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# Subjective Well-Being Measures of Hemodialysis Patients

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## 1. Introduction

In recent years the frequency of intra-dialytic symptoms has been decreasing, improving the patient well-being during treatment sessions. This has mainly been due to technical advances, such as more reliable monitoring devices, better water quality, physiological bicarbonate-based dialysate and machines to control ultrafiltration. Nowadays during hemodialysis (HD), patients suffer less from hypotension, cramps, headache, dizziness, nausea and vomiting (Himmelfarb & Ikizler, 2010; Al-Hilali et al., 2004). However, instead of well-being during dialysis, this chapter examines the well-being of patients between sessions, in their daily lives, focusing on how they perceive their quality of life (QOL). Unfortunately, technical advances in HD have not brought changes in the characteristics of renal replacement therapy: severe dietary restrictions, lost time, dependence on a machine, common occurrence of clinical complications and high mortality. Treatment of end-stage renal disease (ESRD) with HD is thus inherently distressing, causing social and family changes, and interferes profoundly in patients' well-being (Cukor et al., 2007; Tsutsui et al., 2009; Low et al., 2008).

ESRD treated with HD should be highlighted among other chronic diseases concerning its treatment, evolution and life consequences. Treatment depends not only on polypharmacy, but also on artificial replacement of kidney function by a machine – still a deficient method that cannot prevent various complications: osteodystrophy, atherosclerotic disease and risk for infections. This inefficacious replacement of kidney function causes these patients to have a twenty-fold higher chance of death than in the general population (Parmar, 2002). HD patients must adhere to a very restricted diet with controlled ingestion of water. In conventional HD, the patient is submitted to sessions of dialysis for approximately four hours three times a week in a renal unit (plus the time spent commuting to and from the renal unit), a time loss that influences employment, leisure and relationships. It is not surprising, then, that ESRD treated with HD affects QOL more intensely than heart failure, diabetes, chronic lung disease, arthritis and cancer (Mittal et al., 2001).

Therefore dialytic therapy is associated with powerful stressors. The literature shows that successful adaptation to dialysis depends more on personal stress modulators than on objective treatment variables (Tsay et al., 2005; Curtin & Mapes, 2001). Personal modulators are mainly subjective, due to psychology, personality and behaviour (Cukor et al., 2007). These subjective factors cannot be discovered by traditional medical measures like physical signs, laboratory and radiological data. The assessment of these

subjective factors depends on patient reports. Health professionals have to know how patients are doing under dialysis if they want to offer better therapy. Growing awareness of this fact is reflected in the increasing number of randomized controlled trials and studies of new drugs and treatments that include patient-focused issues such as convenience, adherence difficulties, patients' feelings and preferences. How does my patient feel under dialysis? has become a central question.

It is a simple question. Indeed "how do you feel" is used in overall scores. But such a summary score does not comprise the complexity of well-being. Well-being comprises physical functioning, psychological aspects, social environment and spirituality. That is why validated instruments to measure QOL are so useful. They are multi-dimensional, comprising physical, psychological, emotional and social aspects affecting well-being. They are easy to administer and generate scores on a user-friendly numeric scale. This quantitative approach facilitates clinicians' interaction because they are accustomed to quantitative data. In summary, we need to be worried about well-being among HD patients, we already have reliable instruments to measure the main subjective variables involved in well-being, but health professionals trained in using subjective measures are lacking. The main objective of this chapter is to provide information about subjective measures in the area of dialysis.

This chapter first examines the subjective measures most used to assess the feelings of patients undergoing HD. The data are related to conventional HD (four-hour sessions three times a week). But the effects on patient well-being of other modalities (short daily or nightly dialysis) are also discussed. It also describes the main validated instruments to measure subjective aspects closely related to well-being, emphasizing QOL as a central measure. A complete list of instruments would be too exhausting, so it comments on those instruments which have provided relevant results in the field of ESRD and HD. It also presents data on recognized interactions of the type of variables associated with QOL, and whenever possible comments on my own results based on a characteristic sample from a renal unit located in a low-income area of Brazil. I think this sample is similar in many respects to all patients in the world, but with some particularities due to the area's prevailing socioeconomic status, which may be of interest to the reader. Finally, I express some personal views about how to improve QOL among HD patients. I believe opinions are still valuable in the present stage since there are no recommendations based on Level I or II evidence about interventions in order to improve QOL among dialysis patients.

## **2. What are subjective measures and their importance?**

It is easiest to define subjective measures in contrast with objective measures. Traditionally in clinical practice, renal unit teams work with objective measures: physical signs, laboratory and radiological data. These measures are obviously independent of patients' feelings. In a group with high mortality like patients suffering from ESRD, physical signs, laboratory and radiological data serve to indicate poor control of the illness, need for treatment adjustments and risk of hospitalization and death. Meanwhile, subjective measures are generated from patients' reports. In this respect, administering questionnaires to patients elicits information that can be used to calculate subjective measures about patients' feelings, perceptions and judgements that cannot be discovered by objective measures or close observation of patients. It is well established that health professionals underestimate patients' feelings of well-being. Clinicians are often surprised to learn that patients with impairments and

disabilities can perceive life as a good experience, in contrast to patients with more favourable clinical conditions, who can perceive poor QOL (Riis et al., 2005). Reports of family members, friends and caregivers usually do not match patients' real perceptions. Most instruments used for subjective measures show results on scales of how patients perceive their lives (as opposed to years of life remaining), how they feel (irrespective of clinical condition), and the ways they cope (independent of peers' opinions). There are several kinds of subjective measures concerning overall well-being: spirituality, depressive feelings, quality of life, sexual satisfaction and ways of coping. All these subjective measures should play a central role in medicine.

Subjective measures have become important, first, because they can predict clinically relevant outcomes. Spirituality, depressive feelings and QOL are now extensively validated indicators of withdrawal from therapy, hospitalization and death among HD patients (Koenig, 2001; Powell et al., 2003; Spinale et al., 2008; Lopes et al., 2002; Lowrie et al., 2003; Knight et al., 2003; Mapes et al., 2003; Revuelta et al., 2004). For example, withdrawal is the cause of 25% of deaths among HD patients in the United States (Cohen et al., 2003). Second, and most important, these measures have not only been validated as indicators, they have become a main outcome in dialysis treatment. Despite technical advances in dialysis therapy, mortality is still very high, at 15-25% a year (United States Renal Data System, 2003). With such high mortality rates, objective measures only reveal whether patients are in the expected mortality range, without shedding any light on how their life quality and how to improve it. In this scenario of high and stationary mortality, subjective measures have become a main outcome. The chance of improving the patient's remaining life, however short it may be, is the most important end-point of dialysis therapy. Therefore, QOL issues are increasingly being included in studies on HD, such as The Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) and the North Thames Dialysis Study (NTDS), and in the principal guides to clinical practice in dialysis: the Dialysis Outcomes and Practice Patterns Study (DOPPS) and Reduction of Morbidity and Mortality among Hemodialysis Patients (HEMO). The National Kidney Foundation (NKF), through its guidelines published as a series named K/DOQI, now recommends routine monitoring QOL level in clinical attendance of HD patients (Merkus et al., 2000; NKF, 2006). Moreover, besides the importance of subjective measures in the nephrology area, today randomized clinical trials and studies of new drugs and treatments place the survival variable alongside QOL and patients' convenience and well-being. In the final analysis, then, health professionals must increasingly pay attention to subjective measures.

In summary, subjective measures cannot be estimated by observation by either health professionals or families, nor can they be revealed by physical signs or laboratory/radiological data. They depend entirely on patient reports. But many questions arise in formulating subjective measurement techniques: What is important to ask? How can feelings and perceptions be put on a quantitative scale? What elements comprise well-being? All these questions have been addressed in recent studies. Knowledge has increased, to the point where doctors in clinical settings, without the help of specialists, can call on many validated instruments covering various dimensions of feelings. In short, the tools are available to measure patients' well-being to a reasonable degree of accuracy.

### **2.1 The central role of quality of life**

Interest in QOL increased after the Second World War in the context of knowing how ownership of household appliances was influencing people's lives. However, in the medical

field, this interest is more recent. A revision of medical papers detected an exponentially increasing number of articles on QOL during the 90s (Garrat et al., 2002).

The appearance of several validated questionnaires allowed quantitative measurement of QOL. The most popular instruments to measure QOL use numeric scales, making them attractive because clinicians are used to working with quantitative variables. These instruments solved the main problem of studying QOL. Measuring quality entails making subjective judgments about feelings, which can seem very complex to consider in daily medical practice. But when feelings, judgements and opinions are translated into scales, the resulting measurement can be associated with other traditional medical outcomes, like laboratory indicators and morbidity, mortality and adherence rates. This occurred in the 1990s, when QOL scores were validated as a powerful predictor of morbidity and death, not only in large trials, but also in small samples comprising patients from single renal units (Kalantar-Zadeh et al., 2001).

But multidimensionality is the main reason for the central role of QOL among other subjective measures. The World Health Organization's definitions of health and QOL as involving overall (physical, mental and social) well-being and not only the absence of disease were the basis for constructing all the instruments to measure QOL. Due to the broad scope of these definitions, QOL instruments try to capture a central value of life and to summarize perceptions of several life dimensions in a score. In practice, a QOL instrument must assess at least two levels: functioning (ability to perform daily living activities) and perceived well-being (emotional and mental well-being and satisfaction with social activities). These two levels combined in one instrument distinguish QOL measures from other subjective measures. Other measures focus on particular aspects of mental health (depression), personality (spirituality, coping style) and behaviour (sexuality). In contrast to the multidimensionality of QOL measures, the other subjective measures are one-dimensional and cannot capture the central value of life. In a simple view, other subjective measures are related to aspects of our lives and act as measures of well-being. These one-dimensional measures deserve being studied because they can serve as indicators for interventions to improve well-being. However, QOL is more than a measure, it covers the idea of a central life value, and as such QOL is an end-point, an aim of medical therapies.

### **3. Instruments for subjective measurement**

In nephrology, most knowledge of QOL is based on results generated by the Medical Outcomes Study Questionnaire 36-Item Short Form Survey - SF-36 (Ware & Sherbourne, 1992). This is due to the fact the SF-36 has been chosen to measure QOL by important research groups, like the NECOSAD and NTDS, and by the main studies generating guidelines for clinical practice in dialysis, such as the DOPPS and HEMO. SF-36 is a generic instrument (it does not contain specific questions related to any kind of illness). It covers issues relating to eight dimensions of QOL: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. It generates scores from 0 (worst) to 100 (best) for each dimension. There are population parameters of QOL assessed by the SF-36 for several countries, such as the United States, Canada, Australia, Spain, Sweden and England (Hopman et al., 2000; Mishra & Schofield, 1998; Jenkinson et al., 1999; Alonso et al., 1998; Sullivan & Karlsson, 1998). This enables making comparisons of QOL level between patients and healthy people. The SF-36 can be applied to people aged 14 years or older. It takes 20 to 30 minutes to administer, which is feasible in

clinical daily practice. It can be administered by an interviewer, allowing inclusion of illiterate patients, an important portion of HD patients from underdeveloped areas. It can also be self-administered or given by telephone or computer. The major restriction is that the SF-36 does not cover two important dimensions of QOL: sleep and sexual activities. These two dimensions are well covered by the World Health Organization Quality of Life instrument (WHO-QOL), another generic instrument (WHOQOL Group, 1998). Use of the WHO-QOL is more limited in nephrology. It contains 100 items. The SF-36 and WHO-QOL also have brief versions with 12 items and 26 items, respectively.

Some researchers believe QOL among HD patients should be measured by a specific instrument (containing questions related to specific aspects of kidney disease). They argue that specific instruments can better expose difficulties direct related to ESRD and dialysis therapy, and may be more sensitive to detect changes over time. The KDQOL is a specific instrument to measure QOL. It was created in 1994 and has 134 items (Hays et al., 1994). However, the length of the questionnaire makes its clinical application difficult. The short version is used more (KDQOL-SF), containing 80 items divided into 19 dimensions: including the 36 items (eight dimensions) of the SF-36 and another 44 kidney-disease targeted items covering symptoms/problems, effects of kidney disease, burden of kidney disease, cognitive function, quality of social interaction, sexual function, sleep, social support, work status, patient satisfaction and dialysis staff encouragement. The scores on each dimension range from 0 (worst) to 100 (best). Its visibility in nephrology is due to its use in the United States Renal Data System.

The instrument called Evaluation of Individual Quality of Life (SEIQOL) is less used, but due to its particular method, I included it in this review (Moons et al., 2004). In the SEI-QOL, unlike the SF-36, WHO-QOL and KDQOL, patients choose and list the dimensions of QOL they judge relevant. This method facilitates identifying the dimensions of well-being the patient finds important. But it requires a complex process of abstract thinking, excluding a significant number of patients. Moreover, it is partly qualitative and partly quantitative and health professionals are not used to a qualitative approach. The SEIQOL covers three phases: first, patients are asked to name the five most important areas in their life; second, they are asked to score each area using a visual analog scale from 0 (could not be worse) to 100 (could not be better); and third, the named areas are ranked (weighted) and the total of the ranks cannot exceed 100%. The SEI-QOL results are obtained by multiplying the scores (0-100) and weights (0-100%). The method used by the SEI-QOL makes its administration in large samples difficult, but it can be useful in individual approaches.

As stated above, the main advantage of QOL measures is to cover several dimensions. But health professionals with less experience in evaluating QOL measures can be intimidated by the multiple scores from different domains. An overall well-being score would be easier. The QOL Scale (QOL SIS) is a single-item that I believe it can be used as a training score by inexperienced teams, and can serve to stimulate further consideration of using multidimensional instruments (Patel et al., 2002). The QOL SIS is an item contained in the McGill QOL questionnaire - MQOL (Cohen et al., 1995). The MQOL has several items, one of which directly asks patients about their overall assessment of their perceived QOL. This item can be used alone, in which case it produces the Feinstein Score (Lara-Munoz & Feinstein, 1999). The Feinstein Score ranges from 0 (very bad) to 10 (excellent). I strongly suggest that inexperienced renal unit teams test it as a preliminary approach to subjective measures.

Spirituality, defined as perception of meaning and purpose of life and not only as organized religion or a belief in a higher being, can be measured by validated instruments. The

Spiritual Well-Being Questionnaire (SWBQ) and Spiritual Belief Scale have only been used in a few studies with HD patients, but their results have clinical relevance. Spirituality was associated with QOL measures, satisfaction with life and perception of depression (Patel et al., 2002; Finkelstein et al., 2007). The SWBQ contains 20 items, five for each of four domains: personal, communal, environmental, and transcendental spiritual well-being (Gomez & Fisher, 2003). Respondents indicate how they feel in relation to 20 statements (items) over the past six months. All items are rated according to the 5-point Likert scale, ranging from "never" to "always do". The Spiritual Belief Scale was used in the study of Patel and associates (2002). The questionnaire has four items, each scored on a scale of 0 to 10. Two items measure the perceived importance of faith and its helpfulness in coping with ESRD and the other two items involve perception of the importance of attending religious services and its helpfulness in coping with ESRD.

The Beck Depression Inventory (BDI) is the standard instrument for screening clinical depression (Craven et al., 1988). The BDI covers 21 categories of symptoms. Each category has four levels of severity of that symptom, scored from 0 (little or no distress) to 3 (severe distress). The final score is the sum of the responses to the 21 symptom-items. The validated cut-off of score range of 14 to 16 corresponds to psychiatric diagnosis of major depressive disorder (Hedayati et al., 2006). As an alternative to the BDI, there is a short form (10 items) of the Epidemiological Studies Depression Screening Index (CES-D). The CES-D is not as widely validated as the Beck Depression Inventory, but has fewer questions, so it can be administered more quickly. It can be helpful as a screening tool of depression (Andresen et al., 1994). Each item of the CES-D is scored from 0 to 3 points and the total score ranges from 0 to 30. The CES-D was used in the DOPPS (score  $\geq 10$  as an indicator of probable depression) and was validated in comparison to the standard BDI (Lopes et al., 2004; Hedayati et al., 2006).

Erectile dysfunction among men is a well-established complication of dialysis. There are many studies in the literature on this theme. The International Index of Erectile Function (IIEF) is the standard instrument to assess male sexual functioning (Rosen et al., 1997). Most studies apply the six questions covering erectile function, but the instrument also covers orgasmic function (2 questions), sexual desire (2 questions), intercourse satisfaction (3 questions) and overall satisfaction (2 questions). The IIEF gives results according to four categories: no, minimum, moderate and advanced dysfunction. On the other hand, there is much less literature on the sexual aspects of women undergoing HD, although a validated instrument is available, the Female Sexual Function Index (FSFI). It is a 19-item questionnaire covering six domains of sexual function: desire, arousal, lubrication, orgasm, satisfaction and pain. The minimum score is 1.2 and the maximum is 36. A score  $< 26.55$  indicates the presence of sexual dysfunction (Wiegel et al., 2005).

Coping is defined as the cognitive and behavioral efforts to manage, reduce or tolerate external and internal demands and conflicts among them (Lazarus & Folkman, 1984). In the context of ESRD, external demands are the various stressors associated with dialysis therapy. The coping method works as a modulator of stressors. The way patients cope with stress can determine how they will be affected by the problem. According to the theory of coping, patients' efforts may be to manage or alter the source of stress (problem-oriented coping) or to regulate stressful emotions (emotion-oriented coping) (Lazarus & Folkman, 1984). In other words, problem-oriented coping aims to make direct changes in a stressful situation whereas emotion-oriented coping seeks to ameliorate emotions associated with a problem. The Jalowiec Coping Scale (JCS) was the first version, with 40 items and results

summarized in problem-oriented (15 items) and emotion-oriented (25 items) coping styles (Jalowiec & Powers, 1981). There is a second version of the JCS with 60 questions on coping strategies, classified into eight types: confrontative (10 items), evasive (13 items), supportive (5 items) and self-reliant (7 items) behaviors pertaining to problem-oriented coping; and emotive (5 items), palliative (7 items), optimistic (9 items) and fatalistic (9 items) behaviors pertaining to emotion-oriented coping (Jalowiec, 1991). The results are revealed by the frequency of each coping style or by scores (5-point Likert scale for each item). The JCS has been widely used among well and clinical populations, including studies of ESRD patients (Klang et al., 1996; Lindqvist et al., 1998; Yeh & Chou, 2007; Toimamueang et al., 2003; Lindqvist et al., 2000). In my group, we discern coping style as the principal measure of how intensely dialysis-associated stressors will affect HD patients. We are now working with the perspective that patient education in coping skills can be used to change the risk of poor QOL.

The instruments reported here have generated enough data in nephrology to have a panel of what and how subjective measures mediate patients' perceived QOL.

#### **4. Variables associated with quality of life among hemodialysis patients**

##### **4.1 Objective measures**

Objective measures are those associated with socio-demographic aspects and HD quality-of-care indicators. Most of socio-demographic variables are not modifiable, but quality of HD treatment can be modulated in practice by setting goals: hemoglobin of 11-12 g/dl, equilibrated Kt/V  $\geq 1.2$ , phosphorus of 3.5-5.5 g/L, and adequate nutrition. This section discusses the frequency and duration of dialysis sessions as objective variables in emerging modalities of short daily or nocturnal dialysis.

Age: Older age does not necessarily mean worse QOL among HD patients. Older patients compensate for physical deterioration by adjusting mental outlook aspects. This conclusion is supported by results showing that the main effects of age are on the physical domain of QOL rather than the mental domains (Deoreo, 1997; Singer et al., 1999; Lamping et al., 2000). Older people (> 65 years) perceive less decline of QOL and more satisfaction with life when compared to younger patients (Rebollo et al., 2001; Kimmel et al., 1995). In large samples from the HEMO Study as well as in small samples from single renal units, older patients on HD have better QOL than do younger patients (Unruh et al., 2008; Abdel-Kader et al., 2009). Maybe the larger gap between expected and actual QOL among younger patients makes the treatment restrictions more disturbing to them.

Gender: Among healthy people in countries like Canada, the United States and England, where the SF-36 has been used to estimate QOL in the general population, it has been found that men have better QOL than women (Ware, 1993; Jenkinson et al., 1999; Hopman et al., 2000). This gender difference is not found among HD patients (Kalantar-Zadeh et al., 2001). It seems that stressors associated with dialysis therapy, which are common to both genders, are powerful enough to overcome the gender aspects determining difference within the general population.

Race: African-American HD patients in the United States reported significantly better psychological well-being than non-African-Americans (Owen et al., 1998; Hicks et al., 2004; Unruh et al., 2004a). In countries like Brazil, with more miscegenation, it is difficult to classify patients according to race, so there are not extant studies of race-based differences.

Socioeconomic status: Brazil is a large country and has great regional socioeconomic disparities as well as local class differences. Most studies of HD samples are from the

southeast region, which is the country's richest, where many universities are located. I work in northeast Brazil, which is a generally poor region. Last year in a chapter of a Brazilian book, I concluded that QOL level is lower among HD patients from low-income areas (Cruz & Cruz, 2010). A previous Brazilian study showed that QOL scores of high-socioeconomic HD patients tended to increase more over time than did the scores among low- and middle-class patients within a sample of eight dialysis units in the state of São Paulo (Sesso et al., 2003).

**Travel time:** Depending on the region, renal units can be very far from where patients live. In the north and northeast of Brazil, there are few renal units, and patients have to travel long distances to for dialysis (Ritt et al., 2007). In our renal unit, in the city of Sobral in northeastern Brazil, 80% of the patients undergoing regular HD live outside the city where the renal unit is located, in small towns within a radius of 144 miles. My research team has been unable to detect differences regarding laboratory values, adherence, QOL and depression according to the patient travel time. This may be because patients in our region who live in small rural communities are accustomed to traveling long distances to obtain government services of all types. However, in a large sample, longer travel time is associated to higher mortality and decreased QOL (Moist et al., 2008).

**Anemia:** With the spreading use of erythropoietin, several studies about the relationships between anemia control and QOL have been performed. The current recommendation is to achieve partial control of anemia (hemoglobin of 11-12 g/dl) due to potentially adverse cardiovascular events at higher hemoglobin levels (Besarab et al., 1998; Singh, 2008; Phrommintikul et al., 2007). Distinct approaches to patients with or without symptomatic cardiac disease concerning target hemoglobin are subject to debate, and the results are contradictory (Canadian Erythropoietin Study Group, 1990; Furuland et al., 2003). There are several studies showing better QOL with higher hemoglobin as well as showing no differences of QOL according to hemoglobin level. In a recent systematic review with meta-analysis, Clement et al. (2009) included only 11 studies from a total of 231 and concluded that hemoglobin levels in excess of 12 g/dl lead to small and not clinically meaningful improvements in QOL. The authors suggested, due to safety concerns, targeting treatment to hemoglobin levels in the range of 9-12 g/dl as opposed to hemoglobin > 12 g/dl.

**Kt/V index:** The dialysis dose, estimated by the Kt/V index, was a constant variable of interest in the early studies of QOL. The hypothesis was that higher dose would be associated with better QOL. With the exception of studies with small samples (Powers et al., 2000; Manns et al., 2002), no correlation between Kt/V and QOL was found (Kalantar Zadeh et al., 2001; Mittal et al., 2001). The advent of new membranes has rekindled interest in the relationships between high flux membranes and QOL. But once again, this time in a multi-center randomized trial, neither the dose (Kt/V 1.45 vs. 1.05) nor the dialysis membrane (high flux vs. low flux) demonstrated clinically meaningful benefits (Unruh et al., 2004b).

**Malnutrition:** There are several reports of associations between nutritional status and QOL through nutritional markers: creatinine, albumin, calf circumference and protein/energy intake (Ohri-Vachaspati & Seghal, 1999; Allen et al., 2002; Kalantar-Zadeh et al., 2001; Fujisawa et al., 2000; Raimundo et al., 2006). In our renal unit, we found different patterns of relationships between nutritional status and QOL according to gender: malnutrition and low protein intake correlated with low QOL among women but not among men.

**Frequency and duration of dialysis sessions:** An important current issue is the potential of more frequent and longer dialysis sessions to improve several clinical outcomes. As stated above, studies of dialysis dose and different membrane types in the context of conventional

HD have not shown an influence on QOL. In other studies, dialysis modalities with more frequent and longer dialysis sessions, like nocturnal (5 sessions weekly, 6 to 10 hours/session) or short daily dialysis (6 sessions weekly, 2 to 3.5 hours/session), in comparison with conventional HD, have been shown to have a positive influence on QOL (Lindsay, 2004; Culleton et al., 2007; Van Eps et al., 2010). However, everywhere in the world, but particularly in developing countries, the necessary economic and organizational changes will be the main obstacles to conducting more frequent dialysis on a large scale. This is certainly true in Brazil. First, current reimbursement by the National Health System is limited to thrice-weekly hemodialysis, so increased reimbursement to support more frequent and longer dialysis will be necessary. Second, daily HD will overtax the present capacity of renal units, so resources are needed to set up new and accessible satellite dialysis units.

#### 4.2 Subjective measures

Objective measures are traditional and well-managed by clinicians. Nonetheless, QOL among HD patients remains poor. The increasing knowledge of subjective measures can be the key for more effective interventions to improve QOL.

**Depression:** The high prevalence - nearly 30% - and the role of depression in affecting well-being among HD patients are well established (Cukor et al., 2006). But there are limited studies focused on treatment of depression in HD patients. Serotonin reuptake inhibitors and psychotherapy can be indicated (Blumenfeld et al., 1997; Kimmel & Peterson, 2006). But it is difficult to employ successful routines to treat depression in practice (Wuerth et al., 2003). Among HD patients, depressive feelings are associated with low QOL, and are predictors of both death due to any cause and withdrawal from dialysis (Lopes et al., 2004; Berlim et al., 2006; Drayer et al., 2006). Patients' social support interacts with depression, but once again subjective modulators have a central role. Better social support among individuals high in the personality trait of "agreeableness" was associated with a decrease in depressive symptoms, whereas social support had little effect on depression change for individuals ranked as low in "agreeableness" (Hoth et al., 2007).

**Sexuality:** Sexuality is a complex aspect of human lives because it comprises physiological needs and social demands. Dialysis therapy negatively affects sexual function both among men and women. Several well-known factors are associated with erectile dysfunction among men on HD: gonadal dysfunction; hyperprolactinemia; zinc, iodine and manganese deficiencies; hyperparathyroidism; uremic neuropathy; arteriosclerosis; anemia; and use of antihypertensives (Palmer, 1999). Some studies have found a prevalence of erectile dysfunction as high as 80% (Rosas et al., 2001). In the experience of my team, nearly half of young patients (20 to 50 years old) present erectile dysfunction and have significantly lower mental health assessed by the SF-36 when compared to patients with the same age range without erectile dysfunction. There are few studies on the sexuality of women undergoing HD. But similar to our experience among men, Seethala et al. (2010) found 46% sexual dysfunction among sexually active women on dialysis, assessed by the FSFI. But in contrast to men, sexual dysfunction among women has not been associated with low well-being, assessed by the Illness Effects Questionnaire (Seethala et al., 2010). No doubt, women must be studied more to confirm the differences between them and men concerning sexuality as a measure of well-being and QOL.

**Spirituality:** The relationship of spirituality, physical health and well-being is well documented in the literature (Levin & Vanderpool, 1991; Ellison, 1991; Powell et al., 2003).

In the nephrology area, there are reports of better QOL and less depression among dialysis patients with greater perception of spirituality and religiosity (Patel et al., 2002; Finkelstein et al., 2007). People identified as spiritual report better social support (Patel et al., 2002). Cumulative positive effects of social support and spirituality can explain lower mortality and better well-being (Spinale et al., 2008). Nevertheless, more studies on spirituality are necessary among HD patients. But it is promising that spirituality and social support could be targets of intervention. Strategies aiming at engaging patients in discussions about their spiritual concerns together with planning activities to involve patients' social support networks in treatment problems could improve subjective and objective outcomes.

Coping style: Common sense as well as scientific evidence shows that the way people face difficult situations is the main measure of the effects of stress in their lives. This explains why in clinical practice there are patients with many handicaps who still perceive their lives as pleasant, while others with fewer problems do not. This is also the basis of the importance of all subjective measures discussed here. Coping tests are simple and can be used by dialysis staff without psychologists' help. Moreover, coping style is a modifiable variable, which can be changed by adaptation training programs. My study team found a correlation between emotion-oriented coping and poor QOL regarding the physical (physical functioning and role-physical) and mental (role-emotional and mental health) dimensions of the SF-36, in line with other studies of chronic disease patients, including the ESRD (Bombardier et al., 1990; Wahl et al., 1999; Dunn et al., 1994). In my view, coping is a potent measure and can be a suitable target for interventions to improve QOL. This personal view is addressed in more detail in the next section.

## 5. How to improve well-being among hemodialysis patients

When thinking about how to improve QOL among HD patients, two facts must be considered. First, despite a great number of studies, there are no recommendations possible based on Level I or II evidence (Madhan, 2010). The reason is that while there are many cross-sectional studies of QOL, there is a lack of interventional and randomized controlled trials. Second, there has been no improvement of QOL among dialysis patients in the past decade (Gabbay et al., 2010). Recent technical advances and treatment guidelines have not been associated with changes in QOL, although a study of a small sample showed it was possible to improve QOL associated with better quality-of-care indicators (Lacson et al., 2009). Thus, targeting the current quality-of-care indicators concerning anemia, nutrition, dialysis dose, phosphorus level and vascular access must be the first step. These indicators are well known by clinicians. But this first step is not enough. Dialysis associated stressors are powerful. So what else can be done? Faced with a lack of adequate evidence, opinion is what determines efforts to improve QOL. As an assistant nephrologist, medical professor and researcher on QOL and correlators, I suggest, based on my study results, that physiotherapeutic approaches along with psychological interventions can minimize the effects of dialysis on patients' well-being.

Dialysis patients have very low physical domains of QOL compared to healthy people. On the other hand, mental aspects are the same or even higher than in the general population (Perneger et al., 2003; Kusek et al., 2002). In my experience, the dimension role-physical (from the SF-36) consistently presents the lowest score among HD patients. Questions which generate role-physical score are related to difficulties in work and other daily activities

resulting from poor physical health. Thus, physical interventions, like physical conditioning programs, occupational activities and physiotherapeutic approaches must be tried on individuals and also as collective activities in renal units.

ESRD requires an individual to make a number of adjustments. To do so, patients need to understand their situation (cognitive effort) and modify their behavior (behavioral effort). The kinds of these efforts determine their coping style. I believe coping style is the principal measure between treatment-related stressors and outcomes. In my view, coping is the best variable for intervention and potentially the most correlated with QOL. I have detected emotion-oriented coping associated with poor QOL. Emotion-oriented coping is associated with passive personality traits, a sense of powerlessness and denial (Gilbar et al., 2005; Klang et al., 1996). Fortunately, coping is a modifiable variable. Patient education in coping skills can be used to change the risk of poor QOL (Tsay et al., 2005). I propose adaptation training programs aiming to improve patients' coping skills.

Finally, the emerging modalities with more frequent dialysis, like nocturnal or daily dialysis, are promising to enhance QOL. However, the implementation of sufficient renal units to offer this dialysis frequency demands time and resources. Moreover, these modalities may not be acceptable to some patients. It will be even more difficult to offer these modalities on a large scale in underdeveloped countries, where reimbursement of dialysis sessions is very low and there is lack of renal units that even offer conventional HD. Only time will tell whether more frequent dialysis will be standard treatment in the future.

## 6. Conclusion

Well-being is a main outcome in treatment of ESRD patients with dialysis. However, scientific evidence is lacking about interventions to improve well-being. The best way of assessing patients' well-being is to estimate the QOL level using validated instruments. Over the last decade neither technical advances nor quality-of-care guidelines have been enough to improve QOL among HD patients. Emerging knowledge about subjective measures associated with QOL can be the key for effective interventions. Clinicians must be familiar with subjective measures and use them in their daily practice to try to improve the well-being of patients undergoing HD. After 50 years of the widespread of dialysis treatment, the improvement of QOL among dialysis patients remains a formidable challenge.

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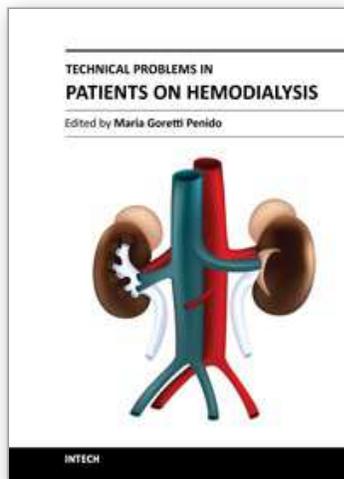
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## **Technical Problems in Patients on Hemodialysis**

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This book provides an overview of technical aspects in treatment of hemodialysis patients. Authors have contributed their most interesting findings in dealing with hemodialysis from the aspect of the tools and techniques used. Each chapter has been thoroughly revised and updated so the readers are acquainted with the latest data and observations in the area, where several aspects are to be considered. The book is comprehensive and not limited to a partial discussion of hemodialysis. To accomplish this we are pleased to have been able to summarize state of the art knowledge in each chapter of the book.

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