

# Physical Health Score Assessment May Not Predict Mental Health Score of Dialysis Patients

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*The state of physical and mental health has been an important factor influencing the quality of life in the hemodialysis patient population. The SF-36 in the past, and now the KDQOL-36 questionnaire have been used routinely to assess illness perception and quality of life (QOL) among hemodialysis patients. However, it is not clear whether these surveys can truly predict the effect of physical illness on mental health. We present routine quality improvement data from a small cohort studied in an urban dialysis unit in which the social worker performed standard questionnaires per mandate, compared results to unstructured verbal interviews, and noted a poor correlation. The patients who were not expected to have negative perceptions of quality of life actually had negative findings. The findings were more prominent for the mental health aspect of the survey than the physical health aspect, which correlated with patients' symptoms. A total of 92 patients were surveyed and interviewed, and their mental health score could not be correlated in 44% of patients who had a low mental health score and 17.5% of those with a high mental health score.*

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## INTRODUCTION

There are various scales and questionnaires used to assess quality of life (QOL) in the general population. However, many of these have not been adequate in the hemodialysis cohort, where the need is imperative, as the incidence of patients starting dialysis in the U.S. is estimated at > 100,000 persons per year (USRDS, 2015). Numerous studies have evaluated the effects of chronic kidney disease (CKD) on patients' QOL and particular aspects of their lives. In one Brazilian study, the areas associated with the lowest QOL were related to employment status, CKD burden, general health, and physical function (Cavalcante et al., 2013). Other studies have observed a correlation between anxiety and depression and poor QOL in ESRD patients (Olagunju, Campbell, & Adeyemi, 2015). While the QOL surveys have been major tools used in many studies, there is still the need to assess whether these surveys are effective methods of assessment.

Dialysis units use standard QOL questionnaires to assess mental and physical health in their patients. The SF-36 is a Short Form Health Survey that evaluates a set of generic and easily administered QOL measures related to chronic disease. In the past, the assessment of QOL in CKD patients used the SF-36 questionnaire with additional areas relevant to the CKD population. More recently, KDQOL-36 was developed and validated for use in the CKD population (Hays, Kallich, Mapes, Coons, & Carter, 1994). The KDQOL-36 uses a shorter version of SF-36 (SF-12), with 24 kidney-specific questions. The 24 kidney-specific questions address items such as fluid restriction, diet restrictions, symptoms after dialysis, and personal appearance. It is used

routinely as part of CMS requirements for the assessment of dialysis patients' QOL, and is performed on patients by the unit social worker annually. Exclusions to performing a QOL assessment using the KDQOL include: patients under 18; patients unable to complete the survey due to dementia, cognitive impairment, and active psychosis; non-English speakers/readers (if the survey is not available in their native language or an interpreter is not available); dialysis time of less than 3 months; and patient refusal. While the survey has become available in many languages over time, it may not be available in all dialects (Kidney Disease Quality of Life (KDQOL) Instrument, n.d.).

Aspects of CKD evaluated by the KDQOL-36 include disease interference with patients' lives in terms of time and daily activities or frustration with disease. In addition, focus is placed on the effects of CKD on diet and personal life. Although these are appropriate additions to the SF-36 survey, they may not be adequate to correlate a disease state with QOL in all patients. In addition to particular factors related to CKD such as those described above, there are specific cultural differences and perceptions that cannot be overcome by simply correlating symptoms with CKD. Moreover, one study noted better QOL when patients perceived their illness seriously, leading to better adherence to treatment (Nabolsi, Wardam, & Al-Halabi, 2013). This is important because cultural variations can influence understanding of and seriousness toward a disease. Additionally, cultural variations can alter responses to the questions asked on these surveys. For example, a question pertaining to personal life issues such as sexuality and personal appearance may appear

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inappropriate, leading to refusal to participate or dishonest answers. It was not clear whether specific cultural aspects are addressed when performing our QOL surveys. The importance of language and cultural sensitivity was exemplified in a study done on a population of multiple sclerosis patients (Michel et al., 2015). In this study, surveys were done in a variety of languages. The results demonstrated better insight into individual perception when culturally sensitive QOL surveys were used (Michel et al., 2015).

Quality of life assessments are performed by our social workers to estimate disease burden to analyze how perception of illness can affect disease self-management. An additional goal is to recognize barriers to effective care. In fact, if illness perception prevents effective medication and treatment administration, it can prevent further care such as renal transplant, as this would reflect a patient having poor self-management during the pre-transplant psychosocial assessment (Lim, 2014). Therefore, it is imperative to have a true assessment of the mental and physical health in our facility's dialysis population.

In this paper, we discuss some issues related to the QOL surveys that have been used in the dialysis cohort. We look at the results of a QOL survey (SF-36) in comparison to a verbal survey, both performed by the dialysis unit social worker. This is important, since CKD treatment is a large part of our healthcare system and there is a perception of disease burden that is based on the types of surveys used (Cavalcante et al., 2013). It is important to understand the variations in the disease perceptions, as they can affect the perception of the extent of the CKD burden.

## METHODS

The SF-36 questionnaire was given to patients by the unit social worker in an urban outpatient dialysis unit in Philadelphia, PA. The unit social worker also performed non-structured verbal interviews with each of the patients to be used in comparison to the SF-36 answers. The total number of patients was 92. The average age was 57 years; the F:M ratio was 64:46; 40% had diabetes, and 10% had amputations.

The statistical analysis of data was done using the IBM SPSS V.22 with a Pearson chi score. This study was conducted in the years 2007–2008. The study was exempt from IRB by Dialysis Corporation, Inc., East Falls, PA, since it was part of a routine quality improvement project. Of note, at the time of this study, KDQOL-36 was not established as the standard QOL survey. Hence, SF-36 was used at this dialysis unit.

The three general aspects assessed by the SF-36 survey were: Physical Component Summary (PCS), Mental Component Summary (MCS), and Mental Health (MH). Physical Component Summary (PCS) correlates with physical functioning and body pain scales. Mental Component Summary

(MCS) correlates with mental health, role-emotional, and social functioning scales. Mental Health (MH) scale includes: nervousness, feeling down-in-the-dumps, peaceful, sad, and happy. The vitality, general health, and social functioning scales correlated with both PCS and MCS. The score of the survey can vary with each individual, so a particular range is not given, although a lower score correlates with lower QOL (Hays, Sherbourne, & Mazel, 1993).

## RESULTS

The results of the SF-36 questionnaire revealed 19.6% (18/92) of patients had an MH score of less than 52, and (80.4%) 74/92 had a score higher than 52. 27.2% of patients (25/92) had MCS score less than 42, and 57.6% (53/92) had PCS score less than 34. The social worker's observations with the non-structured verbal interview questionnaire differed when compared with SF-36 survey in terms of the MH scale. 44% (8/18) of the patients with low MH scores and 17.5% (13/74) of those with high MH scores could not be predicted by the unit social worker closely following the patients using SF-36 in addition to routine interactions with patients. The social worker observed these patients on a routine basis, some for many years through routine patient care rounds. The discordance was surprising because she was unable to correlate the patients with low and high MH scores. The predictability using unstructured interview by the social worker was better with the higher MH score when compared to low MH scores (Pearson chi = 5.9 and  $p$ -value = 0.015). This means the social worker's observations were more correlated and predictable in patients with a higher MH score, and less correlated in those with a lower MH score. Those expected to have a lower MH score due to a negative attitude towards their chronic illness did not have lower MH scores. Furthermore, in terms of correlation of MH scores with QOL, there was more correlation in the group with better reported QOL than those reporting poor QOL (Pearson chi = 11.1 and  $p$ -value = 0.001). These two statistically significant findings may suggest that unstructured interviews and casual assessment may not be a good screening tool to assess mental health in those with poor illness perception and QOL, and supports the use of structured measurement of mental health.

The unit social worker had expected certain results based on her non-structured and casual observations of patients but was unable to correlate these expectations with the standard SF-36 survey. In effect, it was assumed that those patients with a negative attitude or more debilitating medical conditions will have lower QOL per survey results, but this was not the case. On the other hand, while the surveys are validated and effective tools in assessing QOL using mental and physical health questions, there can be limitations. These can be related to patient-specific factors, such as acute stressors, cultural variations, socioeconomic status, and varying degree of understanding the survey, per patient level of education.

## DISCUSSION

An assessment of illness perception and mental health and its correlation with the physical health state is an important aspect predicting morbidity and mortality in patients. Although there are multiple factors, such as socioeconomic status, education level, and multiple comorbidities that affect QOL (Cavalcante et. al, 2013), “disease burden” plays an important role in perception of illness and future outcomes. While this is important in the general population, we particularly discuss the effects and benefits of these assessments in the dialysis cohort. Assessments are performed by dialysis unit social workers, using the standard SF-36 questionnaire in the past, and since 2008, the KDQOL-36.

As we noted with the results of this study in the outpatient dialysis unit, there was poor correlation of mental health scores and QOL when survey answers were compared with the non-structured verbal interview questionnaires performed by the unit social worker. The predictability was poor in those patients with lower MH scores more than those with higher MH scores. Additionally, those with reported poor QOL had lower correlations with MH scores. Therefore, it can be concluded that there is more difficulty in subjectively identifying patients with worse mental health status.

One of the explanations for this finding from the unit social workers and staff was likely related to patient mobility and freedom. The amputee patient who has poor mobility is out of the home and interacting with persons while at dialysis; these patients do not perceive their illness as a hindrance but as a way of staying involved with the outside world. The younger patient who is otherwise well and is working, is now bound to a dialysis session for 4 hours 3 times a week, may perceive his illness as a giant setback in routine life.

The assessments and scales used to evaluate QOL and mental health in outpatient dialysis units can vary among different companies, but generally it is standardized for an annual QOL assessment using the KDQOL-36, based on current CMS guidelines. While the new assessment questionnaires include CKD-specific questions, there may still be lack of correlation due to patient-specific factors not addressed by the survey. Using the results of our study, we noted that a correlation between routine observations and survey results was not always predictable. While this may be specific to one dialysis unit or social worker, there still needs to be thought as to what factors still need work to have a more robust assessment of QOL in the dialysis cohort. The surveys are available in many languages, but not every single language and dialect, and patients with negative disease attitudes or perceptions may be refusing to participate. Evaluating QOL in survey participants is of great value, but we are still missing assessments of patients who consistently refuse and those may be the patients who need immediate help. Therefore, this is a concern that remains and needs further evaluation on a larger scale to assess whether our routine surveying tools are effective measures of our patients’ QOL.

The results of data analysis from this small quality care study exemplify that there is need for a more robust method of assessment of the mental status of our dialysis population to be able to recognize true illness perceptions. We need a method to individualize our assessments as they pertain to every patient. While we cannot coerce patients to participate, we must try to identify the reasons for poor QOL and high disease burden in our patients by individualizing our assessments on a routine basis. Social work plays an important part in helping improve hemodialysis patients’ QOL.

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