Kidney Function Surveillance in the National Spina Bifida Patient Registry: A Retrospective Cohort Study.

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Abstract

Purpose: Chronic kidney disease affects 25–50% of patients with spina bifida. Guidelines recommend kidney function surveillance in these patients, but practice patterns are unknown. Variations in kidney function surveillance were assessed across patients with spina bifida, with the hypothesis that the treating clinic and spina bifida type would be associated with kidney function surveillance.

Materials and Methods: A retrospective cohort study was conducted from 2013–2018 within the National Spina Bifida Patient Registry in the United States. Follow-up was anchored at the 2013 visit. Participants with either an outcome event within 2 years of follow-up or >2 years of follow-up without an outcome event were included. Primary outcome was kidney function surveillance, defined as at least one renal ultrasound and serum creatinine within 2 years of follow-up. Primary exposures were clinic and spina bifida type, which were analyzed with covariates including sociodemographic and clinical characteristics in logistic regression models for their

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association with the outcome. Sensitivity analyses were performed using different kidney function surveillance definitions.

Results: Of 8351 total patients, 5445 were included, with median 3.0 years' follow-up. Across 23 treating clinics, kidney function surveillance rates averaged 62% (range 6–100%). In multivariable models, kidney function surveillance was associated with clinic, younger age, functional lesion level, non-ambulatory status, and prior bladder augmentation. Treating clinic remained a significant predictor of kidney function surveillance in all sensitivity analyses.

Conclusions: Within the National Spina Bifida Patient Registry, wide variation exists in practice of kidney function surveillance across treating clinics, despite adjustment for key patient characteristics.

Introduction

Patients with spina bifida (SB) face an increased lifetime risk of chronic kidney disease (CKD) due to neurogenic bladder.[1–3] Effective urological interventions, including initiation of clean intermittent catheterization, anticholinergic therapy, or augmentation cystoplasty, may prevent CKD development and progression.[4] Since CKD is often a silent condition, application of kidney-protective urologic interventions to slow kidney injury depends directly on timely detection through kidney function surveillance (KFS).

Traditionally, KFS relies on a biomarker, such as serum creatinine (SCr), to calculate estimated glomerular filtration rate (eGFR), or imaging, such as renal bladder ultrasound (RBUS), to detect hydronephrosis. Guidelines for management of neurogenic bladder recognize the importance of KFS and the potential for CKD, with all recommending periodic "kidney imaging" and most recommending "kidney function" testing.[5–11] More frequent KFS is recommended for SB patients with myelomeningocele. Real-world implementation of guideline recommendations is unknown. Given that prior work showed significant differences in bladder reconstruction surgical rates across treating clinics,[12] institutional practice patterns may likewise be a potential factor in KFS guideline adherence.

We assessed practice patterns of KFS in the largest, contemporary, multi-institutional cohort of patients with SB in the United States. KFS was hypothesized to vary significantly by both the individual clinic treating the patient and by type of SB.

Methods

Study Design

This is a retrospective cohort study using data from the National Spina Bifida Patient Registry (NSBPR). The NSBPR is sponsored by the Centers for Disease Control and Prevention (CDC) and was initiated in 10 treating clinics in 2009 to collect longitudinal data from birth through adulthood from patients having any of 4 diagnoses (myelomeningocele

(MMC), meningocele, lipomyelomeningocele, or fatty filum).[13] Data were collected by patient interview, questionnaire, or chart abstraction using standardized data collection at time of enrollment (initial encounter) and follow-up visits (annual visit). The current NSBPR database includes 37 treating clinics across the United States with a centralized data entry system that facilitates data analysis and allows for quarterly data quality audits. The NSBPR reflects "real-world" experience; clinical care is not standardized and is at the discretion of treating physicians. Close interaction with and support from the SB Association aim to promote improvements in longitudinal SB clinical care.

In 2013, the CDC activated Version 2 data collection for NSBPR, which involved routinely recording SCr and RBUS findings. Thus, the first Version 2 visit in 2013 was deemed the "baseline" visit. The time window for KFS was anchored starting 6 months before the baseline visit to capture any laboratory values or imaging obtained on dates prior to the baseline visit; follow-up began at this 6-month pre-baseline visit mark and went through end of 2018.

Study Population

All patients with SB enrolled in NSBPR with available data from a clinic visit beginning in 2013 (when Version 2 was introduced) or later were eligible. Inclusion criteria included having either an outcome event (RBUS and SCr) within 2 years after the baseline visit (in 2013 or later), or at least two years of follow up without the outcome event. Patients were excluded if they had less than two years of follow up and an outcome event did not occur. Clinics with <30 enrolled patients in NSBPR were excluded to avoid selection bias. Institutional review board approval was obtained locally. Informed consent was obtained from participants or parent/guardians at initial NSBPR enrollment.

Outcomes, Exposures, and Covariates

The primary outcome was KFS, which was defined as having a SCr and RBUS each checked at least once within a 2-year follow-up period. The tests could occur on different dates. This 2-year window was chosen given that the more conservative guidelines[9] recommend kidney function or imaging testing once every 1–2 years.

The primary exposure of interest was treating clinic, which was considered as a categorical variable in the analyses. The multi-disciplinary clinics enrolled participants in NSBPR and ranged in clinical volume (from <100 patients with SB per year to >300 per year). A secondary exposure of interest was SB type (MMC vs non-MMC).

Covariates that were adjusted for in analyses included age, sex, race/ethnicity, and insurance, dependency on clean-intermittent catheterization (CIC), prior bladder augmentation history, functional lesion level, and mobility status. No urodynamic data were included because KFS is recommended in patients with SB regardless of urodynamic characteristics.[5–8]

Sensitivity Analyses

Three sensitivity analyses were performed with KFS re-defined as having: (1) SCr and RBUS each checked at least once within a 1-year window; (2) RBUS only within a 2-year window; (3) SCr only within a 2-year window.

Statistical Analysis

Cohort characteristics were assessed with frequencies for categorical variables. Univariable and multivariable logistic regression analyses were performed to fit associations between exposures and outcomes.

During the exploratory data analysis for the primary outcome, a significant interaction was noted between the exposures of interest (SB type and treating clinic). This meant that the association between SB type and KFS varied by clinic, and vice versa. The interaction term was included in the multivariable logistic regression analysis along with its component primary variables. Participants with missing values in one or more of the exposures were excluded from the analysis.

All statistical analyses were performed with SAS (version 9.4; SAS Institute, Cary, NC) with a two-tailed alpha of 0.05 determining significance.

Results

Of 8351 patients in NSBPR with a baseline visit in 2013, those with <2 years of follow-up without the outcome event (n=2795) and who were at clinics with <30 participants (n=111) were excluded, leaving 5445 patients at 23 treating clinics who were included for analysis (Figure 1). A comparison of excluded and included patients showed the final cohort to be younger and to have more severe SB phenotype, with more myelomeningocele diagnoses, more thoracic-level lesions, and more non-ambulators (data not shown). Among the 5445 included patients, median follow-up was 3.0 years (interquartile range [IQR] 2.0–4.0 years), 33% were <5 years old, 48% were male, 80% had MMC, 37% were non-ambulators, 61% used CIC, and 10% had prior bladder augmentation (Table 1).

Of 5445 included patients, 3384 (62%) underwent KFS within a 2-year window. Among 23 clinics, rates of KFS ranged 6 to 100% (Figure 2). Median time between SCr and RBUS was 1 month (IQR 0–7 months). Significant univariable associations were found with clinic, MMC SB type, higher lesion levels, non-ambulatory status, prior bladder augmentation, non-private insurance status, age, and race (Table 1). Of the 3384 who underwent KFS, 79% underwent at least one additional SCr or RBUS during follow-up.

On multivariable analysis, with an interaction term included for SB type and clinic, SB type was no longer statistically significant, but clinic remained so (Table 2). Other covariates significantly associated with KFS were younger age, level of lesion, non-ambulatory status, and prior bladder augmentation.

In the adjusted sensitivity analyses, results for the primary exposure of clinic did not change in significance (data not shown). Of eligible patients, 45% underwent KFS within a 1-year

window (Figure 3a). Average KFS rate was much higher when KFS was defined as RBUS-only (93%) versus SCr-only (69%) within a 2-year window (Figures 3b and 3c).

Discussion

Rates of KFS, conservatively defined as a SCr and RBUS within a 2-year window, averaged 62% and ranged from 6 to 100% across 23 NSBPR clinics. Treating clinic was significantly associated with KFS, despite adjustment for covariates that reflected case mix and SB severity. These results suggest that, as hypothesized, local practice patterns may play a large role in KFS and CKD detection in patients with SB.

Despite guidelines recommendations[5–10] to regularly monitor kidney function and upper tract changes in patients with SB, we found only 62% adherence when a conservative definition of KFS was used. A specific clinical concern is that 24% of patients with prior bladder augmentation did not meet the KFS outcome. KFS rates were higher (93%) when defined as RBUS-only within a 2-year window, suggesting that the low primary outcome KFS adherence rate is driven by clinics not regularly checking SCr. Substantial disagreement and lack of specificity among guidelines may explain these findings. Most guidelines recommend "kidney imaging" surveillance with RBUS, but few guidelines that mention "kidney function" surveillance specifically address SCr. The 2012 International Children's Continence Society guidelines[5] recommend annual or biannual RBUS in toddlers to emerging adults, but do not mention laboratory testing. The 2008 European Association of Urology (EAU) Neuro-Urology guidelines[11] recommend annual "blood biochemistry" without being specific. The updated 2016 EAU Neuro-Urology guidelines[9] recommend that "renal function should be checked in case of…possible deterioration" and that the "interval between investigations should not exceed 1–2 yr" without specifying what these investigations might entail. Similarly, the 2018 EAU Pediatric Urology guidelines[8] on neurogenic bladder state that "lifelong follow-up" and "regular investigation…is mandatory" but do not specify methods or frequency of surveillance. The 2012 National Institute for Health and Care Excellence (NICE) guidelines[6] for neurogenic lower urinary tract dysfunction recommend surveillance RBUS at 1–2 year intervals and is the only one that specifically recommends against isolated use of SCr or eGFR in isolation, instead advocating for measured or isotopic GFR testing. On the contrary, the 2018 SB Association guidelines[10] acknowledge limitations of SCr in children with low muscle mass, but still recommend reflex SCr testing only if RBUS changes were noted in children ages 1–6 years old and annual SCr in older children. Regardless of which guideline the clinics generally follow, the ambiguities in recommended surveillance interval and specific tests to use likely contribute to heterogeneity in adoption of guidelines into clinical practice.[14, 15]

Lack of consensus and clarity in the guidelines is likely driven by uncertainty regarding the optimal method for KFS and whether implementation of KFS will improve outcomes, as demonstrated by low levels of evidence described within these guidelines. Monitoring kidney health on a regular basis in patients with SB would ideally allow earlier detection of CKD development or progression, and would therefore ideally allow earlier implementation of effective urological interventions. This, however, remains to be proven with high-quality evidence. For example, even simply measuring kidney function accurately in patients with

SB is difficult, especially with SCr, due to lower muscle mass from which SCr is derived.[16] It is no surprise that the NICE guidelines[6] found no published quality of life or effectiveness data for accurate economic analysis of KFS strategies. Larger studies with long-term follow-up linking KFS to CKD outcomes and end-stage kidney disease would help provide the higher-quality evidence needed to inform future implementation studies of effective KFS strategies.

In the absence of definitive guidelines, clinicians aim to make the best decisions for their patients, but clinical judgements are often influenced by local practice patterns. Previous work from the NSBPR examining surgical bladder reconstruction rates found treating clinic to be a significant predictor of outcome, despite adjustment for patient-level risk factors.[12] We found similarly that, even after adjustment for patient-level risk factors, including prior bladder augmentation, SB type, level of lesion, ambulation status, and CIC-dependency, treating clinic remained significantly associated with KFS. Clinic size did not seem to be visually associated with KFS rate (Figure 2). Certain clinics may involve nephrologists early in SB care, possibly driving up KFS rates.[17] Since granular data on physician composition were not available, this hypothesis remains to be studied.

We posit that local practice patterns can be modified to improve KFS rates. More detailed examination of clinics with higher KFS rates can reveal how their better guideline adherence can be transferred to clinics with lower KFS rates. Similar to how the Michigan Urological Surgery Improvement Collaborative, a physician-led quality improvement collaborative, is working to introduce interventions that result in tangible reductions in outcome variation, [18, 19] the NSBPR offers the chance to improve care of patients with SB. Additionally, qualitative assessment through individual site visits can help decipher clinic-specific barriers to guideline implementation or identify system-level obstacles to KFS. For example, it is possible that clinics refused to check SCr regularly because of concerns over its validity.[6, 16] Issues like easing patient travel burden[20] or improving access to care, which are abilities inherent in a clinic social worker's value,[21] may improve KFS adherence.

The present study has several limitations. As a retrospective cohort analysis, the results are subject to selection bias and unmeasured confounding. Excluded patients, however, were compared to included patients, with the latter cohort having more severe disease characteristics. This suggests that KFS should have been even higher in the analyzed cohort. Potential ascertainment bias is possible from clinics being unaware of Version 2 requiring SCr and RBUS data, but this is unlikely due to regular teleconferences and meetings leading up to activation of Version 2 in 2013. It is possible that data abstractors left required fields on Version 2 data collection forms blank, which can be determined through future individual clinic site visits. We did not adjust for baseline kidney function, SCr trends over time, nor presence of a pediatric nephrologist, all of which may be associated with KFS. However, this cohort lacked certain data values (e.g., height) required to calculate eGFR and lacked granularity of team composition. Current creatinine-based eGFR equations also may be inaccurate and unreliable,[16] so actual CKD burden was not assessed for this study. Lack of KFS could not be clearly interpreted to mean either absence of physicians ordering the tests, or patient non-compliance with the ordered tests. Misclassification bias of SCr or RBUS tests is possible, although the NSBPR has data audits set in place to prevent data entry

errors. Our cohort derives from clinics who participate in the NSBPR; our results do not reflect the national population (where vulnerable patients may not be seen in clinic) nor non-NSBPR clinics. Lastly, it is possible that some patients had only their serum cystatin-C but not SCr checked, because NSBPR does not capture cystatin-C values. Given, however, that cystatin-C is both costlier and less routinely used than SCr,[22] it is more likely that no serum testing was done than cystatin-C alone.

Despite these limitations, our study has several strengths. The NSBPR is the largest, longitudinal, clinical cohort of patients with SB in the United States, and incorporates clinics of varying sizes and locations. The robust sample size and SB spectrum captured in NSBPR allow investigation of "real-world" practice patterns of outcomes such as KFS, which reflects inherent "real-world" obstacles to clinical care, such as insurance, language, or travel barriers, or unwillingness to undergo blood tests. Furthermore, our robust sensitivity analyses confirmed the significant association between treating clinic and KFS. Our finding of low KFS rates in clinics selected to be in NSBPR and with tailored processes in place to facilitate participation suggests a large guideline-to-practice gap that must be studied.

In conclusion, we found that 62% of patients with SB, seen in 23 clinics participating in NSBPR, underwent KFS defined as a SCr and RBUS within a 2-year window. Treating clinic was significantly associated with KFS even after adjustment for clinical risk factors. Development of studies examining associations between KFS and CKD outcomes and interventions to improve KFS rates can be pivotal as key next steps to protect the kidney health of patients with SB.
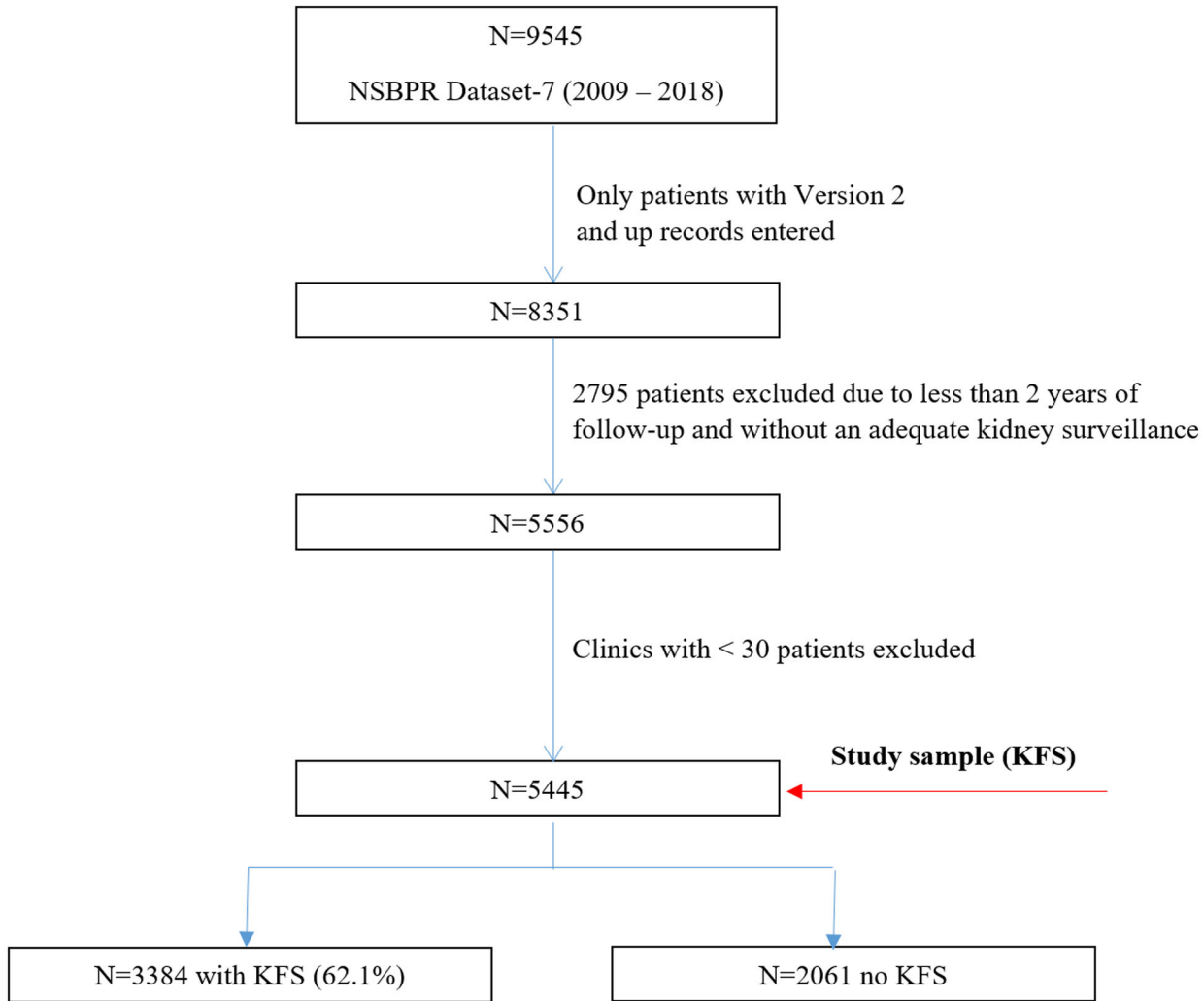
Acknowledgement

References

1. Malakounides G, Lee F, Murphy F et al.: Single centre experience: long term outcomes in spina bifida patients. J Pediatr Urol, 9: 585, 2013 [PubMed: 23602844]

2. Veenboer PW, Bosch JL, van Asbeck FW et al.: Upper and lower urinary tract outcomes in adult myelomeningocele patients: a systematic review. PLoS One, 7: e48399, 2012 [PubMed: 23119003]

3. Ouyang L, Bolen J, Valdez R et al.: Characteristics and survival of patients with end stage renal disease and spina bifida in the United States renal data system. J Urol, 193: 558, 2015 [PubMed: 25167993]

4. Dik P, Klijn AJ, van Gool JD et al.: Early start to therapy preserves kidney function in spina bifida patients. Eur Urol, 49: 908, 2006 [PubMed: 16458416]

5. Bauer SB, Austin PF, Rawashdeh YF et al.: International Children's Continence Society's recommendations for initial diagnostic evaluation and follow-up in congenital neuropathic bladder and bowel dysfunction in children. Neurourol Urodyn, 31: 610, 2012 [PubMed: 22532312]

6. NICE: Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease, 2012

7. Blok B, Padilla-Fernández B, Pannek J et al.: EAU Guidelines on Neuro-Urology 2018 In: European Association of Urology Guidelines. 2018 Edition. Arnhem, The Netherlands: European Association of Urology Guidelines Office, vol. presented at the EAU Annual Congress Copenhagen 2018, 2018

8. Radmayr C, Bogaert G, Dogan HS et al.: EAU Guidelines on Paediatric Urology 2018 In: European Association of Urology Guidelines. 2018 Edition. Arnhem, The Netherlands: European Association of Urology Guidelines Office, vol. presented at the EAU Annual Congress Copenhagen 2018, 2018

9. Groen J, Pannek J, Castro Diaz D et al.: Summary of European Association of Urology (EAU) Guidelines on Neuro-Urology. Eur Urol, 69: 324, 2016 [PubMed: 26304502]

10. Guidelines for the Care of People with Spina Bifida, 4th ed: Spina Bifida Association, 2018

11. Stohrer M, Blok B, Castro-Diaz D et al.: EAU guidelines on neurogenic lower urinary tract dysfunction. Eur Urol, 56: 81, 2009 [PubMed: 19403235]

12. Routh JC, Joseph DB, Liu T et al.: Bladder Reconstruction Rates Differ among Centers Participating in National Spina Bifida Patient Registry. J Urol, 199: 268, 2018 [PubMed: 28830753]

13. Thibadeau JK, Ward EA, Soe MM et al.: Testing the feasibility of a National Spina Bifida Patient Registry. Birth Defects Res A Clin Mol Teratol, 97: 36, 2013 [PubMed: 23125114]

14. Greenfield S: Clinical Practice Guidelines: Expanded Use and MisuseExpanded Use and Misuse of Clinical Practice GuidelinesEditorial. JAMA, 317: 594, 2017 [PubMed: 28196236]

15. Klasco RS, Glinert LH: Language for Actionable Recommendations in Clinical Guidelines: Avoiding Hedging and EquivocationLanguage for Actionable Recommendations in Clinical GuidelinesLanguage for Actionable Recommendations in Clinical Guidelines. JAMA, 317: 583, 2017 [PubMed: 28196262]

16. Chu DI, Balmert LC, Arkin CM et al.: Estimated kidney function in children and young adults with spina bifida: A retrospective cohort study. Neurourol Urodyn, 38: 1907, 2019 [PubMed: 31286557]

17. Jander A, Nowicki M, Tkaczyk M et al.: Does a late referral to a nephrologist constitute a problem in children starting renal replacement therapy in Poland?--a nationwide study. Nephrol Dial Transplant, 21: 957, 2006 [PubMed: 16339164]

18. Luckenbaugh AN, Auffenberg GB, Hawken SR et al.: Variation in Guideline Concordant Active Surveillance Followup in Diverse Urology Practices. J Urol, 197: 621, 2017 [PubMed: 27663459]

19. Womble PR, Linsell SM, Gao Y et al.: A Statewide Intervention to Reduce Hospitalizations after Prostate Biopsy. J Urol, 194: 403, 2015 [PubMed: 25896556]

20. Livingston EH, Burchell I: Reduced access to care resulting from centers of excellence initiatives in bariatric surgery. Arch Surg, 145: 993, 2010 [PubMed: 20956769]

21. Lewis J, Frimberger D, Haddad E et al.: A framework for transitioning patients from pediatric to adult health settings for patients with neurogenic bladder. Neurourol Urodyn, 36: 973, 2017 [PubMed: 27276694]

22. Chew JS, Saleem M, Florkowski CM et al.: Cystatin C--a paradigm of evidence based laboratory medicine. Clin Biochem Rev, 29: 47, 2008 [PubMed: 18787643]

Patient inclusion criteria flow chart.

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                        ┌──────────────────────────────┐
                        │         N=9545               │
                        │                              │
                        │  NSBPR Dataset-7 (2009 – 2018)│
                        └──────────────────────────────┘
                                      │
                                      │   Only patients with Version 2
                                      │   and up records entered
                                      ▼
                        ┌──────────────────────────────┐
                        │         N=8351               │
                        └──────────────────────────────┘
                                      │
                                      │   2795 patients excluded due to less than 2 years of
                                      │   follow-up and without an adequate kidney surveillance
                                      ▼
                        ┌──────────────────────────────┐
                        │         N=5556               │
                        └──────────────────────────────┘
                                      │
                                      │   Clinics with < 30 patients excluded
                                      ▼
                        ┌──────────────────────────────┐                  Study sample (KFS)
                        │         N=5445               │  ◄─────────────
                        └──────────────────────────────┘
                             │                    │
                             ▼                    ▼
        ┌───────────────────────────┐   ┌───────────────────────────┐
        │  N=3384 with KFS (62.1%)  │   │    N=2061 no KFS           │
        └───────────────────────────┘   └───────────────────────────┘
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Figure 1.
Participant Selection Flowchart, **National Spina Bifida Patient Registry, 2013–18**.
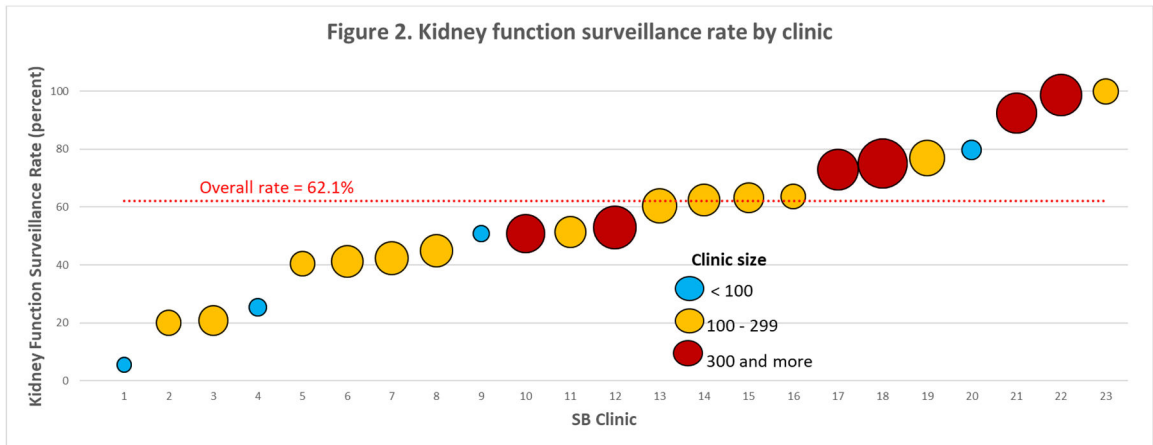
Figure 2.
Kidney Function Surveillance rates varied significantly across Treating Clinics (n=23 clinics, 5445 patients; p<0.001), **National Spina Bifida Patient Registry, 2013–18**.
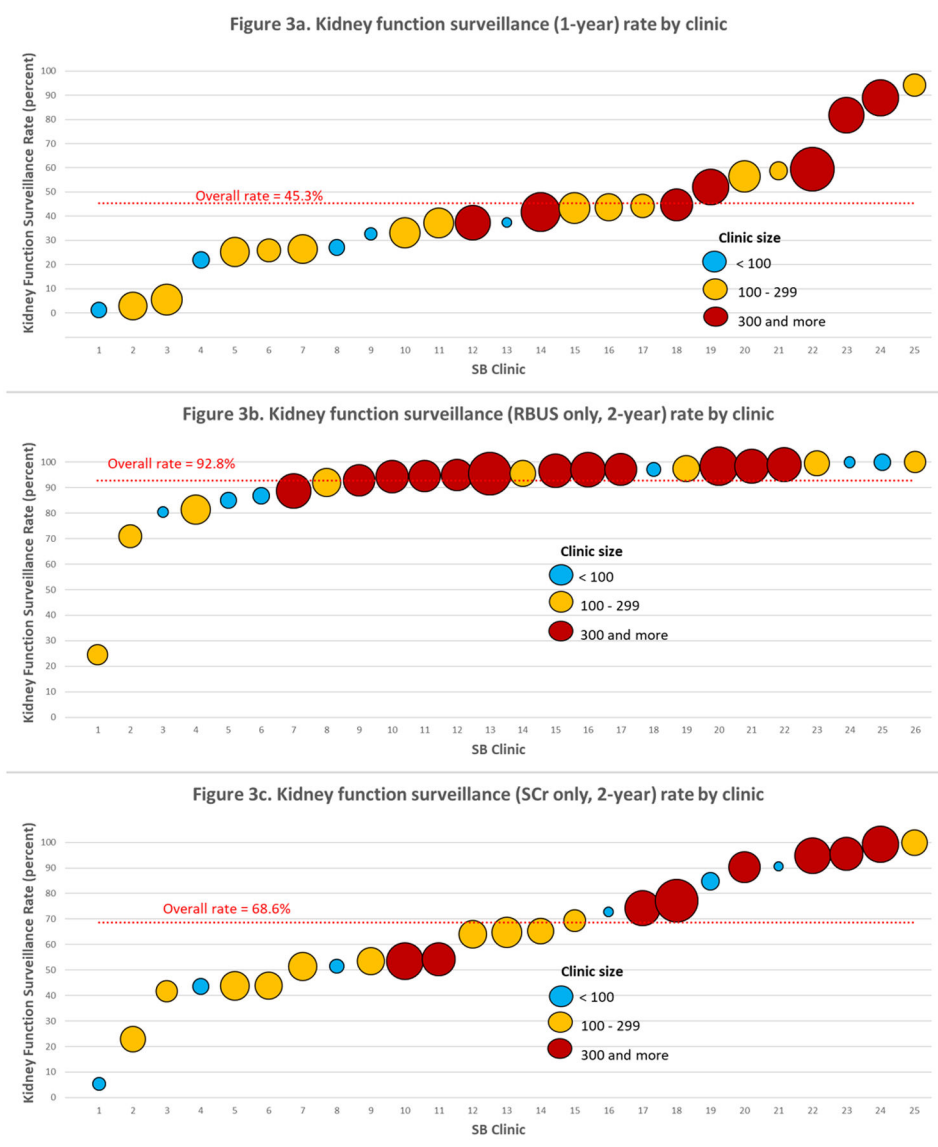
Figure 3.
Kidney Function Surveillance rates in sensitivity analyses. (a) Kidney Function Surveillance rates using 1-year window; (b) Kidney Function Surveillance rates using ultrasound-only in 2-year window; (c) Kidney Function Surveillance rates using serum creatinine-only in 2-year window. All rates varied significantly across Treating Clinics (p<0.001), **National Spina Bifida Patient Registry, 2013–18**.

Table 1.

Distribution of key demographic and clinical characteristics by kidney function surveillance in the National Spina Bifida Patient Registry, 2013–18.

Variables	Overall n (%) or statistics (N=5445)	N (%) or statistics by kidney function surveillance		
		Yes (n=3384)	No (n=2061)	P-value
Baseline age group				
Younger than 5	1797 (33.0)	1195 (66.5)	602 (33.5)	
5 to <12	1640 (30.1)	855 (52.1)	785 (47.9)	
12 to <20	1153 (21.2)	791 (68.6)	362 (31.4)	
20 or older	855 (15.7)	543 (63.5)	312 (36.5)	<0.0001[*]
Sex				
Male	2586 (47.5)	1593 (61.6)	993 (38.4)	
Female	2859 (52.5)	1791 (62.6)	1068 (37.4)	0.43
Race/Ethnicity (N=5423)				
Non-Hispanic White	3360 (62.0)	2037 (60.6)	1323 (39.4)	
Non-Hispanic Black	402 (7.4)	283 (70.4)	119 (29.6)	
Hispanic or Latino	1208 (22.3)	792 (65.6)	416 (34.4)	
Other	453 (8.4)	260 (57.4)	193 (42.6)	<0.0001[*]
SB diagnosis				
Myelomeningocele	4375 (80.3)	2798 (64.0)	1577 (36.0)	
Other diagnosis	1070 (19.7)	586 (54.8)	484 (45.2)	<0.0001[*]
Baseline functional level of lesion				
Thoracic	833 (15.3)	553 (66.4)	280 (33.6)	
High-Lumbar	509 (9.3)	353 (69.4)	156 (30.6)	
Mid-Lumbar	1437 (26.4)	906 (63.0)	531 (37.0)	
Low-Lumbar	929 (17.1)	603 (64.9)	326 (35.1)	
Sacral	1737 (31.9)	969 (55.8)	768 (44.2)	<0.0001[*]
Baseline ambulation status				
Community Ambulators	2699 (49.6)	1523 (56.4)	1176 (43.6)	
Household Ambulators	386 (7.1)	229 (59.3)	157 (40.7)	
Therapeutic Ambulators	363 (6.7)	211 (58.1)	152 (41.9)	
Non-Ambulators	1997 (36.7)	1421 (71.2)	576 (28.8)	<0.0001[*]
Baseline CIC use (N=5444)				
Yes	3337 (61.3)	2082 (62.4)	1255 (37.6)	
No	2107 (38.7)	1301 (61.7)	806 (38.3)	0.65
Baseline health insurance				
Any private	2583 (47.4)	1506 (58.3)	1077 (41.7)	
Non-private	2862 (52.6)	1878 (65.6)	984 (34.4)	<0.0001[*]
Bladder augmentation before baseline (N=5369)				
Yes	512 (9.5)	388 (75.8)	124 (24.2)	

		N (%) or statistics by kidney function surveillance		
Variables	Overall n (%) or statistics (N=5445)	Yes (n=3384)	No (n=2061)	P-value
No	4857 (90.5)	2956 (60.9)	1901 (39.1)	<0.0001[*]
Site ID				
1	228 (4.2)	94 (41.2)	134 (58.8)	
2	415 (7.6)	220 (53.0)	195 (47.0)	
3	275 (5.1)	166 (60.4)	109 (39.6)	
4	75 (1.4)	19 (25.3)	56 (74.7)	
5	228 (4.2)	117 (51.3)	111 (48.7)	
6	253 (4.6)	107 (42.3)	146 (57.7)	
7	236 (4.3)	106 (44.9)	130 (55.1)	
8	141 (2.6)	57 (40.4)	84 (59.6)	
9	55 (1.0)	3 (5.5)	52 (94.5)	
10	286 (5.3)	220 (76.9)	66 (23.1)	
11	202 (3.7)	42 (20.8)	160 (79.2)	
12	336 (6.2)	171 (50.9)	165 (49.1)	
13	368 (6.8)	340 (92.4)	28 (7.6)	
14	377 (6.9)	275 (72.9)	102 (27.1)	
15	545 (10.0)	409 (75.0)	136 (25.0)	
16	94 (1.7)	75 (79.8)	19 (20.2)	
17	65 (1.2)	33 (50.8)	32 (49.2)	
18	388 (7.1)	383 (98.7)	5 (1.3)	
19	234 (4.3)	146 (62.4)	88 (37.6)	
20	204 (3.7)	129 (63.2)	75 (36.8)	
21	143 (2.6)	91 (63.6)	52 (36.4)	
22	145 (2.7)	29 (20.0)	116 (80.0)	
23	152 (2.8)	152 (100.0)		<0.0001[*]

[*] Statistically significant at 0.05 significance level.

Table 2.

Multiple logistic regression with site*SB type interaction on kidney function surveillance (n=5346) in the National Spina Bifida Patient Registry, 2013–18

Variables	Odds Ratio (95% CI)	P-value
Baseline age group		<0.0001 *†
Younger than 5 †		
5 to <12	0.55 (0.46 – 0.66)	<0.0001
12 to <20	0.95 (0.77 – 1.17)	0.63
20 or older	0.60 (0.47 – 0.78)	0.0001
Sex		
Male †		
Female	1.04 (0.91 – 1.19)	0.52
Race/Ethnicity		0.1205 †
Non-Hispanic White †		
Non-Hispanic Black	1.35 (1.02 – 1.80)	0.0370 *
Hispanic or Latino	0.98 (0.81 – 1.20)	0.87
Other	0.89 (0.70 – 1.14)	0.35
SB diagnosis		
Myelomeningocele †		
Other diagnosis	--	0.99
Baseline functional level of lesion		0.0011 *†
Thoracic	0.81 (0.61 – 1.07)	0.1418
High-Lumbar	1.27 (0.95 – 1.71)	0.1085
Mid-Lumbar	1.07 (0.88 – 1.31)	0.49
Low-Lumbar	1.33 (1.08 – 1.65)	0.0073 *
Sacral †		
Baseline ambulation status		<0.0001 *†
Community Ambulators †		
Household Ambulators	1.13 (0.86 – 1.48)	0.38
Therapeutic Ambulators	1.16 (0.87 – 1.55)	0.30
Non-Ambulators	2.44 (1.99 – 2.99)	<0.0001 *†
Baseline CIC use		
Yes †		
No	0.96 (0.82 – 1.12)	0.57
Baseline health insurance		
Any private †		
Non-private	1.11 (0.96 – 1.28)	0.1726
Bladder augmentation before baseline		

Variables	Odds Ratio (95% CI)	P-value
Yes	2.17 (1.67 – 2.80)	<0.0001 [*]
No [†]		
Clinic ID		<0.0001 [*‡]
Clinic*SB type interaction		<0.0001 [*‡]

[†]: Reference group

[‡]: Overall p-value

[*]: Statistically significant at 0.05 significance level