



Quality of life in patients on peritoneal dialysis

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INTRODUCTION

Quality of life (QL) issues are now recognised as important outcome measures in health care, cost-effective analyses of the efficacy of medical care and clinical trials, and therapeutic interventions for chronic conditions, including end-stage renal disease (ESRD). QL also factors in the decision-making process for dialysis treatment selection.¹ The past decade has seen a tremendous surge in research publications that have included measures of QL. A search on PubMed in March 2007 using the terms 'quality of life' and 'dialysis' yielded 1951 publications of which 1330 were published within the last 10 years. Haemodialysis (HD) is still the primary focus of treatment in many of these studies; only a relatively low number of studies examine quality of life in patients on peritoneal dialysis (PD). PD has less research compared to HD because it is a newer therapy and until recently, has been limited to selected ESRD patients requiring dialysis.

With the increased incidence of ESRD worldwide due to an aging world population, and the increasing prevalence of comorbid diseases,²⁻⁵ the demand for renal replacement therapy (RRT) is also on the rise. Advances in RRT techniques such as PD have not only improved survival⁶ but PD is also now regarded as a viable option for the elderly and patients with more comorbid medical conditions.⁷⁻¹⁰ Nevertheless, PD remains intrusive and burdensome on patients' lives. With patients on PD now living longer, their perceptions of the effect of PD treatment on their survival and quality of life should also be an important consideration in their clinical management.

Our chapter discusses 1) the complexity involved in the definition of QL; 2) the various instruments used in QL assessment with PD patients; 3) the psychometrics of QL instruments; 4) determinants of QL in PD patients, and 5) recommendations for future direction in the assessment of and interventions aimed at improving QL in PD patients.

DEFINITION OF HEALTH-RELATED QUALITY OF LIFE

Defining QL is complex as it can encompass a wide range of factors including psychological, cognitive, social, economic, political, cultural, spiritual, and physical factors.¹¹ The World Health Organization (WHO)¹² defines health as 'a state of complete physical, psychological and social well-being and not merely the absence of disease or infirmity.' Whilst specifying the important domains of QL, the WHO definition is too broad and simplistic, implicitly covering dimensions

such as education opportunities, social freedom or economic development opportunities which are not of direct clinical relevance or concern when assessing treatment outcomes of chronically ill patients. Of pertinence to patients and health care providers are aspects of QL related to health or health-related quality of life (HRQL), namely the physical, psychological, and social functioning domains. However, the definition of HRQL in clinical research is still debated. Schipper *et al*¹¹ conceptualised HRQL as ‘the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient.’ (p. 16). Patrick and Erickson¹³ defined HRQL as a ‘value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy’. Wilson and Cleary¹⁴ formulated HRQL as a continuum of biological/ physiological factors at one end, and increasing in complexity to include measures of physical functioning and psychological well-being at the other end. The relationships between these factors are mediated by personal and environmental factors. Figure 1 provides a schematic representation of the relationships between the factors, as proposed by Wilson & Cleary.¹⁴

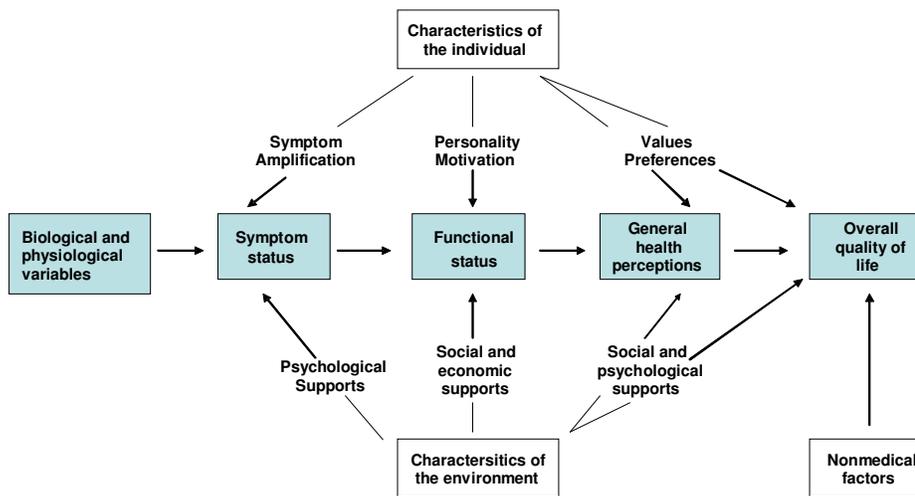


Figure 1. Conceptual model depicting relationships between patient outcome variables in HRQL (Wilson & Cleary, 1995, pg 60)

This lack of consensus on the definition of HRQL is also present in ESRD research on this topic.¹⁵ Early research into HRQL of dialysis patients had focused physical functioning as an outcome measure,¹⁶ before evolving into multidimensional assessments to include other aspects such as social and psychological functioning.¹⁷ Recent studies have also addressed the perceptions of dialysis patients of their illness and treatment as determinants of HRQL.¹⁸

A criticism of global health scores generated from multidimensional assessments is that they might not reflect a patient's actual HRQL.¹ For example, an ESRD patient with an amputation might describe poor physical functioning but who is otherwise having a better QL after starting dialysis, will have a low global QL score due to the poor physical functioning. Also most HRQL measures are not patient-centered as the domains being assessed might not be of critical relevance to the patients, or patients' choice of answers could be restricted.^{1;16} Kalantar-Zadeh & Unruh¹⁶ envision a more patient-centred approach to HRQL assessment in which patients themselves determine the HRQL domains most salient to them, and information on these domains are then elicited, for example, via semi-structured interviews, as in the Schedule of Evaluation of Individual Quality of Life – Direct Weighted (SEIQoL-DW).¹⁹ The SEIQoL-DW assesses not only the level of patients' functioning, but patients nominate and rate the areas of HRQL of importance to them. Kalantar-Zadeh and Unruh¹⁶ described that a small sample of dialysis patients using the SEIQoL-DW identified HRQL domains often not captured in the SF-36 as being important such as family, marriage, sexual functioning, and spirituality.

PSYCHOMETRICS OF HRQL MEASURES

Given the multidimensional and subjective nature of (health related) quality of life, assessment of HRQL can be challenging, and selection of a suitable HRQL measure from the many that have been developed can be daunting. A HRQL measure can consist of a single item, such as a global health item²⁰ or more common are measures made up of several items or questions.²¹⁻²³ These items can be added up to form domains or dimensions, which are aspects of HRQL of interest that are being measured. Therefore, HRQL measures can also be single or multi-dimensional.

Distinction should also be made if a measure is used for discriminative or evaluative purposes.²⁴ A discriminative measure aims to differentiate HRQL between individuals or groups, whilst an evaluative measure is used to detect change in HRQL over time. An example of both a

discriminative and evaluative measure is the Short-Form 36 (SF-36).²³ A comparative study using the SF-36 showed that patients with a kidney transplant, HD, and PD had poorer HRQL compared with the normal controls, but that kidney transplant patients reported better HRQL when compared with either HD or PD patients.²⁵ The SF-36 has also been used in large cohort studies such as the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) to assess changes in HRQL in dialysis patients over time.²⁶

Depending on the purpose of its use, the hallmarks of a good HRQL measure are its reproducibility and its accuracy in measuring what it claims to measure.²⁷ Both the reproducibility and accuracy of a measure can be evaluated on its psychometric properties such as reliability, validity, responsiveness, interpretability, and ease of administration.

RELIABILITY

Reliability refers to the consistency of a measure. There are several estimates of reliability. Internal consistency refers to the homogeneity of a measure and is indicated by the correlation between items in the scale, or within a scale domain.²⁸ When using an observer-rated or proxy-assessed measure of HRQL, the inter-rater or inter-observer reliability of the measure should be determined to ensure a consistency of ratings that different raters and observers might give to the phenomenon being observed.²⁹ The kappa statistic is often used to determine agreement for measurements collected on nominal or ordinal scales, whilst the intraclass correlation indicates agreement for measurements made on a continuous scale.^{30;31}

Test-retest reliability refers to the consistency of results when the measure is repeatedly administered at different time-points to the same individual. As is with inter-rater reliability, test-retest reliability can be established with the kappa statistic. Multi-item measures should have good internal consistency reliability to ensure there is agreement between items on the measured domain. Internal consistency is indicated when a commonly used estimator, the Cronbach alpha is above 0.70.³²

VALIDITY

A HRQL instrument is considered valid if it measures what it is designed to measure. Types of validity include criterion validity, content validity, and construct validity. Criterion validity is the most difficult to establish with HRQL measures as it requires the measure to be compared to a 'gold standard', for which none exists in HRQL assessment. Content validity refers to the comprehensiveness of the items in sampling the domain of interest.³³ Construct validity is

established by comparing results between different measures that are supposed to measure similar constructs, and the extent these results are consistent with theoretically hypothesised relationships between the measure and the patient group.^{27;34}

RESPONSIVENESS

When using HRQL as an outcome measure of therapeutic efficacy, it is of clinical interest to determine treatment effects on HRQL over time. Therefore, a responsive HRQL measure has to be sensitive in detecting clinically relevant changes over period of follow-up. Related to the sensitiveness of a measure, is the issue of floor and ceiling effects. Presence of such effects especially at the baseline measurement reduces the responsiveness of the measure, as it will be less sensitive in detecting changes in patients' HRQL.³⁵ Responsiveness can be evaluated with the effect size, standardised response mean and/or the responsiveness statistic.^{1;36}

INTERPRETABILITY

Interpretability refers to the ease from which clinically meaningful information can be derived from quantitative HRQL results.^{27;33} A score obtained in a discriminative study should signify whether that individual has normal, mild, moderate or severe impairment in HRQL. Likewise in evaluative studies, changes in HRQL score (even if small in magnitude) should be interpretable in terms of its clinical significance. The baseline measurement should be considered when interpreting change in patients' HRQL scores.³⁷ A small change in a patient with very low baseline functioning might be more clinically important compared to a higher functioning patient registering the same magnitude of change.

METHOD OF ADMINISTRATION, LENGTH, COST OF ADMINISTRATION

The mode of administration is an important consideration when collecting HRQL data as it can influence the response rate. Table 1 summarises the strengths and weaknesses of the various methods of data collection. Interviewer-conducted (either in person or via the telephone) assessments often generate higher adherence compared to self-assessments as response burden is reduced.²⁷ Non-response bias in interviewer assessment is minimised compared to self reports as HRQL information from vulnerable subgroups such as the elderly, severely ill, disabled or those with language/literacy difficulties can be collected.³⁸ Data quality in interviewer assessments can be better than that of self-reports as interviewers can prompt or probe for further details.³⁹ Another advantage of interviewer assessment is that longer questionnaires are

also more feasible as respondent burden is reduced. A randomised trial with community-dwelling elderly women on length of questionnaire and response rate demonstrated that an increase in length of questionnaire decreased the response rate.⁴⁰ However, interviewer-conducted assessments are resource-intensive, incurring higher costs and requiring more time. A study comparing mailed surveys and telephone interviews on the SF-36 reported that telephone interviews were 77% more expensive than the mailed survey.⁴¹ There is also a possibility of underreporting of sensitive items in interviewer assessments.⁴¹ Self-reports are cost-efficient and afford a modicum of response anonymity to sensitive questions. Although response rate to mailed questionnaires are higher, these mailed self-reports have also more missing data.⁴¹ Computer-based adaptive HRQL measures, using multi-media technology could bridge the gap of assessing vulnerable groups, collect precise and practical information for clinical use, and remain cost-effective.⁴²⁻⁴⁴

Table 1. Modes of administration of HRQL measures

Mode of administration	Strengths	Weaknesses
Interviewer	Good response rate; minimizes missing items and errors of misunderstanding	Resource-intensive, high cost; decrease willingness to reveal problems or sensitive issues; limited format of instrument
Telephone	Minimizes missing items and errors of misunderstanding; less resource-intensive than interviewer-conducted assessment	Underreporting of sensitive issues
Self	Cost efficient; involves patient with research and clinical care, empowerment	Issue of non-compliance, missing items, misunderstanding
Proxy	Reduce response burden on target group	Possible differences in perceptions from target group
Computer-based	Able to tailor individual questionnaires by branching, time efficient, assess vulnerable subgroups	Limited by access to computers

adapted from ref (27) and ref (43)

MEASURING HRQL IN PD PATIENTS

HEALTH PROFILES

A wide variety of health profiles used to evaluate HRQL in ESRD patients have been adequately discussed in other reviews.^{16;17;34;45;46} Health profiles provide a description of the health status of an individual based on several HRQL domains. Component scores or a total HRQL scale score are often generated from health profiles. Health profiles can be generic or disease-specific.

Generic measures

Generic assessments have been developed for a wide application to different population groups and allow for comparison of HRQL among different (healthy) populations or patients with chronic diseases.²⁷ As generic assessments are by definition not designed to assess HRQL issues specific to a disease, they are less sensitive in detecting changes in HRQL due to treatment.⁴⁷

SF-36

The SF-36²³ is a generic multi-dimensional HRQL instrument developed for use with various populations.⁴⁸⁻⁵⁰ The SF-36 has 36 items measuring eight dimensions of HRQL: physical functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, mental health, vitality, body pains, and general health perceptions. Items in each subscale are added together to form subscale scores, which are transformed to a 0-100 scale, with higher scores indicating a better HRQOL. The eight subscale scores can be further combined into the physical (PCS) and mental (MCS) component summary score.

The SF-36 is widely applied in comparative studies of HRQL in ESRD patients, and with the general population.⁵¹⁻⁵³ The psychometrics of the SF-36 are sound. Studies with ESRD patients show that it has good internal consistency.^{26;53;54} A large study comparing the HRQL of 16,755 HD and 1,260 PD patients using the SF-36 reported that similar PCS were found in both HD and PD groups, whilst PD patients scored higher on the MCS compared with HD patients.⁵¹ Shorter versions, the SF-12 and SF-8 have since been developed.^{28;55} The SF-12 has been used with dialysis patients.^{56;57}

Nottingham Health Profile (NHP)

The NHP provides a brief assessment of perceived health for use with various populations.⁵⁸ It consists of two parts. Part 1 has 38 yes/no items assessing 6 domains: physical mobility, pain, social isolation, emotional reaction, energy, and sleep. Examples of items include: 'I am tired all the time', 'Things are getting me down', 'I feel I am a burden to people'. Weighted scores with a range of 0-100 are calculated for each domain, and higher scores are indicative of more problems in the domain. The second part assesses the impact of health on 7 life areas. Both parts can be used independently and Part 2 is not scored. A small number of comparative studies with PD patients have used the NHP.^{25;59-63} A Dutch study comparing the HRQL of HD and PD patients in The Netherlands and in Curacao showed only slight differences in HRQL between the groups as measured with the NHP.⁵⁹

Sickness Impact Profile (SIP)

The SIP was developed to assess changes in behaviours as a consequence of illness.⁶⁴ It consists of 136 items descriptive of activities of daily living, divided into 12 categories. Patients endorse statements that best describe them that day and that are related to their health. Examples of SIP items are: 'I walk more slowly', 'I am going out less to visit people', 'I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen'. Endorsed items are scored with a numeric scale value reflecting level of dysfunction; higher scale scores indicate greater dysfunction. In addition to individual category scores, an aggregate Psychosocial score can be derived from 4 categories, whilst a Physical aggregate score is calculated from 3 categories. The SIP can be administered by an interviewer or as a self-report, and takes 20-30 minutes to complete. Although the SIP is a reliable and valid instrument,²⁸ and has been used with ESRD patients,⁶⁵ a study comparing the psychometrics of the SIP and the NHP in a small sample of dialysis patients reported that the NHP was more feasible to administer as it was shorter and easier to understand, and that the internal consistency of the NHP was slightly better compared with the SIP.⁶⁶ Also, the responsiveness of the SIP to detect change has not been well demonstrated.²⁸ A short version of the SIP consisting of 68 items is also available and has been proven to be reliable.⁶⁷

Disease-specific measures

Specific instruments were developed to assess aspects of HRQL of a disease of interest that are not or inadequately assessed in generic measures. The decision to use a disease-specific or a generic instrument depends on the research objectives, as both types of measurements can be complementary.⁶⁸ Disease-specific measures in ESRD such as the Kidney Disease Quality of Life (KDQOL)²¹ include both generic and disease-specific HRQL aspects. A search on PubMed showed that no HRQL instruments had been developed specifically for PD patients.

Kidney Disease Quality of Life

The Kidney Disease Quality of Life (KDQOL) instrument is a self-report questionnaire consisting of 134 items.²¹ It has the SF-36 as its generic core and is supplemented with items of relevance to the HRQL of dialysis patients. Disease-specific items assess symptoms/problems, effects of kidney disease on daily life, burden of kidney disease, cognitive function, work status, sexual function, quality of social interaction, and sleep. Included are also items relating to social support, encouragement from dialysis staff, patient satisfaction with care, and a global rating of health. A shorter version, the KDQOL-SF was subsequently developed in view of the length of the original version. The KDQOL-SF includes the SF-36 supplemented with 43 disease-specific

items from the domains identified in the original version.⁶⁹ The KDQOL-SF is easy to administer, requiring approximately 16 minutes for completion. The KDQOL-SF is a validated and reliable instrument,⁷⁰⁻⁷³ used widely with both PD and HD patients.⁷⁴⁻⁷⁶ The HRQL of a small sample of PD patients showed deterioration over a follow-up of 2 years in the KDQOL dimensions of physical health, mental health, kidney disease issues, and patient satisfaction.⁷⁷

CHOICE Health Experience Questionnaire (CHEQ)

The CHOICE Health Experience Questionnaire (CHEQ) was recently developed for the Choices for Health Outcomes in Caring for End-Stage Renal Disease (CHOICE) study.⁷⁸ The CHEQ is a self-report designed to measure HRQL, and also to discriminate between dialysis modality and dialysis dose on HRQL. It includes the generic measure SF-36, with an additional 6 disease-specific domains (diet, freedom, time, body image, dialysis access, and symptoms). The CHEQ consists of 83 items and requires approximately 25 minutes completion time. Although the reliability and validity of CHEQ have been established,⁷⁸ this instrument has not been used by other research groups.

UTILITY/PREFERENCE-BASED MEASURES

Utility or preference-based measures were designed for cost utilities purposes and assess patients' preference and values for a health state.⁷⁹ Patients' health preferences are combined into a single indicator, usually a numeric representation of a health between 0 and 1, with 0 being death and 1 having optimal health.^{80;81} Often regarded as interchangeable, the terms 'HRQL' and 'health status' however, are conceptually different. A meta-analysis on the relationship between HRQL and health status concluded that patients determine their HRQL and health status differently.⁸² Rating of HRQL is influenced by mental health whilst physical functioning is more important in patients' perceptions of their health status. While utility measures are useful in the analysis of treatment effects and its cost-effectiveness, they might be inappropriate measures for HRQL.⁸² Utility measures are synonymous with the biomedical approach of disease, whilst HRQL measures are reflective of a biopsychosocial perspective.⁸³

EuroQol/ED-5D

The EuroQol/EQ-5D provides a descriptive profile from which an index value of health status is derived.⁸⁴ It consists of 5 items measuring the dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has 3 possible levels of severity. Furthermore, patients can rate their health on the Visual Analogue Scale (VAS) which is a picture of a thermometer calibrated on a scale of 0 ('worst imaginable health state') to 100 ('best

imaginable health state'). The EuroQol/EQ-5D is easy to administer and is reliable⁸⁵ for use with PD samples.^{76;80;86} A Swedish study using data collected with the EuroQol concluded that PD had a more favourable cost-utility ratio compared with HD for ESRD patients who have no contraindications to either of the dialysis therapies.⁸⁷

Time Trade-Off

The Time Trade-Off (TTO)⁸⁸ is a utility instrument that measures the number of life years a person will (hypothetically) exchange for improvement in HRQL. It can be assumed that patients with poor HRQL will be more willing to have shortened life years in return for improved HRQL compared to patients with good HRQL. However, studies suggest weak to poor correlations between health profiles such as the SF-36 and the TTO in dialysis patients.^{80;89} PD patients measured on the SF-36 had poor HRQL, whilst high TTO scores indicated that these patients valued their health status highly.⁸⁰ This suggests that the SF-36 and the TTO measure different aspects of HRQL as impaired physical and mental functioning might not be reflected in the value patients place on their health.⁸⁰

PROXY ASSESSMENTS

Proxy reports refer to information collected on behalf of the patient from their family/caregivers or from the clinical staff. Proxy reports are useful when the patients are too old or young, severely ill, or have communicative difficulties or cognitive impairments.³⁹ However, the reliability of proxy reports on a subjective concept like patients' HRQL has been debated.⁹⁰ A study on agreement between nephrologists, nurses and patients on patients' health rating over time showed lower correlations between ratings by patients and clinical staff as compared to ratings between clinical staff.^{90;91} In general, proxy reports tend to underestimate the HRQL of patients.^{90;92;93} Agreement between proxy and self-reports are usually low for HRQL domains with greater subjectivity and less visibility such as pain intensity, affect or fatigue. Accuracy improves when rating patients' physical functioning or symptoms.^{93;94} Proxy assessments of overt aspects of physical functioning like mobility and activities of daily living, or of symptoms such as nausea and fatigue show higher agreement probably because these aspects provide visual cues to patients' experience.⁹⁰

Karnofsky Index

Originally developed for use with cancer patients undergoing chemotherapy, the Karnofsky Index (KI)²² is a proxy assessment widely used to evaluate physical functioning in ESRD patients.^{95;96} The KI is scored on a range of 0-100 on 11 scales, with higher scores indicative of better

functioning. The KI is not a true measure of HRQL as it is limited by its narrow focus on physical functioning, and that it is a proxy assessment.¹⁶ A study on agreement between two nephrologists using the KI with HD patients reported a low kappa score of 0.29.⁹⁵

Determinants of HRQL in PD patients

PD has been a lifesaver for many patients with ESRD. However, the burdens of the disease and its therapy can still impact negatively on the quality of life. While biological/ physiological factors such as serum albumin levels, anaemia, and residual renal function have been previously studied for their association with HRQL in PD patients, research is now also focusing on the more complex psychological aspects of patients' personality and perceptions on their HRQL. As illustrated in Figure 1, biomedical factors are only distal correlates of HRQL. The perception of patients of biomedical issues mainly determine (HR)QL, for example, poorer self-ratings of health have been associated with higher morbidity and mortality.⁹⁷⁻⁹⁹

CLINICAL FACTORS

The study of biological and physiological factors and their association with HRQL in PD patients has particular resonance with clinicians and clinical practice. However, the relationships between clinical factors and HRQL are not as robust as expected,¹⁰⁰ because HRQL is largely determined by the perceptions of the patient.^{18;101-104} Nevertheless, research into some clinical factors such as haemoglobin, glomerular filtration rate, and nutrition has shown some association with HRQL in dialysis patients.

Haemoglobin/anaemia

The management of anaemia with recombinant human erythropoietin has been associated with improved HRQL in dialysis patients.^{105;106} Increased oxygen transport following normalized haemoglobin levels has been associated with better cognitive and physical function.¹⁰⁷ As part of a multi-centre randomised trial, a Swedish study showed that dialysis patients with normalised haemoglobin levels had improved QL on all domains as measured by the Kidney Disease Questionnaire at 48 weeks from baseline.¹⁰⁸

Glomerular filtration rate (GFR)

PD preserves residual renal function better than HD.¹⁰⁹ An association between a decline in GFR and HRQL has been suggested although results are inconclusive. The Modification of Diet

in Renal Disease (MDRD) study showed that renal deterioration and symptom severity were correlated with declining QL in HD patients.¹¹⁰ Results from the Adequacy of peritoneal dialysis in Mexico (ADEMEX) trial suggest that improving small solute clearance was not associated with improved HRQL in PD patients.¹¹¹ From the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD), Termorshuizen *et al* suggest that residual renal function and peritoneal clearance should not be considered as equivalent.¹¹² The authors found a 12% improved survival of PD patients with every 1 ml/min/1.73m² increase in rGFR whilst no effect of peritoneal clearance on survival was found. This difference in effects of rGFR and peritoneal clearance was also noted on several HRQL dimensions as measured by the SF-36 and the KDQOL.

Nutrition

Protein-energy malnutrition (PEM) is a common occurrence in dialysis patients, consistently associated with poor outcomes.¹¹³⁻¹¹⁵ An Italian study found that increasing levels of serum albumin correlated positively with physical functioning, with a 30-point difference measured on the SF-36 physical functioning subscale between the lowest and highest levels of serum albumin.⁵³ Mittal *et al*¹¹⁶ reported that for every 1 g/dl increase in serum albumin, the physical functioning score on the SF-36 improved by 1.8 in their sample of PD patients. Kalender *et al*¹¹⁷ found that increased serum albumin was associated with better physical functioning. Conversely, an increase in the inflammation marker C-reactive protein (CRP) correlated with both poorer physical and mental functioning for HD patients. However, there was no relationship between serum albumin and CRP levels on HRQL in PD patients. HD patients who were depressed had significantly poorer nutritional status compared with non-depressed patients.¹¹⁸

PSYCHOSOCIAL FACTORS

As quality of life is by definition a subjective entity, major determinants of HRQL are individual characteristics such as personality and perceptions. As illustrated in Figure 1, biomedical factors translate, partly, into HRQL issues via psychological and social processes.

Personality

A study on personality factors and mortality in a group of pre-dialysis patients who were followed for a mean of 49 months found that a 1-point increase in conscientiousness was associated with a 6.4% lower mortality risk, and a 1-point increase in neuroticism was associated with a 4.8% increase in mortality.¹¹⁹ Conscientiousness reflects a patient's self-discipline, self-control, dependability, and the will to achieve, whilst neuroticism infers generalised emotional distress or chronic negative affect.¹²⁰ Dialysis patients with higher conscientiousness scores showed better

medical adherence compared with patients who had a lower conscientiousness score.¹²¹ Personality qualities could also implicitly influence adherence to a dialysis training program.¹²² This study found that poorer adherence to a dialysis training program by incident PD patients was associated with an increased risk of peritonitis. Research with other patient groups suggests motivation and self-efficacy as important factors in adaptation to treatment demands.¹²³⁻¹²⁵ For example, two PD patients with similar clinical prognosis will have different levels of functioning if one of them is more determined to be self-sufficient and have control of their treatment. Having a sense of humour can be protective against the rigors and stress of dialysis. A small study suggests that dialysis patients with a sense of humour lowered their mortality risk by 31%, after accounting for demographics and clinical variables.¹²⁶

Perceptions of illness/wellbeing, satisfaction

Psychological factors such as perceptions of illness and satisfaction levels can also determine HRQL. Leventhal's Self-Regulation Model (SRM) postulates that a person when confronted with an illness, will create a perception or cognition of the illness as an (mal)adaptive mechanism.^{127;128} With its focus on the psychological aspects of HRQL, the SRM can be considered an extension to the model outlined in Figure 1, which exemplifies the biomedical approach to measuring HRQL in chronic illness. The SRM has been well-tested and studies with other chronic illnesses suggest possession of positive illness perceptions¹²⁹⁻¹³¹ is associated with better wellbeing.¹³²

Studies with mainly HD samples suggest that patients who perceive having more control and fewer consequences due to their disease had better health outcomes.¹⁰¹⁻¹⁰⁴ Patients with negative perceptions of their illness have increased risk of depression,¹³³ poorer adjustment to the disease and treatment,¹³⁴ and have poorer HRQL.¹⁸

Patients who perceive ESRD as a negative intrusion into their lifestyle are more likely to have poorer treatment compliance¹³⁵ and higher symptom burden.¹³⁶ Symptoms are subjective perceptions of physical, emotional or cognitive changes experienced by the patient.^{14;137} Correlations between symptoms and clinical variables are often low,^{26;77;138} and the clinical pathophysiology underlying symptoms is still unclear.¹³⁹ A negative correlation between physical symptom distress and HRQL has been well-demonstrated in ESRD patients.^{26;138;140} Common symptom complaints such as pain, fatigue, itch, poor appetite, poor sleep and 'restless legs', and sexual dysfunction, have been associated with reduced HRQL in PD patients.^{100;141-144} Patients

who report feeling more pain and regard it as a negative intrusion into their lives were more likely to express pessimism and anxiety,¹⁴¹ and a decrease in their HRQL.¹⁴⁵

Affective symptoms such as depression are common in dialysis patients. Nearly 50% of a sample starting dialysis met the diagnosis of depression, when measured on the Beck Depression Inventory (BDI).¹⁴⁶ Among chronic PD patients, prevalence of depression varies between 25%-50%.^{113;116;147} However the diagnosis of depression in dialysis patients is confounded by the similarities in somatic symptoms of depression with those of uraemia, such as fatigue, poor appetite, sleep disturbances, and cognitive disturbances.¹⁴⁸ It has been suggested that the Cognitive Depression Index (CDI),¹⁴⁹ a subset of the BDI assessing only the affective aspects of depression such as guilt, hopelessness, irritation, and suicidal ideation, is a more reliable instrument of depression among dialysis patients.¹⁴⁹ Variation in depression prevalence could also be explained by the use of different assessment methods. In a study comparing agreement in depression diagnosis, 45% of the sample was depressed using the BDI cut-off score of 11, while only 12% met the criteria of the Diagnostic and Statistical Manual of Mental Disorders - 3rd Ed (DSM-III) for depression.¹⁵⁰ Despite its prevalence depression in patients with PD is under-researched^{151;152} and under-treated. Watnick *et al*¹⁴⁶ reported that only 16% of patients who meet the criteria for depression at the start of dialysis received treatment for their depressive symptoms. However, patients' resistance could also hamper treatment for their depression. A study into the feasibility of pharmacotherapy for depression in PD patients found that less than half of those eligible agreed to receive treatment.¹⁴⁷ Depressed patients have a higher risk of malnutrition, peritonitis, poorer treatment compliance, and poorer psychological adjustment to disease and treatment, which in turn could affect HRQL.^{134;152-156} A 10-point decrease in the mental component score (MCS) of the SF-36 was associated with a 28% increase in mortality risk.¹⁵⁷

Patients who perceive having more control over their illness and treatment reported better physical functioning,¹⁰⁴ and improved affective state over time.¹³⁴ A study with PD patients who were given no choice in treatment modality reported poorer mental and affective states compared with those who had elected for PD.¹⁵⁸ Patients with adequate pre-dialysis care and a planned start to dialysis are more likely to choose for PD, and present with better mental and physical functioning compared with patients with an unplanned dialysis initiation.¹⁵⁹ PD patients who are more satisfied with the level of care provided by the dialysis team report having better HRQL.¹⁶⁰

Having access to social support has been linked to better health outcomes and survival in ESRD patients.¹⁶¹⁻¹⁶⁴ We found that patients who perceive an insufficiency in social companionship and daily emotional support, had a higher mortality.¹⁶⁵ Being able to reciprocate socially is also associated with better survival in dialysis patients.¹⁶³

DEMOGRAPHICS

HRQL is also mediated by factors such as patients' demographics. There are suggestions of racial and cultural differences on HRQL in PD patients. Black male patients reported having less satisfaction with care they received compared with whites,¹⁶⁶ in addition, white patients perceived their HRQL better than their Asian counterparts.^{74;166} Another study found that Indo-Asian patients had lower acceptance and adjustment to their illness compared with white patients.¹⁶⁷ Gender differences have also been observed in the HRQL of PD patients. Female PD patients reported higher sexual functioning, as measured on the KDQOL, when compared with males.¹⁶⁶ Male PD patients scored lower on all four dimensions of the KDQOL (physical health, mental health, kidney disease issues, and patient satisfaction) compared with female PD patients.⁷⁷ The association between socioeconomic status and HRQL in dialysis patients has not been widely investigated. A small follow-up study which examined socioeconomic status on HRQL of HD patients concluded that patients in the high socioeconomic status group had improved HRQL scores on the SF-36 after 6 months follow-up compared with those in the low socioeconomic status group.¹⁶⁸ PD patients with lower socioeconomic status had a higher risk of developing dialysis-related peritonitis compared with those from a higher socioeconomic status.¹⁶⁹

FUNCTIONING

Functioning, in particular physical functioning has been also studied for its association with HRQL in PD patients. Functioning could be determined by perception of symptom burden. For example, complaints of fatigue and poor sleep¹⁷⁰⁻¹⁷² could result in poorer level of physical functioning. Poorer physical functioning, as measured by decreased participation in social and leisure activities, and activities of daily living, has been associated with poorer HRQL,^{171;173} and higher morbidity and mortality.¹⁷⁴

The impact of dialysis on work participation and HRQL should also not be overlooked. Compared with the general population, patients on dialysis are less likely to have employment¹⁷⁵ due to treatment restrictions.^{171;175} Dialysis patients with employment report having better HRQL

compared with those without work.¹⁷⁶⁻¹⁷⁸ Patients who perceive that their health and dialysis treatment are limiting their ability to work, are less likely to be employed, resulting in a self-fulfilling prophecy.¹⁷⁷ A study suggests that the poorer cognitive functioning in dialysis patients could also compromise their ability to work.¹⁷⁹

HRQL BETWEEN DIFFERENT CATEGORIES OF DIALYSIS PATIENTS

Patients on dialysis have consistently lower HRQL when compared with the general population, especially in physical functioning.^{104;176;180} Comparative studies suggest that HRQL also differs within dialysis patients, such as PD versus HD, or between PD patients either on continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD). However, evidence to suggest one mode of dialysis is better than the other in impacting on/improving HRQL is still inconclusive.

PD VERSUS HD

Studies into the efficacy of dialysis modality on HRQL show mixed results. Some studies suggest that both PD and HD patients had similar HRQL.^{86;181} A small study using a questionnaire developed by a committee of clinicians experienced in dialysis, reported that PD patients scored higher than HD on measures assessing family life, independence, religion/spirituality, energy level, and living situation.¹⁸² This study also included a free-text section in which patients identified positive and negative aspects of their treatment. Positive aspects of PD treatment frequently cited were: improved strength/energy, being alive and well, ability to perform therapy at home, able to perform treatment during sleep, and increased independence. Patients cited problems with supplies, frequency/length of treatment, bloating/pain, interference with sleep, and changes in routine as negative aspects of PD treatment. A large study with 16,755 HD and 1,260 PD patients reported that PD patients scored higher on the mental processes of the SF-36 after adjusting for demographic and clinical variables.⁵¹ However, comparisons of these results are difficult, given the cross-sectional design of the studies and the use of prevalent patients.

A randomised controlled trial would be an ideal study design to overcome the methodological issues of these previous studies. The only randomised trial investigating HRQL of PD and HD patients compared the mean quality-adjusted life year (QALY) scores between the two treatment modalities, and found a small difference favouring HD patients after 2 years follow-up.¹⁸³

However, these results could be confounded due to the small sample of 38 patients. The Netherlands Co-operative Study on the Adequacy of Dialysis (NECOSAD), a longitudinal observational study using incident dialysis patients, suggests that PD patients have a more pronounced decline in the SF-36 physical function scores over 18 months follow-up compared with HD patients.¹⁰⁰ Results from the Choices for Healthy Outcomes in Caring for End-stage Renal Disease (CHOICE) study indicate that HRQL in both modalities improved but on different domains. PD patients fared better than HD patients in terms of finances, whilst HD patients reported better physical functioning, general health perception, and sleep compared with PD patients after 1 year of treatment.¹⁸⁴ The Dialysis Morbidity and Mortality Study (DMM) Wave 2 reported that after 1 year, PD patients had more favourable evaluations of the effects of kidney disease, the burden of kidney disease, staff encouragement, and satisfaction with care compared with HD patients.¹⁸⁵ In a meta-analysis of 61 studies, PD patients were characterised by a better well-being and less distress than HD patients.¹⁸⁶

However, the differences in HRQL between the modalities could be due to inadequate adjustment for case mix¹⁸⁷ or other factors such as differences in HRQL scores prior to start of dialysis which make for comparison between the modalities difficult. Korevaar *et al*¹⁸⁸ demonstrated that even after extensive adjusting for case mix, the HRQL scores just before start of dialysis were different for patients who would start with PD compared with those who would start with HD. Patients who eventually start with PD had higher HRQL as measured with the SF-36 at this pre-dialysis phase compared with the pre-HD patients. They concluded that future comparative studies on HRQL between these two modalities needed to include the baseline HRQL at or before the start of dialysis to reduce possible selection effects.

The differences in HRQL could also suggest that both modalities might not be comparable.¹⁸⁹ A model of integrated care has been suggested in which PD and HD should be regarded as complementary modalities on a continuum for patient care rather than as 'competitive alternatives'.¹⁹⁰ Patients starting dialysis who have no contraindications for either HD or PD are more likely to choose PD over HD,¹⁹¹ probably because PD allows for greater autonomy and freedom in lifestyle, such as employment.¹⁸⁹ In their editorial, van Biesen *et al*¹⁹⁰ recommend that PD should be the initial therapy for patients with no contraindications, as its advantages include better renal function preservation, and better quality of life and survival in the first few years of dialysis compared with HD. In this model of integrated care, transfer to HD will be closely monitored when problems of PD such as patient burnout, infections, or dialysis inadequacy compromises the well-being of the patient.

CAPD VERSUS APD

Investigations have also been done on possible differences in HRQL of patients on different modes of PD, for example, HRQL differences between patients on continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). A small randomised study comparing the HRQL benefits of CAPD and APD with the SF-36 showed that APD patients reported having significantly more time for work, family, and social activities compared with CAPD, although there was a tendency of more sleep problems with the APD sample than that of the CAPD.¹⁹² In another study, APD patients were found to have better mental health, and less anxiety and depression compared with CAPD patients.¹⁹³ Although APD is a more costly option than CAPD, the associated HRQL benefits such as better mental health and maintenance of employment could offset its higher cost.¹⁹²

PAEDIATRIC PD PATIENTS

Peritoneal dialysis (PD) is the dominant mode of therapy for paediatric patients requiring dialysis. Two-thirds of paediatric patients are on PD.¹⁹⁴ However research on the HRQL of paediatric ESRD patients is limited compared with the adult ESRD population. No long-term, prospective study has been conducted on this paediatric population.¹⁹⁵ As with the adult population, there is also a lack of consensus on the definition and measurement of HRQL in the paediatric population. Studies often compare the HRQL of children with a chronic illness to their healthy peers, although knowledge on the normative process of children adapting to a chronic illness is sparse.¹⁹⁶

When assessing HRQL in paediatric PD patients, issues important to adult PD patients like employment, sexual functioning, and death are less relevant to paediatric patients. Of more concern to the paediatric patient are issues like growth, academic performance, exercise, self-reliance and functional development, and psychological/emotional development.¹⁹⁷⁻¹⁹⁹ Children on dialysis have to contend with a lifelong reliance on a machine for their survival, differentiating them from their peers during this pivotal stage of their personal development. Complications with treatment could result in missed school attendance, affecting not only their academic and functional development, but also further isolate them from their peers.¹⁹⁵ Children on dialysis who experienced greater functional impairment as a consequence of their illness were more likely to be depressed, anxious, and exhibit more behavioural problems.²⁰⁰

ELDERLY PD PATIENTS

Studies suggest that HRQL of dialysis patients is negatively associated with age, especially in the domains of physical functioning, cognitive and affective functioning.⁶⁰ A possible explanation for this differential age effect on HRQL of dialysis patients could be that measures used in previous studies reflect the domains of more relevance to younger patients and have poorer validity for use among older patient groups as more weight tend to be allotted to physical health. This, together with confounding by age and comorbidity could result in lower HRQL scores for the older patients.²⁰¹ Using the patient-centred measure, Schedule for the Evaluation of Individual Quality of Life – Direct weighting (SEIQoL-DW) instrument to assess QL domains of importance to dialysis patients, McKee *et al*²⁰¹ noted that whilst both young and old dialysis patients had similar nominations on the domains of family and marriage/relationships, only the younger patients nominated work opportunity/standard of living. Among the older patient group, the top nominated domain was leisure activities.

Comparative studies of age effects on HRQL have often used both HD and PD patients.^{87;135;202} To our knowledge, only one study has looked at the effect of age in younger and older PD patients. In this retrospective study younger (between 40-60 years of age) and older (over 70 years of age) non-diabetic PD patients had similar rates of PD-related complications, and older patients were more likely to have better adjustment to treatment and having comparable or better physical and social state at 1 year follow-up compared with younger patients as reported on the Karnofsky Index and with patient interviews.²⁰³

CAREGIVERS' HRQL

Successful adaptation to PD treatment especially for the elderly is also very much dependent on the availability of caregivers. De Vecchi *et al* reported that 12% of younger and 43% of older PD patients in their study required assistance with their dialysis at one year of follow-up.²⁰³ Few research has looked into the issues of caregiver distress and burnout, although caregivers of dialysis patients have poorer HRQL compared with the general population.^{204;205} Caregivers of PD patients when compared with HD caregivers, fared worse on the physical aspect, and the mental components of the SF-36; vitality, social aspect, emotional aspect, and mental health.²⁰⁵ A Spanish study reported similar findings in which younger caregivers of elderly dialysis patients who perceived having insufficient social support, reported experiencing greater feelings of burden, poorer HRQL, and have a higher risk for clinical depression.²⁰⁴ A study exploring the coping strategies of dialysis caregivers' and their HRQL suggest that male spousal caregivers

showed less optimistic, supportive, and palliative coping compared with female spouses. In general spouses with emotive, evasive, and fatalistic styles of coping had poorer HRQL.²⁰⁶ A questionnaire has been recently developed to assess burden of care among caregivers of PD patients.²⁰⁷ Although the validity and reliability of this questionnaire has been reported, it has not been used by other research groups.

WITHDRAWAL FROM TREATMENT

As medical care becomes more patient-focused, the recognition of patient's autonomy to withdraw from treatment when the perceived discomforts of treatment exceed its benefits is also increasing.²⁰⁸ Withdrawal from dialysis is a common occurrence and accounts for approximately one in five deaths among dialysis patients.^{209;210} Patients who withdraw from dialysis have been characterised as being older, with higher level of physical and cognitive impairments, and more comorbid conditions.^{211;212}

This high prevalence of deaths due to dialysis withdrawal coupled with the inclusion of older and sicker ESRD patients into dialysis programmes highlights the need for better communication between clinicians and their patients regarding end-of-life issues.^{213;214} A small qualitative study with HD patients, identified the following domains as being important for quality end-of-life care: avoiding inappropriate prolongation of dying, strengthening relationships with loved ones, relieving burden, having a sense of control, and receiving adequate pain and symptom management.²¹⁵ Family's perspectives elicited on ESRD deaths showed that approximately 75% of family members perceived that the patients were in pain during the last week of life.²¹⁶ Majority of family members reported that patients described the pain as moderate to severe, and occurring most or all the time. Nearly half of the family respondents felt that relieve of pain should have been of greater importance for the patient. The Renal Palliative Care Initiative (RPCI) has been developed to integrate palliative medicine into nephrology.²¹⁷ The RPCI, a collaborative work between Baystate Medical Center and eight dialysis centres from the Connecticut River Valley proposed interventions in symptom assessment, symptom treatment guideline, morbidity and mortality conferences, spiritual care, advance care planning, hospice referral, and bereavement services.

IMPROVING HRQL

Improvement in physical functioning through exercise rehabilitation has been shown to improve HRQL in dialysis patients.²¹⁸ A small study of PD patients in Hong Kong showed improvements in the KDQOL domains of burden of kidney disease and physical functioning after undergoing a 12-week exercise programme.²¹⁹ Another study compared the benefits of exercise coaching during predialysis or after start of dialysis.²²⁰ Patients were offered a one year programme consisting of 6 months exercise coaching and a further 6 months of follow-up. The authors concluded that exercise rehabilitation offered at predialysis stage was more beneficial for patients' HRQL rather than after start of dialysis.

Besides exercise rehabilitation, ensuring that PD patients have continued good social support from the start of dialysis is also crucial for improving HRQL. Clinical care providers could tailor intervention programmes to improve social support based on patients' needs, such as recommendations to appropriate programmes like self-help groups²²¹ or psycho-educational programmes^{154;222-224} designed to promote self-efficacy in coping with dialysis. Besides providing relevant medical information regarding lifestyle changes due to dialysis, clinical care providers should also highlight to patients and family/caregivers the relational dynamics involved in lifestyle changes.²²⁵ Patients and their family/caregivers could be made aware of potential conflicts that could arise when communicating encouragement and support for lifestyle change.

Given the chronic nature of PD treatment, clinical care providers should encourage patients to be an active participant in the self-management of their day-to-day care. Self-management refers to the health promotion and patient education programmes developed to encourage behaviour change and assist in adjustment to a chronic illness.^{226;227} Christensen *et al*²²⁸ reported on the efficacy of a behavioural self-regulation intervention for adherence in patients on HD, in which patients divided into small groups, discussed a self-regulation protocol with psychologist-trainers. The target behaviour was adherence to fluid restrictions which was a major self-regulatory task in these patients. Encouraging results from this study should spur further development of such self-regulatory based interventions in patients on PD.

FUTURE TRENDS AND CONCLUSIONS

The evaluation of HRQL in PD patients has evolved from survival to include more complex psychosocial factors. As HRQL assessment becomes more patient-centred, evaluation of patients' perceptions of their health and illness should be an integral part of the evaluation process.

As more patients with ESRD are being offered PD as the first-line treatment, HRQL assessment tools specific to PD patients across the different age spectrum should be developed. This would allow for a more comprehensive understanding by clinical care providers of HRQL issues important to this patient group, which can then be used to improve patients' care. Clinical management of chronic illnesses is moving towards a model of collaborative care,²²⁹ whereby patients and clinicians work in partnership for the benefit of improving patients' HRQL through a complementary offering of both traditional and self-management education programmes. For example, a randomised controlled trial comparing the effects of self-management interventions versus traditional care on morbidity and mortality of PD patients could be initiated.

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