

Importance of hemodialysis-related outcomes: comparison of ratings by a self-help group, clinicians, and health technology assessment authors with those by a large reference group of patients

Inger M Janssen¹
 Fueloep Scheibler²
 Ansgar Gerhardus^{3,4}

¹Department of Epidemiology and International Public Health, University of Bielefeld, Bielefeld, ²Department of Non-Drug Interventions, Institute for Quality and Efficiency in Health Care, Cologne, ³Department for Health Services Research, Institute for Public Health and Nursing Research, University of Bremen, ⁴Health Sciences Bremen, University of Bremen, Bremen, Germany

Background: The selection of important outcomes is a crucial decision for clinical research and health technology assessment (HTA), and there is ongoing debate about which stakeholders should be involved. Hemodialysis is a complex treatment for chronic kidney disease (CKD) and affects many outcomes. Apart from obvious outcomes, such as mortality, morbidity and health-related quality of life (HRQoL), others such as, concerning daily living or health care provision, may also be important. The aim of our study was to analyze to what extent the preferences for patient-relevant outcomes differed between various stakeholders. We compared preferences of stakeholders normally or occasionally involved in outcome prioritization (patients from a self-help group, clinicians and HTA authors) with those of a large reference group of patients.

Participants and methods: The reference group consisted of 4,518 CKD patients investigated previously. We additionally recruited CKD patients via a regional self-help group, nephrologists via an online search and HTA authors via an expert database or personal contacts. All groups assessed the relative importance of the 23 outcomes by means of a discrete visual analog scale. We used descriptive statistics to rank outcomes and compare the results between groups.

Results: We received completed questionnaires from 49 self-help group patients, 19 nephrologists and 18 HTA authors. Only the following 3 outcomes were ranked within the top 7 outcomes by all 4 groups: safety, HRQoL and emotional state. The ratings by the self-help group were generally more concordant with the reference group ratings than those by nephrologists, while HTA authors showed the least concordance.

Conclusion: Preferences of CKD patients from a self-help group, nephrologists and HTA authors differ to a varying extent from those of a large reference group of patients with CKD. The preferences of all stakeholders should form the basis of a transparent approach so as to generate a valid list of important outcomes.

Keywords: patient preferences, hemodialysis patients, patient-centered outcomes, preference elicitation, rating scale

Background

For some years now, more and more emphasis has been placed on patient-centered health care as well as on active patient involvement in clinical research and health technology assessment (HTA).¹⁻⁴

The Institute of Medicine (IOM) defined patient-centered care 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.”⁵

Correspondence: Inger M Janssen
 Department of Epidemiology and International Public Health, University of Bielefeld, PO Box 10 01 31, 33501 Bielefeld, Germany
 Tel +49 221 3568 5358
 Email inger.scheike@uni-bielefeld.de

The need for patient engagement in health care research is widely recognized, and measures are being undertaken in many areas to promote further engagement.^{3,6} One area of interest is the definition and rating of patient-relevant outcomes. However, the decision as to which outcomes are important enough to be evaluated in clinical research or HTA is still largely made by clinicians or HTA authors; patients are only occasionally involved in this process.

It is unclear to what extent the importance that clinicians or HTA authors assign to certain outcomes reflects the importance assigned by patients. Several studies have found discrepancies between preferences of patients and those of other stakeholders.^{7,8}

Moreover, if patients are involved, this normally happens in an unstructured manner by consultation with a small group of patient representatives (eg, members of a self-help group). It is unclear to what extent they represent the perspective of the total population of patients with a specific condition.

Hemodialysis is a time-consuming and long-term intervention for the treatment of chronic kidney disease (CKD) and affects many different outcomes. While there are obvious ones, such as mortality, morbidity and health-related quality of life (HRQoL), others related to the impact on daily living or the provision of health care (eg, journey time to dialysis or its duration) may also be important.⁹

We had previously conducted a survey of 4518 CKD patients treated by hemodialysis to investigate the relative importance that patients assign to various outcomes and found that the 3 most important ones were the safety of treatment, HRQoL and satisfaction with care.¹⁰ However, the involvement of such a large patient sample in outcome prioritization in clinical research or HTA would not normally be feasible in practice.

We therefore aimed to investigate to what extent the preferences of 3 stakeholder groups normally or occasionally involved in outcome prioritization in clinical research or HTA deviate from the preferences of a large reference group of patients. For this purpose, we compared the preferences of members of a self-help group for CKD, nephrologists and HTA authors with those of a reference group with CKD in respect of the importance of hemodialysis-related outcomes.

Participants and methods

Stakeholder groups

Reference group: CKD patients from a quality management program in nephrology

The reference group consisted of CKD patients treated by hemodialysis in the centers of the Board of Trustees for

Dialysis and Renal Transplant (Kuratorium fuer Dialyse und Nierentransplantation [KfH]), the largest nonprofit provider of hemodialysis in Germany. It comprises >200 units treating ~18,000 patients per year and sends an annual survey to all of its patients as a part of its quality management program “Quality in Nephrology” (QiN).¹¹ Our questionnaire was included in the survey of 2008. A detailed description has been published elsewhere.¹⁰

CKD patients from a self-help group

As patient representatives, we included patients recruited from a regional self-help group for CKD, the Lower-Rhine Section of the Kidney Interest Group (Sektion Niederrhein, Interessengemeinschaft Niere e.V.). A paper-and-pencil version of the questionnaire was distributed during a regional meeting of this group; in addition, the group’s office was provided with paper-and-pencil versions to distribute in further meetings. The office also sent the link of the online version of the questionnaire to all members of the self-help group with known email addresses.

Nephrologists

We identified nephrologists by selecting the largest city of each of the 16 German federal states and identified outpatient dialysis centers in these cities via a Google search. We contacted a total of 80 centers that had a website with an email address. We sent them a link of the online questionnaire and asked them to participate and also to forward the link to further nephrologists. In addition, a nephrologist collaborating with our project disseminated the link in national nephrology meetings.

HTA authors

A total of 25 HTA authors included in the Institute for Quality and Efficiency in Healthcare database of external experts or personally known to the authors of this paper were contacted via email and provided with a link of the online questionnaire. They were asked to participate and also to forward the link to further HTA authors.

Questionnaire

Outcomes for inclusion in the questionnaire were identified using patient input; details are described elsewhere.¹⁰ In short, a group discussion was held with patients from a self-help group to identify the important outcomes. A pretest was conducted with 5 patients, not otherwise involved in the project, to assess the comprehensibility of the questions and the completeness of the outcomes used.

Subsequently, 23 hemodialysis-related outcomes were identified and added to a routinely conducted annual survey

(“Reference group: CKD patients from a quality management program in nephrology” section). We only considered patient-relevant outcomes, defined as how a patient feels, functions or survives.¹² Surrogate outcomes, that is, outcomes not directly perceptible by patients (eg, laboratory values), were not considered.

On the basis of a systematic literature search for instruments for assessing preferences, we chose a rating scale in the form of a discrete visual analog scale (VAS) to rate the preferences for the 23 outcomes.⁷ This scale consisted of 9 categories, ranging from “not important” (1) to “very important” (9). A complete list of the 23 outcomes and their definition in the questionnaire is listed in Table 1. Patients from the reference group and the self-help group were asked to indicate how important the outcomes were to them by assigning a score from 1 to 9; similarly, nephrologists and HTA authors were asked to indicate how important they thought that these outcomes were to patients.

Sociodemographic data were collected from all 4 groups. In addition, we collected information on diabetes diagnosis, time on dialysis in years, and education, and occupation, from the patients. From nephrologists, we collected information on work experience, the average number of patients treated and the work setting (hospital or practice).

Patients, nephrologists and HTA authors were informed about the purpose of the questionnaire and were asked to give informed consent. The paper-and-pencil versions were handed out together with a consent form and a return envelope. In the online version, the participants were requested to check a box to confirm their informed consent before proceeding with the questionnaire. The data of the entire questionnaire were collected within a quality assurance framework, and a specially assigned data protection commissioner ensured that patient data were dealt with correctly according to German data protection laws. Only data of patients who gave written informed consent were considered.

Data analysis

Descriptive statistics (mean scores and standard deviation) were used to calculate the ratings of the importance of the 23 outcomes. The results from the QiN survey¹⁰ were used as a reference to which the other groups were compared (reference group). Comparisons with this group were performed in the following 2 different ways:

- (1) In the first analysis, we compared the 7 top-ranked outcomes. The number of outcomes evaluated and reported is usually restricted both in clinical research and in evidence synthesis. While there is no general international

Table 1 Outcomes included in the questionnaire

| Outcomes | Wording in questionnaire “Please state how important the following goals and requirements are for you in the treatment of chronic kidney disease.” ^a |
|----------------------------|--|
| Life expectancy | Maximum increase in life expectancy |
| GI symptoms | Prevention of gastrointestinal symptoms |
| Accompanying symptoms | Reduction or prevention of accompanying symptoms (eg, restless leg syndrome and insomnia) |
| Hospital stays | Reduction in hospital stays |
| Emotional state | Improvement or preservation of a good emotional state |
| HRQoL | Improvement of health-related quality of life |
| Physical functioning | Improvement or preservation of physical functioning |
| Nausea/drop blood pressure | Prevention of nausea or drop in blood pressure during treatment |
| Itching | Prevention of itching during treatment |
| Traumatic punctures | Prevention of traumatic punctures or painful treatment |
| Journey time | Journey time to dialysis that is as short as possible |
| Dialysis duration | Individually adjustable dialysis duration |
| Flexible organization | Flexible organization of dialysis appointments |
| Collaboration | No necessity to collaborate during treatment |
| Work | The possibility to work despite dialysis treatment |
| Satisfaction | Satisfaction with care at the clinic |
| Access to nursing staff | Accessibility of nursing staff during dialysis treatment |
| Access to medical staff | Accessibility of medical staff during dialysis treatment |
| Choice of nursing staff | Choice of nursing staff |
| Choice of medical staff | Choice of medical staff |
| Information | Detailed individual information on disease, treatment and diet |
| Participation | Participation in treatment |
| Safety | Safety of treatment (eg, functioning of the dialysis machine or other instruments and sterility of the dialysis solution) |

Note: ^aTranslated from German; patient version (nephrologists and HTA authors were asked how important the goals and requirements were for patients).

Abbreviations: GI, gastrointestinal; HRQoL, health-related quality of life; HTA, health technology assessment.

consensus on the exact number of outcomes to be reported, the Cochrane Collaboration and the Grading of Recommendations Assessment, Development and Evaluation working group report up to 7 outcomes.^{13,14} Outcomes not included in this list are not usually considered in the weighing of benefits and harms of an intervention.

- (2) In the second analysis, we compared the extent of deviations in the rankings when all 23 outcomes were considered. We compared the rankings of the 3 stakeholder groups for each outcome with those of the reference group, counting how often the outcomes differed by 0–2, 3–5, 6–8 or >8 ranks. In addition, we compared the 7 top-ranked outcomes of the 3 stakeholder groups with each other, without considering the reference group.

Results

Participants

In the QiN study, we had previously analyzed 4518 questionnaires from hemodialysis patients. In this study, we received 49 completed questionnaires from the self-help group (Table 2). While most characteristics were similar in the 2 patient groups, patients from the self-help group were on average younger, had diabetes less often and had spent

more time on dialysis. They were also more often employed and were more likely to have higher education. We received 18 completed questionnaires from HTA authors and 19 from nephrologists (Table 3). On average, HTA authors had 6 years of HTA experience and nephrologists had 20 years of experience in treating patients with CKD and, at the time of the survey, were each responsible for 40–150 patients.

Ranking of outcomes

Comparison of the 3 stakeholder groups with the reference group

Variations in the 7 top-ranked outcomes

Detailed results of the importance ratings (mean and standard deviation) are listed in Table S1. Figure 1 shows the 7 top-ranked outcomes of all 4 groups. The following 3 outcomes were ranked within the top 7 by all groups: safety, HRQoL and emotional state.

Self-help group versus reference group: 5 outcomes were ranked within the top 7 outcomes by both groups. Both groups ranked safety in the first place. However, the self-help group rated physical functioning (rank 2 versus rank 11) and traumatic punctures (rank 5 versus rank 9) as being more important than did the reference group. In contrast,

Table 2 Characteristics of patient groups

| Characteristics | Reference group (4,518) | Self-help group (49) | Group differences (P-value) |
|---|-------------------------|----------------------|-----------------------------|
| Age (years), mean (SD) | 66.6 (13.9) | 51.0 (14.2) | <0.001* |
| Age categories (years), n (%) | | | |
| 0–20 | 6 (0.1) | – | |
| 21–40 | 248 (5.5) | 17 (34.7) | |
| 41–60 | 1,032 (22.8) | 15 (30.6) | |
| 61–80 | 2,611 (57.8) | 17 (34.7) | |
| 81–100 | 621 (13.7) | – | |
| Sex, male (%) | 2,640 (58.4) | 27 (55.1) | 0.638* |
| Have diabetes | 1,793 (39.7) | 3 (6.1) | <0.001* |
| Time on dialysis, mean (SD) | 4.4 (5.3) | 9.1 (9.0) | 0.003* |
| Time on dialysis, categories n (%) | | | |
| 0–1 year | 1,446 (32.0) | 3 (6.1) | |
| 2–4 years | 1,516 (33.6) | 10 (20.4) | |
| 5–10 years | 989 (21.9) | 14 (28.6) | |
| >10 years | 421 (9.3) | 9 (18.4) | |
| Occupation, n (%) | | | |
| Student | 26 (0.6) | 1 (2.0) | |
| Unemployed | 198 (4.4) | 2 (4.1) | |
| Employed | 435 (9.6) | 20 (40.8) | |
| Retired | 3,421 (75.7) | 26 (53.1) | |
| Education, n (%) | | | |
| No school leaving certificate | 277 (6.1) | – | |
| Basic school leaving certificate | 2,315 (51.2) | 20 (40.8) | |
| Intermediate school leaving certificate | 865 (19.1) | 13 (26.5) | |
| Advanced school leaving certificate | 176 (3.9) | 8 (16.3) | |
| Higher education degree | 337 (7.5) | 8 (16.3) | |

Note: *Independent t-test.

Table 3 Characteristics of HTA authors and nephrologists

| Characteristics | HTA authors (18) | Nephrologists (19) |
|---|---|--|
| Sex, male (%) | 6 (33.3) | 16 (84.2) |
| Profession | Clinician: 2 ^a Research associate: 14 | 18 specialists in internal medicine |
| Education (university degree for HTA authors, qualification in nephrology for clinicians) | Medicine: 2 Health economics: 3 Health sciences/public health: 6 Others ^b : 4 | 18 have held a qualification in nephrology for a mean of 15.1 years (range: 1–27 years) |
| Work experience (mean) | Mean 6.1 years of experience in HTA (range: 1–11 years) | 20.1 years of experience in the treatment of patients with CKD (range: 5–35 years) On average 96 patients treated (range: 40–150) |
| Work setting/status | | 17 (89.5%) work in a practice and 15 (78.9%) are self-employed |

Notes: ^aOne works both as a clinician and as a research associate. ^bOther degrees include: economics, geography, dietetics and psychology.

Abbreviations: CKD, chronic kidney disease; HTA, health technology assessment.

hospital stays and accompanying symptoms were rated by the reference group as being more important.

Nephrologists versus reference group: 4 outcomes were ranked within the top 7 outcomes by both groups. Both groups had a similarly high ranking for satisfaction with care (rank 2 versus rank 3). However, nephrologists rated access to nursing staff (rank 1 versus rank 8), physical functioning (rank 5 versus rank 11) and nausea/drop in blood pressure (rank 6 versus rank 10) as being more important than did the reference group. In contrast, hospital stays, accompanying symptoms and hemodialysis duration were rated by the reference group as being more important.

HTA authors versus reference group: 4 outcomes were ranked within the top 7 outcomes by both groups. Both groups had a similarly high ranking for HRQoL (rank 1 versus rank 2). However, HTA authors rated work (rank 2 versus rank 23), life expectancy (rank 3 versus rank 15) and physical functioning (rank 5 versus rank 11) as being more important than did the reference group. In contrast, satisfaction with care, accompanying symptoms and hemodialysis duration were rated by the reference group as being more important.

Deviations when all 23 outcomes are considered

Figure 2 shows the extent of deviations in the rankings of all outcomes for each of the 3 stakeholder groups compared to the ranking by the reference group. In the comparison of the rankings by the self-help group with those by the reference group, 18 outcomes were ranked with very small or small differences and 5 outcomes were ranked with large or very large differences.

In the comparison of the rankings by the nephrologists with those by the reference group, 17 outcomes were ranked with small or very small differences and 6 outcomes were ranked with large or very large differences.

In the comparison of the rankings by the HTA authors with those by the reference group, 13 outcomes were ranked with small or very small differences and 10 outcomes were ranked with large or very large differences (even a difference of 21 ranks for 1 outcome, work).

Comparison of the self-help group, nephrologists and HTA authors

Figure 3 shows the 7 top-ranked outcomes of the 3 stakeholder groups. As stated, they agreed on 4 outcomes (safety, physical functioning, HRQoL and emotional state). Outcomes that were ranked within the top 7 solely by one group were traumatic punctures and hemodialysis duration (self-help group), access to nursing staff and nausea/drop in blood pressure (nephrologists), as well as work, life expectancy and hospital stays (HTA authors).

Discussion

The aim of this study was to investigate to what extent the preferences of 3 stakeholder groups (CKD patients from a self-help group, nephrologists and HTA authors) normally or occasionally involved in outcome prioritization in clinical research and HTA deviate from the preferences of a large reference group of patients with CKD. Only 3 outcomes, which were safety, HRQoL and emotional state, were consistently ranked within the top 7 outcomes by all 4 groups. Depending on the group asked, the outcomes included in the top 7 varied considerably. This is problematic as often only a single stakeholder group is involved in outcome prioritization in clinical research and HTA.^{15,16}

Although the rankings of the self-help group were more similar to those of the reference group than the rankings of clinicians and HTA authors, there were notable deviations, which may be explained by the fact that survey results are affected

| Rank | Reference group | Self-help group | Nephrologists | HTA authors |
|------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1 | Safety | Safety | Access to nursing staff | HRQoL |
| 2 | HRQoL | Physical functioning | Satisfaction | Work |
| 3 | Satisfaction | HRQoL | Emotional state | Life expectancy |
| 4 | Hospital stays | Emotional state | HRQoL | Emotional state |
| 5 | Accompanying symptoms | Traumatic punctures | Physical functioning | Physical functioning |
| 6 | Hemodialysis duration | Satisfaction | Nausea/drop blood pressure | Safety |
| 7 | Emotional state | Hemodialysis duration | Safety | Hospital stays |
| 8 | Access to nursing staff | Hospital stays | Hospital stays | Participation |
| 9 | Traumatic punctures | Accompanying symptoms | Traumatic punctures | Journey time |
| 10 | Nausea/drop blood pressure | Nausea/drop blood pressure | Information | Accompanying symptoms |
| 11 | Physical functioning | Participation | Accompanying symptoms | Satisfaction |
| 12 | Information | Itching | Itching | Information |
| 13 | Access to medical staff | Information | Work | Dialysis organization |
| 14 | GI symptoms | Life expectancy | Access to medical staff | Nausea/drop blood pressure |
| 15 | Life expectancy | Work | Life expectancy | Traumatic punctures |
| 16 | Dialysis organization | Access to nursing staff | GI symptoms | Access to nursing staff |
| 17 | Itching | Dialysis organization | Hemodialysis duration | Hemodialysis duration |
| 18 | Participation | GI symptoms | Participation | GI symptoms |
| 19 | Journey time | Journey time | Dialysis organization | Itching |
| 20 | Collaboration | Access to medical staff | Journey time | Access to medical staff |
| 21 | Choice of medical staff | Choice of medical staff | Choice of nursing staff | Choice of medical staff |
| 22 | Choice of nursing staff | Choice of nursing staff | Choice of medical staff | Choice of nursing staff |
| 23 | Work | Collaboration | Collaboration | Collaboration |

Figure 1 Comparison of outcomes.

Notes: Lines link outcomes that are within the top 7 outcomes in all 4 groups. The top 7 outcomes of the reference group are marked in gray.

Abbreviations: GI, gastrointestinal; HRQoL, health-related quality of life; HTA, health technology assessment.

by sampling bias if participants are selected nonrandomly,^{17–19} as was the case with the self-help group in our study, who, for instance, were younger than patients in the reference group. However, an exploratory analysis comparing patients of both groups within similar age strata did not yield results that were more similar to each other; factors other than age, therefore, seem to have led to different results. Specific factors that differ from those in the general patient population might be difficult to identify and even more difficult to control for. This has to

be taken into account when considering preferences elicited only from patients in a specific subgroup.

The 2 outcomes ranked highest by the nephrologists were access to nursing staff and satisfaction with care at the dialysis clinic, indicating that clinicians place more emphasis on outcomes related to clinic organization than do patients and HTA authors.

Outcomes ranked quite differently by HTA authors than by the reference patients include life expectancy and the

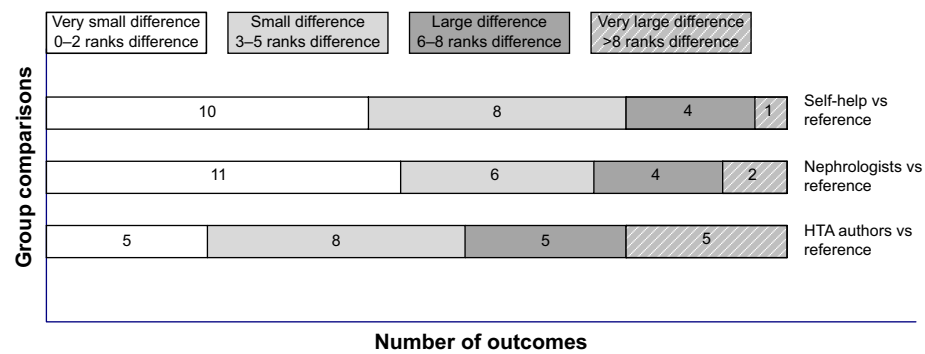


Figure 2 Extent of differences in outcome rankings between the self-help group, nephrologists and HTA authors versus the reference group.

Notes: Each bar represents 1 of the 3 groups versus the reference group. Colored fields indicate how many outcomes were ranked differently to the rankings of the reference group, while numbers in the fields indicate the quantity of outcomes this applies to. The first bar starts with 10 outcomes ranked with very small differences (0–2 ranks) by the self-help group versus the reference group. The next field shows that 8 outcomes were ranked with small differences (3–5 ranks) versus the reference group.

Abbreviation: HTA, health technology assessment.

possibility to work despite dialysis; these were rated to be far more important by HTA authors. The fact that life expectancy (rank 15) was not considered by the reference patients to be as important as other outcomes might be explained by the fact that CKD is no longer an acute life-threatening condition. The possibility to work (ranked last) is understandably not so important for a patient group that is largely retired. When evaluating the importance of outcomes, the HTA authors were probably influenced by their past experiences concerning which outcomes can be reliably measured in clinical studies.

Strengths and limitations

The strength of our study is the possibility to compare the importance of outcomes for 3 stakeholder groups normally or

occasionally involved in the process of outcome prioritization with the results of a large reference group of patients whose preferences are not usually available.

We chose a discrete VAS to enable the elicitation of preferences for a large number of outcomes. Other methods, such as conjoint analysis, analytical hierarchy process and utility assessment methods, are also used for this purpose, but as they are not suitable for dealing with the large number of outcomes analyzed in our study, they were not feasible alternatives.^{7,15} Although a ceiling effect was observed, we were able to establish a ranking of outcomes and to compare the ranks between the different samples.

Nonrepresentative samples (such as patients from a self-help group) do not necessarily provide exact estimates of the preferences of a large patient population. However,

| Rank | Self-help group | Nephrologists | HTA authors |
|------|-----------------------|----------------------------|----------------------|
| 1 | Safety | Access to nursing staff | HRQoL |
| 2 | Physical functioning | Satisfaction | Work |
| 3 | HRQoL | Emotional state | Life expectancy |
| 4 | Emotional state | HRQoL | Emotional state |
| 5 | Traumatic punctures | Physical functioning | Physical functioning |
| 6 | Satisfaction | Nausea/drop blood pressure | Safety |
| 7 | Hemodialysis duration | Safety | Hospital stays |

Figure 3 The 7 top-ranked outcomes of stakeholder groups.

Note: Shaded outcomes are also among the 7 top-ranked outcomes of the reference patient group.

Abbreviations: HRQoL, health-related quality of life; HTA, health technology assessment.

in decision-making in clinical research and HTA, the input of health care professionals is not based on a representative sample either.

Comparison with previous research

Studies using preference elicitation methods have been published increasingly over the last decade.^{7,16,20} In our previous descriptive review on methods to prioritize outcomes, we identified several studies comparing preferences for the outcomes of different stakeholders; most of them compared preferences of patients and clinicians.⁷ The studies identified were conducted in different health care settings and used different methods to evaluate the importance of outcomes. Most studies showed notable differences between preferences of patients and other stakeholders, that is, either different hierarchies or at least different strengths of preferences for outcomes.

We did not identify a single study comparing the preferences of any of the 3 stakeholder groups, and investigated with such a large reference group as the one included in our analysis; furthermore, we are not aware of studies comparing the preferences of HTA authors or dialysis patients with those of other groups.

Preference elicitation methods, especially multicriteria decision analysis (MCDA), are being increasingly used for reimbursement decisions in HTA.^{20,21} A systematic review of studies applying MCDA methods in decisions addressing the trade-off between costs and benefits found that the majority of studies used health outcomes as a criterion to elicit preferences from different stakeholder groups. Interestingly, health policy decision makers were more intensely involved, while patient involvement was limited.¹⁵

Implications of research findings

The choice of important outcomes has implications for the evaluation of efficacy in clinical research and consequently of comparative effectiveness in HTAs. The explicit elicitation of preferences from different stakeholder groups can make the process of clinical research and HTA more transparent and add important dimensions.^{22,23}

The question arises as to how outcomes reflecting patient preferences can be identified for decision-making in clinical research and HTA in a valid and feasible manner. Our study indicates that even though some deviations exist, the preferences of a self-help group might represent an adequate proxy for a large patient population with the same condition.

The preferences of clinicians and HTA authors deviated to a greater extent from those of the reference group but not so much that they should be discarded in cases where direct

access to patient groups is not feasible. More importantly, their insights are relevant for outcomes not perceptible but still potentially important to patients (eg, clinical outcomes). Furthermore, they can advise on outcomes that might not be of major importance to the individual patient but to the health care system or society in general.

The Standardized Outcomes in Nephrology-Hemodialysis (SONG-HD) initiative is working on a core outcome set for all trials in hemodialysis involving patients and health professionals.²⁴ However, further research is needed to analyze how preferences of different groups can be implemented in research decisions.²⁵

Conclusion

Our study indicates that preferences of different stakeholders (CKD patients from a self-help group, nephrologists and HTA authors) differ to a varying extent from those of a large reference group of patients with CKD. The involvement of self-help groups might be a feasible means of including patient preferences in outcome prioritization, but the effects of the mode of sampling have to be considered in the interpretation of results. In addition, the preferences of health care professionals such as clinicians and HTA authors should be considered, as only the combination of all preferences forms the basis of a transparent discussion on important outcomes in clinical research and HTA.

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Disclosure

The authors report no conflicts of interest in this work.

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Supplementary material

Table S1 Ratings of importance of outcomes by the stakeholder groups

| Outcomes | Reference group | | Self-help group | | HTA authors | | Nephrologists | |
|----------------------------|-----------------|------|-----------------|------|-------------|------|---------------|------|
| | Mean (SD) | Rank | Mean (SD) | Rank | Mean (SD) | Rank | Mean (SD) | Rank |
| Safety | 8.33 (1.6) | 1 | 8.59 (1.4) | 1 | 7.00 (2.0) | 6 | 8.11 (1.5) | 7 |
| HRQoL | 8.23 (1.5) | 2 | 8.33 (1.6) | 3 | 8.28 (1.0) | 1 | 8.42 (1.2) | 4.5 |
| Satisfaction | 8.16 (1.5) | 3 | 7.96 (1.9) | 6 | 6.00 (2.0) | 11.5 | 8.53 (0.7) | 2 |
| Hospital stays | 8.07 (1.7) | 4 | 7.84 (2.2) | 8 | 6.78 (1.9) | 7 | 8.05 (1.4) | 8 |
| Accompanying symptoms | 8.02 (1.7) | 5 | 7.82 (2.0) | 9.5 | 6.22 (1.7) | 10 | 7.68 (1.1) | 11.5 |
| Hemodialysis duration | 8.00 (1.6) | 6 | 7.88 (1.9) | 7 | 5.33 (2.2) | 17.5 | 7.21 (1.6) | 17 |
| Emotional state | 7.97 (1.7) | 7 | 8.08 (2.0) | 4 | 7.50 (1.2) | 4 | 8.50 (1.0) | 3 |
| Access to nursing staff | 7.96 (1.7) | 8 | 7.33 (2.2) | 16 | 5.50 (2.1) | 16 | 8.79 (0.4) | 1 |
| Traumatic punctures | 7.93 (1.7) | 9 | 8.06 (1.6) | 5 | 5.72 (1.6) | 15 | 7.79 (1.2) | 9.5 |
| Nausea/drop blood pressure | 7.92 (1.8) | 10 | 7.82 (2.0) | 9.5 | 5.78 (1.5) | 14 | 8.26 (0.9) | 6 |
| Physical functioning | 7.84 (1.9) | 11 | 8.53 (1.4) | 2 | 7.33 (1.9) | 5 | 8.42 (1.0) | 4.5 |
| Information | 7.83 (1.7) | 12 | 7.69 (2.0) | 13 | 6.00 (2.8) | 11.5 | 7.79 (1.6) | 9.5 |
| Access to medical staff | 7.75 (1.8) | 13 | 6.38 (2.3) | 20 | 4.44 (1.6) | 20.5 | 7.47 (1.5) | 14.5 |
| GI symptoms | 7.55 (2.0) | 14 | 6.9 (2.6) | 18 | 5.33 (1.3) | 17.5 | 7.26 (1.4) | 16 |
| Life expectancy | 7.54 (2.2) | 15 | 7.63 (2.4) | 14 | 7.56 (1.8) | 3 | 7.47 (1.5) | 14.5 |
| Dialysis organization | 7.50 (2.0) | 16 | 7.28 (2.1) | 17 | 5.94 (1.9) | 13 | 6.56 (2.1) | 19 |
| Itching | 7.48 (2.1) | 17 | 7.71 (2.2) | 12 | 5.22 (1.7) | 19 | 7.68 (1.6) | 11.5 |
| Participation | 7.25 (2.1) | 18 | 7.78 (1.9) | 11 | 6.67 (1.7) | 8 | 7.05 (1.7) | 18 |
| Journey time | 6.62 (2.6) | 19 | 6.84 (2.5) | 19 | 6.33 (1.6) | 9 | 5.79 (2.1) | 20 |
| Collaboration | 6.34 (2.4) | 20 | 4.4 (2.6) | 23 | 3.61 (1.7) | 23 | 4.95 (2.1) | 23 |
| Choice of medical staff | 6.15 (2.7) | 21 | 5.88 (2.6) | 21 | 4.44 (2.5) | 20.5 | 5.00 (2.4) | 22 |
| Choice of nursing staff | 5.85 (2.7) | 22 | 5.67 (2.7) | 22 | 3.78 (2.1) | 22 | 5.05 (2.4) | 21 |
| Work | 4.50 (3.0) | 23 | 7.39 (2.7) | 15 | 7.61 (1.2) | 2 | 7.63 (1.6) | 13 |

Abbreviations: GI, gastrointestinal; HRQoL, health-related quality of life; HTA, health technology assessment.

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