Journal of Pediatric Urology (2017) **13**, 390.e1—390.e6

Agreement between electronic medical records and self-reported urologic domains in the National Spina Bifida Patient Registry (NSBPR): Implications for future research

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Keywords
Agreement; Self-report; Medical record; Continence; Spina bifida; Myelomeningocele

Received 9 January 2017
Accepted 10 April 2017
Available online 15 June 2017

Summary

Background

Self-report (SR) is an efficient data collection method. However, SR data have been shown to be discrepant with medical record (MR) documentation, which raises questions about using SR to supplement retrospective chart review in research. In this study, pediatric spina bifida (SB) patients who completed SR interviews about continence status and personal bladder/bowel management were identified. We examined agreement between SR data and Urology provider notes in MRs.

Objective

This study aimed to (1) identify demographic, medical, or methodological factors that might contribute to SR/MR disagreement; (2) postulate how these findings might be significant clinically; and (3) recommend improvements to SR data collection and MR documentation.

Study design

Our institution participates in the National Spina Bifida Patient Registry (NSBPR). NSBPR-enrolled subjects typically complete annual interviews about their urologic outcomes; we consider this to be a form of SR. After identifying patients who interviewed within 1 month of an encounter with a urology provider, we systematically reviewed and compared their SR responses to the MR. Overall SR/MR agreement (no. of agreeing data pairs/no. of complete data pairs) and strength of agreement (kappa, κ) were assessed. Agreement about daytime continence status was assessed for children $\geq$5 years or in younger children who were toilet trained. Analyses were also stratified by diagnosis, type of bladder management, and ethnicity.

Results

Eleven urologic domains were analyzed for 176 patients. Overall SR/MR agreement was $\geq$90% for nine out of 11 domains (figure). Daytime urinary and stool incontinence (DUSI) domains demonstrated the lowest overall agreement, at 69% and 74% respectively. Patients with myelomeningocele (MM) and those on clean intermittent catheterization demonstrated twice as much SR/MR disagreement about DUSI than patients without MM and those who void. There was no significant difference in rates of SR/MR agreement about DUSI when analyzed by ethnicity, race, and ambulatory function status. Among cases of SR/MR disagreement about DUSI, the SR and MR had a roughly equal percentage of better outcomes reported for both UI and SI.

Discussion

There was strong SR/MR agreement for the majority of urologic data we analyzed. Medically complex patients faced lower SR/MR agreement, which is consistent with findings in other patient populations. Biased reporting by patients/families or providers was not found.

Conclusion

Minimizing SR/MR disagreement through standardized data collection methods and tools, improved definitions of patient outcomes, and documentation of respondent identity will improve large, multisite studies that utilize SR and MR concurrently.

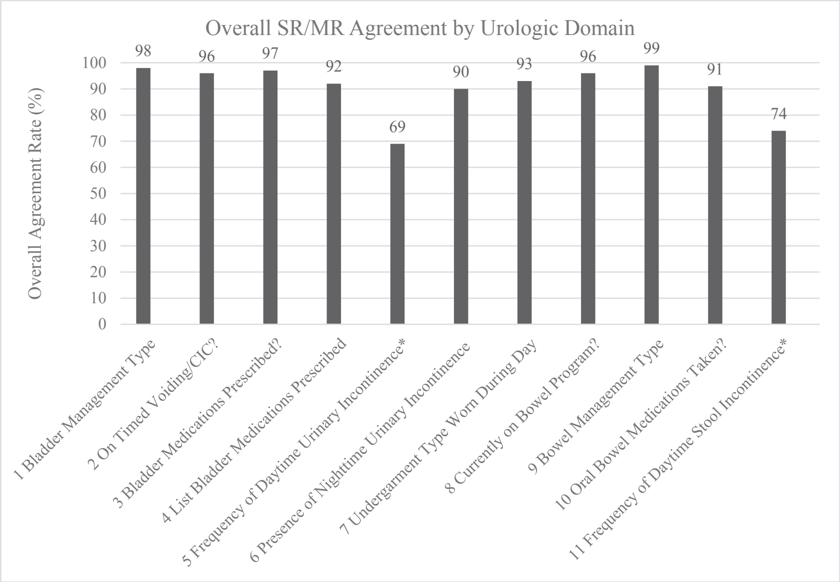

Figure Overall SR/MR agreement by urologic domain.

http://dx.doi.org/10.1016/j.jpurol.2017.04.025
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Introduction

Patient self-report (SR) often complements medical record (MR) documentation in the settings of clinical research, public health surveillance, and patient care. SR carries many advantages: it is cost- and time-efficient, easily standardized, often prospective, and relatively free of clinician bias [1–5]. The MR, although limited by incomplete documentation, cost/time required for retrospective review, and reviewer error, is also advantageous and widely used in research because of its richness and integration with patient care [1–3,5,6,14–16].

Studies show that SR and the MR can be discrepant with each other, with SR/MR agreement rates as low as 41% in a sample of the literature [1–12]. Agreement may differ across studies as a result of variability in patient populations, research methodologies, or differences in patient and provider attitudes about the purposes of SR and the MR. SR offers information about patients' adherence to treatment or perceptions of their own health, but the MR likely highlights providers' beliefs about what disease processes are most important to address at a given time. Researchers have argued that provider recognition of patient symptoms and treatment experiences—presumably reflected in SR/MR agreement—is associated with better patient outcomes, treatment compliance, and patient satisfaction [1,13]. As such, we should strive for SR/MR agreement about patient symptoms and outcomes. SR/MR consistency would also allow researchers to utilize either data source to estimate disease incidence and prevalence [1,4,7].

At our institution, spina bifida (SB) patients are followed longitudinally as part of a multi-site research study, the National Spina Bifida Patient Registry (NSBPR) [17]. During annual appointments, clinical outcomes for the NSBPR are recorded by research staff using a structured interview and questionnaire. We consider this prospectively collected data to be a form of SR. After noticing discrepancies between this SR data and concurrent MR documentation by our providers, we set out to systematically examine SR/MR agreement about urologic outcomes recorded in our SB clinic.

The objectives of this study were to (1) identify demographic, medical, or methodological factors that might contribute to discordant SR/MR data; (2) postulate how these findings might be significant clinically; and (3) recommend improvements to SR data collection and MR documentation involving pediatric SB patients.

Methods

SR data collection and cohort identification

As stated previously, our SB research staff collect SR urologic data from patients via annual, in-person interviews using a structured questionnaire. Patients eligible for this study were those who completed a SR interview between December 2014 and January 2016, within 1 month of a urology provider visit and subsequent MR documentation.

SR interviews included 11 questions assessing bladder and bowel management, incontinence, and medication use. Both patients and parents/guardians were allowed to provide SR data. If a patient and parent/guardian disagreed with each other about any SR outcome, research staff asked clarifying questions and facilitated discussion; data were recorded only after consensus was reached. Some interview questions required patients to respond in a dichotomous (yes/no) manner, but other questions allowed multiple response choices. Two interview questions captured the frequency of daytime urinary and stool incontinence (SI) on a Likert-like scale [18]. Research staff provided clear instructions to patients/families as outlined on the NSBPR SR questionnaire: (1) daily incontinence was "Greater or equal to than once a day"; (2) weekly incontinence was "Less than once per day, more than or equal to once per week"; (3) monthly incontinence was "Less than once per week, greater than or equal to once per month"; (4) less than monthly incontinence was "Less than monthly"; (5) no incontinence was defined as "Never". All patients and families spoke English or utilized language interpreters during SR interviews.

MR data collection

Retrospective MR data collection was completed by the same research staff that conducted all SR interviews. These researchers were blinded to SR responses when reviewing the MR. To allow for SR/MR comparison, MR documentation was categorized into 11 urologic domains paralleling the 11 SR interview questions. For example, provider MR documentation about patient bladder and bowel medication use was compared with SR responses to interview questions 4 and 10, respectively. For incontinence data, if MR documentation explicitly mentioned the frequency with which a patient experienced urinary incontinence (UI), reviewers recorded this data on the Likert-like scale used for the SR interview questionnaire.

If a provider failed to document a domain in the MR, the missing domain was considered incomplete. However, some assumptions were made with regard to incomplete MR data: (1) all patients on clean intermittent catheterization (CIC) were assumed to be on a timed voiding/CIC regimen; (2) patients who voided to their diaper were not considered to be on timed voiding; and (3) any patients described in the MR simply as "continent" were assumed to be continent only during the daytime, while continence overnight was not assumed. Patients using indwelling catheters and those with cutaneous incontinent vesicostomy were excluded from continence analyses.

Agreement analysis

We only performed SR/MR agreement analysis for complete SR/MR pairs. For the Daytime Urinary and Stool Incontinence (DUSI) domains, children younger than 5 years old were excluded unless they were toilet trained. Overall agreement (number of agreeing data pairs/number of complete data pairs) was reported for all domains. We considered any overall agreement rate $\geq$90% to be acceptable.

We also compared SR/MR agreement about DUSI between groups of patients based on diagnosis, bladder management, ethnicity, race, and ambulatory function

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