periode geprobeerd om iets te verbeteren in een van deze gebieden?

Zo ja, kies hieronder maximaal twee gebieden die u de afgelopen tijd actief hebt proberen te verbeteren.

Maak een top 2, waarbij u het meest bezig bent geweest met nummer 1 en iets minder met nummer 2 van de twee gebieden die u kiest.

Als u aan geen van deze gebieden actief hebt gewerkt, kunt u de optie "niet van toepassing" invullen.

Beperkingen op het gebied van…

1. vermoeidheid of slaapproblemen
2. pijn
3. jeuk
4. spanning, angst of bezorgdheid
5. sombere of neerslachtige stemming
6. mijn sociale omgeving
7. dagelijkse activiteiten
8. afhankelijkheid
9. anders, namelijk …
10. niet van toepassing

Gebied 1: Ik heb gewerkt aan beperkingen op het gebied van _____

Gebied 2: Ik heb gewerkt aan beperkingen op het gebied van _____

Zelfmanagement

1. <u>Baseline: Scoren huidig functioneren – zelfmanagement</u>

Onderstaande vragen gaan over zelfmanagement. Denk aan de afgelopen 2 weken. Geef aan in hoeverre het u lukt om gezond te leven op de volgende gebieden.

ZELFMANAGEMENT In welke mate lukt het u…	*Helemaal niet*	*Enigszins*	*Redelijk goed*	*Goed*	*Heel erg goed*
a. …om uw medicijnen altijd volgens voorschrift te nemen?	1	2	3	4	5
b. …om gezond te eten?	1	2	3	4	5
c. …om voldoende te bewegen?	1	2	3	4	5
d. …om een gezond lichaamsgewicht aan te houden?	1	2	3	4	5
e. …om niet te roken?	1	2	3	4	5

2. <u>Baseline: Prioriteiten stellen – zelfmanagement</u>

Maak een top 2 van gebieden die te maken hebben met uw huidige zelfmanagement, die u het **liefst** zou willen verbeteren en waarop u zich actief wilt inzetten de komende tijd. Hierbij vindt u prioriteit 1 het meest relevant en prioriteit 2 iets minder relevant van de twee gebieden die u kiest.

Zelfmanagement op het gebied van…

1. medicijnen nemen
2. gezond eten
3. voldoende bewegen
4. gezond lichaamsgewicht
5. niet roken
6. anders, namelijk …

Prioriteit 1: _____

Prioriteit 2: _____

3. <u>Nameting: Scoren zelfwaargenomen verandering – zelfmanagement</u>

Geef voor onderstaande stellingen over uw huidige zelfmanagement aan of het uitvoeren of volhouden ervan u ten opzichte van de vorige keer minder goed of beter lukt, of dat uw situatie gelijk gebleven is. Het is niet erg als u niet meer precies weet wat u toen heeft ingevuld, een globale inschatting is voldoende.

ZELFMANAGEMENT In vergelijking met de vorige keer dat ik deze vragenlijst invulde lukt het mij minder goed/beter om…	*Veel minder goed*	*Minder goed*	*Een beetje minder goed*	*Even goed*	*Een beetje beter*	*Beter*	*Veel beter*
6. mijn medicijnen altijd volgens voorschrift te nemen.	-3	-2	-1	0	1	2	3
7. gezond te eten.	-3	-2	-1	0	1	2	3
8. voldoende te bewegen.	-3	-2	-1	0	1	2	3
9. een gezond lichaamsgewicht aan te houden.	-3	-2	-1	0	1	2	3
10. niet te roken.	-3	-2	-1	0	1	2	3

4. <u>Nameting: Gebieden waar actief aan gewerkt is – zelfmanagement</u>

Heeft u in de afgelopen periode geprobeerd om iets te verbeteren in een van deze gebieden?
Zo ja, kies hieronder maximaal twee gebieden die u de afgelopen tijd actief hebt proberen te verbeteren. Maak een top 2, waarbij u het meest bezig bent geweest met nummer 1 en iets minder met nummer 2 van de twee gebieden die u kiest.

Als u aan geen van deze gebieden actief hebt gewerkt, kunt u de optie 'niet van toepassing' invullen.

Zelfmanagement op het gebied van…

8. medicijnen nemen
9. gezond eten
10. voldoende bewegen
11. gezond lichaamsgewicht
12. niet roken
13. anders, namelijk …
14. niet van toepassing

Gebied 1: Ik heb gewerkt aan mijn zelfmanagement op het gebied van _____
Gebied 2: Ik heb gewerkt aan mijn zelfmanagement op het gebied van _____

Supplementary File 3

Intercorrelations

QoL items

The results of the exploratory intercorrelation analyses between the PPPQ QoL items as measured in the CKD and dialysis sample are shown in Table S1. Regarding the baseline items as measured in the CKD sample, moderate to large correlations were found between the fatigue item and the items on pain, itch, depression, and daily activities; between the pain and daily activities items; between the anxiety item and the items on depression, social environment, and daily activities; between the depression and social environment items; and between the social environment and daily activities items; with correlations varying from r = .32 (fatigue and depression) to r = .65 (anxiety and depression). Thus, these correlations indicated that experienced limitations in these QoL areas were associated with limitations in other QoL areas. Between the other items, insignificant or small correlations were found (r-values $\leq$ .27). In the dialysis sample, moderate to large correlations were found between the fatigue item and the items on anxiety, depression, social environment, and dependency; between the itch and the social environment items; and between the depression item and the items on social environment and daily activities; with correlations varying from r = .30 (itch and social environment) to r = .71 (fatigue and social environment). Between the other baseline items, insignificant to small correlations were found (r-values $\leq$ .29).

Regarding the progress items as measured in the CKD sample, moderate to large correlations were found between all of the progress items of the PPPQ, with correlations varying from r = .38 (fatigue and itch) to r = .78 (social environment and daily activities). Thus, these correlations indicated that progress in one QoL area is generally associated with progress in other QoL areas. In the dialysis sample, moderate to large correlations were found between the fatigue item and the items on pain, anxiety, depression, daily activities, and dependency; between the pain item and the items on itch and daily activities; between the itch and daily activities items; between the anxiety item and the items on depression, social environment, daily activities, and dependency; between the depression item and the items on daily activities and dependency; and between the social environment and daily activities items; with correlations varying from r = .30 (anxiety and social environment) to r = .98 (anxiety and depression). Between the other progress items, non-existent or small correlations were found (r-values $\leq$ .29).

Table S1. Intercorrelations between the Quality of Life items of the Personalized Priority and Progress Questionnaire (PPPQ)

	CKD patients (N = 121)							Dialysis patients (N = 22)							
Baseline items	1.	2.	3.	4.	5.	6.	7.	1.	2.	3.	4.	5.	6.	7.	8.
1. Fatigue	-							-							
2. Pain	.37**	-						.08	-						
3. Itch	.32**	.17	-					.009	.17	-					
4. Anxiety	.27**	.12	.15	-				.51*	.13	-.07	-				
5. Depression	.33**	.07	.10	.65**	-			.43*	.11	.27	.23	-			
6. Social environment	.22*	.23*	.26**	.57**	.37**	-		.71*	.25	.30	.09	.49*	-		
7. Daily activities	.45**	.34**	.16	.33**	.26**	.43**	-	.18	.29	.05	-.22	.38	.17	-	
8. Dependency	-	-	-	-	-	-	-	-.33	.15	.16	-.25	-.03	.10	.10	-
Progress items															
1. Fatigue	-							-							
2. Pain	.48**	-						.32	-						
3. Itch	.38**	.46**	-					.13	.61**	-					
4. Anxiety	.56**	.49**	.59**	-				.64**	.11	.18	-				
5. Depression	.43**	.50**	.60**	.79**	-			.65**	.10	.24	.98**	-			
6. Social environment	.49**	.40**	.41**	.53**	.51**	-		.19	.09	.13	.30	.27	-		
7. Daily activities	.54**	.43**	.42**	.40**	.45**	.78**	-	.32	.60**	.41	.31	.31	.36	-	
8. Dependency	-	-	-	-	-	-	-	.42	.28	.29	.45*	.44*	.10	.12	-

*p<.05; **p<.01. Abbreviations: CKD, chronic kidney disease.

Self-management items

The results of the exploratory intercorrelation analyses between the PPPQ self-management items as measured in the CKD sample are shown in Table S2. Regarding the baseline items, moderate correlations were found between the healthy diet and weight maintenance items ($r = .45$) and between the physical activity and weight maintenance items ($r = .46$). Between the other baseline items insignificant or small correlations were found (r-values $\leq .28$). With regard to the progress items, large correlations were found between the healthy diet item and the items on physical activity ($r = .64$) and weight maintenance ($r = .65$) and between the physical activity and weight maintenance items ($r = .61$). A moderate correlation was found between the medication adherence and non-smoking items ($r = .42$) Between the other progress items insignificant or small correlations were found (r-values $\leq .28$).

Table S2. Intercorrelations between self-management items of the Personalized Priority and Progress Questionnaire (PPPQ) in a CKD sample ($N = 121$)

Baseline items		1.	2.	3.	4.	5.
1.	Medication adherence	-				
2.	Healthy diet	.26**	-			
3.	Physical activity	-.01	.29**	-		
4.	Weight maintenance	-.12	.45**	.46**	-	
5.	Non-smoking	.28**	-.08	-.09	-.03	-
Progress items						
1.	Medication adherence	-				
2.	Healthy diet	.28**	-			
3.	Physical activity	.20*	.64**	-		
4.	Weight maintenance	.21*	.65**	.61**	-	
5.	Non-smoking	.42**	.09	.04	.06	-

*$p<.05$; **$p<.01$. Abbreviation: CKD, chronic kidney disease.