

PROMs and the ESRD Patient: A Time to Rethink Our Approach

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Preface:

I am writing this manuscript from the perspective of a practicing nephrologist who has been a medical director of dialysis facilities for 44 years. Much of my research has been directed at understanding the psychosocial impact of kidney disease on patients and their families—trying to understand the patient’s perspective and the uniqueness of each patient’s experience. A major concern of mine has been the challenge of understanding the patients’ perspective – symptoms, quality of life, general health status, depression, anxiety, etc. It is now well documented that there is a major discrepancy between patient’s and provider’s perception of a variety of symptoms and quality of life measures. While it is encouraging that CMS has mandated that some patient reported outcome measures (PROMs) be included in patient evaluations, these have not, from my perspective, had a major impact on patient care. A challenge that remains to be addressed is how to incorporate PROMs into routine care so that communication between providers and patients can result in effective interventions in individual patient care. The burdens on patients of completing PROMs and on providers of processing PROMs need to be kept in mind. And, most importantly, we should focus not only on obtaining and recording PROMs but on understanding how their administration and analysis can translate into appropriate and meaningful management strategies.

Introduction:

Patient reported outcome measures (PROMs) have been incorporated into the care of ESRD patients for several years, primarily as research tools exploring the relationships between these measures and "hard" outcomes such as mortality and hospitalizations (1-8). It has been suggested that PROMs should also be incorporated as part of routine clinical practice (9,10). In fact, it is now mandated by CMS that dialysis facilities ask patients to complete the Consumer Assessment of Healthcare Providers and Systems (CAHPS) In-Center Hemodialysis (ICH) Survey questionnaire semi-annually and the KDQOL-36 annually. In addition, patients are expected to be evaluated for depression and pain once a year. Despite these initiatives, there is now an increasing consensus amongst clinicians that these

mandates have been of limited value in terms of adequately capturing the patients' experience with their chronic disease and informing health care providers of their symptoms, limitations, and concerns for several reasons (9,10). The CAHPS-ICH questionnaire deals primarily with patients' perception of their care in the facility -- the appearance of the facility, whether the facility is treating the patient with respect and whether it is providing appropriate education. The questionnaire deals with generic facility issues but may not really address the specific concerns of an individual patients or their physicians. The KDQOL-36 provides 5 summary scores—the physical component score (PCS) and mental component score (MCS), burden of kidney disease score, symptom and problem score, and the effect of kidney disease on daily life score. The problem with these scores from a clinician's standpoint is that it is not clear how being informed of these scores translates into information that is clinically useful in terms of managing a patient's problems. A low PCS or MCS score is associated with a higher hospitalization rate and mortality rate but does not define the areas of difficulty that a patient is experiencing (see below). In that sense, it is not all that different than selected laboratory findings, such as serum albumin and C reactive protein. Thus, while these scores are predictors of mortality, they do not inform clinicians about what should be done to improve the care of the patient.

The burden of kidney diseases and the effect of kidney disease on daily life scores ask very generic questions about burden, frustrations, and limitations imposed on patients by their kidney disease. The symptom and problems score uses 12 questions focused on specific symptoms--but these symptoms are rarely looked at as isolated symptoms requiring attention but as part of the summed symptoms and problem score. And what if an individual patient's concerns are not addressed in the standardized questionnaire? How can health care providers capture the specific and unique concerns of the patient -- those that are important for the individual patient? Can the appropriate incorporation of PROMs into routine care be helpful and improve patients' perception of their care? Can these questionnaires provide useful information to clinicians to help target their approach and management of individual patients?

PROMs and “Hard” Outcomes:

Several PROMs have importantly been shown to correlate with "hard" outcome measures such as mortality and hospitalization rates (1-3,6-8). These associations have been documented in several studies using the SF-36 questionnaire and various questions addressing the presence of depressive symptoms (1-3, 6-8). DOPPS publications and data from the Fresenius and NECOSAD data bases have clearly documented a robust association between the PCS and MCS scores of the SF-36 questionnaire as well as depressive symptoms and both mortality and hospitalization rates. The NECOSAD data base also indicated a strong association between the single question dealing with patients' perception of their general health (taken from the SF-36) and mortality – patients assessing their general health as poor had a 3.5 fold greater mortality rate than those assessing their general health as excellent or good (7). While SF-36 scores in individual patients can change over time with ongoing dialysis therapy (and it is important to document these changes), it appears that the absolute value of the measure is more important than the change in predicting outcomes (11). In addition, it is noteworthy that cross sectional studies have shown that there has been an overall improvement in SF-36 scores from the 1990s to the present time, with the most dramatic changes being seen in several domains, especially bodily pain, vitality, role-emotional and mental health (6). Why these improvements have occurred is not clear. Possible reasons include better standardization of dialysis care, reflected in improved vascular access, better volume and blood pressure control, improved dialysis prescriptions, etc, which have resulted in a significant decline in mortality rates in ESRD patients (12). Building on these improvements, it is now time to move towards a true patient centered care approach.

Recent Emphasis on Patient-Centered Care:

Recent work has emphasized the importance of appreciating patients' experiences with their illness and healthcare delivery in general (9,10,13). This work suggests that the focus of care shift from an arbitrary adherence to rigid standards of care, moving towards more flexible standards of care that seek to understand the patients' perception of their experience—their symptoms, goals, and objectives of care – a true model of “patient centered care.” This shift in patient management is especially important since it is now well recognized that health care

providers often do not appreciate patients' symptoms and impairments (14-17). Thus, focusing on care that meets these pre-determined arbitrary standards presents problems from a patient centered care approach. Certainly meeting arbitrary standards of care is important in providing a minimum standard that should be achieved in general. But these standards need to coincident with the individual patient's goals and objectives. What if these standards undermine an individual's experience of perception of his/her quality of life? For example, prolonging the duration of peritoneal dialysis therapy on a cyclor or adding an extra peritoneal dialysis exchange to meet the arbitrary goal of achieving a KT/V urea of 1.7 must be put in the context of individual patient's lifestyle and the impact of changing the dialysis regimen to meet this arbitrary goal. But if meeting that goal becomes a primary objective of therapy, then patient care becomes compromised and what the cornerstone of patient care should be (symptom management and meeting patients needs) will not be addressed (13,16). While this applies to our health care system in general, it certainly is relevant to the care of patients with ESRD. Studies that have looked at the issue of health providers understanding of ESRD patient's symptoms or concerns have generally found a wide discrepancy with patient reported symptoms or concerns and health care provider perceptions of what these are (14-17). This underscores the importance of developing improved communication between patients and providers and a better understanding of the concerns of patients by providers.

This emphasis on patient centered care is occurring not just in the United States, but globally as well and has been attracting increasing attention around the world (16,18-20). It is now a mantra for health care reform in the United Kingdom and Canada with patient centered care approaches to ESRD care being developed in the United Kingdom and Ontario, Canada (16,18-20). The challenges these countries are facing are how to implement an effective and meaningful patient centered care approach and integrate this into routine patient care.

There are major limitations of the measures currently being used:

It is the impression of many that current approaches of assessing the patient's experience are not satisfactory and are not particularly clinically useful, thus, undermining the health provider's ability to implement a true patient centered care

approach. There are three main limitations to the current practice patterns in ESRD care.

a) Limitations because of variability of an individual's PROM results:

One of the challenges in utilizing the results of PROMs is the observation that the results of the questionnaires for individual patients vary over time (21-24). Thus, giving questionnaires annually or semi-annually does not provide a dynamic understanding of a patients' areas of difficulty. Time varying analyses have been used in studies correlating quality of life measures with various outcome measures (23,24). Studies that measured various PROMs on a more frequent basis have documented substantial variability in these measurements (21,22). And clinicians caring for ESRD patients are very much aware of the dramatic changes that can occur for ESRD patients because of their multiple co-morbidities, myriad medications, and complex treatment regimens. Clinicians have been reluctant to utilize more frequent assessments because of concerns about patient burden and the potential problem of repetitive testing. It is important to note that this has not been a barrier or limited PROM utilization in other disciplines (see below).

b) Limitations in terms capturing individual patient's experiences:

As mentioned above, the goal of care for any patient is to treat both the underlying illness as well as the symptoms associated with that illness (9,13,19). What makes the care of ESRD patients so challenging is that patients have a multitude of symptoms that may be associated with their underlying ESRD, varied co-morbidities, and/or multiple medications that have been prescribed by any one of several health care providers (19,25). Dialysis patients on average take about 10-12 different medications per day.

While the questionnaires currently in use in dialysis facilities clearly document a marked reduction in many quality of life domains compared to the general population, it is not clear how documenting this improves

the clinicians' understanding of each patient's experience of dialysis. It is important to emphasize that each patient's experience is unique. This point is underscored in the book *The Age of Insight* by the Nobel Prize neuroscientist Eric Kandel. He writes about art in Vienna at the start of the 20th century and notes that we need to understand that each individual, because of unconscious and conscious processes, sees the same painting (*or experiences the same event*) differently, uniquely interpreted and reconstructed by his or her brain (26). Michael Kimmelman, an art critic for the New York Times, supports Kandel's thought by observing that "Art is not just about what's great or famous...It's a mirror we hold up that looks different to everyone who sees it, and whose beauty lies in us and our capacity to dream..." (27). That is, each individual is unique and experiences events, art, treatments, and symptoms uniquely. Understanding that unique experience is the challenge for health care providers; this unique experience may be difficult to capture with standardized, inflexible questionnaires.

c) **Limitations in terms utilizing PROMs in the management of patients:**

One of the challenges with the use of PROMs in routine patient care is what one does with the results when the data is obtained. Currently, the results of the KDQOL-36, which is given annually, are summarized in each patient's chart. Are individual symptoms addressed? Is their adequate follow-up for those patients who seem to be depressed? Does the facility have the infrastructure to deal with the results —assess the data, develop treatment plans for domains of concern, etc? Is the facility directing appropriate resources to address these issues? The answer, in general, is no. The challenges of developing the framework in which to process this information constructively requires careful thought and planning. Recently, most dialysis facilities have worked to address the issues necessary to meet Quality Incentive Program (QIP) and Five Star Rating requirements. For example, anemia and vascular access coordinators have been designated. But what about identifying and treating anxiety, depression, or the individual concerns of each patient? The work load of the social worker, nurses, and technicians and the

burden of documentation for all health care providers does not permit these issues to be addressed satisfactorily (9).

Lessons from Other Specialties:

It is interesting that the importance of incorporating PROMs into patient care has been recognized in several other health care areas. PROMs have been identified and included as part of routine care; studies clearly show that this inclusion is appreciated by patients as well as clinicians and can result in improved outcomes for patients. There are certainly lessons that the nephrology community can learn from examining some of these approaches. It is particularly interesting to note that electronic testing is now attracting increased attention and is seen as useful in facilitating reporting to clinicians, permitting more frequent testing, avoiding the drawbacks of repetitive testing, providing useful feedback to clinicians and improving outcomes. Most of the studies are recent, having been reported in 2016-2017; selected pertinent studies will be cited.

1. Electronic reporting of outcomes post operatively: Gynecology and Neurology

A web based reporting system was developed to capture PROs in the post operative period of women who had undergone gynecological surgery (28). Patients were asked to complete weekly questionnaires for 6 weeks with email alerts being sent to nurses when concerning patient responses were noted. 98% of patients found the electronic reporting easy to use, 84% found it useful, and 82% would recommend it to other patients.

At the neurological institute at the Cleveland Clinic, patients are asked to complete a series of questionnaires electronically prior to their visit or at the time of the visit on a tablet (13,29,30). The results of the questionnaire are incorporated into the patient's electronic medical record. Questionnaires used include the PHQ9 for depression screening, the European Quality of Life (EQ5D) questionnaire for general HRQOL screening, and disease specific scales developed by the clinical experts within each disease focused center. Examples of the latter include Headache Impact Test 6 in the Headache Center and the Amyotrophic Lateral Sclerosis (ALS) Functional Rating Scale in the ALS clinic. 92% of patients found the questionnaire system easy to use and 77% felt it benefited their overall care

(29). It is important to note that this model incorporated both standardized, generic PROMs as well as ones developed by the clinicians in the individual clinics.

2. Computerized adaptive testing: Psychiatry

There is a robust literature developing on the use of computerized adaptive testing (CAT) to establish diagnoses for patients with psychiatric disorders. This subject has recently been reviewed (31-34). Data has shown, for example, that CAT can be used to diagnose a major depressive disorder (MDD) in a large cohort of patients in a psychiatric clinic with a sensitivity and specificity of 0.95 and 0.87 when using a structured clinical interview and DSM-IV criteria as the standard of diagnosis (32). This compares to a sensitivity and specificity of 0.70 and 0.91 for the Patient Health Questionnaire 9 (PHQ9). Similar results were observed for the diagnosis of generalized anxiety disorder and mania using CAT (32).

There are several advantages to CAT. A given level of diagnostic precision can be reached much more rapidly than in a test which uses a standardized, inflexible set of questions (32). Adaptive testing focuses on items which are most relevant for an individual patient at each stage of the testing. What is so important about the adaptive testing is that it results in a 50-90% reduction in the number of items that need to be administered with no significant change in diagnostic accuracy. In addition, CAT can be repeatedly administered without response set bias because the questions adapt to the patient responses, which will vary over time (32).

3. Oncology: the importance of PROMs

Incorporating PROMs into routine care of patients as well as clinical trials has been getting increasing attention in the oncology literature. In large part this has occurred because of the recognition of both the importance of including PROMs in clinical cancer trials and the observation that, in cancer clinics, health care provider assessment of patients' experiences, symptoms, and quality of life are discordant (13). Thus, several studies have shown that the routine incorporation of PROMs into care enhances both the patients' as well as the clinicians' experience. It is argued that oncologists understand that in assessing the value of an individual therapy, it is important to recognize that treatment value cannot be summarized in an individual metric -- a multifaceted approach is necessary focusing on what is important to the recipient of care-- the patient (13).

The incorporation of electronic capturing of self report assessments has been well validated in the oncology literature in a series of recent studies (13,35-40). It is clear that the use of computers or tablets is not viewed negatively by patients (35,36). The use of electronic testing has been shown to be useful in several domains. First, they are useful in informing clinicians of patients' perception of symptoms and quality of life. Secondly, they have been shown to be useful in providing feedback to patients in how to communicate with and inform clinicians about the presence of symptoms. And, thirdly, they have been shown to have a positive impact on "hard" outcomes, such as emergency department (ED) visits and hospitalizations.

For example, Basch et al have reviewed and underscored the importance of incorporating PROMs into both routine clinical care as well as clinical trials for oncology patients (38). These authors point out that methods are evolving to integrate PROMs into routine clinical trials to examine the impact of cancer treatments on HRQOL as well as enhance the detection of adverse events. Thus, the European Organization for Research and Treatment of Cancer has directed the formation of an importance initiative (the Setting International Standards in analyzing Patient Reported Outcomes and Quality of Life Endpoints Data) to provide recommendations on how to incorporate PROMs into cancer clinical trials (40). It has been well established that the incorporation of PROMS into the routine care of cancer patients results in reduced hospitalizations and emergency department visits and compliance with longer courses of chemotherapy (13,39). A randomized trial involving 766 patients receiving chemotherapy and assigned to usual care or care involving electronically reported symptoms for which severe or worsening symptoms were noted and alerts were sent to the health care team resulted in lower mortality rates, improved quality of life, and reduced emergency department visits (39). In addition, routine use of PROMs for cancer patients can result in improved communication with clinicians. For example, Berry et al demonstrated in a randomized trial that the adaptation of electronic report assessments to enable patients to receive self-care education and coaching to report symptoms and quality of life issues to clinicians resulted in significantly more specific patient verbal reports of areas of concern to treating clinicians (35).

PROMs, CAT, and Routine Patient Care:

Basch has recently underscored the importance of using PROMS to "Harness Patient's Voices to Improve Care" in an important New England Journal of Medicine article (13). He emphasizes the utility of using electronically administered PROMs, incorporating these into the electronic medical record accompanied by automatic notifications to health care providers of symptoms or functional issues of concern. PROMs can easily be tracked longitudinally. Basch points out that this approach can improve HRQOL, enhance patient-clinician communication, reduce emergency department visits, and improve survival. There may be significant logistic challenges to incorporating the electronic PROMs into electronic health records. But the benefits of doing so need to be emphasized -- not only in terms of individual patient care but also from the standpoint of analyzing the effectiveness of different treatments and patterns of care.

CAT offers a way to individualize administration of PROMS, minimizing the burden to patients, and avoiding the problem of repetitive testing since each testing session would be different. It has been suggested that CAT can facilitate the monitoring of the overall quality of life of patients. A recent publication proposed a model of screening for the World Health Organization Quality of Life-100 item questionnaire using a much reduced number of questions with individual adaptive responses and high degree of reliability (31). Three hundred and twenty WHOQOL-100 questionnaire were used and a CAT simulation model was developed to calibrate item banks using item response theory, which included psychometric assessments of differential item functioning, local dependency, unidimensionality, and reliability. Simulated assessments were as reliable as paper-based forms of the WHOQOL with a much reduced number of items used.

Challenges of Current ESRD Care in the United States and PROM Use:

Incorporation of routine use of PROMs into ESRD care in the United States has not happened despite the fact that research studies have clearly shown a relationship between several PROMs and mortality and hospitalization (as noted above) and the use of PROMs has been shown to be helpful in assessing patients' responses to different treatment modalities (41-44). This is particularly important as the nephrology community evaluates the potential benefits of home HD or more

frequent HD. Relatively short-term studies (one year or less) comparing more frequent HD (in-center or home) to conventional three times/week HD have shown significant improvements in several HRQOL measures with more frequent HD when assessed by PROMs (41-44) -- but the long term effects have not been evaluated and the impact of the therapy on the patients' caregivers have not received sufficient attention.

The reasons why PROMs have not been used more effectively in ESRD care are multi-factorial. The intense focus in dialysis units on raising certain basic standards to internationally agreed upon standards of care has directed considerable resources to achieving these goals. Many of these goals have been included in CMS's Five Star Rating program and Quality Improvement Program for dialysis units. This has encouraged dialysis units to place a large emphasis on vascular access, anemia management, targeted KT/Vs, nutrition management, etc. Nurse coordinators and dieticians have often been charged with addressing these domains. The constrained resources in the dialysis units have not been directed at focusing attention on the patients' experience and symptom management (9,10). The annual KDQOL-36 and semi-annual questionnaires (CAHPS-ICH) administered to patients are generally addressed by social workers assigned to dialysis facilities and provide limited useful clinical or research-related information. The limitations of these questionnaires have been discussed above.

It is important to note that symptom management for ESRD patients, given the existing organization and allocation of resources, can indeed be challenging (45). For example, pain is a common complaints amongst ESRD patients, but there are limited therapeutic options and most of those options (such as narcotics) can have adverse effects. Depression is also prevalent, occurring in 25-30% of prevalent dialysis patients in cross-sectional analysis (21). But management of depressive symptoms is difficult -- even with the assistance of a trained nurse or social worker (21,46-48). An anxiety disorder is present in up to 45% of dialysis patients-- but how these disorders should be managed has not been defined (49). Marital discord (50), sexual dysfunction (51), family problems (52), financial issues, etc are also common among ESRD patients -- but how does the unit find the resources to deal with these challenging areas of difficulty. Many of these domains require someone to sit down and talk to the patient to explore those problem areas

that are most impactful for that particular individual. Whose responsibility is this? Can CAT be useful?

How Do We Move Forward?

There is no question that it is important to incorporate PROMs into the routine care of ESRD patients-- for the reasons already mentioned, including the association of PROMs with "hard" outcomes, the meaning for the individual patient, the limited appreciation of patient symptoms and concerns by clinicians, and the poor HRQOL assessments indicated by patients. It is important to keep in mind that patient responses will vary over time and simply administering a questionnaire annually or semi-annually will not really focus attention on patients' areas of difficulty. So how then do facilities and clinicians embrace PROMs in a practical and meaningful way?

Domains of difficulty for ESRD patients have been well established using validated PROMs. These areas of difficulty are outlined in Table 1. Addressing these domains is challenging given the multitude of problems presented by ESRD patients. These problems span the breadth of a comprehensive review of systems from physical complaints to cognitive difficulties to psychosocial and/or interpersonal problems. Thus, understanding the importance of each of these problematic domains for the individual patient is what is most important. The significance of each of these areas needs to be put in the context of the individual patient and the other problems presented by that individual – cardiovascular disease, hypertension, fluid overload, adequacy of dialysis, anemia, bone and mineral metabolism, metabolic disorders, etc. And it is important to keep in mind that simply documenting that an area of difficulty is present does not mean an individual patient wants to have this area addressed by health care providers and become a focus of his/her treatment plan. For example, Mor et al showed that although many women receiving chronic HD are sexually inactive, most are satisfied with their sexual life and few wish to learn about treatment options (54). And, Weisbord et al observed that despite documenting a high degree of depressive symptoms and pain in a cohort of HD patients, assigning a nurse manager to address pain and depressive symptoms in a randomized trial did not result in improved pain or depressive symptoms compared to the control group which received standard care (21). Wuerth et al noted that about half of patients

maintained on PD had high BDI scores but only half of these patients wanted to pursue a structured interview to document the degree of depression that was present (47). Do these findings suggest effective interventions are problematic or does this challenge us to develop innovative approaches?

It is important to remember that for PROMS to be clinically useful, they need to be adaptable to the individual patient. Lessons from other specialties would suggest that electronic reporting of symptoms and CAT offer the best options for doing repetitive testing, adapting the questions asked to individual patient responses. For example, if lack of sexual activity is not perceived by a patient as a problem, then inquiring in depth about this area will not be fruitful. Or, if a patient has a low score on the PHQ2, then administering a full depression screen may not be worthwhile. Importantly, little work has been done in dialysis facilities on CAT or individualization of PROMs. This is an area that is ripe for further study.

But it needs to be emphasized that including PROM screening will require that adaptive changes be developed in how dialysis facilities address patient reported problems. This requires thought and clearly a modification in current practice patterns. As recently noted by Nissenson, the quality paradigm must shift if we are "...to rekindle the aspirations of the creators of the (ESRD) program, whose primary goal was to improve the lives of the patients afflicted with this ... condition."

Potential barriers to the incorporation of PROMs into routine care:

There are certain problems with routine PROM administration that should be raised. How will patients complete the PROM if they are cognitively or visually impaired? If CAT becomes a standard of care, how will patients who do not have computers or tablets complete the questionnaires? Assistance and/or equipment will need to be provided by the dialysis team or family members. The problem of repetitive testing is a potential issue, but as mentioned above, this has not been a problem in other fields of medicine and is much less of a problem with CAT.

Regulatory Concerns and Documentation:

A concern with the use of PROMs in routine care is how they will be utilized by regulatory agencies as well as the dialysis organizations. Standards have been set

by CMS to compare the quality of care amongst dialysis facilities. And, if certain standards are not met, there can be financial penalties. Most of the standards which have already been established, such as hemoglobin levels, percent of patients with fistulas, percent of patients with hypercalcemia are readily assessed with objective measurements,

PROMs are different for several reasons. The PROMs that could best capture the patients' experience have not been well defined, as noted in the discussions above. Therefore, there needs to be flexibility in determining which PROMs are most useful and what are the best modes of administration. Arbitrary, standardized measures cannot be recommended at this time. Facilities should be able to adapt and modify the routine use of PROMS if a useful and efficient methodology is to be developed. Encouraging facilities to be innovative is what is most important –as opposed to the arbitrary dictation of rigid standards. An open dialogue between patient and provider should be encouraged if the PROMs are to be helpful. Patients need to understand that their responses will be used by providers to address their needs and problems. Providers need to make sure patients understand this and that reports of domains of difficulty will not be seen negatively by the provider. It also needs to be recognized that individual patient problems may be unrelated to the dialysis procedure itself and thus the ability of the dialysis facility to impact on these problems may be limited. Examples might include development of unrelated illnesses, family difficulties, economic hardships, marital discord, etc. Thus, using "scores" from PROMs to compare dialysis facilities is not appropriate and can in fact be counter-productive.

Conclusion and Recommendations:

How then can a regulatory agency be assured that PROMs are being administered and utilized to improve patient care? The challenge is how to make sure this is happening without stifling innovative thinking and undermining the beneficial effects of routine PROM administration, An approach that makes sense would be to require that PROMs be included as part of routine patient care. Which instruments to use and how they are to be administered should not be specified. Appropriate documentation should be provided in patient's records, and plans should be outlined to address areas of concern with appropriate follow-up

evaluations. The process of incorporating PROMs into routine patient care will gradually evolve and more standardized approaches will ultimately develop.

Thus, I would recommend the following:

1. Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues indicated in Table 1
2. Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
3. Encourage innovative approaches given the lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences
4. Require that there be documentation that domains of individual patient concerns have been acknowledged and that a plan to address these concerns has been noted. Plans could include addressing the problem using facility resources or making referrals to other health care providers or community resources.
- 5.

Table 1

- a) depression
- b) anxiety
- c) a wide variety of physical symptoms
- d) family and marital discord
- e) sexual dysfunction
- f) caregiver burden
- g) satisfaction with care and dialysis treatment regimen
- h) cognitive impairment
- i) impact of treatment regimen on their life
- j) physical functioning
- k) fatigue

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End-stage renal disease (ESRD) is a debilitating condition that results in impaired quality of life, significant morbidity, and premature death.^{113,114} The majority of patients with ESRD receive renal replacement therapy in the form of conventional hemodialysis (HD), delivered 3 days per week for 3–5 hours per session, or peritoneal dialysis (PD). CVD mortality is 5 to 30 times higher in dialysis patients than in subjects from the general population of the same age, sex, and race.^{113,114} View chapter Purchase book. Racial Differences in Kidney Disease and End-Stage Kidney Disease in the USA. Recent advances in our understanding of genetic variants in APOL1 and the role of inflammation may lead to novel diagnostic and treatment strategies in tackling sociocultural influences on CKD/ESRD care.