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Original Article

Sexual and reproductive health behaviors and experiences reported by young women with cystic fibrosis

Traci M. Kazmerski [a,b,*], Gregory S. Sawicki [a], Elizabeth Miller [c,d], Kelley A. Jones [c], Kaleab Z. Abebe [e,f], Lisa K. Tuchman [g], Sigrid Ladores [h], Ronald C. Rubenstein [i,j], Scott D. Sagel [k], Daniel J. Weiner [c], Joseph M. Pilewski [e], David M. Orenstein [c], Sonya Borrero [d,e,l]

[a] Division of Respiratory Diseases, Department of Medicine, Boston Children's Hospital, Boston, MA, United States
[b] Institute for Healthcare Improvement, Cambridge, MA, United States
[c] Children's Hospital of Pittsburgh of UPMC, Department of Pediatrics, University of Pittsburgh School of Medicine, Pittsburgh, PA, United States
[d] Center for Women's Health Research and Innovation (CWHRI), University of Pittsburgh School of Medicine, Pittsburgh, PA, United States
[e] Department of Medicine, University of Pittsburgh Medical Center, University of Pittsburgh, Pittsburgh, PA, United States
[f] Center for Research on Health Care Data Center, Division of General Internal Medicine, University of Pittsburgh, Pittsburgh, PA, United States
[g] Division of Adolescent and Young Adult Medicine, Children's National Health System, Washington, DC, United States
[h] University of Alabama-Birmingham, School of Nursing, Birmingham, AL, United States
[i] Division of Pulmonary Medicine, Cystic Fibrosis Center, The Children's Hospital of Philadelphia, Philadelphia, PA, United States
[j] Department of Pediatrics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, United States
[k] Department of Pediatrics, Children's Hospital Colorado, University of Colorado School of Medicine, Aurora, CO, United States
[l] VA Pittsburgh Center for Health Equity Research and Promotion, Pittsburgh, PA, United States

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Abstract

Background: The prevalence of general and disease-specific sexual and reproductive health (SRH) concerns is unknown in the United States (U.S.) female CF population. This study aimed to describe and compare the SRH experiences and behaviors of young women with CF with the general U.S. population.

Methods: Young 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 the U.S. National Survey of Family Growth (NSFG) using logistic regression adjusting for confounders.

Findings: A total of 188 young women with CF (mean age 19.7 ± 2.7 years) completed the survey; data were compared to 1997 NSFG respondents (mean age 19.6 ± 0.10 years). Fifty-four percent of women with CF reported having had vaginal sex with a male partner compared to 66% of U.S. women ($p = 0.55$). Women with CF were less likely to have ever used contraception (55% vs. 74%, $p = 0.0001$) or have been tested for sexually transmitted infections in the past year (19% vs. 34%, $p = 0.001$) compared to the general population. Two percent of women with CF reported having ever been pregnant compared to 24% of U.S. women ($p < 0.0001$). One-third of young women with CF reported perceived pubertal delay, 16% urinary incontinence, 16% sexual dysfunction, and 49% yeast infections.

Interpretation: Young women with CF face significant SRH concerns and appear to be experiencing gaps in SRH care provision. Opportunities exist for intervention development around this aspect of comprehensive CF care.

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

* Corresponding author at: Division of Respiratory Diseases, Boston Children's Hospital, 1 Autumn St. Box #16, Boston, MA 02215, United States.
E-mail address: traci.kazmerski@childrens.harvard.edu (T.M. Kazmerski).

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1. Introduction

Advances in therapy and chronic disease management have led to dramatic increases in the life expectancy for people with cystic fibrosis (CF) [1]. However, despite these improvements, females with CF have a lower median survival relative to males despite accounting for nutritional status, pulmonary function, and airway microbiology [2–4].

In addition to this gender disparity, young women with CF experience a variety of sexual and reproductive health (SRH) concerns. In the United States (U.S.), young women age 15–24 years old endure the highest rates of sexually transmitted infections (STIs), unintended pregnancy, and intimate partner violence (IPV) [5–7]. Along with these general SRH challenges, young women with CF face several disease-specific SRH issues, including pubertal delay, high rates of vulvovaginal candidiasis with frequent antibiotic use, urinary incontinence (UI), sexual dysfunction, concerns regarding contraceptive choice, decreased fertility, and adverse effects of pregnancy [8–14]. The prevalence of such SRH issues in the U.S. female CF population is unknown. Defining the SRH experiences and behaviors of young female patients with CF is important both to improve comprehensive clinical care and serve as a gateway to explore the contribution of SRH on CF-specific health outcomes.

The purpose of this study is to describe the general and disease-specific SRH experiences and behaviors of young women with CF and to compare these findings to the general U.S. population. We hypothesized that young women with CF would have similar SRH behaviors compared to their healthy counterparts, yet would have gaps in SRH care provision. Findings from this study will define the unique healthcare needs of this population and will inform the development of future SRH interventions that improve the overall health for female patients with CF.

2. Methods

Young women with CF ages 15–24 years were recruited to participate in a survey investigating SRH topics including sexual history, STIs, IPV and reproductive coercion (RC), contraceptive use, and pregnancy experiences and attitudes. CF-specific SRH concerns examined included puberty and menstruation, UI, vulvovaginal candidiasis, sexual functioning, CF disclosure to sexual partners, and concerns regarding pregnancy/parenthood. Participants also completed general demographics and self-reported CF health status items (see Online Data Supplement-Patient Survey). Survey content was informed by our prior qualitative work [15,16]. Select survey items were derived from the National Survey of Family Growth (NSFG), prior patient-based surveys, the Female Sexual Functioning Index-6 (FSFI-6), and validated IPV and RC measures [10,11,17–19].

The survey was administered from June 2015 to September 2016 at five CF centers, including both adult and pediatric centers (2 from two different states in the Northeast, 1 in the Southeast, 1 in the West, and 1 in the Mid-Atlantic region). Participants completed the survey during a clinic visit or hospitalization. Data were collected anonymously to encourage disclosure of SRH behaviors/experiences. Study data were collected and managed using REDCap electronic data capture tools [20]. The Institutional Review Board of each site approved this study.

Descriptive statistics were used to summarize demographics and SRH issues. Demographics and general SRH experiences/behaviors were compared to data for 15–24 year old women from the NSFG, a nationally representative survey of people age 15–44 years conducted by the CDC [17]. The NSFG data was downloaded in its raw form to conduct these analyses and recommended NSFG guidelines on survey design and weighting were applied to account for its complex sampling design. Continuous variables were represented using means and standard deviations for the CF sample and weighted mean and standard errors for the NSFG; similarly, categorical variables were represented with 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 explored via Wald log linear chi-squared testing for categorical variables and linear regression for continuous variables, which allowed for incorporation of NSFG sampling design. To account for observed significant demographic differences between the groups, multivariable logistic regression examining relationships between the samples and SRH outcomes (such as sexual activity or contraception use) was performed adjusting for race, ethnicity, highest level of education and current work/school status.

Using the women in the CF sample only, SRH issues were explored across self-reported markers of CF disease; differences were explored using the Chi-square test for categorical outcomes and unbalanced ANOVA for continuous outcomes. Fisher exact tests were used when cell counts were 5 or less. 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). Table 1 describes the sample's demographics and CF health characteristics. 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, ethnicity, level of education, current work or school status, and self-reported health status.

3.2. General SRH behaviors and experiences

While nearly all women with CF and in the NSFG sample had reached menarche, the mean age at which women with CF reported menarche was later (13.1 ± 1.3 years compared to 12.4 ± 0.05 years in the NSFG sample, $p < 0.0001$). 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, but this difference was not statistically significant (p =

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