

## Routine Use of the PedsQL™ for Assessment of Quality of Life in Pediatric Dialysis Patients

Kristin L. Stockard, LICSW, Department of Social Work, Seattle Children's Hospital

Kristy D. Seidel, MS, Department of Biostatistics, Fred Hutchinson Cancer Research Center

Joseph T. Flynn, MD, MS, Division of Nephrology, Seattle Children's Hospital, Department of Pediatrics, University of Washington School of Medicine

---

*To comply with new Centers for Medicare and Medicaid Services (CMS) regulations requiring regular assessment of patient quality of life (QoL) by dialysis programs, we administered the PedsQL™ survey instrument to every eligible dialysis patient in our program beginning in October 2008. We compared findings between groups of our patients assessed from October 2008 through January 2010, and also with results of previously published multi-center studies. Compared to prior published studies using the PedsQL, the overall scores for patients and parents were lower in this routine collection of survey responses. Unexpectedly, we found that HD patients and patients living at greater distances from our center had better QoL scores than PD patients and those living closest to the medical center. These results require re-examination in larger, multi-center studies.*

---

### INTRODUCTION

The Centers for Medicare and Medicaid Services (CMS) published new Conditions for Coverage for End-Stage Renal Disease Facilities in April 2008 (CMS, 2008). These regulations, which took effect in October 2008, were the first new regulations in approximately 30 years, and brought many changes to dialysis programs. One of the new conditions requires social workers to use a validated quality of life (QoL) tool to assist in the psychosocial assessment of all chronic dialysis patients. Tools that had only previously been utilized in research settings are now incorporated into routine social work assessments across a broader patient population.

The Measures Assessment Tool (CMS, 2014) utilized by dialysis facility assessors expects that social workers will assess QoL via the KDQOL™ (Hays, Kallich, Mapes, Coons, & Carter, 1994). This instrument uses a Physical Composite Score and a Mental Composite Score for which the RAND Corporation has previously established normative responses (Hays, Prince-Embury, & Chen, 1998) and, along with the Dialysis Outcomes and Practice Patterns Study (DOPPS), has also been used to establish a correlation between QoL and morbidity and mortality (Mapes et al., 2003). Unfortunately, the KDQOL is only validated for patients aged 18 and older. Pediatric dialysis social workers are left to search for an appropriate assessment tool without specific guidance from CMS.

The PedsQL™ (Varni & Limbers, 2009; Varni, Limbers, & Burwinkle, 2007a; Varni, Limbers, & Burwinkle, 2007b) is one such QoL tool that has been developed and validated in several pediatric patient populations. The PedsQL Generic Core Scale addresses general questions about general physical health, school and social/emotional functioning, providing a QoL score that could be compared to a healthy population. In addition to the Generic Core Scale (used to measure QoL across healthy and ill populations), many

disease-specific modules have been developed, including an end-stage renal disease (ESRD) module. The Generic Core Scale and the ESRD Module are designed to be completed by the patient and also by a parent (or parent proxy, as appropriate). The PedsQL tool is validated for patients aged 2 to 18 years who can speak English or Spanish (Goldstein et al., 2008). Age range adjustments can be made to accommodate developmental delays. While the PedsQL has been validated for pediatric ESRD patients in research settings (Goldstein et al., 2008; Varni et al., 2007b), no data exist on the results of its routine application.

The Dialysis Program at Seattle Children's Hospital (SCH) implemented use of the PedsQL survey in October 2008 to meet the CMS mandate to assess QoL. In this report, we examine results from our initial experience of routinely using the PedsQL in order to determine how the quality of life for SCH hemodialysis (HD) patients compares to that of SCH peritoneal dialysis (PD) patients; whether quality of life among SCH dialysis patients varies across age, gender, and ethnicity; and whether distance from the medical center in our geographic region has a significant impact on quality of life.

### METHODS

The PedsQL was administered by the dialysis social worker to every eligible dialysis patient (English or Spanish-speaking only, ages 2 to 18) enrolled in our program beginning in October 2008. This gave us a baseline for each patient. Since that time, eligible patients are administered the appropriate PedsQL module during 90-day, "unstable," or annual comprehensive assessments. Patients aged 18 and over are given the KDQOL for assessment. Only results of the PedsQL are included in this report.

The PedsQL (Varni et al., 2007a; Varni et al., 2007b, Varni & Limbers, 2009) is administered to patients, who complete survey questions about their own quality of life, and

---

**Corresponding author:** Kristin Stockard, Division of Nephrology, Seattle Children's Hospital, 4800 Sand Point Way NE, Mailstop OA.5.250, Seattle, WA 98105-0371; [kristin.stockard@seattlechildrens.org](mailto:kristin.stockard@seattlechildrens.org)

to parents, who complete survey questions about how they perceive the quality of life of their child. The Generic Core Scale has 23 questions, while the ESRD Module has 34 questions. For each question, respondents are asked to describe how much of a problem the particular item has been over the last 4 weeks (“never a problem”; “almost never a problem”; “sometimes a problem”; “often a problem”; or “almost always a problem”). The Toddler Report (for children ages 2 to 4) is only completed by parents and has a reduced number of questions. The Young Child Report (for ages 5 to 7) has the full complement of questions, but reduced response options (“never”; “sometimes”; and “almost always”). The Young Child Report also has an optional tool with a smiling face, a straight face, and a frowning face to allow children to demonstrate their responses more visually. The Child Report (for ages 8 to 12) and the Teen Report (for ages 13 to 18) have slightly different phrasing, but each allows children and parents the full complement of questions with the full complement of responses.

The PedsQL is scored on a scale of 0 to 100, with higher numbers correlating with better quality of life. The Generic Core Scale generates a physical health subscore, a psychosocial health subscore, and a total score. The ESRD Module generates a total score and seven subcategory scores: general fatigue, disease symptoms, treatment problems, family and peer interactions, worries, perceived personal appearance, and communication.

For this analysis, we examined the first 15 months (October 2008 to January 2010) of PedsQL surveys administered in our dialysis program. All surveys completed during this time were included in this review. The Seattle Children’s Hospital Institutional Review Board approved retrospective data collection for this report. SCH had previously purchased a user agreement for routine use of the PedsQL and all disease-specific modules.

### Statistical Analysis

We divided the patients by the following characteristics for purposes of analysis: dialysis modality (peritoneal dialysis (PD) vs. hemodialysis (HD)), gender, age, ethnicity (Caucasian vs. Hispanic), and by geographical areas. [Tables 1 and 2](#) show that we did collect surveys from patients and parents of racial/ethnic groups other than Caucasian and Hispanic. However, the numbers of subjects in these groups were too small to include separately in the statistical analysis, thus analysis was completed for Caucasian vs. Hispanic only. For the geographical comparison, we divided our service area into three parts: Seattle Metro (defined as King, Snohomish, and Pierce counties), other parts of Washington State, and out of state (which included patients from Alaska and Montana). For the analysis of the Generic Core Scale, the data from outside the Seattle Metro area were sparse, and therefore the geographic categorization was collapsed into two levels, Seattle Metro and outside of Seattle Metro.

**Table 1.** ESRD Module scores according to selected patient characteristics

	PedsQL™ ESRD Module:					
	Patient self-reported			Parent-reported		
	n	Mean (SD)	p-value <sup>†</sup>	n	Mean (SD)	p-value <sup>†</sup>
<b>Dialysis Modality:</b>						
Peritoneal	20	57.7 (17.0)	p = 0.28	22	58.5 (17.3)	p = 0.57
Hemodialysis	19	63.6 (16.6)		19	61.5 (14.5)	
<b>Patient Gender:</b>						
Female	17	59.0 (16.5)	p = 0.63	19	55.4 (15.6)	p = 0.10
Male	22	61.8 (17.5)		22	63.7 (15.6)	
<b>Patient Age Group:</b>						
Child ≤ 12 yrs	10	61.5 (19.1)	p = 0.83	14	61.7 (13.9)	p = 0.60
Teenager (13–18 yrs)	29	60.2 (16.4)		27	59.0 (17.1)	
<b>Patient’s Ethnicity:</b>						
Caucasian	21	61.4 (19.3)	p = 0.10	25	64.4 (13.1)	p = 0.01
Hispanic	11	54.1 (12.2)		12	50.4 (13.4)	
Other/multiple	7	68.1 (13.3)		4	60.3 (29.1)	
<b>Residence Location:</b>						
Seattle Metro	21	61.1 (16.7)	p = 0.97	21	57.7 (18.0)	p = 0.70
Other WA county	13	60.7 (13.0)		15	62.4 (12.0)	
Out of state	5	58.1 (28.2)		5	61.5 (19.4)	

<sup>†</sup>The p-values for the comparisons of means were computed using a Generalized Estimating Equation (GEE) modeling approach.

**Table 2.** Generic Core Scale scores according to selected patient characteristics

	PedsQL™ Generic Core Scale:					
	Patient self-reported			Parent-reported		
	n	Mean (SD)	p-value	n	Mean (SD)	p-value
<b>Dialysis Modality:</b>						
Peritoneal	10	63.0 (15.9)	p = 0.98	10	53.1 (19.3)	p = 0.71
Hemodialysis	7	63.2 (14.0)		7	49.7 (20.5)	
<b>Patient Gender:</b>						
Female	8	58.0 (13.7)	p = 0.17	7	44.1 (14.7)	p = 0.18
Male	9	67.6 (14.8)		10	57.0 (21.0)	
<b>Patient Age Group:</b>						
Child ≤ 12 yrs	3	71.9 (9.2)	p = 0.08	4	49.0 (17.2)	p = 0.72
Teenager (13–18 yrs)	14	61.2 (15.2)		13	52.5 (20.4)	
<b>Patient's Ethnicity:</b>						
Caucasian	9	66.7 (16.7)	p = 0.31 <sup>†</sup>	9	53.4 (23.0)	p = 0.45 <sup>†</sup>
Hispanic	7	58.9 (12.6)		7	45.9 (11.7)	
Other/multiple	1	59.8 (n/a)		1	77.2 (n/a)	
<b>Residence Location:</b>						
Seattle Metro	10	57.2 (12.6)	p = 0.04	11	44.8 (15.7)	p = 0.03
Outside Seattle Metro	7	71.5 (14.0)		6	64.3 (20.1)	

<sup>†</sup>The p-values for the comparisons of means were computed using a Generalized Estimating Equation (GEE) modeling approach.

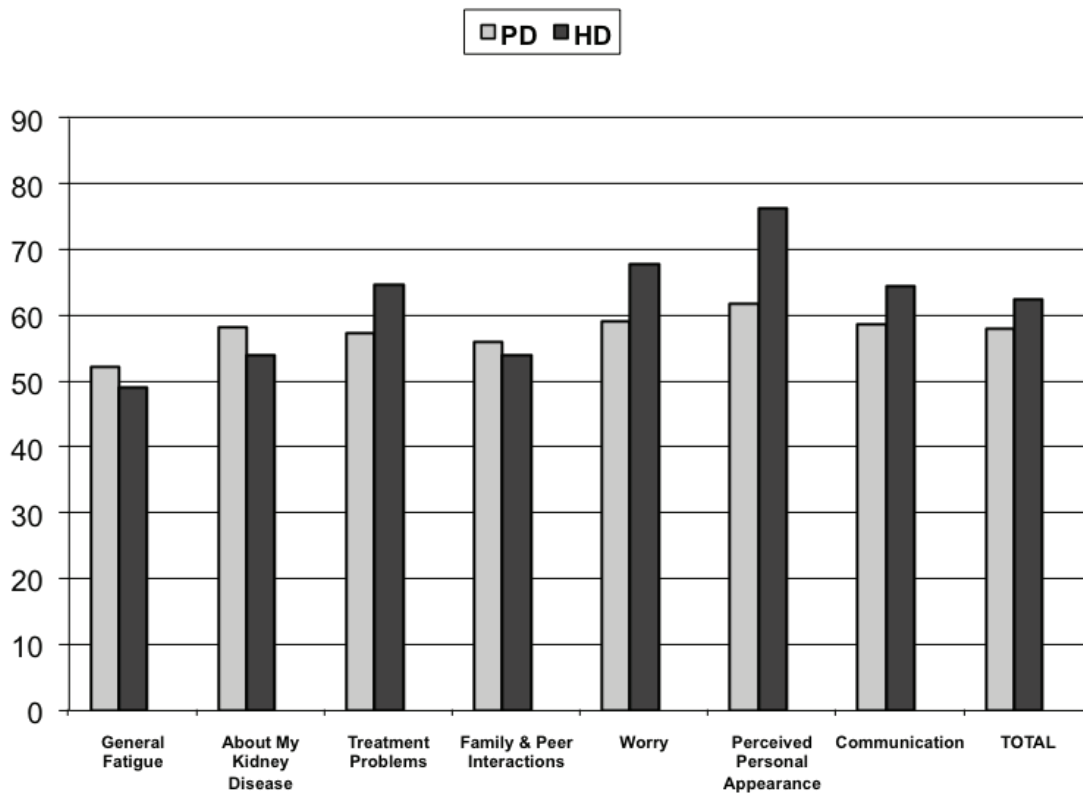
Scores on the ESRD Module and Generic Core Scale of the PedsQL were summarized with means and standard deviations. Patient self-reported and parent-reported data were summarized separately. Comparisons of mean scores by dialysis modality (PD vs. HD), gender, age group, ethnic group and residence location were performed using Generalized Estimating Equation (GEE) methodology. Use of GEE modeling was necessary because some subjects completed the PedsQL modules on more than one occasion and the observations contributed by the same person may be correlated. The GEE modeling approach to testing for differences between group means accounts for any within-subject correlation. For categorical factors having more than two levels (ethnicity and residence location), the p-value presented is from a joint test for the significance of the factor as a whole in the GEE model. For visits at which both patient and parent completed the PedsQL modules, differences between the paired parent and patient scores were also assessed. GEE modeling was used to obtain standard error estimates and compute 95 percent confidence intervals for the mean parent-patient difference. Scatter plots of the paired parent-patient scores were also generated and displayed along with the Pearson correlation coefficient (r).

## RESULTS

From October 2008 through January 2010, a total of 39 patients and 41 parents completed surveys. While most of these patients and parents represent a pair, some children did not have parents present to complete the parent reports, and some parents completed surveys while their children were not developmentally capable of doing so. As seen in [Table 1](#), our patients represented a roughly even split between HD and PD. They were largely over the age of 12 years, more than 50 percent were Caucasian, and more than 50 percent were from within the three Washington (WA) counties closest to the medical center.

The most statistically significant differences in the parents' survey responses were seen in ethnicity (p = 0.01), with the parent-reported mean ESRD score being lowest among Hispanic children ([Table 1](#)). Similarly, the children's self-reported ESRD scores were lowest in the Hispanic group; however, those differences did not reach statistical significance (p = 0.10). Also of note in [Table 1](#) is the trend toward lower parent-reported ESRD Module scores for female patients versus male patients, although this comparison did not reach statistical significance (p = 0.10). Geography had no significant impact on the scores in this module.

Results according to dialysis modality are highlighted in [Figure 1](#). For many of the categories, HD patients scored higher than PD patients. In the ESRD Module, HD patients scored higher in the areas of treatment problems, worry, perceived personal appearance, and communication.

**Figure 1.** Mean scores across ESRD Scale categories by dialysis modality (PD vs. HD)

We did not have access to the Generic Core Scale at the beginning of this study period, and only obtained the extra scale midway through the time frame covered by this study. The results of the Generic Core responses represent 17 patients and their parents (see [Table 2](#)).

While geography did not reflect an impact on QoL in the ESRD Module scores, there was some impact reflected in the Generic Core Scale scores as seen in [Table 2](#). Patients living closest to the hospital (residing in the three surrounding counties of King, Snohomish, and Pierce) had a significantly lower QoL (57.2 mean total patient score) than those living at greater distances (71.5 mean total patient score,  $p = 0.04$ ). A similar difference in QoL scores was seen among parents, with the mean total parent score among those living greater distances from SCH being 64.3, compared to a score of 44.8 for those from surrounding counties ( $p = 0.03$ ).

The overall patterns seen in the Generic Core Scale scores showed some similarities to those seen for the ESRD Module scores, with a marked, albeit not statistically significant differential between female patients and male patients. Patients and parents consistently rated girls lower on the QoL scale compared to boys (female patient total mean score 58.0, male patient total mean score 67.6; parent for girls 44.1, parent for boys 57.0). Also of note in [Table 2](#), dialysis patients 12

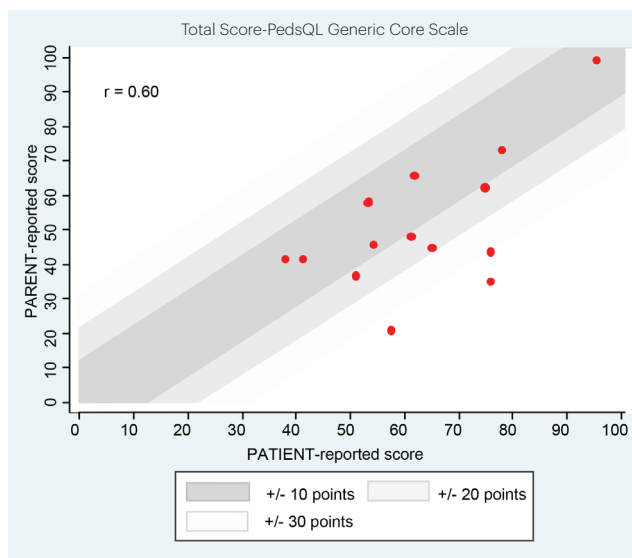
years old and younger had substantially higher QoL scores than their adolescent counterparts (71.9 total mean score vs. 61.2), a difference which approached statistical significance ( $p = 0.08$ ). However, parent-reported QoL scores did not show the same trend.

By observation, patients' and parents' surveys did not always have numerically equivalent scores, but often shared overall rankings of the categories addressed by the ESRD Module. For example, the patient and the parent might not agree on the numeric responses to the questions about fatigue, but both might agree that issues of fatigue are more problematic for the patient than issues of personal appearance. [Table 3](#) shows the paired comparisons of responses supplied by the patient versus responses supplied by his/her parent. Of note, ratings by patients and their parents differed much more dramatically on the Generic Core Scale than the ESRD Module. Also of note, patients tended to rate their physical health better (mean score 64.0) than their psychosocial health (mean 61.8), while parents tended to rate the child's psychosocial health better (mean 52.8) than their physical health (mean 48.7).

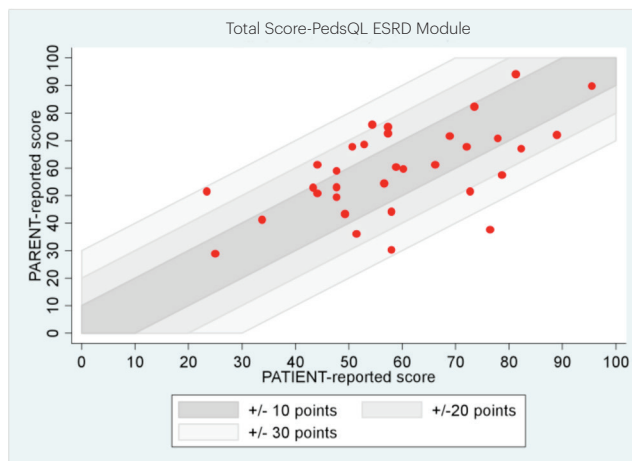
[Figures 2 and 3](#) demonstrate a distinct difference between the way patients and their parents scored on the Generic Core Scale versus the ESRD Module. For the Generic Core

Scale, Figure 2 shows that there are many pairs in which the parent-reported score was more than 10 points below their child's patient-reported score, but there are no pairs in which the parent-reported score exceeded the child's score by that much. For the ESRD Module, the scatter around the central  $\pm 10$  point band is more even, with discrepancies between parent- and child-reported scores occurring in both directions (Figure 3). For both the Generic Core Scale and ESRD Module, about half of the patient-parent pairs studied scored within a  $\pm 10$  point spread.

**Figure 2:** Generic Core Scale scores correlated between patient and their parent-proxy



**Figure 3:** ESRD Module scores correlated between patient and their parent-proxy



## DISCUSSION

In this report we show that routine application of the PedsQL in a pediatric ESRD population can provide important insights into QoL which may reflect the unique characteristics of the dialysis center and the patient population it serves. These insights will help social workers and the full interdisciplinary dialysis team to attend to individual care planning as well as program development.

Some results are not unexpected. For example, our data demonstrate that Hispanic patients rate their quality of life lower than other patients. It is important to note here that

**Table 3.** Comparison of patient-self-reported and parent-reported Generic Core Scale and ESRD Module scores

PedsQL™ ESRD Module component:	Patient self-reported Mean (SD)	Parent-reported Mean (SD)	Difference (95% Conf. Int.) †
General fatigue (n = 30)	53.3	46.7	+6.6 (-2.7, 15.9)
Kidney disease symptoms (n = 32)	54.7	57.2	-2.6 (-9.0, 3.9)
Treatment problems (n = 33)	53.8	63.1	-9.3 (-18.4, -0.2)
Family & peer interactions (n = 32)	57.3	50.0	+7.3 (-2.1, 16.7)
Worry (n = 33)	62.1	62.0	+0.2 (-6.7, 7.0)
Perceived physical appearance (n = 33)	67.9	64.6	+3.3 (-6.5, 13.1)
Communication (n = 32)	63.0	62.8	+0.2 (-9.8, 10.2)
TOTAL SCORE (n = 33)	59.3	59.3	0.0 (-5.4, 5.5)
<b>PedsQL™ Generic Core Scale component:</b>			
Physical (n = 15)	64.0	48.7	+15.3 (6.6, 24.0)
Psychosocial (n = 15)	61.8	52.8	+9.0 (-0.4, 18.4)
TOTAL SCORE (n = 15)	62.6	51.3	+11.2 (2.6, 19.9)

†The 95% confidence interval for the difference between means were derived using a standard error estimate derived from a Generalized Estimating Equation (GEE) model. This approach accounts for any correlation that may exist among multiple observations contributed by the same patient-parent pair at different visits.

the PedsQL is validated in the English and Spanish languages only and is not validated for use with an interpreter. The patient population captured in these responses is not as racially or ethnically diverse as the total SCH dialysis population. These results, therefore, tell us more about the Hispanic population represented, and less about other racial and ethnic patient groups. Studies in adult dialysis patients have shown Hispanic patients to have lower QoL scores than other non-Hispanic groups (Lopes et al., 2003). Hispanic patients are more likely to have residency or immigration status that disqualifies them from certain support programs and other resources. Hispanic patients are more likely to require the use of interpreters during medical appointments. Regardless of the skill and expertise of the interpreter, communication is always more challenging through translation. These issues are well known to affect QoL assessment in Hispanic populations, and may explain why there are so few published data on Hispanic patients with kidney disease (Porter, Vijil, Unruh, Lora, & Lash, 2010).

Other results are curious, but not entirely surprising. For example, when thinking about the difference between patient self-reported Generic Core Scale physical health (mean score 64.0) compared to parent-reported Generic Core Scale physical health (48.7), it is easy to speculate on these differences (Table 3). Social workers understand families as systems (Schriver, 2011). Children and parents occupy unique roles in the family system, but parents once played the child role in their own family of origin. Parents are more likely to have had a healthy childhood themselves, and are likely to have at least one other healthy child at home for comparison. Parents with healthy childhoods are likely to see how much their chronically ill child is disadvantaged in their physical health by comparing to their own childhood, or another sibling, or simply from life experience. Children who have lived with kidney disease for as long as they can remember may not view or understand their own limitations in the same way. Perhaps, patients are even aware of an improved feeling of energy since starting dialysis after a long period of decline because their chronic kidney disease progressed prior to initiating treatment. However, these are speculations only, and it is clear that further research in these areas is needed. Pediatric social workers are able to work directly with patients and their parents, allowing for exploration of these questions in routine practice.

Still, other results of this analysis challenge our assumptions about what we think is best for pediatric ESRD patients. Most notably, with the assumption that PD patients would show a somewhat higher QoL than their HD counterparts (Goldstein et al., 2009), the fact that these results show even a small difference in the opposite direction presents interesting questions worthy of further exploration. In pediatrics, we have long presumed that PD offers a better quality of life for children and their families. PD treatments are done in the home, which allow children to attend school and parents to work. Dialysis facilities are asked to consider the home treatment options for each and every patient in recognition

that home modalities facilitate rehabilitation. And in fact, Goldstein et al. (2009) confirmed such beliefs in their multi-center study showing that transplant patients had higher QoL scores than PD patients, who in turn had higher QoL scores than HD patients. Our results may challenge that presumption.

In general, our patients scored lower on the PedsQL than pediatric dialysis patients in previously published studies (Goldstein et al., 2008; Goldstein et al., 2009; Varni & Limbers, 2009). This may represent the difference in a study population compared to a general patient population. The prior studies also represent multiple centers across the country, while ours is a single-center analysis.

The geography of our service region may make these findings unique to our center and not generalizable to other pediatric dialysis programs. SCH serves a geographic region that is vast and diverse, including the states of Washington, Alaska, Montana, and Idaho. Because distance from the medical center limits modality choice and creates greater financial hardships, we anticipated that distance would negatively correlate with QoL. Finding that those patients living furthest from the medical center showed better QoL than those living closest, we now wonder whether distance is not as much a factor as urban versus rural lifestyles. While we do not see a significant difference in socio-economic status between these groups, we do recognize that urban poverty is experienced differently from rural poverty (Churilla, 2008). We also wonder about the differences in service delivery expectations. Urban residents can typically shop for groceries, go to the gym, use an ATM, and visit a pharmacy 24 hours a day somewhere close to home. With that level of immediate service access, the need to drive even 30 miles from Tacoma to Seattle, passing several adult dialysis centers on the way, may seem like a real hardship. Rural residents live with the understanding and the expectation that not everything is readily available. The 10-hour drive from Kalispell, MT, to Seattle may seem quite reasonable, given there are no pediatric dialysis providers in the entire state of Montana. Some studies in adult patient populations suggest that rural communities experience less access to healthcare and lower health literacy, two issues correlated with lower health-related QoL (DiSipio, Hayes, Newman, Aitkin, & Janda, 2010; Spont et al., 2011; Wang et al., 2013). It is possible that access at a distance, combined with the high health literacy of parents trained to perform PD, removes these barriers for our pediatric population.

Attribution Theory (Weiner, 1974; Weiner, 1986; Gordon and Graham, 2005) suggests that a person's perception of his personal situation is what most determines how he will feel about that situation. In healthcare, the perception of problems can have an impact on the care of problems (Cella et al., 2007; Lewis & Daltroy, 1990; Pallant, Misajon, Bennet, & Manderson, 2006). Health behavior theories help us think about how personal experiences, beliefs, and opinions shape health perceptions and health behaviors (Brewer

& Rimer, 2008). PD and HD patients seem to perceive a different sense of control over some aspects of their lives, and therefore seem to have different expectations. HD patients are not able to attend school full time. This has always been seen as a significant barrier to academic achievement and social acclimation. It also means that, given these barriers, HD patients do not have the same expectations for school success, and their QoL scores seem to reflect less concern about school problems. On the other hand, PD patients are expected to attend school full time and keep up with their peers even while going home every night to dialyze for 10 to 12 hours. Perhaps PD patients feel added pressure to perform at school. We need to consider whether the PD patients work hard to “fit in” and “be normal” during a time when HD patients do not feel that same pressure; similarly, home PD may place increased burdens on parents than in-center HD, thus contributing to a perceived lower QoL.

The dialysis center can be a very supportive and caring environment for pediatric patients. HD patients attending chronic treatments 3 to 5 times per week not only have ample opportunities to meet other patients in their own situation, but understand that a number of adults (nurses, social workers, etc.) care about them as young people. HD provides consistency and routine. It is possible that the support our HD patients receive in the dialysis unit positively balances the disruption they experience at home and school. It is also possible that our PD patients feel more isolated in their treatment with less opportunity to connect with other patients in situations similar to their own. These patients may also feel that they are a burden to their family (the parents who perform and manage their treatment) in a way that HD patients do not.

When faced with known barriers, it is important that we, as social workers, continue to support families in coping with those barriers. Quality of life is impacted more by how a person handles what happens in his or her life than by the events themselves. We may not be able to remove all the barriers our patients face, but we may still be able to impact their coping and adjustment in the face of those barriers. For example, at SCH it will be important for our dialysis team to think creatively about how best to support our Hispanic patients. We may have little impact on their residency or immigration status or on the community services available to such patients, but we have much to offer them in the way they experience their dialysis care. We can team with our bilingual Spanish social worker, our pastoral care team, and our patient navigators to consider programmatic opportunities for improving support and coping strategies for these families.

Looking at individual items from the surveys, patients of all ages scored “I feel thirsty” and “I get tired” the lowest of all individual items. In the “worry” section, parents did not perceive their children to be worried that “I will get sick if I don’t take my medicines.” However, adolescents showed that they do indeed worry about this issue. Individual items such

as these can tell us something about the adherence problems that are typically seen in a dialysis population. It also tells us something about how we might begin to address adherence as an interdisciplinary team. If we can find ways to tap into these worries at the same time we are helping kids cope with thirst and fatigue, we may be able to make some headway in the perpetual adherence battle.

The results shared here are a snapshot of the dialysis patients served by one pediatric dialysis program. It is unclear how these results translate to other settings or even to a different window of time within our own program. What is evident, however, is that these measurements give us new opportunities to challenge our assumptions. Dialysis programs have long understood the value of interdisciplinary approaches to care and the importance of patient and family involvement in care planning and decision making. These results are an important reminder of the individuality of our patients, the resiliency of children with chronic illness, and the value in ongoing psychosocial assessments of coping and adjustment. These results will give social workers new directions in clinical work, research, and psychosocial leadership within the interdisciplinary team.

## LIMITATIONS

There are a number of important limitations to this study that are discussed throughout but should be highlighted again here. The sample size is relatively small. Due to the language and age restrictions of the survey, the sample is not fully representative of the patients in our program. For example, the sample does not include infants or young adults (18–21) who are part of our program. The sample does not include patients whose primary language is neither English nor Spanish. In several instances, the small sample size limited the scope of the statistical analysis: patients from both MT and AK were grouped together as “out of state”; African-American and Asian patients were excluded from the ethnicity comparison; and children from the “toddler,” “young child,” and “child” age groups were lumped together into a single group of children 12 and under to be compared with teens. The study is also limited by the short time frame of examination. Finally, the geographic service area of our center is incomparable to any other dialysis program in the United States. That alone may make this review incomparable to any other dialysis program in the United States.

## CONCLUSION

The impetus for mandating the use of QoL surveys during routine psychosocial assessment of dialysis patients comes from social work-driven research in the adult population showing a strong correlation between low QoL scores and higher morbidity and mortality rates (Mapes et al., 2003; Tsai et al., 2010). As social workers integrate QoL surveys into routine practice, we are now tasked with using this data not just to inform individual patient care planning, but for larger program development within the dialysis unit as well. There is no normative data for the PedsQL that allows a spe-

cific score to hold interpretive meaning in the way that the KDQOL offers. Pediatric dialysis social workers are tasked now with developing such interpretive norms through collaborative review of the data now being collected in routine practice. These reviews may allow pediatric social workers to also ask whether QoL has a significant impact on morbidity and mortality in children on dialysis.

## REFERENCES

- Brewer, N. T., & Rimer, B. K. (2008). Perspectives on health behavior theories that focus on individuals. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (pp. 149–165). San Francisco, CA: Jossey-Bass Publishers, Inc.
- Cella, D., Yount, S., Rothrock, N., Gershon, R., Cook, K., Reeve, B., et al. (2007). The Patient-Reported Outcomes Measurement Information System (PROMIS): Progress of an NIH roadmap cooperative group during its first two years. *Medical Care*, *45*, S3–S11.
- Centers for Medicare & Medicaid Services (CMS). (2008). Medicare and Medicaid Programs: Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule 42 CFR Parts 405, 410, 413, et al. 73 *Federal Register* 20369 (April 15, 2008). Retrieved from <http://www.cms.hhs.gov/cfcsandcops/downloads/esrdfinal-rule0415.pdf>
- Centers for Medicare & Medicaid Services (CMS). (2014, November 6). ESRD Surveyor Laminates [downloadable zip file]. Retrieved December 1, 2014, from: <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Dialysis.html>.
- Churilla, A. (2008). Urban and rural children experience similar rates of low-income and poverty. *Carsey Institute Reports on Rural America*, *2*, 1–4.
- DiSipio, T., Hayes, S., Newman, B., Aitken, J., & Janda, M. (2010). Does quality of life among breast cancer survivors one year after diagnosis differ depending on urban and non-urban residence? A comparative study. *Health and Quality of Life Outcomes*, *8*, 3.
- Goldstein, S. L., Graham, N., Warady, B. A., Seikaly, M., McDonald, R., Burwinkle, T. M., et al. (2008). Measuring health-related quality of life in children with ESRD: Performance of the generic and ESRD-specific instrument of the Pediatric Quality of Life Inventory (PedsQL). *American Journal of Kidney Diseases*, *51*, 285–297.
- Goldstein, S. L., Rosburg, N. M., Warady, B. A., Seikaly, M., McDonald, R., Limbers, C., et al. (2009). Pediatric end stage renal disease health-related quality of life differs by modality: A PedsQL ESRD analysis. *Pediatric Nephrology*, *24*, 1553–1560.
- Gordon, L. M., & Graham, S. (2005). Attribution Theory. In N.J. Salkind (Ed.), *Encyclopedia of human development* (pp. 143–146). Thousand Oaks, CA: SAGE Publications, Inc.
- Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., & Carter, W. B. (1994). Development of the Kidney Disease Quality of Life (KDQOL) instrument. *Quality of Life Research*, *3*, 329–338.
- Hays, R. D., Prince-Embury, S., & Chen, H. (1998). *RAND-36 Health Status Inventory*. San Antonio, TX: The Psychological Corporation.
- Lewis, F. M., & Daltroy, L. H. (1990). How causal explanations influence health behavior: Attribution Theory. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health education and health behavior: Theory, research, and practice* (pp. 92–114). San Francisco, CA: Jossey-Bass Publishers, Inc.
- Lopes, A. A., Bragg-Gresham, J. L., Satayathum, S., McCullough, K., Pifer, T., Goodkin, D. A., et al. (2003). Health-related quality of life and associated outcomes among hemodialysis patients of different ethnicities in the United States: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Kidney Diseases*, *41*, 605–615.
- Mapes, D. L., Lopes, A. A., Satayathum, S., McCullough, K., Goodkin, D. A., & Locatelli, F. (2003). Health-related quality of life as a predictor of mortality and hospitalization: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney International*, *64*, 339–349.
- Pallant, J. F., Misajon, R., Bennet, E., & Manderson, L. (2006). Measuring the impact and distress of health problems from the individual's perspective: Development of the Perceived Impact of Problem Profile (PIPP). *Health and Quality of Life Outcomes*, *4*, 36.
- Porter, A. C., Vijil, J. C., Jr., Unruh, M., Lora, C., & Lash, J. P. (2010). Health-related quality of life in Hispanics with chronic kidney disease. *Translational Research*, *155*(4), 157–163.
- Schrivier, J. M. (2011). *Human behavior and the social environment: Shifting paradigms in essential knowledge for social work practice* (4th ed.). Boston, MA: Pearson.
- Spoont, M., Greer, N., Su, J., Fitzgerald, P., Rutks, I., & Wilt, T. J. (2011). *Rural vs. urban ambulatory health care: A systematic review*. Washington, D.C.: Department of Veterans Affairs. VA-ESP Project #09-009.
- Tsai, Y. C., Hung, C. C., Hwang, S. J., Wang, S. L., Hsiao, S. M., Lin, M. Y., et al. (2010). Quality of life predicts risks of end-stage renal disease and mortality in patients with chronic kidney disease. *Nephrology Dialysis Transplantation*, *25*(5), 1621–1626.
- Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007a). How young can children reliably and validly self-report their health-related quality of life? An analysis of 8,591 children across age subgroups with the PedsQL™ 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, *5*, 1.
- Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007b). Impaired HRQOL in children and adolescents with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities using the PedsQL™ 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, *5*, 43.



- Varni, J. W., & Limbers, C. A. (2009). The pediatric quality of life inventory: Measuring pediatric health-related quality of life from the perspective of children and their parents. *Pediatric Clinics of North America*, *56*, 843–863.
- Wang, C., Li, H., Li, L., Xu, D., Kane, R. L., & Meng, Q. (2013). Health literacy and ethnic disparities in health-related quality of life among rural women: Results from a Chinese poor minority area. *Health and Quality of Life Outcomes*, *11*, 153.
- Weiner, B. (1974). *Achievement motivation and Attribution Theory*. Morristown, NJ: General Learning Press.
- Weiner, B. (1986). *An attributional theory of motivation and emotion*. New York: Springer-Verlag.