



Original Article

Sexual and reproductive health care utilization and preferences reported by young women with cystic fibrosis

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Abstract

Background: This study aimed to describe and compare the sexual and reproductive health (SRH) care utilization among young women with cystic fibrosis (CF) with the general United States (U.S.) population.

Methods: Women with CF ages 15–24 years from five geographically diverse U.S. CF centers participated in a survey investigating SRH. Results were summarized and compared to a nationally representative sample of young women aged 15–24 who participated in the U.S. National Survey of Family Growth (NSFG) using logistic regression to adjust for confounders.

Results: A total of 188 women with CF (19.7 ± 2.7 years) completed the survey; data were compared to 1997 NSFG respondents (19.6 ± 0.10 years). Women with CF had lower lifetime rates of ever obtaining a Pap smear or pelvic exam (26% vs. 57%; $p < 0.001$) and similar rates of HPV vaccination (44% vs. 43%; $p = 0.64$) compared to NSFG respondents. Thirty-seven percent of women with CF reported seeking contraception and <10% reported contraceptive counseling, STI testing/counseling, or pregnancy testing in their lifetime. In the prior 12 months, 41% of NSFG respondents reported seeking contraception, 24% received contraceptive counseling, 22% STI testing/counseling, and 23% pregnancy testing. A minority of women with CF received or discussed SRH care in the CF setting, although 66% wanted to discuss SRH with their CF team.

Conclusions: Young women with CF report low rates of SRH care utilization and desire SRH discussions in the CF setting. Interventions should target improved SRH care delivery and encourage patient-provider communication around SRH in the CF care setting.

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Keywords: Sexual and reproductive health; Women's health; Cystic fibrosis

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1. Introduction

Young women with cystic fibrosis (CF) not only experience typical sexual and reproductive health (SRH) concerns, but also face a variety of disease-specific issues, including delayed puberty, high rates of yeast infections due to frequent antibiotic use, urinary incontinence (UI), sexual dysfunction, unique considerations regarding contraceptive choice, decreased fertility, and adverse effects of pregnancy [1–7]. Advances in CF therapy and disease management over the last 25 years have led to dramatic increases in survival, with over half of all people with CF now over the age of 18 [8]. As more women with CF become adults, they increasingly face SRH decisions and require access to health care services for both general and CF-specific SRH issues.

In the United States (U.S.), a CF multidisciplinary team (including physicians, nurses, dietitians, social workers, and physical and respiratory therapists) provides care for >90% of patients with CF in centers accredited by the CF Foundation (CFF). All patients are encouraged to have quarterly visits, usually starting in infancy for their entire lives [9]. In this care model, adolescents often identify their CF physician as their “de facto” primary care provider (PCP) and, thus, may use the CF setting for SRH care provision [10]. Both CF providers and patients agree that addressing CF-specific SRH concerns is important, and that CF providers have a role in SRH care [11]. However, despite this shared recognition that SRH should be discussed in the subspecialty setting, U.S. CF center directors note that they infrequently address SRH and no standardization of SRH care or referral exists in the current care model [12].

To explore the potential impact of this gap around SRH in the CF care model, this study sought to identify SRH care utilization and preferences toward SRH care delivery among young women with CF. We hypothesized that young women with CF would have decreased SRH care utilization compared to the general U.S. population and the majority would prefer to have SRH discussions with a member of the multidisciplinary CF team.

2. Methods

Women with CF ages 15–24 years in a convenience sample from five U.S. CF centers were recruited by the research team to participate in a survey investigating SRH behaviors and experiences, SRH services sought, patterns of care utilization (both generally and in the CF care setting), discussions around SRH topics in the CF care setting, and preferences regarding SRH care delivery (see Appendix-SRH CF Patient Survey). Survey content, development, and demographics are described in greater detail elsewhere [7]. Content was informed by prior qualitative and survey-based work. Additionally, select survey items were derived from the National Survey of Family Growth (NSFG) to allow for comparison to a nationally representative sample [1,2,11–14].

The survey was administered from June 2015 to September 2016 at five geographically diverse CF centers. Participants completed the survey on an iPad during a regularly scheduled clinic visit or hospitalization. Data were collected anonymously to

encourage the disclosure of SRH care decisions and preferences. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Pittsburgh [15]. The Institutional Review Board for each site approved this study; the University of Pittsburgh served as the coordinating site.

Descriptive statistics were used to summarize results. Demographics and SRH care utilization responses were compared to data for 15–24 year old women from the 2011 to 2013 National Survey of Family Growth (NSFG) [14]. NSFG is a publicly-available, nationally-representative survey of men and women age 15–44 years ($n = 10,416$ in the 2011–2013 sample) conducted by the CDC to understand SRH behaviors and outcomes in the U.S. Additional details on the NSFG survey and methodology have been published elsewhere [16]. Continuous variables were represented using means and standard deviations for the CF sample and weighted mean and standard errors for the NSFG. Categorical variables were represented using raw percentages for the CF sample and weighted percentages for the NSFG. To account for any missing data, percentages were calculated based on total $n = 188$ in the CF sample. Differences in demographics between young women with CF and the NSFG sample were further explored via Wald log linear chi-squared testing for categorical variables and linear regression for continuous variables. We adjusted for any demographic variables that were significantly different between the groups in bivariate analysis. Sampling weights were used in all analyses to account for the survey design of the NSFG study. Statistical analyses were conducted using SAS Version 9.3 (SAS II; SAS, 9 ed., SAS Institute, Cary, NC, USA; 2003).

3. Results

3.1. Demographic and CF-related health characteristics

A total of 188 young women with CF (mean age 19.7 ± 2.7 years) completed the survey out of 206 eligible participants approached (91% response rate). The majority of respondents were single (91%) and white (91%). Twelve respondents were of Hispanic ethnicity (6%). Sixty-two percent of respondents were attending school and 24% were working full or part time. Thirty-seven percent of respondents in the CF sample rated their CF disease as “mild”, 55% as “moderate”, and 7% as severe. Seventy-one percent self-reported a baseline forced expiratory volume in 1 s of >70% predicted; 59% had been hospitalized in the past year. Thirteen percent had a gastrostomy tube and 31% had CF-related diabetes. Ten percent reported having CF-related liver disease. Socio-demographic data were compared to women age 15–24 years from the NSFG survey ($n = 1997$; mean age 19.6 ± 0.10 years). Significant differences between the samples were found for race ($p < 0.001$), ethnicity ($p < 0.001$), level of education ($p < 0.001$), and current work or school status ($p < 0.001$). Fifty-four percent of young women with CF reported a history of vaginal sex with a male partner compared to 66% of women in the NSFG ($p < 0.001$). Table 1 summarizes the demographics of the samples.

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