



Pregnancy among mothers with spina bifida

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Summary

Introduction

Recognizing the importance of sexual and reproductive health to patients with spina bifida (SB), pediatric urologists have taken responsibility for initiating conversations regarding this topic with adolescent and young adult SB patients. However, the sexual and reproductive health of women with SB remains under-investigated. It is unknown how many women are having babies, what mode of delivery is used, and if this has changed over time with the increasing life expectancy of these patients. A better understanding of pregnancy and delivery among young women with SB will enable urologists to provide more informed, comprehensive counseling to patients.

Objective

We sought to compare hospitalizations for delivery in women with and without SB to determine differences in the mode of delivery used and changes in the rate of deliveries over time.

Study design

Using the Healthcare Cost and Utilization's National Inpatient Sample, we identified all hospitalizations for delivery in 2003–2013. After distinguishing between hospitalizations among women with and without SB, temporal trends analysis and bivariate comparison were performed to determine differences in patient and hospital characteristics and mode of deliveries.

Results

We identified 10,147 hospitalizations for deliveries among women with SB and 42,197,763 among women without. Of all hospitalizations for deliveries, the percentage of deliveries by women with SB increased by 56% between 2003 and 2013 (629–925 deliveries per year, $p < 0.001$). Women with SB hospitalized for a delivery differed from those without SB. They had a higher number of comorbidities and were more likely to be white, have Medicare or private insurance, live outside a city, and deliver at an urban teaching hospital (all $p < 0.001$). Women with SB were significantly more likely to undergo a caesarean section (see Figure, 52.4% of women with SB vs. 31.9% of those without, $p < 0.001$), although nearly half were able to undergo vaginal delivery. For women with SB, 25.9% of all deliveries occurred by age 22, which did not differ significantly from women without SB (24.7% of all deliveries).

Discussion

There are significant differences in the characteristics and mode of delivery between women with and without SB who are hospitalized for a delivery. The number of deliveries among these women are significantly increasing and over a quarter of the deliveries occur by age 22.

Conclusion

With increasing rates of deliveries and young age at delivery for women with SB, it is imperative that pediatric and transitional urologists initiate discussions on sexual and reproductive health beginning in adolescence.

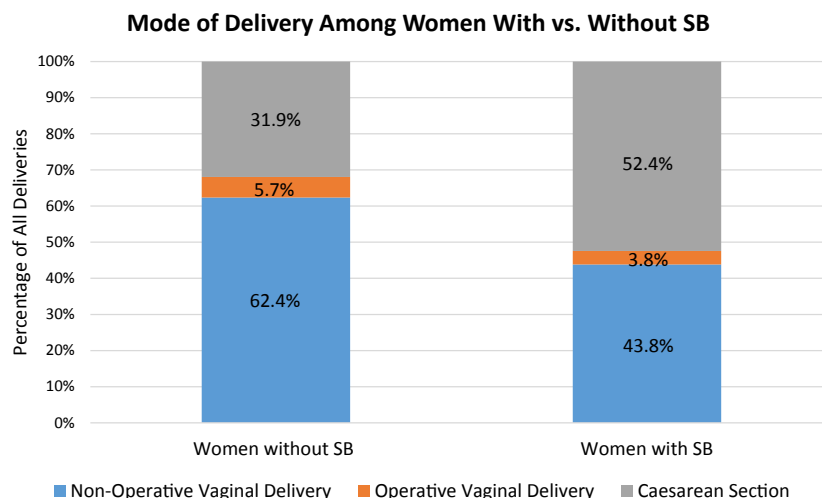


Figure Mode of delivery used by women with and without spina bifida in 2003–2013.

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Introduction

Historically, only 60% of infants born with spina bifida (SB) survived beyond the first year of life [1], but the past few decades have been transformative for people born with this birth defect. Innovations such as ventricular shunts for treatment of hydrocephalus and urinary diversion procedures for preserving renal function have greatly improved survival such that, for the first time, approximately 85% of people born with SB are now surviving into adulthood [2]. As a consequence, the providers who care for these patients are managing health issues that were previously not a concern.

Perhaps no health issue has been more under-investigated in the SB population than female sexual and reproductive health. Yet this topic is important to quality of life for these women, many of whom would like to have children of their own [3–5]. As genitourinary specialists with expertise in SB care, urologists have recognized our role in discussing sexual and reproductive health with our SB patients [6,7]. Therefore, a better understanding of pregnancy and delivery among women with SB is needed to enable urologists to provide more comprehensive and informed counseling to these women. Currently it is unknown how many women with SB of child-bearing age are having children, or if this number has been increasing with improved survival of SB women. It is also unknown what modes of delivery are being used for these women and if these differ from women without SB.

In this context, we conducted a retrospective cohort study using national discharge data. After identifying hospitalizations for a delivery among pregnant women with and without SB, we determined who is having children, where, trends over time, and how these two groups of women compare. We hypothesized that as more patients with SB are living into adulthood, more are also becoming mothers. Additionally, we hypothesized that caesarean section is the dominant mode of delivery for women with SB. Findings from our study have clinical implications for urologists who, given their prominent role in SB management across a life course, are well-positioned to counsel patients on this topic.

Materials and methods

Data source and study population

For this study, we analyzed data from the National (Nationwide) Inpatient Sample (NIS), which was developed by the Healthcare Cost and Utilization Project and sponsored by the Agency for Healthcare Research and Quality. The NIS is the largest all-payer inpatient database in the USA; it is a 20% sample of discharges from participating hospitals, weighted estimates from which are generalizable to the universe of hospital discharges [8]. Prior to 2012, the NIS was a sample of discharges from all participating hospitals; weighted estimates are used to allow for comparisons before and after this revision. The sample frame includes all women hospitalized for a delivery between 2003 and 2013.

First, all women discharged from the hospital after any type of delivery were classified through Clinical

Classification Software groups (Appendix 1). We then distinguished between deliveries among women with and without SB using relevant International Classification of Diseases, Ninth Revision (ICD-9), Clinical Modification diagnosis codes (Appendix Table 1). We also distinguished among women with SB occulta, SB without hydrocephalus, and SB with hydrocephalus (Appendix Table 1).

Statistical analysis

For our initial analytic step, we examined differences between women with and without SB who were hospitalized for delivery. Specifically, the women were compared with respect to a variety of sociodemographic factors including their age on admission, race/ethnicity (white, black, Hispanic, or other), income (based on ZIP-code level data), insurance status (self-pay, private, Medicaid, Medicare, no charge, or other), and level of urbanicity. The patients' level of comorbidity was also compared using the Elixhauser method [9]. The hospitals where these women were admitted were characterized based on their bed size, teaching status, and ownership. For these bivariate comparisons, parametric and non-parametric tests were used where appropriate.

We then measured rate of hospitalization for delivery (per 100,000) among women with and without SB and among the subtypes of SB. The frequency of the various modes of delivery (non-operative vaginal, operative vaginal, or cesarean) within each group was calculated. Operative vaginal delivery was defined as a delivery which requires vacuum extraction, the use of forceps, or breech delivery.

Finally, we fit multinomial logistic regression models to evaluate significant changes over time in rates of delivery and mode of delivery among women with and without SB. All analyses were performed at the type I error level of 0.05 using SAS version 9.4 (Cary, NC, USA).

Results

We identified 10,147 hospitalizations for deliveries among women with SB and 42,197,763 among women without. Of the women with SB, 47.7% did not have hydrocephalus, 18.7% had hydrocephalus, and 33.6% had spina bifida occulta. Women with SB hospitalized for a delivery differed from those without SB in several significant ways. They had a higher mean number of comorbid conditions (0.66 vs. 0.33 in women without SB, $p < 0.001$). They were also more likely to be white, have private insurance or Medicare, live outside a city, and deliver at an urban teaching hospital (all $p < 0.001$) (Table 1).

Of all hospitalizations for deliveries, the percent of deliveries by women with SB increased by 56% between 2003 and 2013 (629–925 deliveries per year, $p < 0.001$; Fig. 1). The mean age at delivery for women with SB was 27.3 years (standard deviation (SD) 12.8); the mean age at delivery for women without SB was 27.6 years (SD 13.4). Of all hospitalizations for deliveries in each group, 4.6% occurred before age 18 in women with SB versus 5.4% for women without ($p = 0.426$). Approximately a quarter of hospitalizations for delivery occurred by age 22 in each group (25.9% for women with SB and 24.7% for women without). However, a

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