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Original Article

Health profiles and health preferences of dialysis patients

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Abstract

Background. Health-related quality of life (HRQOL) of haemodialysis (HD) and peritoneal dialysis (PD) patients has been assessed with health profiles and health preferences methods. Few studies have used both types of HRQOL instruments. The main objective of this study was to assess the relationship between information from the two types of HRQOL instruments in dialysis patients.

Methods. We interviewed 135 patients, using two health profiles (Short Form 36 and EuroQol/EQ-5D) and two health preferences methods (Standard Gamble and Time Trade Off). Socio-demographic, clinical, and treatment-related background data were collected from patient charts and during the interview. Relationships between the outcome measures were assessed with Pearson correlation coefficients. Multiple regression models were used to study the relationship of HRQOL outcomes to background variables.

Results. The HRQOL of dialysis patients as measured with health profiles was severely impaired. The health preferences scores were higher (0.82–0.89) than scores previously reported in the literature. Correlations between health profiles and health preferences were poor to modest. HRQOL outcomes were poorly explained by background characteristics. Differences between HD and PD groups could not be demonstrated.

Conclusions. Health profiles and health preferences represent different aspects of HRQOL. An impaired health status may not be reflected in the preference scores. Coping strategies and other attitudes towards health may affect the preference scores more than they influence health profile outcomes. The added value of health preferences methods in clinical research is limited.

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Introduction

Many different questionnaires and interview techniques, either generic or disease-specific, have been used for the assessment of health-related quality of life (HRQOL) in end-stage renal disease (ESRD) patients [1,2]. Generic HRQOL measures cover all important aspects of health and are intended to be applicable in a wide variety of conditions, patients, and demographic groups. Therefore, they can be used to compare a patient group suffering from a certain disease with other patient groups and with general population samples. Within the group of generic measures, a distinction can be made between health profiles and preference or utility-based measures [3]. Health profiles describe the health status of a person on a number of domains, such as physical, psychological, and social function. Preference-based measures aim to express HRQOL in a single indicator; often a number between 0 and 1, where 0 represents death and 1 represents full health.

The experience with preference measurements in dialysis patients is relatively limited. A MedLine literature search identified 16 studies using preference measurements in dialysis and renal transplant patients [4–19]. Most studies that applied preference measurements have assessed small patient groups and focused on renal transplantation and haemodialysis (HD). Peritoneal dialysis (PD) was only covered in two Canadian studies from the 1980s [4,7], and in one more recent publication that included 30 PD patients [14]. Only two studies reported on the relationship between health profiles and health preferences in ESRD patients [10,18]. Both studies found low to moderate correlations between the two types of instruments (correlation coefficients between 0.15 and 0.31). The purpose of the present cross-sectional study was to

compare health preference methods with health profiles in HD and PD patients. Two health preferences methods (Standard Gamble (SG) and Time Trade Off (TTO)) and two health profiles (Short-Form 36 and EuroQol/EQ-5D) were used to study HRQOL.

Subjects and methods

Study design and patients

A total number of 135 dialysis patients participated in this study. These patients participated in a prospective cohort study on the adequacy of dialysis, the NECOSAD-I study [20]. The 135 patients interviewed were treated in 13 of the 49 dialysis centres in The Netherlands. The study was approved by the ethical committees of all participating centres. In the period October 1993 to March 1995, all new patients in these 13 centres were asked to participate in NECOSAD. All patients who had not been withdrawn from NECOSAD by the time we started the present HRQOL study and who had received the same dialysis treatment for at least 3 months were considered for inclusion. Further inclusion criteria were written informed consent, age above 18 years, adequate eyesight to enable the administration of questionnaires and an adequate understanding of the Dutch language. Interviews were conducted at patients' homes by one of three trial nurses, who received training to administer the HRQOL questionnaires. For HD patients, interviews were carried out on non-dialysis days.

Background variables

At the interview, data were collected on sex, age, marital and employment status, and educational level. Data on primary diagnosis, dialysis adequacy, current treatment, treatment history, length of time on dialysis, and presence of comorbid diseases at the start of dialysis were obtained from the NECOSAD study and the patient's nephrologist. Primary diagnosis of renal failure was classified according to the ERA–EDTA classification. Adequacy of dialysis was expressed as weekly total K_t/V_{urea} in HD and PD patients. HD K_t/V_{urea} was estimated using a second generation Daugirdas formula [21]. The weekly K_t/V_{urea} in PD patients was calculated as the peritoneal K_t/V_{urea} per 24 h multiplied by 7.

Questionnaires used to assess HRQOL

HRQOL was assessed with the Short-Form 36 (SF-36) Health Survey, EuroQol/EQ-5D, SG, and TTO. The four questionnaires were always administered in this sequence. The first two questionnaires were self-completed. The interviewer then continued with the administration of the SG and TTO.

The SF-36 Health Survey generates a profile of scores on eight dimensions of quality of life [22]. These dimensions are (i) physical functioning, (ii) role functioning—physical, (iii) bodily pain, (iv) general health perception, (v) vitality, (vi) social functioning, (vii) role functioning—emotional, (viii) mental health. Raw scores on the eight scales are transformed to calculate a score between 0 and 100, where a higher score indicates better health. The physical and mental components of the eight scales are combined into a Physical Component Summary (PCS) and a Mental Component Summary (MCS). The two summary measures are standardized to have a mean of 50 and a standard deviation of 10 in the general population and, therefore, allow for easy comparison of patient scores with general population scores. SF-36 scores of persons of similar age (55–64 years) were derived from a validation study in the Dutch population [23].

The EQ-5D or EuroQol is a generic questionnaire, consisting of a classification system ($EQ\text{-}5D_{profile}$) and a Visual Analog Scale (EQ_{VAS}) [24]. The $EQ\text{-}5D_{profile}$ covers five domains of health (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), each with three levels of functioning: (level 1, no problems; level 2, some problems; level 3, severe problems). The EQ_{VAS} is a graduated, vertical line, anchored at 0 (worst imaginable health state) and 100 (best imaginable health state). The patient is asked to mark a point on the EQ_{VAS} that best reflects his/her actual health state.

The SG is a method to measure preferences for health states [25]. The respondent is presented with two alternatives and asked to choose the one most preferred. The first alternative offers the certainty of staying in the current health state for the remainder of the respondent's life. The second alternative is a gamble with specified probabilities for both the positive outcome of the gamble (a normal health state for the remainder of time) and the negative outcome (immediate death). These probabilities are varied until the respondent is indifferent between the gamble and living in his/her current health state. The SG score, a score between zero and one, is calculated as one minus the risk percentage at the point of indifference, divided by one hundred. An SG score of 0.80 implies that a person is prepared to take a gamble with 20% risk of dying immediately and 80% chance to improve his current health to normal health. The SG score reflects the value a person assigns to his own health state. In our study, the concept of the SG was practiced with a visual aid, using imaginary health states. Afterwards, the patient was asked to value his own current health state.

The TTO method is also a preference-based method [4,7]. Patients are asked whether they are prepared to give up some remaining time of their lives, in order to improve their current health state to normal health. The time perspective that is presented to the patient corresponds with statistical life expectancy of people of the same age and sex. The quotient of the chosen number of years in a normal health state over statistical life expectancy yields the TTO score. A TTO score of 0.80 implies that a person is indifferent between living 8 years in excellent health *vs* 10 years in his current health state. We practiced the TTO concept with imaginary health states, before the patient was asked to value his/her own current health state.

Statistical analysis

Differences between HD and PD treatment groups were tested by means of Student's *t*-test or Mann–Whitney *U*-test, as appropriate. Categorical variables were compared using the Pearson χ^2-test. Mann–Whitney *U*-test was used for non-response analysis. In order to be able to control for case-mix differences, the association between background variables (see above) and main quality of life outcomes was studied with multiple regression models. A forward stepwise selection strategy was chosen, using the *F*-statistic with $P = 0.05$ as the criterion level for selection. To search for violations of necessary assumptions in multiple regression, normal plots of the residuals of the regression models were produced. The

relationship between health profiles and health preference measures was assessed with Pearson correlation coefficients. Analyses reported here are based on treatment at the time of the interview. A two-sided *P*-value of 0.05 was chosen as cut off for statistical significance.

Results

Patient characteristics

In April 1995, 193 patients still participated in the NECOSAD study. Eight patients (4%) could not be interviewed because they were medically unstable or had language problems. A group of 24 patients (13%) was withdrawn from follow-up in the NECOSAD study before an interview could be scheduled, either because of transplantation, death, or transfer to a non-participating dialysis centre. Finally, 26 patients (14%) refused to participate in the present study. This resulted in 135 patients (70%) who were interviewed.

Table 1 lists the main demographic, clinical, and treatment characteristics of the 135 patients interviewed, according to treatment modality. Sixty-nine patients were treated with HD and 66 with PD (59 CAPD and seven APD). The HD and PD groups differed significantly with respect to age and educational level. On average, PD patients were 5 years younger and better educated than HD patients. No other demographic and clinical differences were found between the groups.

Table 1. Patient characteristics according to treatment modality (mean, SD, range, or per cent)

	HD ($n = 69$)	PD ($n = 66$)
Age[a]	60 (15) 21–87	55 (13) 25–79
Male	52%	66%
Married/living together	75%	86%
Employed	19%	30%
Educational level[a]		
Low	32%	20%
Intermediate	64%	73%
High	4%	12%
Primary kidney disease		
Glomerulonephritis	10%	13%
Renal vascular disease[b]	25%	23%
Nephritis	16%	11%
Cystic kidney disease	10%	11%
Diabetes mellitus	7%	15%
Others and unknown	32%	27%
Number of comorbid conditions	1.75 (1.40) 0–6	1.80 (1.29) 0–7
Type of comorbid condition		
Cardiovascular	62%	77%
Diabetes mellitus	12%	18%
Malignancy	9%	3%
Weekly K_t/V_{urea} (total)	3.7 (0.89) 2.0–5.8	2.0 (0.43) 1.3–2.9
Therapy change in past 6 months	12%	8%
Months on dialysis	15 (3) 7–23	15 (4) 7–22
Months on this modality	12 (5) 3–23	13 (5) 3–21

[a] $P < 0.05$, HD *vs* PD.
[b] Including hypertensive nephrosclerosis.

Results of SF-36

The upper part of Table 2 contains the two SF-36 summary scores for physical (PCS) and mental (MCS) HRQOL. HD and PD patient groups did not differ with regard to PCS and MCS scores. The mean PCS score of this sample of dialysis patients was 1.2 SD ($P < 0.001$) below the mean score for a general population sample of the same age. The mean MCS score of both groups of dialysis patients was not different from the reference group.

Results of EQ-5D

As shown in Table 2, self-rated health status on the EQ_{VAS} was similar for both patient groups, with scores of 60 and 62 on a scale from 0 to 100. Table 3 shows the proportion of HD and PD patients that indicated having some or severe problems on the five dimensions of the $EQ\text{-}5D_{profile}$. None of the differences between HD and PD patients were significant. Patients turned out to have problems on all five dimensions. Most problems were present with 'daily activities': 61% of the patients could not perform their daily activities normally. Approximately half of the patients reported some or severe difficulties with 'mobility' and 'pain'. Fourteen per cent of the patients had difficulties with self-care, such as bathing and dressing independently. In this patient sample, 24% of responders felt anxious and/or depressed.

Results of SG and TTO

Answers to SG could not be obtained in five patients (3.7%) and answers to TTO could not be obtained in 14 (10.4%) patients. This non-response was caused by patient refusal to answer and/or cognitive problems in understanding the SG and TTO concepts. The reasons for refusal were diffuse and included religious reasons, familial circumstances, and patient fatigue. Responders and non-responders to SG and/or TTO were compared

Table 2. Mean (SD and range) scores on health-status and health-preference questionnaires

Outcome parameter	HD ($n = 69$)	PD ($n = 66$)
Health profiles		
SF-36 PCS[a,b]	37.6 (10.6) 15–58	38.3 (10.7) 16–56
SF-36 MCS[a]	47.9 (12.3) 14–66	48.4 (11.0) 23–65
VAS		
EQ_{VAS} (scale 0–100)	60.3 (17.7) 5–100	62.4 (20.3) 10–95
Health preferences		
SG (scale 0–1)	0.86 (0.19) 0.2–1.0	0.82 (0.23) 0.0–1.0
TTO (scale 0–1)	0.89 (0.17) 0.15–1.0	0.87 (0.21) 0.0–1.0

[a] Standardized to general population mean (mean 50, SD 10).
[b] $P < 0.001$, compared with a similar age-group from the general population [23].

Table 3. Proportion of HD and PD patients showing none (level 1), some (level 2), or severe (level 3) problems on EQ-5D$_{profile}$

EQ-5D dimension[a]	HD			PD		
	Level 1	Level 2	Level 3	Level 1	Level 2	Level 3
Mobility	46.4	53.6	0.0	57.6	39.4	3.0
Self-care	82.6	14.5	2.9	89.4	9.1	1.5
Daily activities	40.6	39.1	20.3	37.9	50.0	12.1
Anxiety/depression	78.3	20.3	1.4	74.2	22.7	3.0
Pain	59.4	36.2	4.3	53.0	42.4	4.5

[a]Differences between modalities not significant ($P > 0.05$).

Table 4. Analysis of non-response to SG ($n = 5$) and/or TTO ($n = 14$)

Feature	Non-responders mean (SD)	Responders mean (SD)
Age[a]	67 (11)	56 (14)
No. of comorbid conditions	1.9 (1.6)	1.8 (1.3)
Time on dialysis (months)	14 (2.4)	15 (3.9)
SF-36 PCS score[b]	34 (12)	38 (10)
SF-36 MCS score[b]	44 (16)	49 (11)
EQ$_{VAS}$ score[a]	48 (16)	63 (19)

[a]$P < 0.01$, responders *vs* non-responders.
[b]Standardized to the general population mean (mean 50, SD 10).

with respect to age, number of comorbid conditions, time on dialysis, and HRQOL as measured with health profiles. Results of the non-response analysis are shown in Table 4. Compared with responders, non-responders were older and had a worse self-rated health as assessed with the EQ$_{VAS}$.

The lower part of Table 2 shows the mean SG and TTO scores of both patient groups. HD and PD patients groups valued their health status equally high ($P > 0.05$), with scores between 0.82 and 0.89.

Association between background variables and HRQOL outcomes

The results of the multiple regression analyses to explain the independent associations between demographic, clinical, and treatment variables on the one hand and outcome variables on the other hand are shown in Table 5. The number of comorbid conditions was negatively associated with all HRQOL outcomes, except MCS. Age was negatively associated with PCS and with the EQ$_{VAS}$ score. Employed patients had better PCS and EQ$_{VAS}$ scores. The number of months on dialysis was negatively associated with MCS and EQ$_{VAS}$ scores. Treatment modality was not associated with any of the HRQOL outcomes. The models constructed showed that HRQOL was poorly explained by the background variables under study (total adjusted R^2 from 1.9 to 18.2%).

Relationships between health profiles and health preferences

The correlations between health profiles outcomes and health preference measurements are shown in Table 6. Correlations between the two types of questionnaires were poor to modest ($r = 0.03-0.31$). With regard to the TTO, the highest correlations were found with SF-36 scales social functioning ($r = 0.29$), bodily pain ($r = 0.23$), and vitality ($r = 0.21$). The SF-36 domains that correlated best with the SG score were vitality ($r = 0.31$), mental health ($r = 0.29$), and social functioning ($r = 0.24$).

Discussion

The present cross-sectional study using four different HRQOL measures showed a similar impairment of quality of life in HD and PD patients. Compared with a general population sample of similar age, impairments were most obvious in the physical components of health profiles, but much less for the mental components. The preference-based measures yielded relatively high scores for dialysis patients. Multiple regression analysis showed that background variables, such as the presence of comorbid diseases, explained 15% of physical HRQOL and 18% of the VAS. Correlations between the different HRQOL tests were poor to modest. These findings will be discussed in the following sections.

The severely reduced physical HRQOL of dialysis patients in comparison with the general population has been reported in many other studies (reviewed in [26]). The equivalence of HRQOL in HD and PD patients found in the present study is in accordance with the results of other recently published investigations [27,28], but could also be related to the inadequate power to detect differences between groups. Given the number of patients included in our study, the power was adequate ($\beta > 80\%$) to detect differences of 5.3 (PCS) to 5.7 (MCS) units in the scale scores between PD and HD patient groups. Our study adds to the existing nephrologic HRQOL literature because we have not only applied health status measures but also health preference measurements. Preference-based instruments have been used less often than health

Table 5. Multiple regression analysis[a] to study the association between demographic, clinical-, and treatment-related variables and outcome variables, expressed as standardized regression coefficient β, partial R^2 and total R^{2b}

	SF-36 PCS	SF-36 MCS	EQ_{VAS}	SG	TTO
Age	−0.14 (2.0%)		−0.19 (2.6%)		
Employment status	0.18 (3.3%)		0.16 (7.0%)		
No. of comorbid conditions	−0.28 (8.9%)		−0.20 (3.7%)	−0.19 (3.0%)	−0.14 (1.9%)
No. of months on dialysis		−0.17 (3.3%)	−0.24 (4.9%)		
Total R^2	15.1%	3.3%	18.2%	3.0%	1.9%

[a]No violations of necessary assumptions in multiple regression analyses were detected.
[b]Associations shown in the table were the only significant associations found. The number in each cell refers to the standardized regression coefficient β, indicating the relative importance of the independent variable: the higher the β coefficient the higher the contribution of the independent variable in the regression equation. The bracketed number in each cell symbolizes R^2, the explained variance of the dependent variable accounted for by the single independent variable. Total R^2 is the percentage of variation of the dependent variable score that is accounted for by the independent variables together.

status measures and only three studies have reported on health preferences of PD patients [4,7,14]. The present study has shown that health preferences of HD and PD patients were similar. A remarkable finding of the present study was the high scores (0.82–0.89) obtained using the preference measurements. These values indicate that patients on average valued their current health state as 82–89% of normal health. The average TTO value found in the present study (0.88), was similar to the value found after renal transplantation (0.87) in a study from the 1980s [4]. Typical values of prevalent dialysis patients are in the 0.40–0.70 range, with two exceptions of patients reporting values above 0.80 [10,19]. Highest scores were found in patients with a renal transplant [4,16], in patients using erythropoietin [9], and in more recently published studies [6,10,12,19].

Why do our scores differ from scores found previously? We excluded patients with language or vision problems from our study, but, due to the nature of preference measurement, such positive patient selection must also have been present in other series. Besides, the SF-36 outcomes in our patients are similar to other published SF-36 scores of dialysis patients [29,30], making it less likely that our higher preference scores are caused by selection bias. Our patients were recruited from a clinical study on adequacy of dialysis. Consequently, patients were monitored intensively by highly motivated staff members. This may have had a positive influence on perceived HRQOL. Further, widespread use of erythropoietin (Epo) among study patients (85%) may have played a role. Most of the previous work on preferences of dialysis patients stems from the pre-Epo period. Of the three studies that have reported on the contribution of Epo to health preference scores, one small study ($n = 28$) showed higher TTO scores after introduction of Epo [9]. However, a large ($n = 118$) placebo-controlled randomized trial [5] and an observational study in 40 patients [17] showed stable TTO scores after the introduction of Epo, despite improvements in the physical and fatigue domains of HRQOL. Given the fact that the best evidence is provided by the randomized trial, we do not consider Epo use as an important factor to explain our relatively high preference scores.

The influence of non-responders on the high average preference scores has at best been limited. The patients in our sample that did not respond to SG and/or TTO (12%) were older and had a worse self-rated health than responders. In the unlikely event that all non-responders to the TTO had valued their current health state at 0, the average TTO score still would have been 0.79. Finally, it has to be considered that preference-based methods are less reliable than suggested [4,7,31], at least in a cross-cultural context, because cultural differences present between countries or continents might have a strong influence on the valuation of health. In the present study, some patients refused to answer SG and TTO for religious reasons. It is possible that this religious factor resulted in unwillingness of patients to trade-off quality and quantity of life or to accept a gamble with a negative outcome, resulting in higher scores than in non- or less religious populations. Also, cultural differences in the attitude towards risk may exist. Our finding of high preference values in Dutch dialysis patients is in accordance with data from other international comparative research [32], which showed that The Netherlands, among 48 countries, scored highest on several well-being scales. A positive general attitude to life in The Netherlands might, therefore, have influenced preference scores in our study. We suggest that health preference scores of similar patient populations may not easily be compared if elicited in different countries or continents. The influence of cultural differences on health preferences and the transferability of study results to other countries remains a subject for future study.

Correlations between health preferences methods and health profiles were absent to moderate (maximal Pearson's r 0.31). This finding is in accordance with results of previous research in ESRD patients [10,18], pre-dialysis patients [33], and other seriously ill patients [34,35], but could also be contributed to insufficient variance in the data or insufficient statistical power to detect correlations. Correlation as a measure of association depends on the variance of values found. Because patients' preference scores in the present study concentrated at the upper end of the scale, high correlations are unlikely. The sample size used was

large enough to detect correlations as low as 0.25 with adequate statistical power, but most correlation coefficients were below that threshold. Two studies which have used multiple regression analyses to study the independent associations between health profiles and health preferences found R^2 values of 19 and 0% [33,34]. We have not reported such multivariate analyses because it is instantly clear from the low Pearson correlation coefficients (Table 6) that health preferences scores cannot be explained by health profile outcomes. The implication of this finding is that both types of questionnaires truly reflect different aspects of the HRQOL concept. The health profiles assess patients' functioning on different domains of quality of life, whereas the health preferences methods elicit individual judgements of the value of the current health status, relative to full health and death. The implication is that the two types of questionnaires may lead to different conclusions on HRQOL of dialysis patients. The descriptive questionnaires SF-36 and EQ-5D indicated that quality of life of dialysis patients in this study was severely impaired. Despite these impairments, patients valued their health status as high as 82–89% of normal health. The discrepancy between the results of the descriptive questionnaires and the preference measurements might be explained by the fact that the coping mechanism, through which patients gradually learn to adapt to their new situation and to accept the fact that it will remain unchanged, is more reflected in the preference-based methods than in the descriptive questionnaires. The reality for many ESRD patients seems to be that, despite the severe physical limitations experienced in everyday life, they subjectively experience a relatively high quality of life.

Table 6. Correlation (Pearson's *r*) between descriptive instruments and preference measurements

		TTO	SG
SF-36[a]	PF	0.18	0.16
	RP	0.15	0.23[c]
	BP	0.23[b]	0.23[c]
	GH	0.14	0.16
	VT	0.21[b]	0.31[c]
	SF	0.29[c]	0.24[c]
	RE	0.11	0.07
	MH	0.15	0.29[c]
	PCS	0.21[b]	0.21[b]
	MCS	0.19[b]	0.23[c]
EQ-5D	Mobility	−0.15	−0.18[b]
	Self-care	0.03	−0.07
	Daily activities	−0.19[b]	−0.20[b]
	Pain	−0.16	−0.13
	Anxiety/depression	−0.18[b]	−0.20[b]

[a]Abbreviations: PF = physical functioning, RP = role functioning—physical, BP = bodily pain, GH = general health perceptions, VT = vitality, SF = social functioning, RE = role functioning emotional, MH = mental health, PCS = Physical Component Score, MCS = Mental Component Score.
[b]$P < 0.05$.
[c]$P < 0.01$.

The multivariate regression analyses (Table 5) failed to show obvious relationships between socio-demographic-, clinical-, and treatment-related variables and health preferences scores. Previous research showed that health preferences were also not correlated with clinical variables, such as haematocrit, haemoglobin, and glomerular filtration rate [33]. If health preferences scores are poorly explained by both health status (Table 6) and socio-demographic, clinical-, and treatment-related variables (Table 5), what else constitutes a person's preference score? Besides, by coping behaviour of patients, the preference scores may be influenced by beliefs about health, previous experiences and knowledge, a person's attitude towards risk and time and non-health related factors, such as financial status, family circumstances, and social support [31]. These confounders hamper the strict interpretation of the preference scores as the valuation of health status only and, consequently, the use of health preference methods in clinical HRQOL studies, especially in populations of chronic patients. In such populations, the coping process may prevent patients from using the whole range of possible scores [36]. Two of the three prospective Epo studies that used the TTO instrument reported no difference in health values after treatment with Epo had been started [5,17]. Also, a study in survivors of myocardial infarction concluded that health values are stable over time, despite changes in health status [37]. This further reduces the usefulness of health preference methods, especially in prospective studies. Other disadvantages of health preferences methods include the necessity of an interviewer situation, the relatively high non-response and the unknown influence of cross-cultural factors on health values of patients. Until these issues are resolved, the use of health preferences methods should be limited to a research context.

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