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Reproductive Futures in Focus: Contraceptive Choices Among Individuals With Cystic Fibrosis—Patterns, Preferences, and Influencing Factors

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ABSTRACT

Introduction: Advancements in the care of people with cystic fibrosis (PwCF) have made discussions about reproductive health increasingly important. Rising rates of both intended and unintended pregnancies highlight the need for effective contraception counseling. Understanding current contraception use patterns and identifying priorities for contraception education amongst PwCF are therefore essential.

Methods: A web-based survey was developed in partnership with Community Voice, a virtual community of PwCF and their family members supported by the Cystic Fibrosis Foundation. The survey was distributed over a 5-week period (June–July 2025) to participants from Community Voice and Elevate. Females with cystic fibrosis aged 18 years and older were eligible to participate.

Results: Ninety-seven PwCF completed the survey, representing 27 U.S. states and four Canadian provinces. Among individuals currently using contraception, the most common methods were intrauterine devices (34%), combined oral contraceptives (28.3%), and condoms/barrier methods (24.5%). Although 90% of PwCF were not actively trying to conceive, only 55% reported using a form of birth control. Knowledge-based questions revealed persistent misconceptions about the impact of common antibiotics on contraceptive effectiveness. While most PwCF (68.1%) wanted contraception information from their CF care team, only 28.9% reported receiving such education. Side effects were a major factor in decision-making: 78.9% selected contraceptive methods based on side-effect profiles (valued more than efficacy), 68.6% reported experiencing side effects, and side effects were the leading reason for contraception discontinuation.

Conclusion: CF care teams can play a critical role in initiating and supporting conversations about contraception. Team members, including pharmacists, can provide medication counseling and help PwCF select contraceptive methods that align with their individual goals and needs.

1 | Introduction

Cystic fibrosis (CF) is an autosomal recessive disease that affects multiple organ systems. CF is caused by variants in the CF transmembrane conductance regulator (CFTR) protein, which regulates chloride ion transport across epithelial cell membranes. CF primarily affects the lungs, pancreas, liver, and

reproductive organs. Advances in CF treatments, including CFTR protein modulators, have significantly improved life expectancy [1]. Recently, reproductive health has become an increasingly important aspect of comprehensive CF care. As survival rates are improving, there is a growing number of females with CF reaching reproductive age [2].

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Historically, females with CF were thought to have lower fertility than females in the general population due to thicker cervical mucous, poor nutrition, and irregular ovulation [3, 4]. Since the introduction of CFTR modulators (CFTRm), specifically highly effective modulator therapies such as ivacaftor and elexacaftor/tezacaftor/ivacaftor (ETI), the number of unintended pregnancies has increased and only about half of reproductive-aged females with CF are using contraception methods [5, 6]. The rising fertility rates and current trends in contraception use highlights the need to understand knowledge and perceptions surrounding sexual and reproductive health (SRH) among females with CF.

2 | Methods

To better understand attitudes and knowledge surrounding contraception use among females with CF, a survey was developed by a panel of pharmacists at five accredited CF centers across the United States. Survey questions were developed based on themes identified in the existing literature and areas that remained incompletely addressed by prior research. The survey was created in collaboration with Community Voice, a virtual community of people with CF (PwCF) aged 13 and older, along with their family members. Community Voice provided valuable feedback on survey design and question development before distribution. This community fosters the sharing of ideas, perspectives, and experiences to inform future CF research and care [7].

The final 37-item, web-based questionnaire included demographic questions and items in three key areas: contraception use and preferences, basic knowledge regarding contraception, and preferences for contraception education and counseling. No individually identifiable information was obtained from survey respondents. Survey respondents were able to abstain from answering any questions. Study data were collected and managed using REDCap electronic data capture tools hosted at UVA Health [8, 9]. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources. The survey was distributed by Community Voice and Elevate, a virtual community of PwCF in Canada. Survey responses were collected from June 24, 2025 through July 25, 2025 with a reminder distributed through Community Voice midway through the open period. Inclusion criteria included females with cystic fibrosis 18 years and older. All responses were anonymous, and it was estimated that it would take participants about 10 min to complete the survey. This study was reviewed by the University of Virginia Institutional Review Board for Health Sciences Research (IRB-HSR) and was determined to be exempt under 45 CFR 46.104(d)(2)(i) because it involved only anonymous survey procedures in which no subject identifiers were recorded. Participants were provided with an introductory statement describing the purpose of the study, eligibility criteria, anonymity, confidentiality, and intended use of de-identified responses; participation was

voluntary, and completion of the anonymous survey indicated informed consent. Survey responses were summarized using descriptive statistics. Because all survey items were optional, response rates varied across questions. Analyses were performed using the number of respondents who answered each item as the denominator. Surveys that were not submitted could not be reviewed and were therefore excluded from the final analysis.

3 | Results

A total of 97 PwCF responded to the survey, including 82 individuals from the United States and 13 from Canada. The most common age groups were 25–34 years (35, 36.1%) and 35–44 years (35, 36.1%). Overall, 74 PwCF reported currently taking a CFTRm (Table 1), while 23 were not on CFTRm therapy. Ten PwCF reported historical, but not current, use of a CFTRm. Reasons for stopping a CFTRm included side effects, cost, feeling worse on therapy, and/or having undergone a lung transplant. Reported reasons for not having ever used a CFTRm included concerns about side effects, fear that the modulator might worsen other health conditions, feeling healthy without therapy, ineligibility for treatment, lack of discussion with the CF care team, liver failure, and/or post-transplant status.

Table 1 presents a breakdown of pregnancy statistics. Among the five PwCF currently pregnant, only three reported that their pregnancies were planned. Of the 32 PwCF with a previous pregnancy, 14 reported using a CFTRm at that time, and 23 indicated that their prior pregnancy had been planned. Twenty-five previously pregnant PwCF carried their pregnancy to term.

3.1 | Contraception Use/Methods

Figure 1 displays an overview of contraception use by PwCF. Slightly over half of respondents report currently using contraception (55%), while 90% reported that they were not actively trying to conceive. Among 74 respondents who reported being sexually active, 65 reported that they were not trying to conceive. Of these 65 respondents, 41 (63.1%) reported current contraceptive use. The most common methods currently used are intra-uterine devices (IUDs), combined oral contraceptives, and condoms or other barrier methods. The most common reasons for current contraception use are to prevent pregnancy (33/53, 62.3%), reduce symptoms and/or length of menstrual cycle (14/53, 26.4%), and other reasons (6/53, 11.3%). Other reasons for using contraception included treatment of menopause symptoms, reducing pancreatitis attacks, preventing hemoptysis/pulmonary symptoms and for endometriosis symptoms. Eleven PwCF (11.5%) reported the use of CFTRm influenced their choice of contraception; 85 PwCF (88.5%) reported it did not; and one individual did not answer. Sixteen PwCF (16/85, 18.8%) reported experiencing contraception failure. Fifty-nine PwCF (59/86, 68.6%) have experienced side effects while on contraception, which proved to be the most common reason for discontinuation (Figure 2). Other reasons for contraception discontinuation in PwCF included product discontinuation, tubal ligation, partner vasectomy, hysterectomy, inability to conceive, becoming pregnant, not being

TABLE 1 | Baseline characteristics (N = 97).

Characteristic	N (%)
Age	
18–24 years old	12 (12.4)
25–34 years old	35 (36.1)
35–44 years old	35 (36.1)
45–54 years old	11 (11.3)
55–64 years old	3 (3.1)
65 years or older	1 (1.0)
Country	
United States	82 (84.5)
Canada	13 (13.4)
Not specified	2 (2.1)
Region of United States as defined by US Census	
Northeast (CT, ME, MA, NH, RI, VT, NJ, NY, PA)	5 (6.1)
South (DE, FL, GA, MD, NC, SC, VA, WV, DC, AL, KY, MS, TN, AR, LA, OK, TX)	27 (32.9)
Midwest (IL, IN, MI, OH, WI, IA, KS, MN, MO, NE, ND, SD)	17 (20.7)
West (AZ, CO, ID, MT, NV, NM, UT, WY, AK, CA, HI, OR, WA)	16 (19.5)
Not specified	17 (20.7)
CFTR Modulator Usage	
Currently taking	74 (76.3)
History of taking	10 (10.3)
Never taken	13 (13.4)
Current CFTR Modulator Usage	
Ivacaftor	4 (5.5)
Elexacaftor/tezacaftor/ivacaftor	59 (80.9)
Vanzacaftor/tezacaftor/deutivacaftor	10 (13.7)
PwCF reported to be sexually active with at least one male partner	
Yes	74 (77.1)
No	22 (22.9)
Currently planning or trying to conceive	
Yes	9 (9.8)
No	83 (90.2)
Currently Pregnant	
Yes	5 (5.4)
No	88 (94.6)
Currently Pregnant Planned	
Yes	3 (60.0)
No	2 (40.0)
Prior Pregnancy/ies	
Yes	32 (34)
No	62 (66)
History of Emergency Contraceptive Use	

(Continues)

TABLE 1 | (Continued)

Characteristic	N (%)
Yes	29 (30.5)
No	66 (69.5)
Modulator Taken During Pregnancy	
Ivacaftor	2 (14.3)
Elexacaftor/tezacaftor/ivacaftor	12 (85.7)

Note: Demographic and clinical characteristics of adult females with cystic fibrosis participating in the survey. Values are presented as number (percentage).

sexually active, blood clots, and cancer. Eight of the 43 PwCF not taking contraception are no longer of child-bearing age; thus, reported no current need for contraception. When selecting a method for contraception, PwCF most commonly listed side effects as a consideration (Figure 3).

3.2 | Knowledge Questions

When asked about the effect of CFTRm on the female body and ability to get pregnant, responses were varied. A total of 76 (76/96, 79.2%) PwCF agreed conception was difficult for females with CF prior to CFTRm. Seventy-eight (78/97, 80.4%) PwCF believed there has been an increase in pregnancies for females with CF after the FDA approval of ETI. Forty-eight PwCF (48/97, 49.5%) felt that antibiotics are linked to reduced efficacy of birth control.

3.3 | Education Timing/Resources

All PwCF reported receiving contraception-related information from a variety of sources, including their CF care team (28, 28.9%), primary care provider (PCP) (24, 24.7%), obstetrician/gynecologist (OB/GYN) (69, 71.1%), the Cystic Fibrosis Foundation (CFF) (9, 9.3%), Cystic Fibrosis Canada (2, 2.1%), social media (11, 11.3%), school (4, 4.1%), family or friends (18, 18.6%), and other sources (10, 10.3%). Other sources reported included the health department, nowhere, online, and podcasts.

When asked about preferred sources of information, most PwCF indicated their CF care team (64/94, 68.1%) and OB/GYN (76/94, 80.9%) are their top choices, followed by their PCP (31/94, 33.0%), CFF (28/94, 29.8%), family or friends (19/94, 20.2%), social media (10/94, 10.6%), Cystic Fibrosis Canada (5/94, 5.3%), other sources (5/94, 5.3%), and school (4/94, 4.3%).

Overall, most participants preferred that contraception be prescribed by their OB/GYN (65/96, 67.7%) rather than by other providers, including pulmonologists (17/96, 17.7%), PCPs (11/96, 11.5%), pharmacists (1/96, 1.0%), or others (2/96, 2.1%).

All survey participants agreed that contraception should be discussed as part of CF care, though there was variability in the preferred age to initiate these discussions. Nearly half of PwCF surveyed believe this discussion should be started at 12 or 13 years of age (47/96, 49%).

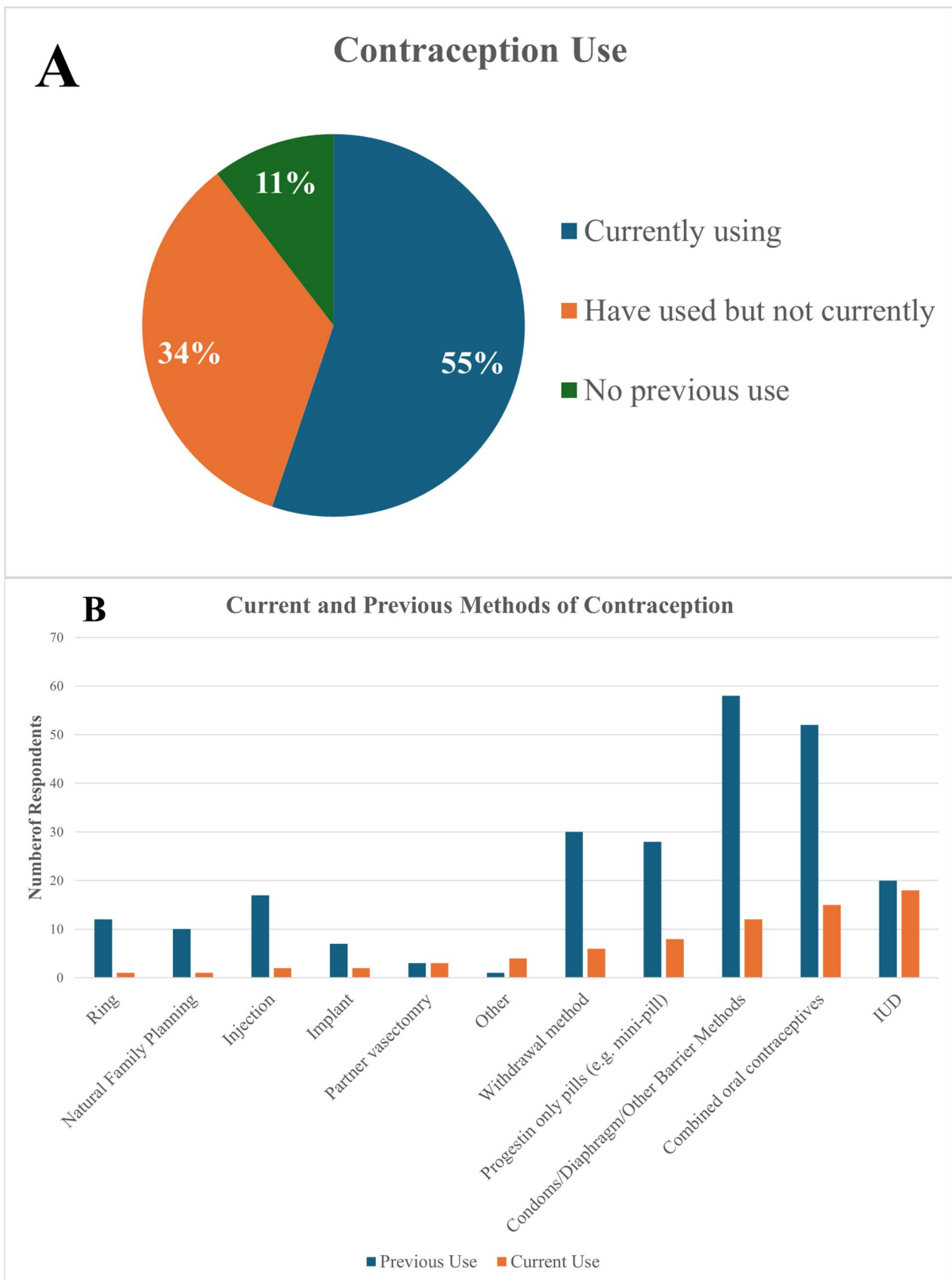


FIGURE 1 | Contraception use and methods among adult females with cystic fibrosis ($n = 96$). (A) Overall contraception use among respondents. (B) Reported current and previous methods of contraception. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

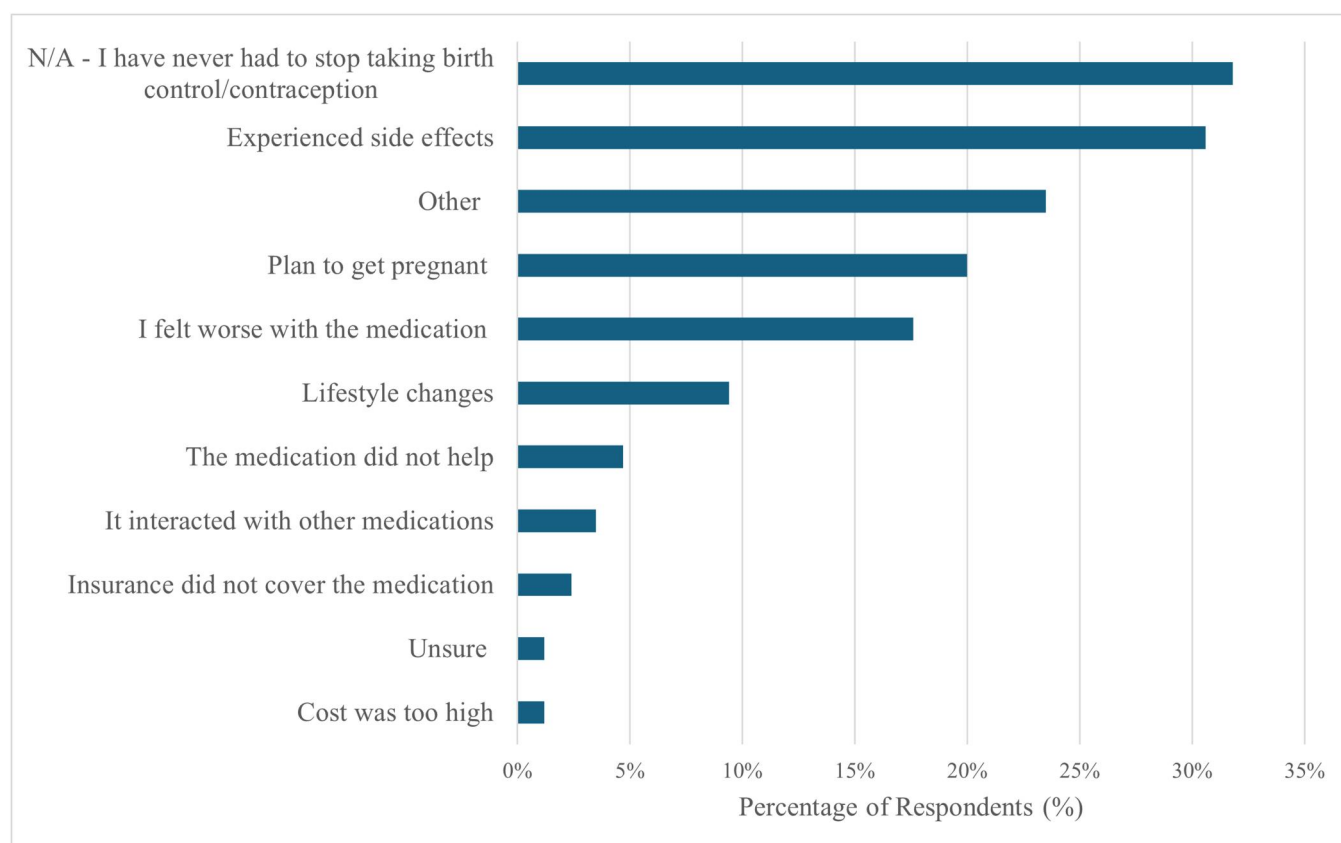


FIGURE 2 | Reasons for discontinuing contraception among respondents ($n = 85$). Data are shown as the percentage of respondents selecting each reason. Participants were allowed to select more than one response. [Color figure can be viewed at wileyonlinelibrary.com]

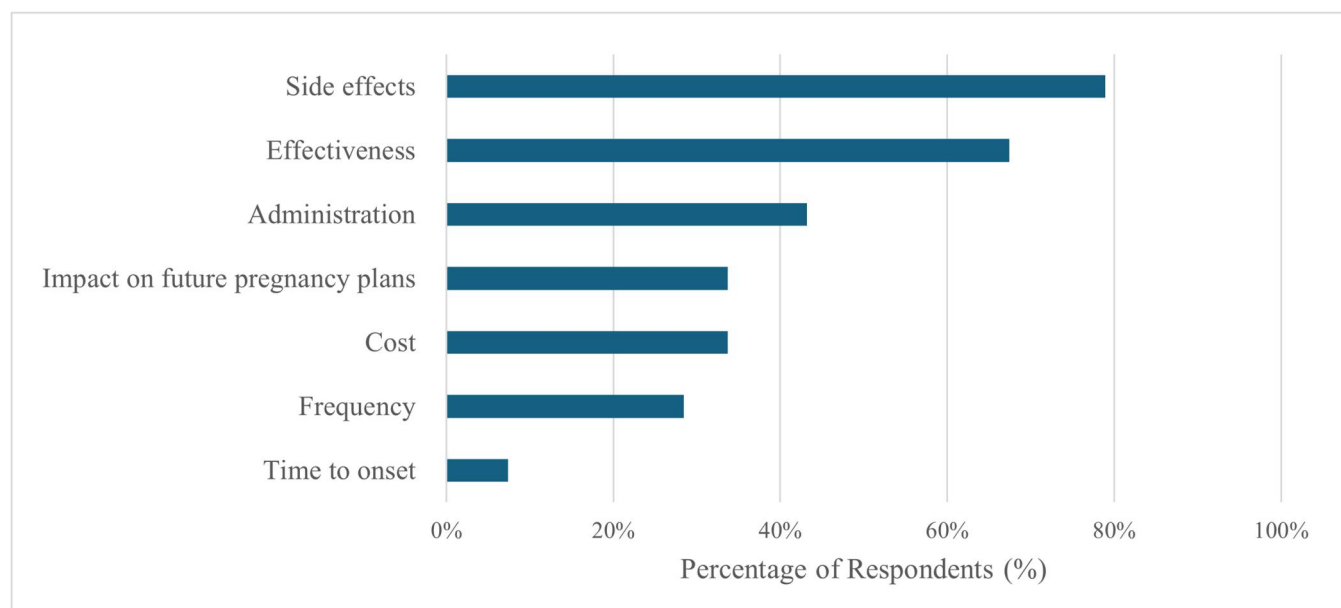


FIGURE 3 | Patient considerations influencing contraception selection among respondents ($n = 95$). Values represent the percentage of respondents identifying each factor as important in their contraception decision-making. Participants were permitted to select more than one response. [Color figure can be viewed at wileyonlinelibrary.com]

Among PwCF who recalled receiving contraception counseling from their CF team, 33 (34.0%) could not remember when the topic was first discussed, 20 (20.6%) reported that it was never discussed, and 16 (16.5%) stated that the discussion occurred

after age 19. A smaller number of PwCF recalled receiving information at younger ages: one before age 10, three at age 13, four at age 14, five at age 15, one at age 17, nine at age 18, and one at age 19.

4 | Discussion

As stated previously, SRH has gained visibility within the CF community since the widespread use of CFTRm and noted increased rates of pregnancy within PwCF [2]. Recent guidance from the Cystic Fibrosis Foundation further reinforces this point and highlights the need for reproductive health education, discussions, and shared decision-making [10]. Almost 90% of our study respondents endorse using contraception at some time in their life, with the highest current rates of IUD, oral contraceptives and condom/diaphragm. Godfrey et al. previously reported that despite almost universal contraceptive use, unintended pregnancy among PwCF remains common [11]. Emergency contraception use in the general population has increased in recent years with 33% of sexually active females reporting a history of use in a recent survey [12]. Emergency contraception use amongst PwCF was similar in our survey at 30.5%. In addition, over 18% of our survey respondents indicated experiencing an incident of contraceptive failure. While our survey size is limited, two out of the five currently reported pregnancies (40%) were unplanned. These statistics may be further substantiated by the fact that 90% of survey respondents stated they were not actively trying or planning to conceive; however, only 55% reported current use of contraception. Contraceptive use remained low even among sexually active women who reported that they were not trying to conceive, with only 63.1% reporting current use. The current survey did not directly evaluate the reasons for this discrepancy. However, underutilization of contraception may reflect limited discussion of reproductive health and insufficient shared decision-making regarding preferred methods of pregnancy prevention. Most females with CF demonstrated awareness of increased fertility in the era of CFTR modulators, suggesting that factors other than limited knowledge may contribute to contraceptive non-use. Peng et al. previously reported an increased rate of exacerbations in PwCF with, more preterm births, lower APGAR scores, and more intensive care unit stays in individuals reporting unplanned pregnancies, validating the relationship between unplanned pregnancies and lung health in PwCF and the importance of continued discussion around contraceptive use and family planning [13].

Our survey respondents cited many concerns regarding adverse effects of contraception. Nearly 70% of PwCF endorsed side effects with their current choice of contraception and 30.6% stated it led to contraception discontinuation. Surprisingly, 78.9% of PwCF stated that their primary driver for selection of contraception was based on side effect profile, ranking even more important than efficacy (67.4%). These results suggest that patient counseling of potential adverse effects of contraception may not be optimized, leaving PwCF surprised or unaware of risks. We encourage CF care teams to take an active role in educating patients about these topics and medications, even when they are not the direct prescribers. The impact of medication misinformation or improper contraceptive use can be substantial, particularly given the risks associated with contraception discontinuation in females of childbearing age, especially in the post-CFTRm era.

Interestingly, we also chose to capture information on SRH knowledge of PwCF to identify any areas of misinformation

present within our community. While there appears to be a general understanding of increased pregnancy rates following CFTRm usage, nearly half of PwCF remained unsure if commonly used antibiotics could be responsible for reduced efficacy of birth control. Numerous organizations, including the American College of Obstetricians/Gynecologists, World Health Organization, and Centers for Disease Control and Prevention have emphasized that most antibiotics (e.g., amoxicillin, ciprofloxacin, sulfamethoxazole/trimethoprim) do not interfere with hormonal contraception and do not require use of a back-up method. The exceptions are antibiotics that induce hepatic metabolism (e.g., rifampin, griseofulvin) [14–16]. Delivering this education should not be limited to prescribers and can be emphasized by all members of the CF care team. More specifically, pharmacists, who were added as required team members during the 2024 care team update are well-informed and trained to discuss the potential for adverse effects and medication interactions [17].

The age of appropriateness to start discussions surrounding SRH in the general population continues to be vague, with the American Academy of Pediatrics advocating for these discussions starting in early adolescence [18, 19]. Within our survey, the majority of PwCF responded that contraception should be discussed earlier than 18 years old; however, most said it was either not discussed, or they don't remember it being discussed before age 18. The multidisciplinary CF care team is critical to fostering these conversations, with multiple team members contributing complementary expertise to provide consistent, developmentally appropriate SRH education. A coordinated, team-based approach may also help maintain continuity of these discussions across pediatric and adult care transitions.

The role of pharmacists varies greatly between practice locations and may be dependent on training, institutional and geographic abilities, and overall care-team involvement. However, much research has already been published on the impact of pharmacists on CF care teams. These benefits have shown influential in monitoring adherence, identification of drug-drug interactions, and improving access to high-cost therapies [20–23]. As life expectancy for PwCF continues to increase, the need for further involvement in SRH care, menopause, and chronic disease management is expected. The ability to work under collaborative practice agreements with prescribing abilities for management of conditions may be beneficial to meet the growing demands of this maturing and aging CF population.

While most PwCF endorsed wanting to receive SRH information from their OBGYN, our study concurs with past results that PwCF also want to receive counseling from their CF team [6]. Only 28.9% of survey respondents are currently receiving contraception education from their CF care team, compared to the 68.1% of PwCF who wanted to receive this info from the CF care team. Various modules and training programs exist for PwCF transitioning from pediatric to adult care with many adjusting contents to include SRH topics [24, 25]. Our study suggests that PwCF prefer this information to be first delivered around 13 years of age (range: < 10 to 18). A previous survey of CF clinicians found similarly that contraception, fertility, and pregnancy were most often initially discussed at 16–18 years of age or at the time of the first adult CF encounter [26]. While an

emphasis on SRH education within adolescents will likely be appreciated, the results of our study suggest that PwCF of all age ranges would likely benefit from reviewing this information. Continued development of accurate resources will add to the existing literature and ensure the widespread access of SRH education to PwCF and CF care teams [27, 28].

We acknowledge that our study is not without limitations. The inability to delineate each response to those with multiple selections increases the difficulty of identifying correlations within respondents' answers. While time constraints and ability to access the internet may have limited response rates, we feel that our broad geographic and international presence aided in recruitment of a diverse study population. Content validity was not formally assessed beyond review by Community Voice; however, we believe the survey was sufficiently comprehensive while minimizing the potential for respondent fatigue. Our study only included members of Community Voice and Elevate and may not be completely representative of the entire CF population.

Despite these limitations, the study population was broadly representative of the current population of PwCF in the United States, based on national registry data. Adults aged 25–39 years constitute the largest proportion of the current U.S. CF population and were similarly the most represented age group in our study. Although adults in the oldest age groups were slightly underrepresented relative to their current prevalence of 8.6% among all PwCF, this finding was not entirely unexpected given the subject matter of the survey [2]. Data from the Canadian CF Registry demonstrate similar trends [29].

The current survey builds on previous literature by expanding the pool of PwCF surveyed. Unlike earlier studies that were limited to participants from specific CF centers, our survey was open to any member of Community Voice or Elevate across the United States and Canada [11]. In addition, the questionnaire was designed to gather more detailed information about preferences related to contraceptive method selection and the provision of contraception education. These findings can help CF care teams better understand the needs and concerns of PwCF as they make decisions about contraception.

5 | Conclusion

SRH will remain an important concern for PwCF as advancements in care continue to improve life expectancy and quality of life. Many PwCF who are not actively trying to conceive reported not currently using contraception, underscoring the need to make discussions about contraception a routine part of CF care. In addition, many PwCF expressed a desire to begin these conversations with their CF care team at an early age. Care teams can draw on the expertise of multiple disciplines to provide tailored counseling about contraceptive options, including potential side effects, to help PwCF feel informed and empowered in their decision-making.

Author Contributions

Kevin P. Lonabaugh: conceptualization, investigation, writing – original draft, writing – review and editing, methodology, validation,

project administration, software, formal analysis, visualization, data curation. **HollyAnn Jacobs:** conceptualization, investigation, writing – original draft, methodology, validation, visualization, writing – review and editing, formal analysis. **Jordan Orofino:** conceptualization, investigation, writing – original draft, writing – review and editing, visualization, validation, methodology, formal analysis. **Leanne Saville:** conceptualization, investigation, writing – original draft, writing – review and editing, visualization, validation, methodology, formal analysis. **Brittany A. Wright:** writing – original draft, investigation, conceptualization, methodology, validation, visualization, writing – review and editing, formal analysis.

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The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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