



# Parental Preferences for Vesicoureteral Reflux Treatment: A Crowd-sourced, Best-worst Scaling Study

Zachary R. Dionise, Juan Marcos Gonzalez, Michael L. Garcia-Roig, Andrew J. Kirsch, Charles D. Scales Jr, John S. Wiener, J. Todd Purves, and Jonathan C. Routh

<b>OBJECTIVE</b>	To quantitatively evaluate parental preferences for the various treatments for vesicoureteral reflux using crowd-sourced best-worst scaling, a novel technique in urologic preference estimation.
<b>METHODS</b>	Preference data were collected from a community sample of parents via 2 best-worst scaling survey instruments published to Amazon's Mechanical Turk online community. Attributes and attribute levels were selected following extensive review of the reflux literature. Respondents completed an object case best-worst scaling exercise to prioritize general aspects of reflux treatments and multiprofile case best-worst scaling to elicit their preferences for the specific differences in reflux treatments. Data were analyzed using multinomial logistic regression. Results from the object-case provided probability scaled values (PSV) that reflected the order of importance of attributes.
<b>RESULTS</b>	We analyzed data for 248 and 228 respondents for object and multiprofile case BWS, respectively. When prioritizing general aspects of reflux treatment, effectiveness (PSV = 20.37), risk of future urinary tract infection (PSV = 14.85), and complication rate (PSV = 14.55) were most important to parents. Societal cost (PSV = 1.41), length of hospitalization (PSV = 1.09), and cosmesis (PSV = 0.91) were least important. Parents perceived no difference in preference for the cosmetic outcome of open vs minimally invasive surgery ( $P = .791$ ). Bundling attribute preference weights, parents in our study would choose open surgery 74.9% of the time.
<b>CONCLUSION</b>	High treatment effectiveness was the most important and preferred attribute to parents. Alternatively, cost and cosmesis were among the least important. Our findings serve to inform shared parent-physician decision-making for vesicoureteral reflux. UROLOGY 128: 71–77, 2019. © 2019 Elsevier Inc.

Vesicoureteral reflux (VUR) is a common, morbid pediatric urologic condition. VUR affects 1%-10% of all children and carries a substantial economic burden of more than \$100 million per year in the United States alone.<sup>1</sup> For many children, VUR has 4 reasonable

treatment options: open ureteral reimplantation, minimally invasive (MIS) ureteral reimplantation, endoscopic injection of a sub/intraureteral bulking agent, or conservative therapy with continuous antibiotic prophylaxis with watchful waiting. In making treatment decisions for their children, parents must make value judgments that weigh treatment attributes such as effectiveness, complication rate, cost, and cosmetic outcome. However, studies have shown that the treating hospital, rather than parental preferences or clinical factors, is the primary driver of VUR treatment choice.<sup>2</sup>

Best-worst scaling (BWS) is a validated multicharacteristic preference evaluation method that has been increasingly used in health-preference research.<sup>3</sup> By asking respondents to rank the extremes of their preferences, repeated BWS questions enable a full-ranking of the alternatives presented. Object case BWS asks respondents to evaluate general characteristics of treatment, called "attributes," (eg, cost or risk of complications) without linking these characteristics to specific interventions.

*This study was granted approval by the institutional internal review board as an exempt study of full internal review board review on the basis that it involved no protected health information.*

**Financial Disclosure:** Mr. Dionise is supported in part by a Urology Care Foundation Summer Medical Student Fellowship from the American Urological Association (AUA). Dr. Routh is supported in part by grant K08-DK100534 from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Neither funding source had any role in the collection, analysis, and interpretation of data; in the writing of the manuscript; or in the decision to submit the manuscript for publication. The authors have no financial relationships relevant to this article to disclose.

From the Division of Urology, Duke University Medical Center, Durham, NC; the Duke Clinical Research Institute, Durham, NC; and the Department of Pediatric Urology, Emory University and Children's Healthcare of Atlanta, Atlanta, GA

Address correspondence to: Jonathan C. Routh, M.D., M.P.H., Division of Urologic Surgery, Duke University Medical Center, DUMC Box 3831, Durham, NC 27710. E-mail: jonathan.routh@duke.edu

Submitted: September 25, 2018, accepted (with revisions): January 31, 2019

Alternatively, multiprofile case BWS estimates how aspects of an experimentally-designed treatment influence respondents' relative preference for the overall treatment. The multiprofile case more closely mirrors clinical decision-making processes faced by patients by requiring respondents to evaluate trade-offs between competing attributes.<sup>4</sup>

The objective of this study was to evaluate parental preferences regarding VUR treatment using object case and multiprofile case BWS. Our aim was to first use the object case to define the characteristics of VUR treatments that parents identify as most important. Then, we used the multiprofile case to evaluate how parents evaluate trade-offs in treatment characteristics when actually choosing a treatment. Our secondary aim was to use the results from the multiprofile case BWS to estimate relative preferences for current VUR treatments. We hypothesized that treatment effectiveness and treatment complication rate would be the most important aspects of treatment.

## METHODS

### Object Case BWS

An object case BWS instrument was developed to identify respondents' relative preferences for 13 treatment aspects referred to as "attributes" (Supplementary Table 1). We presented respondents with 14 BWS questions, each including only a subset of 4 attributes (Supplementary Figure 1). The 4-attribute subset for each BWS question varied, forcing each parent to evaluate trade-offs across all 13 attributes. Attributes were chosen based on clinical experience and prior qualitative and quantitative studies.<sup>5-8</sup> In each question, respondents were asked to select the most and least important attribute in choosing a VUR treatment for their child. The attributes included in each BWS question were prepared according to an experimental design using Sawtooth MaxDiff. The experimental design was appropriately balanced and orthogonal, meaning each attribute appeared and coappeared with each other attribute an equal number of times.

Data were analyzed using a multinomial logistic (MNL) regression model. MNL coefficients represent the intensity of importance for each attribute relative to an omitted attribute (long-term treatment failure). Because logit results do not convey an absolute measure of relative importance, but rather differences in importance across attributes, we transformed the coefficients into probability scaled values (PSVs), which allow relative comparisons across attributes.<sup>9</sup> PSVs sum to 100 and represent the likelihood that a given attribute was chosen as "best" in the experiment; PSVs are also ratio-scaled, that is, an attribute with a PSV = 20 is twice as preferred as an attribute with PSV = 10. Wald Chi-squared tests were used to test MNL coefficient significance relative to zero and to one another.

### Multiprofile Case BWS

The multiprofile case experiment investigated parental preferences in the context of experimentally-constructed VUR treatments. Parents were presented with 10 BWS questions asking them to select the best overall treatment for their child, just as they would in a clinical setting, and also the worst treatment (Supplementary Figure 2). Each VUR treatment profile was

**Table 1.** Multiprofile case BWS attribute levels

Attribute	Levels
Effectiveness	53%, 77%, 88%, 97%
Treatment complication rate	<1%, 4%, 10%, 13%
Societal cost	\$1343, \$6365, \$7059, \$9556
Length of hospitalization	No visit to hospital, Outpatient hospitalization (no overnight), 1 day, 2 days
Doctor recommendation as best treatment	Yes, No
Cosmesis/invasiveness	No scar and no invasive procedure, No scar and endoscopic intervention with anesthesia, Minimally-invasive surgery with anesthesia and small scars (with image), Open surgery with anesthesia and large scar (with image)

described by 6 treatment attributes (effectiveness, societal cost, treatment complication rate, cosmesis and/or invasiveness, doctor recommendation, and hospitalization length if required), which were chosen based on those attributes typically presented to parents making treatment decisions in the clinic (Supplementary Figure 2).

The multiprofile case asked respondents to evaluate VUR treatment profiles defined in terms of the way treatments fulfill those aspects ("attribute levels"). Attribute levels were selected to cover clinically-related values for the 4 treatment alternatives typically offered to parents based on extensive literature review (Table 1).<sup>10-22</sup> The levels for attributes varied across treatment profiles following a balanced, orthogonal experimental design with known statistical properties developed using the Sawtooth choice-based conjoint tool.

Results from the MNL model are log-odds, also called preference weights, indicating how the utility associated with a treatment changes as the levels of an attribute change.<sup>23</sup> Differences in preference weight estimates for the levels in an attribute indicate the importance of changing a treatment attribute from one level to another. The difference between the most and least preferred levels of an attribute indicates the overall relative importance of the attribute, given the range of levels considered in the study.<sup>23</sup>

Predicted choice probabilities were calculated by adding the preference weights for the attribute levels that corresponded to each clinically available VUR treatment. Using the MNL probability density function we calculated the proportion of average parent respondents who would select each treatment profile, given the relative utility of each profile. Two-sided *t* tests were used to test differences between coefficients in the MNL model. All analyses were performed using Sawtooth Lighthouse Studio 9.5.2 and SAS 9.4.

### Survey Instrument

We provided each respondent with an introduction to VUR, its treatments, and possible complications using text, images, and video designed by a board-certified pediatric urologist. Parents were required to answer several basic attention questions during the course of the survey. We introduced the BWS questions by describing each treatment attribute and the range of attribute levels. Parents were first introduced to several example BWS

questions of increasing complexity to ensure that they understood how to answer the questions. Finally, we collected basic demographic information. Survey instruments were completed by a pilot group of 15 parents on the Amazon Mechanical Turk (MTurk) online work interface and feedback was incorporated.

### Data Source

We published the 2 final BWS survey instruments to the Amazon MTurk. MTurk offers a crowd-sourced, US national sample that provides results equally as reliable as traditional methods and has been validated in VUR experiments by our group.<sup>24-27</sup> Members of the MTurk community who were over 18 years old, self-reported parents, and had a >95% approval rating were eligible to participate. Respondents were compensated \$1 to complete each survey. MTurk account-specific and IP address restrictions ensured only one response per parent per survey. Respondents were excluded from analysis if they completed the survey instrument below a reasonable time threshold (4 minutes), as we considered these respondents to be nonattentive.

## RESULTS

### Demographics

In total, 248 and 228 parents completed the object case and multiprofile case BWS survey instruments, respectively, after excluding a total of 26 parents who did not meet response time threshold (Table 2). Overall, most parents were female (71.6%), married (74.2%), 30- to 44-year-old (59.5%), non-Hispanic whites (77.1%) who had no prior experience with VUR (81.7%). Most had an annual household income between \$25,000 and \$74,999 (57.1%) and completed at least a university degree (54.0%).

### Object Case BWS

Parents ranked treatment outcome measures, such as effectiveness of curing reflux (PSV 20.4), risk of future urinary tract infection (UTI) after treatment (PSV 14.9), risk of long-term treatment failure (PSV 14.6), and treatment complication rate (PSV 14.2) as the most important attributes (Table 3). Treatment invasiveness (PSV 7.6) and parent perception of their doctor's reputation (PSV 7.2) were also relatively important attributes. Treatment effectiveness was ~20 times more important than the least important attributes (cosmesis, length of hospitalization, and societal cost) (all  $P < .01$ ).

When responses were stratified by sex, women ranked invasiveness 3 spots higher, antibiotic resistance 3 spots lower, and delay to treatment 2 spots higher in importance when compared to men. However, the rank order of the 4 most important attributes was the same for both sexes. Parents with university and advanced degrees had similar preferences to those with less education, other than placing less importance on risk of future UTI (down 2 spots) and perceived doctor reputation (down 3 spots). Similarly, prior experience with VUR and income level did not change the rank order of the most important attributes.

### Multiprofile Case BWS

Preference weights estimated by the MNL model followed the expected preference pattern within each attribute given the clinical impact of each attribute level, that is, higher complication

rates had smaller preference weights than lower complication rates (Table 4). Preference weights were also roughly linear in continuous variables like effectiveness (Supplementary Figure 3). The preference weight of cosmesis and/or invasiveness for endoscopic injection was significantly higher than those for open surgery and MIS (each  $P < .05$ ), while the preference weights for open surgery and MIS were no different from one another ( $P = .791$ ). Consistent with findings in the object case experiment, treatment effectiveness as a whole had the highest relative importance (50.7%) among the included attributes; complication rate (20.9%), doctor recommendation (12.7%), cosmesis and/or invasiveness (6.2%), length of stay (6.0%), and societal cost (3.5%) were relatively less important.

The estimated predicted choice probabilities (Supplementary Table 2) suggest that an average parent from our sample would select a treatment with characteristics similar to open surgery 74.9% of the time, compared to MIS, endoscopic injection, and antibiotic prophylaxis 9.6%, 8.9%, and 6.6% of the time, respectively.

## DISCUSSION

Consistent with our hypothesis, we found that effectiveness in curing VUR and treatment complication rate were by far the most important treatment attributes, ~20 times more important than cosmesis or societal cost. Unsurprisingly then, we identified that parents associated the most highly effective and least complication prone treatments with the greatest utility. Combining these preferences revealed that the average parent, when presented with information similar to that which we provided in this study, would choose open surgery in nearly 75% of similar clinical situations.

These quantitative findings are largely consistent with the previous largely qualitative literature examining parental preferences in VUR treatment. Of the 13 primary parental preference themes identified in parent interviews by Tran et al, the most commonly considered treatment themes were efficacy, future UTI prevention, daily care burden, antibiotic resistance, and invasiveness.<sup>5</sup> Similar to our findings that cosmesis and cost are relatively less important attributes, only 19% of parents interviewed mentioned post-treatment cosmesis; treatment cost did not emerge as a primary theme.<sup>5</sup>

Parental preference for success rate over cosmesis has been previously documented in pediatric urology. Barbosa et al noted that when parents were told that either robotic or open reimplantation was more effective, parents chose the "more effective" option about 90% of the time.<sup>28</sup> Interestingly, they also observed that parents preferred robotic scars to open scars, whereas we and others find no significant difference in scar preference or even preference for open cosmesis.<sup>7,28</sup>

For other parents, invasiveness seems to influence treatment choice. Callaghan et al found that success rate was "most important" in 90.4% of VUR cases treated by a successful open surgery, but in only 52% of cases treated by a successful endoscopic intervention.<sup>8</sup> Instead, degree of invasiveness was "most important" in 84% of those cases.

**Table 2.** Parent respondent demographic characteristics

Characteristic	Response	Object Case (%)	Multiprofile Case (%)	Overall %
<b>Sex</b>	Male	70 (28.2)	65 (28.5)	28.4
	Female	178 (71.8)	163 (71.5)	71.6
<b>Race</b>	White Non-Hispanic	189 (76.2)	178 (78.1)	77.1
	White Hispanic	21 (8.5)	10 (4.4)	6.5
	Black Non-Hispanic	18 (7.3)	14 (6.1)	6.7
	Black Hispanic	2 (0.8)	4 (1.8)	1.3
	Asian	12 (4.8)	13 (5.7)	5.3
	American Indian or Native Alaskan	0 (0)	1 (0.4)	0.2
	Native Hawaiian or Pacific Islander	1 (0.4)	1 (0.4)	0.4
<b>Age</b>	Multiracial/Other	5 (2.0)	7 (3.1)	2.5
	18-29	55 (22.2)	41 (18.0)	20.2
	30-44	147 (59.3)	136 (59.6)	59.5
	45-60	40 (16.1)	41 (18.0)	17.0
<b>Annual household income</b>	60 and older	6 (2.4)	10 (4.4)	3.4
	Less than \$25,000	23 (9.3)	28 (12.3)	10.7
	\$25,000-\$49,999	77 (31.0)	64 (28.1)	29.6
	\$50,000-\$74,999	71 (28.6)	60 (26.3)	27.5
	\$75,000-\$99,999	41 (16.5)	45 (19.7)	18.1
<b>Highest education completed</b>	\$100,000 and greater	36 (14.5)	31 (13.6)	14.1
	Less than high school	0 (0)	1 (0.4)	0.2
	High school/GRD	61 (24.6)	54 (23.7)	24.2
	Technical/trade school	52 (21.0)	51 (22.4)	21.6
	University degree	93 (37.5)	87 (38.2)	37.8
<b>Marital status</b>	Advanced masters/doctoral degree	42 (16.9)	35 (15.4)	16.2
	Single, never married	34 (13.7)	32 (14.0)	13.9
	Married	183 (73.8)	170 (74.6)	74.2
	Divorced, single	25 (10.1)	18 (7.9)	9.0
	Divorced, remarried	1 (0.4)	0 (0.0)	0.2
<b>Region of residence</b>	Separated	5 (2.0)	8 (3.50)	2.7
	Northeast	45 (18.1)	38 (16.7)	17.4
	South	93 (37.5)	96 (42.1)	39.7
	Midwest	59 (23.8)	47 (20.6)	22.3
<b>Metropolitan status</b>	West	51 (20.6)	47 (20.6)	20.6
	Urban	53 (21.4)	48 (21.1)	21.2
	Suburban	119 (48.0)	116 (50.9)	49.4
<b>Previous experience with VUR?</b>	Rural	76 (30.6)	64 (28.1)	29.4
	Yes	45 (18.1)	42 (18.4)	18.3
<b>Prior overnight hospitalization?</b>	No	203 (81.9)	186 (81.6)	81.7
	Yes	219 (88.3)	205 (89.9)	89.1
<b>Prior surgery?</b>	No	29 (11.7)	23 (10.1)	10.9
	Yes	187 (75.4)	174 (76.3)	75.8
	No	61 (24.6)	54 (23.7)	24.2

The authors speculate that the competing preference for effectiveness vs invasiveness was the factor driving this behavior but were unable to definitively identify the granular attributes that drove the holistic treatment choices they observed.<sup>8</sup>

Although parents clearly identified treatment effectiveness as the most important and desirable attribute in our study, translating this finding to a clinical recommendation

is less straightforward. The difficulty arises primarily from variation in reported success rates for VUR treatments, a topic frequently debated over the last 2 decades in pediatric urology. While some institutions regularly report success rates for endoscopic injection and MIS >90%, others report rates far lower.<sup>10,21</sup> Classically thought to be a result of surgeon experience, this variation is likely also due to differences in patient follow-up and definitions of treatment

**Table 3.** Object case BWS results

Attribute	Logit Coefficient	95% CI <sup>†</sup>	Probability Scaled Value
Effectiveness in curing reflux	1.313	(1.140, 1.486)	20.37
Risk of future UTIs post-treatment	0.054	(-0.104, 0.212)	14.85
Risk of long-term treatment failure	0.00*	N/A	14.55
Treatment complication rate	-0.056	(-0.218, 0.105)	14.22
Invasiveness	-1.207	(-1.370, -1.044)	7.59
Perceived doctor reputation	-1.224	(-1.388, -1.060)	7.50
Doctor recommends as best treatment	-1.295	(-1.461, -1.130)	7.14
Risk of antibiotic resistance	-1.387	(-1.551, -1.223)	6.69
Delay to treatment	-2.813	(-2.986, -2.640)	2.04
Daily burden of care post-treatment	-3.047	(-3.223, -2.871)	1.64
Societal cost	-3.208	(-3.385, -3.031)	1.41
Length of hospitalization	-3.485	(-3.663, -3.306)	1.09
Cosmetic appearance	-3.670	(-3.850, -3.489)	0.91

Object case multinomial logistic regression model.

\* Reference coefficient in model.

<sup>†</sup> 95% CI, 95% confidence interval.**Table 4.** Multiprofile case BWS results

Attribute	Relative Importance (%) <sup>*</sup>	Level	Logit Preference Weight	95% CI <sup>†</sup>	P value
<b>Effectiveness</b>	50.7	53 percent	-1.754	(-1.847, -1.660)	<.001
		77 percent	-0.275	(-0.341, -0.209)	<.001
		88 percent	0.552	(0.481, 0.624)	<.001
		97 percent	1.476	(1.395, 1.558)	<.001
<b>Societal cost</b>	3.5	\$1343	0.155	(0.083, 0.227)	<.001
		\$6365	-0.027	(-0.100, 0.047)	.307
		\$7059	-0.034	(-0.105, 0.038)	.260
		\$9556	-0.094	(-0.169, -0.019)	.019
<b>All complication rate</b>	20.9	<1 percent	0.684	(0.608, 0.760)	<.001
		4 percent	0.251	(0.179, 0.323)	<.001
		10 percent	-0.283	(-0.356, -0.209)	<.001
		13 percent	-0.652	(-0.728, -0.577)	<.001
<b>Length of hospital stay</b>	6	No visit to hospital	0.170	(0.097, 0.242)	<.001
		Same day outpatient hospitalization	0.039	(-0.034, 0.111)	.228
		1 day (overnight, home next day)	-0.041	(-0.113, 0.031)	.212
		2 days	-0.168	(-0.237, -0.098)	<.001
<b>Doctor recommends as best treatment</b>	12.7	Yes	0.402	(0.359, 0.445)	<.001
		No	-0.402	(-0.445, -0.359)	<.001
<b>Cosmetic appearance and Invasiveness</b>	6.2	No scar and no invasive procedure	0.239	(0.166, 0.311)	<.001
		No scar and endoscopic intervention with anesthesia	0.058	(-0.012, 0.128)	0.105
		MIS with anesthesia and small scars	-0.152	(-0.223, -0.080)	<.001
		Open surgery with anesthesia and large scar	-0.145	(-0.218, -0.073)	<.001

Multiprofile case BWS multinomial logistic regression (MNL) model constructed using leveled attributes. Model coefficients are preference weights.

\* Constructed using expanded MNL model including interaction terms.

<sup>†</sup> 95% CI, 95% confidence interval. Significance testing conducted using 2-sided t tests.

success. Variation in success rates may explain why our overall treatment choice prediction deviates from observational data for endoscopic injection in recent clinical practice (~35% vs 8.9% model), but is more consistent for open surgery (~60% vs 74.9% model), which has a greater consensus success rate.<sup>29</sup> With such variation in institutional VUR treatment experience, it is perhaps not surprising that institutional preferences, not clinical factors, have been identified as the primary determinant of VUR treatment choice.<sup>2,30</sup>

Regardless, these experiments have allowed us to develop a preference model that might be applied to as a decision-aid for parents facing a VUR treatment decision. We intend for parents to complete this brief BWS exercise prior to seeing their child's urologist. Then, the urologist can use the revealed preferences to better target face-to-face shared decision-making. Individual surgeons could incorporate their own success rates and surgical outcomes, further customizing the model. This future application of our model bridges a theoretical crowd-sourced study to direct patient care in the clinic.

The results of our study must be interpreted in the context of several limitations. First, we conducted our study using a sample from MTurk rather than parents of children with VUR. If actual parents have inherently different preference structures than those who receive only VUR instruction, then our results may not be generalizable to specific clinical scenarios. Our sensitivity analysis showed that parents in our study who had prior VUR knowledge had largely analogous preferences compared to those who had no prior experience. Further, in areas of more direct overlap our study finds agreement with previous research that sampled parents of children with VUR.<sup>5,8</sup> Nonetheless, our intended future application of similar BWS techniques to evaluate preferences in parents of children with VUR would increase the external validity of this research.

In addition, we presented parent respondents with the concept of societal cost in our survey instrument as opposed to out-of-pocket cost. Though we directly acknowledged to our survey respondents that societal cost was a potentially confusing concept, we did not receive any comments from respondents about the difficulty of considering societal cost. Besides interpreting societal cost appropriately, parents may have interpreted societal costs as out-of-pocket costs, leading our models to *overestimate* the effect of societal cost since societal costs are necessarily greater than out-of-pocket costs. Though the unimportance of cost we observed was noted in prior studies, we were still surprised by its magnitude, especially in a health-care climate that is increasingly cost-conscious.<sup>5</sup>

Last, we presented parents with a general case of VUR, without in-depth discussion of clinical factors like VUR grade. We recognize that clinical factors impact prognosis, treatment effectiveness, complication risk, and treatment recommendation. Future investigation for specific grades of VUR with actual patients will inform the specific value of preference research in the clinical setting.

## CONCLUSION

High treatment effectiveness was the most desirable treatment attribute to parents choosing a treatment for VUR, while complication rate and risk of long-term treatment failure were also relatively important. Cosmesis and societal cost were among the least important. Future research will determine how targeted discussion that aligns with parental preferences might improve shared decision-making for VUR treatment.

## SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.urology.2019.01.045>.

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## EDITORIAL COMMENT



The authors have provided a unique perspective on the management vesicoureteral reflux (VUR) that incorporates parental preferences regarding various aspects of treatment options. They utilized an innovative, crowd-sourced approach to recruit a

national sample of parents online who presumably did not have any “real-world” experience with VUR. Many readers may question whether the wisdom of crowds should supplant the experience of those who have actually dealt with a given scenario in their own children. Previous studies in political science, economics, and psychology, however, have confirmed the external and internal validity of a similar approach to subject recruitment.<sup>1–3</sup> In addition, the description of a “preference model” in the current study is a precursor to the development of a decision aid for parents of children with VUR. The authors have presented a type of “values clarification exercise” that the International Patient Decision Aids Collaboration considers a key component of patient decision aids.<sup>4</sup> Decision aids are tools designed to help people make informed, values-based choices about their healthcare options in partnership with their providers.<sup>5</sup> Shared decision-making represents the state of the art in counseling patients faced with difficult or uncertain medical decisions and its implementation has been widely encouraged by The American Urologic Association.<sup>6</sup> The current study is an important contribution to the pediatric urologic literature because it will have future implications for the dissemination of shared decision-making and the development of decision aids in our field.

**Katherine H. Chan**, Department of Urology, Indiana University School of Medicine, Indianapolis, IN; Department of Pediatrics, Center for Pediatric and Adolescent Comparative Effectiveness Research, Indiana University School of Medicine, Indianapolis, IN

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<https://doi.org/10.1016/j.urology.2019.01.047>  
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