


Are EAU/ESPU pediatric urology guideline recommendations on neurogenic bladder well received by the patients? Results of a survey on awareness in spina bifida patients and caregivers

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Abstract

Aims: The Paediatric Urology Guidelines Panel reports initial experience with patient involvement in spina bifida patient groups to gather information on their awareness of the guidelines and reflection of guideline recommendations.

Methods: The survey was delivered to spina bifida patients/parents via the national society groups in Turkey, Germany, and The Netherlands. Questions included demographic features, medical status, awareness, and agreement on the recommendations given in the guidelines and future expectations.

Results: A total of 291 patients from 3 countries responded to the survey. Mean age was 13.9 ± 12.2 years, male/female ratio 138/151, 75% of all surveys were completed by the caregivers. The medication was taken by 78% of patients (64% anticholinergics). Complete dryness rates for urine and stool were 24% and 47%, respectively. The agreement rates on the recommendations regarding urodynamics, intermittent catheterization, anticholinergics drug use, bowel management, and life-long follow-up were 97%, 82%, 91%, 77%, and 98%, respectively. Only 8% of responders were aware of the European Association of Urology/European Society for Pediatric Urology guidelines. The priorities of patients for future expectations were as the following: quality of life (QoL), surgical techniques, development of new medications and sexuality/fertility issues. Male spina bifida patients preferred new medications and sex/fertility issues more, whereas females favored QoL issues improvement more.

Conclusions: Although the native language of the involved patients was different from English, awareness of guidelines was 8%. The general approval of the recommendations given in the guidelines is quite high. The national society groups showed a great interest to get involved in the creation of the guidelines to improve health care for spina bifida patients.

KEYWORDS

guideline, neurogenic bladder, spina bifida, survey

1 | INTRODUCTION

Spina bifida (SB) is a common birth defect of the neural tube. Clinical symptoms vary widely between patients. However, all patients have been shown to experience a significant deterioration in the quality of life (QoL).¹ Urological interventions are aimed at preventing upper urinary tract damage, facilitating independency in daily life and improvement of QoL. This requires the approach of a multidisciplinary team. The focus of medical care should be adapted to suit the requirements of the various developmental stages of the individual child. For example, continence starts to play an important role from school age. Through adolescence independence and sexuality become more important. Specifically, in this latter group of patients, the transition of care from the pediatric into the adult system needs more attention.^{2,3} To identify which aspects are of main concern to our patients we need their involvement as well as that from their caregivers.

In recent years, medical research has tried to focus more on the patients' perspective on medical care.^{4,5} Traditionally, objective outcome measures such as number of infections, number of incontinence episodes, etc, were used to report or evaluate the success of a specific treatment. One of the ways to gain the patients' perspective in the evaluation of treatment has been the creation of new outcomes measures, ie, patient-reported outcome measures (PROMs).^{6,7} These PROMs assess how the different domains of symptoms affect the QoL of patients, such as urinary incontinence, fecal incontinence, and sexuality.⁸ These patient-centered outcomes can be used in the design of future research.^{9,10} The next step in patient involvement has been the implementation of patient decision aids. By using the preferences of patients models have been created to assist patients in their choice of treatment.⁵ In accordance with this increase in patient involvement, the Paediatric Urology guidelines panel aims to include patients in the development of clinical guidelines. As a first step, we have sent out a survey to SB patients and their caregivers in three different countries regarding the content of our guideline and to identify any areas that need further attention. With the results of this survey, we expect to improve the guideline quality and implementation to the specific patients' preferences.

2 | MATERIAL AND METHODS

Three members of the European Association of Urology/European Society for Pediatric Urology (EAU/ESPU) guideline panel (HSD, LH, RS) composed a survey about

neurogenic bladder patients. The survey included questions on demographic features, medical status, awareness, and agreement on the recommendations given in the guidelines and future expectations. The survey was translated into Turkish, German, and Dutch. The online survey was delivered to the patients and/or parents via national spina bifida societies (Türkiye Spina Bifida Derneği, Bond Ouders Spastische Kinderen, Arbeitsgemeinschaft SpinaBifida und Hydrozephalus). The term "(pseudo)continence" was used to define the complete bladder or fecal continence by means of any medical or surgical intervention. Statistical analysis was done by using the Statistical Package for Social Sciences (SPSS) 15.0 for Windows. Chi-square test was used for the analysis of proportions, Pearson correlation test for correlation analysis and evaluation of means were done by Mann-Whitney test, one-way analysis of variance test, Kruskal-Wallis test and *t* test where appropriate. A *P* value < 0.05 was considered to be statistically significant.

3 | RESULTS

There were 291 responders from 3 countries (Turkey [TR]: 189, Germany [DE]: 53, The Netherlands [NL]: 49) with a mean age of 13.9 ± 12.2 years and a male to female ratio of 138/151 (Table 1). Caregivers constituted 75% of the responders. Seventy-eight percent of patients were using at least one type of medication and 80.5% were on clean intermittent catheterization (CIC). The types of medication were various, with anticholinergic drugs most frequently used (63.9%). Five patients (1.7%) used medications related to chronic renal failure. The distribution of CIC starting age was 45.7%, 31.7%, and 22.4% for <1, 1 to 5, and >5 years, respectively. The complete urinary and fecal (pseudo)continence rates were 24.2% and 46.6%, respectively. Complete urinary (pseudo)continence rates for ages 0 to 5, 6 to 10, 11 to 15, >15 years were 16.2%, 8.5%, 32.5%, and 36.8% (the chi-square test, *P* < 0.001), respectively. Complete bowel (pseudo)continence rates for the same age groups were 45.3%, 21.4%, 51.3%, and 61.6% (the chi-square test, *P* < 0.001), respectively.

The patients' or parents' awareness of the guidelines was 8.4%. Participants were asked whether they agreed with the guideline recommendations or not (Table 2). The agreement rates on the recommendations regarding routine urodynamic studies (UDS), routine CIC, early anticholinergic medication use, the importance of bowel management and life-long follow-up were 97%, 82%, 91%, 77%, and 98%, respectively. We also analyzed whether the agreement rate changes depending on the responder is patient or the caregiver. We found that awareness of

TABLE 1 The main characteristics of participants

	TR (n: 189)	DE (n: 53)	NL (n: 49)	Overall (n: 291)
Age (mean, median, range)	11.8, 8, 0-48	19.8, 16, 1-56	16.6, 13, 0-63	13.9 ± 12.2, 0-63
M/F	89/99	27/25	22/27	138/151
Self/parent	45/143	17/35	12/37	74/215
Medication, yes	73% (137/188)	91% (48/53)	84% (41/49)	78% (226/290)
Antimuscarinic use, yes	58.7% (108/184)	75% (39/52)	71.4% (25/49)	63.9% (172/285)
Oxybutynin use, yes	49.4% (93/188)	44.2% (23/52)	41.7% (20/48)	47.2% (136/288)
History of bladder operation, yes	22.5% (42/187)	36.5% (19/52)	53.1% (26/49)	30.2% (87/288)
Bladder control, complete	23.8% (41/172)	19.2% (10/52)	30.6% (15/49)	24.2% (66/273)
Bowel control, complete	43.4% (72/166)	56% (28/50)	47.9% (23/48)	46.6% (123/264)
Aware of ESPU guide, yes	5.9% (11/186)	11.6% (6/53)	14.6% (7/48)	8.4% (24/287)

Abbreviations: DE, Germany; NL, The Netherlands; TR, Turkey.

Please note that total numbers do not give always 291. Some patients did not answer some questions and the numbers within the parenthesis give the number of responders to that individual question.

guidelines (11.1% vs 7.5%, the chi-square test, $P = 0.342$), agreement rates on the recommendations on UDS (95.8% vs 97.1%, Fisher's exact test, $P = 0.698$), anticholinergics (85.9% vs 92.9%, the chi-square test, $P = 0.075$), bowel management (76.7% vs 78.2%, the chi-square test, $P = 0.789$) and life-long follow-up (100% vs 97.5%, Fisher's exact test, $P = 0.330$) were similar in patient and caregiver responders, respectively. However, the agreement rate on CIC recommendation was lower in patient responders (74% vs 84.8%, the chi-square test, $P = 0.037$).

When asked which area of medical care should be focused on for improvement in the future, priorities of patients were as follows: QoL (55.6%), surgical techniques (24.9%), development of new medications (8.4%), sexuality/fertility issues (6.9%), and all the above (4%) (Table 3). Male SB patients preferred new medications (27% vs 4.3%) and sex/fertility issues (21.6% vs 10.6%), whereas females favored QoL (QoL) issues (37.8% vs 59.6%).

Continence for urine and stool was closely related. The rate of complete (pseudo)continence for stool was 75.3% in patients who were continent for urine vs 36.2% in patients who were incontinent for urine (the chi-square test, $P < 0.001$). In other way, the rate of complete (pseudo)continence for urine in totally stool-continent patients was 41.2% vs 13% in stool-incontinent patients (the chi-square test, $P < 0.001$). The starting age of CIC and medication was significantly related (Kendall's tau b value: 0.324, $P < 0.001$). Thirty percent of patients underwent a bladder operation of any kind.

There were differences in some points between the three nations. Frequency of patients who do not use CIC was higher in TR (24.9% vs 7.8% for DE and 10.2% for NL, $P = 0.002$). Complete urinary (pseudo)continence rate was highest in NL (30.6% vs 23.8% for TR and 19.2% for

DE, $P = 0.006$). Agreement rates for recommendations on early CIC and anticholinergic medication were least in NL (69.4% and 74.5%), whereas approval for a recommendation on the treatment of fecal incontinence was least in TR (72.6%).

4 | DISCUSSION

The management of neurogenic bladder (NB) does not have clearly defined protocols and must be structured depending on the characteristics of both patient and disease. While long-term preservation of renal function must be the main focus of treatment, improvement of urinary continence is important with regard to QoL for patients. Urinary tract function is monitored by imaging (mainly ultrasound), scintigraphy, laboratory, and urodynamic tests.

Many patients will be treated with medication from a young age. Various anticholinergic drugs are used for improvement of urinary incontinence, as well as protection of the upper tract. Antibiotics are administered to prevent urinary tract infections (UTI). Oral laxatives and enemas are used to treat constipation and improve fecal continence, in addition to bowel irrigation. A recent study in adults showed that more than half of the patients were receiving any type of medication.¹¹ In our survey, 78% of responders depend on at least one type of medication. The most frequently used type of drug was anticholinergics (63.9%), other drugs were antibiotics, bowel management medications, chronic renal failure drugs.

Securing safe and complete bladder emptying is an important principle of SB management. CIC is the main treatment in case spontaneous voiding is insufficient.

TABLE 2 Agreement rates of participants on the defined recommendations from the guideline

Questions/Recommendations	Strength rating in the guideline	TR (n: 189)	DE (n: 53)	NL (n: 49)	Overall (n: 291)
<i>Urodynamic studies</i> should be performed in every patient with spina bifida as well as in every child with a high suspicion of a neurogenic bladder to estimate the risk for kidneys and to evaluate the function of the bladder. Agree/do not agree	Strong	176/6 96.7%	52/1 98.1%	46/2 95.8%	274/9 96.8%
In all new-borns with Spina Bifida, <i>intermittent catheterization</i> (IC) should be started soon after birth. In those in whom IC may be delayed, close monitoring for urinary tract infections and kidney and bladder functions is necessary. Agree/do not agree	Strong	156/28 84.8%	45/8 84.9%	34/15 69.4%	235/51 82.2%
Start early <i>anticholinergic medication</i> in the new-borns with suspicion of aneurogenic overactive bladder. Agree/do not agree	Strong	162/10 94.2%	50/2 96.2%	35/12 74.5%	247/24 91.1%
Treatment of <i>faecal incontinence</i> is important to gain continence and independence. Treatment should be started with mild laxatives, rectal suppositories or digital removal of feces. If not sufficient transanal irrigation is recommended, if not practicable or feasible, a MACE/ACE stoma should be discussed. Agree/do not agree	strong	122/46 72.6%	43/9 82.7%	42/6 87.5%	207/61 77.2%
A <i>life-long follow-up</i> of renal and bladder/reservoir function should be available and offered to every patient. Addressing sexuality and fertility counseling starting before/during puberty should be offered. Agree/do not agree	weak	174/3 98.3%	53/0 100%	47/2 95.9%	274/5 98.2%

Please note that total numbers do not give always 291. Some patients did not answer some questions. Abbreviations: DE, Germany; NL, The Netherlands; TR, Turkey.

TABLE 3 Future expectation of the participants about their diseases

Future expectations	TR (n: 189)	DE (n: 53)	NL (n:49)	Total (n: 291)
Quality of life	96	25	31	152
Surgical technique	52	8	8	68
New drugs	8	11	4	23
Sexuality and fertility	13	3	3	19
All	5	4	2	11
Total	174	51	48	273

Abbreviations: DE, Germany; NL, The Netherlands; TR, Turkey.

Please note that total numbers do not give always 291. Since some patients did not answer some questions.

CIC may improve continence status by preventing overflow-incontinence, decreasing upper urinary tract pressure in case of low-compliance bladder, decreasing the incidence of UTI's in case of residual urine and thereby CIC aids in the preservation of renal function in the long term. Wiener reported 76.8% of patients were on CIC,¹¹ which is similar in our survey (80.5%). Our results showed that the ages of starting medication and CIC were significantly related, demonstrating that most of the health professionals recommend starting these two treatments simultaneously.

The definition of incontinence according to ICCS is “uncontrollable leakage of urine” which defines the condition in normal children. However, various definitions are in use and reported continence rates are variable. In our survey, we defined complete continence as being dry. We preferred the term (pseudo)continence to describe the complete bladder or fecal continence by means of any medical or surgical intervention. The rates of complete bladder and bowel continence were 24.2% and 46.6%, respectively. Wiener et al¹¹ reported an increasing continence rate from 36.9% in school-aged children to 48.2% in adults. Bladder and bowel control also improved with age in our study group. Furthermore, continence of urine and stool were directly related. This finding may be attributed to the common pathophysiology of urine and stool control mechanisms.

Patients with NB had a long history of hospitalizations and risk of surgical interventions for urological, neurosurgical or orthopedic problems. At least 30% of patients underwent several urological surgeries and an additional 7% underwent other surgeries. Therefore, it is important to consider surgery associated risks in this population. There is increasing attention for the potential risk of repeated or prolonged anesthesia in children. Furthermore, the development of latex allergy is a well-known risk in SB. The incidence may be as high as 60%.¹²

The EAU guidelines are important referral sources for all urologists all over the world and translated to nine non-English languages (please refer to <https://uroweb.org/guideline/paediatric-urology/?type=archive>). The validated translations of guidelines facilitate the standardization of patient care and management amongst the other countries. Since the guidelines are prepared by and for health professionals, the patients' needs might be overlooked. Understanding the patients' perspective and needs may change our approach to disease and interest areas. This survey study was initiated by the motivation of EAU Guidelines Office on all guideline panels to investigate the possibility of collaboration with patients. The results of the present study would serve as the first step of this project. The main objective of the present study was to assess patient awareness of the current guidelines and patient opinion on guideline recommendations. The EAU/ESPU guidelines were first published in 2001 for health care providers to improve the quality of care of specific pathologies.¹³ However, it is unknown if patients and their families are aware of medical guidelines concerning their medical problems. The survey was short, on-line based and could be answered in 5 minutes. Our primary aim was to simply gather information from this chronic disease patient group with many medical aspects, not to create a validated questionnaire. Despite the fact that the native language of the involved patients was different from English (the language used in the guidelines), the results of this nonvalidated survey demonstrated awareness of this guidelines document among 8% of patients, being highest in NL (14.6%), followed by Germany DE (11.6%), and lowest in TR (5.9%). This most likely reflects the variation in knowledge of the English language. While low, this rate was higher than expected as the guidelines have been developed for health care professionals instead of patients, and as such may be more difficult to access for patients.

The panel members selected 5 amongst 10 recommendations to be asked in the survey. The UDS are among the most performed tests in these patients. In addition, CIC and antimuscarinic medications are the most common treatment modalities to provide bladder control, whereas bowel control is another very common accompanying problem. The remaining 5 questions comprise more technical recommendations and therefore we have considered them as more of interest to health professionals rather than affected patients and/or caregivers. The general patient agreement rate on the guideline recommendations was very high for most topics. For UDS, intermittent catheterization and anticholinergic use there was a strong correlation between the levels of evidence and strength of guideline recommendations and patient agreement (Table 2; UDS: 2-strong vs 97%; CIC: 3-strong

vs 82%; anticholinergic: 2-strong vs 91%). Contrarily, the guideline's strong recommendation on bowel management had a relatively lower agreement rate (fecal incontinence: 3-strong vs 77%). The guideline's weak recommendation on lifelong follow-up has a very high agreement rate (Table 2. lifelong: 3-weak vs 98%). Agreement rates were lowest regarding routine intermittent catheterization and bowel management. This may reflect variations in clinical practice or the burden of recommended treatment in daily life. The original language of the guidelines is English and we have tried to translate the survey as best as we could into the three languages in which it was distributed. This can be another reason for the given variations. When we look at these agreement rates in sight of responders, we found that agreement rates were similar in patient and caregiver responders. However, agreement on the use of CIC was significantly lower in patient responders that can reflect the possible underestimation of caregivers on this considerably disturbing life-long treatment modality.

The responses to open questions in the survey and communication with the national spina bifida societies demonstrated a strong interest in guidelines. The most important outcome of our first experience in patient involvement is to start the collaboration between patients and/or patient support groups and guidelines panels early on in the guidelines production process.

In addition, patients were asked which aspects in the medical care of their disease should be improved. QoL was rated as most important (55.6%), followed by surgical techniques (24.9%), development of new medications (8.4%), sexuality/fertility issues (6.9%) and all of the above (4%). There were gender-specific differences with males focusing on new medications (27% vs 4.3%) and sex/fertility issues (21.6% vs 10.6%), whereas females favored QoL improvement (37.8% vs 59.6%). Preservation of renal function and urinary continence status seem to be issues of more importance from early on in life. Over the last decades' improvements in medical care have led to a strong increase in life expectancy, thereby increasing the importance of sexual and fertility issues for patients. Sexual identity and orientation of SB patients is not different from the general population.¹⁴ The priority that patients assign to sex/fertility issues highlights the need for adequate organization of the transition of care into adulthood in specialized centers. QoL issues become reach increasing significance in patients as they get older. Modern health care aims to focus on medical care and also includes QoL issues. HRQoL and PROMs provide valuable information regarding the patient perspective and can be used to improve the quality of care. There are many general HRQoL PROMs that have been used in patients with NB (General QoL PROMs, General bladder PROMs, NGB-specific PROMs).⁸ The Patient-Centered Outcomes Research Institute is running a

multi-institutional prospective cohort study comparing three different bladder-management strategies (CIC, indwelling catheters, and surgery) which is one of the most recent and comprehensive studies on this issue. So far no outcome data have been published.¹⁵

The presented survey demonstrated some differences between the three countries. In Turkey, the mean patient age was younger, awareness of guidelines was lowest, and frequency of patients without CIC was highest. The rate of bladder surgery, as well as complete urinary continence, was highest in The Netherlands. Agreement rates for recommendations on early CIC and anticholinergic medication were lowest in NL (69.4% and 74.5%). Agreement rate for the recommendation on the treatment of fecal incontinence was lowest in TR (72.6%). Use of medication was highest in DE (91%), though was not statistically significant. These variations may be attributed to the differences in English-speaker rates in the general public, the socioeconomic and cultural circumstances as well as differences in health care systems which can affect the medical practices of the health professionals.

Our study has several limitations. The majority of the responders were the caregivers and this can cause an incomplete or incorrect reflection of the "real condition" of the patient. We do not have the data about the socioeconomic level and demographic features of the caregivers which may affect interpretations of our findings. We do not have information about the number of receivers and do have data about the responders only. The numbers of the participants were not distributed similarly amongst the nations. Nearly half of the responders were from one country and this probably causes some deviations especially for the distribution of age, type of management (medication and surgery) and responders' awareness on guidelines. The deviations make interpretation of results difficult. This was a web-based on-line survey and answers carry the inherent risks of recall bias. The survey was not validated and had a simple design to facilitate the ease of response.

5 | CONCLUSION

Despite the fact that the native language of the involved patients was different from English, the results of this nonvalidated survey demonstrated awareness of this guidelines document among 8% of patients, even though it was primarily developed for health care professionals. Nonetheless, the general approval of the guideline recommendations is quite high. One important outcome of our first experience in patient involvement is the desire of patients and/or patient support groups to be involved early in the process of guideline production.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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