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## Do adult men with untreated hypospadias have adverse outcomes? A pilot study using a social media advertised survey

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**Abstract** *Objective:* Hypospadias is usually treated in childhood. Therefore, the natural history of untreated mild hypospadias is unknown. We hypothesized that men with untreated hypospadias, especially mild, do not have adverse outcomes.

*Materials:* Facebook was used to advertise an electronic survey to men older than 18 years. Men with untreated hypospadias identified themselves and indicated the severity of hypospadias with a series of questions. Outcomes included: Sexual Health Inventory for Men (SHIM), penile curvature and difficulty with intercourse, International Prostate Symptom Score (IPSS), Penile Perception Score (PPS), psychosexual milestones, paternity, infertility, sitting to urinate, and the CDC HRQOL-4 module.

*Results:* 736 men completed self-anatomy questions and 52 (7.1%) self-identified with untreated hypospadias. Untreated hypospadias participants reported worse SHIM ( $p < 0.001$ ) and IPSS scores ( $p = 0.05$ ), more ventral penile curvature ( $p = 0.003$ ) and resulting difficulty with intercourse ( $p < 0.001$ ), worse satisfaction with meatus ( $p = 0.011$ ) and penile curvature ( $p = 0.048$ ), and more sitting to urinate ( $p = 0.07$ ). When stratified by mild and severe hypospadias, severe hypospadias was associated with more adverse outcomes than mild hypospadias.

*Conclusion:* Men with untreated hypospadias reported worse outcomes compared with non-hypospadiac men. Mild untreated hypospadias had fewer adverse outcomes than severe hypospadias. Research is needed to determine if treatment of childhood hypospadias improves outcomes in adults, especially for mild hypospadias.

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## Introduction

Hypospadias is a congenital penile abnormality repaired surgically, usually in childhood [1,2]. Hypospadias is defined as an abnormal proximal location of the urethral meatus on the ventral penis and often includes ventral foreskin deficiency and ventral penile curvature [1,2]. Hypospadias has varying degrees of severity from mild where the meatus is near the tip of penis with minimal or no curvature, to severe cases with the meatus near the peno-scrotal junction with marked curvature [3,4]. In general, the more severe the hypospadias the less common it is [5]. Reasons given to parents for treating hypospadias include splaying of urinary stream or other bothersome urinary symptoms, difficulty with sperm deposition leading to infertility, ventral curvature leading to difficulty with intercourse, and decreased satisfaction with penile appearance which may lead to delayed sexual development. The degree to which these potential concerns become actual issues in men with untreated hypospadias likely depends on the severity of the abnormalities, but the natural history of untreated hypospadias is not well defined [6].

There are occasional adult patients who present to urologists for unrelated issues and are found to have untreated hypospadias, usually mild. These patients often do not know that they have an abnormality, have fathered children, report no sexual difficulties, and stand to urinate without difficulty. Regarding the prevalence of untreated hypospadias in adults, two studies examined 500 and 1244 adult males, respectively, and reported the prevalence of the meatus located on the proximal one-third of the glans or further proximal as 13% and 0.2%, respectively [7,8]. A study in children reported the prevalence of untreated hypospadias as 0.6% [9]. Regarding complications of untreated mild hypospadias, one study identified 56 adult males with untreated mild hypospadias [6]. Of the 56 patients, only one presented with a chief complaint related to hypospadias, 5% expressed dissatisfaction with the appearance of their penis, 32% were unaware they had an abnormality, 5% patients reported sitting to void preferentially, and 95% of the men who attempted fertility were successful. In another study, none of 65 men with untreated hypospadias reported problems with sexual intercourse or preferentially standing to urinate [8]. These studies suggest that untreated mild hypospadias may have a benign course with a low risk of complications.

Urethroplasty surgery for hypospadias has inherent risks such as meatal stenosis, urethrocutaneous fistula, and multiple surgeries [3,10–12]. These complications can be severe and lead to multiple surgeries throughout childhood. This raises the question of why mild forms of hypospadias are treated with urethroplasty when many of these patients will potentially have no complications if left untreated. In addition, with lack of data on the long-term consequences of treating or not treating the mild hypospadias, parents cannot be properly counseled.

Given the low prevalence of untreated hypospadias in adults, one way to recruit enough subjects to have a meaningful study would be by developing an effective advertisement method that can reach hundreds of thousands of adult males. According to statistics on Facebook;

there are close to 225 million active users in the USA, and 50% of the users log onto their Facebook account at least once a day [13]. Advertising on social media is a potentially powerful method to advertise clinical research surveys that need a large number of subjects or to find subjects with rare diseases or conditions to participate in clinical research and has been used successfully in the past [14–19].

We hypothesized that men with untreated mild hypospadias would have similar outcomes to normal men in terms of penile satisfaction, sexual health, bother from penile curvature, urination symptoms, paternity, frequency of sitting to urinate, and health related quality of life (HRQOL). To test this hypothesis, we performed a pilot survey study using a targeted advertising campaign on Facebook.

## Methods

### Survey

Following Institutional Review Board approval, study data were collected over a 4-month period (October 2012–January 2013) and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at University of California San Francisco and described previously [20].

The predictor was whether or not a participant self-identified as having possible untreated hypospadias and the severity of hypospadias based on answers to self-reported anatomy questions supplemented with penile sketches (Fig. 1). Outcomes included the Penile Perception Score (PPS) [21], the sexual health inventory for men (SHIM) score [22–24], the International Prostate Symptom Score (IPSS) [25,26], CDC Healthy Days Core Module (CDC HRQOL-4) [27], paternity status, history of infertility diagnosis or treatment, frequency of sitting to urinate modeled after IPSS questions, penile curvature based on sketches of curvature (Fig. 1), reported degree of difficulty with intercourse from penile curvature modeled after SHIM questions, and sexual milestones attained and age when attained. The survey is shown in Appendix A.

### Pretesting

Because our target population is rare, a proxy measure for the criterion validity of the self-reported anatomy questions was used. Questions were pretested on 26 subjects without hypospadias that included 22 males and four females. Subjects took an online survey that showed a series of penis images with varying anatomy from normal to severe hypospadias. The subjects were asked to pick the sketch that best depicted the anatomy in question in the picture. Results are summarized in Appendix B.

The urethral meatus question had a sensitivity of 100% and specificity of 100% for detecting hypospadias. Pretest subjects' answers to five foreskin/glans appearance questions were able to identify normal circumcised or normal uncircumcised penises with a 100% sensitivity and specificity and hypospadias was identified by the instrument with

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