



Pediatric Urologists' Personal Point-of-view of Health Related Quality of Life

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OBJECTIVE

To assess pediatric urologists' understanding and use of health-related quality of life (HRQOL) resources in clinical practice. HRQOL is becoming an increasingly vital part of patient care. Although HRQOL has been evaluated and instruments have been developed for its assessment for several pediatric conditions, it is underrepresented in pediatric urology.

METHODS

A SurveyMonkey 7-item questionnaire was sent to the members of the Society for Pediatric Urology. The questions inquired as to knowledge of surveys available, views on appropriate age for beginning discussion of HRQOL, patients' and providers' ability to assess patient HRQOL, and the need for disease-specific surveys.

RESULTS

One-hundred and eighteen providers (37.6%) completed the survey. Remarkably, 85.6% of the responders believe disease-focused HRQOL instruments would be useful for specific urologic diseases; however, only 14.4% of the providers state use of any HRQOL instrument. Only 5 unique measures were reported. The majority felt the age at which patients can start reporting his or her HRQOL is 6-8 (41.3%) or 9-11 (31.2%) years. A preponderance of providers believed both themselves and parents could "somewhat" evaluate the patient HRQOL, but the majority believe it is important to inquire about parents' perceptions of patient HRQOL.

CONCLUSION

The overwhelming majority of pediatric urologists believe HRQOL is important but only a minority utilize the available instruments. Further studies are needed to develop instruments to fill this essential gap. *UROLOGY* 88: 179–182, 2016. © 2016 Elsevier Inc.

The World Health Organization defines health as "not only the absence of disease and infirmity, but the presence of physical, mental, and social well-being," and hence health is more than just physiology, form, and function.¹ Health-related quality of life (HRQOL) has emerged as a means to measure the mental and social well-being of patients; this is of particular importance to the growing, maturing pediatric patient, parent, and provider.² In contrast to an increasing body of literature exploring HRQOL in pediatric patients and parents, there is a relative dearth of research exploring the providers' perspectives. Current information regarding the roles of healthcare providers tends to revolve around shared decision-making models rather than HRQOL, and a recent review highlights the paucity of information available.³ However, a few studies specifically examine the roles of providers and HRQOL in obese children and patients with asthma. These studies note a disconnect between the perceptions of patients and providers and the need for further involvement of providers in the domains of HRQOL and outcomes,

again emphasizing the importance of further exploration of the patient-provider-parent triad.^{4,5}

HRQOL is increasingly becoming a vital part of patient care; however, the point of view of the providers is underrepresented in pediatric urology. We feel this is particularly important as providers directly influence the physical, mental, and social well-being of patients at all points of contact in the medical community. Recognizing further need for HRQOL studies, we sought to explore the urologic healthcare providers' current understanding and utilization of HRQOL in their daily practice. We report the first survey examining the awareness, opinions, and experiences of providers when dealing with HRQOL of the pediatric urologic patient. We hypothesized that understanding and utilization of HRQOL instruments would be nominal and believe that gaining a baseline measurement of current practitioners is vital to implementing HRQOL into clinical practice.

MATERIALS AND METHODS

A 7-item SurveyMonkey questionnaire was developed by a senior pediatric urologic attending, pediatric urologic fellow, and urologic resident with a background in researching HRQOL (Appendix). It was distributed to members of the Society for Pediatric Urology (SPU) ($n = 314$). Several reminder emails were sent to increase awareness and encourage participation. The questionnaire queried respondents about their knowledge and use

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of HRQOL assessment tools. The survey then asked participants how well they felt they could evaluate their patients' and parents' HRQOL as related to urologic care, and at what age providers felt patients could accurately begin reporting their own HRQOL.

Additionally, the survey asked if disease-specific HRQOL assessment tools would be beneficial and if so, for which disease states. Specifically, the survey asked responders of their knowledge of the General Vesicoureteral Reflux Survey (G-VUR) and the Postoperative Vesicoureteral Reflux Survey (PO-VUR), and whether they felt these aided in management of patients with VUR.

Analysis of the survey results was carried out through descriptive statistics. The study was approved by an internal institutional review board.

RESULTS

HRQOL Instruments

One hundred and eighteen providers (37.6%) completed the survey. Only 14.4% ($n = 17$) of responders reported having used a HRQOL instrument, including the Pediatric Quality of Life Inventory (PedsQL) 4.0, Parkin Instrument, 36-Item Short Form Health Survey, Child Health and Illness Profile, and SmithKline Beecham Quality of Life and 53.9% felt that the tool adequately captured the HRQOL of patients. Among the responders, 86.4% believed that disease-focused HRQOL instruments would be beneficial to clinical practice particularly for neurogenic bladder (93.1%), dysfunctional voiding (81.4%), hypospadias (78.4%), and enuresis (73.5%) (Table 1).

Providers were asked of their knowledge of the G-VUR and the PO-VUR, one of the only measures specific to a urologic condition. Only 9.3% of the responders had knowledge of either instrument but none of them had ever used it. Additionally, only 13.3% of the responders felt it would aid in the management of patients with VUR, whereas 19.4% felt it would not, and 67.3% were unsure of its benefit.

Assessors of HRQOL

Providers were queried as to how accurately they believed that they and parents could evaluate the HRQOL of a patient. Most of the providers (66.6%) felt that they could "very well," "better than not," or "somewhat accurately" evaluate HRQOL of their patients, but that 87%

of parents were able to evaluate HRQOL "very well," "better than not," or "somewhat." A preponderance of providers felt it was "somewhat" or "more important" to evaluate parents' perceptions of HRQOL (Table 2).

The vast majority of providers felt that patients could begin to accurately report their own HRQOL after the age of 5 years. Forty-one percent of the providers felt patients could begin to accurately convey their HRQOL between the ages of 6 and 8, and 34 (31.2%) reported that the age for accurate reporting is 9-11 years old. Only 9 (8.3%) providers felt patients could begin accurately reporting their HRQOL between the ages of 3 and 5.

DISCUSSION

This survey highlights an important gap in pediatric urologic practice: the division between what we practice, how we would like to practice, and what our patients perceive. This is underscored by the fact that 86.4% of responders believe disease-specific HRQOL instruments would be beneficial; however, only 14.4% have ever utilized one. In addition only 5 separate instruments could be identified. This dearth of HRQOL tools is echoed when conducting literature searches. When searching PubMed for the phrase "health related quality of life pediatric urology," only 15 out of 28 relevant articles were found and no results were returned when searching Ovid for the same parameter. Furthermore, the most used instrument in pediatric HRQOL, the PedsQL, which was also the most frequently named tool in our survey, has 57 modules for both generic and disease-specific disorders, none of which are explicitly designed for pediatric urologic conditions.⁶ None

Table 2. Inquiries into providers and parents ability to evaluate patients' QOL

| | |
|--|------------------|
| Do you feel capable of accurately evaluating your patient's QOL? | |
| Answer options | Response percent |
| Very well | 0.9% |
| Better than not | 19.4% |
| Somewhat | 46.3% |
| Only partially | 24.1% |
| Unable | 9.3% |
| How well do you feel that parents are able to accurately evaluate your patient's QOL? | |
| Answer options | Response percent |
| Very well | 8.3% |
| Better than not | 38.9% |
| Somewhat | 39.8% |
| Only partially | 12.0% |
| Not at all | 0.9% |
| How important do you feel it is to evaluate parents' perception of your patient's QOL? | |
| Answer options | Response percent |
| Very much | 37.0% |
| More than not | 38.0% |
| Somewhat | 20.4% |
| Only partly | 3.7% |
| Not at all | 0.9% |

Table 1. Pediatric urologic conditions for which providers felt a HRQOL instrument would be beneficial

| Conditions | Response Percent |
|------------------------------------|------------------|
| Neurogenic bladder | 93.1% |
| Dysfunctional voiding | 81.4% |
| Hypospadias | 78.4% |
| Enuresis | 73.5% |
| Prune belly syndrome | 68.6% |
| Posterior urethral valves | 63.7% |
| Nephrolithiasis | 45.1% |
| VUR | 40.2% |
| Ureteropelvic junction obstruction | 19.6% |
| Cryptorchidism | 10.8% |

HRQOL, health-related quality of life.

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