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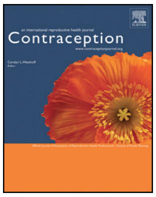

Original research article

Fertility considerations and attitudes about family planning among women with cystic fibrosis☆,☆☆

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ABSTRACT

Objective: Our objective was to explore knowledge, attitudes and beliefs about pregnancy and contraceptive decision-making among reproductive-aged women with cystic fibrosis.
Study design: In this qualitative study, we used purposive sampling of reproductive age women enrolled in the Adult Cystic Fibrosis program at Penn Medicine. We conducted semistructured one-on-one interviews lasting 30–60 min. Interviews were audio-recorded and transcribed verbatim. Data were analyzed using thematic analysis.
Results: We interviewed 24 women. Participants described shortened life span, personal health status and impact of cystic fibrosis on a potential child as three factors that were central to family planning. Future pregnancy intentions, perception of fertility including misconceptions and provider counseling influenced related contraception utilization.
Conclusions: Women with cystic fibrosis described thoughtful considerations about desired pregnancies to be planned during times of optimal health. Gaps in knowledge may limit a woman's ability to make the most informed family planning decisions.
Implications: Having cystic fibrosis directly affects women's decisions around pregnancy and family planning. Understanding what motivates women with cystic fibrosis to use or not to use contraception can improve family planning care delivery to this population.

1. Introduction

Advancement in treatment of cystic fibrosis (CF) has increased life expectancy to a median age of approximately 40 years [1]; thus, fertility and reproduction are emerging health considerations for this population. Women with CF are considered subfertile; however, most women with CF have normal reproductive anatomy and develop regular menstrual cycles [2,3,4,5,6]. Approximately 50%–75% of women with CF who attempt pregnancy can conceive [2,3,6,7,8].

Pregnancies complicated by maternal CF have increased from 3 per 100,000 deliveries in 2000 to almost 10 per 100,000 in 2010 [9]. Pregnant women with CF have an increased risk of pneumonia, mechanical ventilation, renal failure and preterm delivery; and they have a 76-fold increased risk of death during pregnancy compared to healthy peers [10]. Beginning pregnancy with poor lung function further increases the likelihood of maternal death [10].

As more women with CF live through reproductive years, optimal timing of pregnancies requires they have access to effective and safe contraception. The Centers for Disease Control and Prevention's *U.S. Medical Eligibility Criteria for Contraceptive Use* offers guidelines for contraception in women affected by CF [11,12]. Data show that women with CF use contraception of any type less often than the general population (49% vs. 65%) [13]; commonly utilize methods with high "typical-use" failure rates: >70% use combined oral contraceptive pills, condoms, and natural family planning; and have unintended pregnancy rates similar to the general population [5,6,11,14].

Limited data exist that address contraceptive use and preferences in women with CF, and what does exist are quantitative survey data or retrospective chart reviews [5,6,14,15,16]. Qualitative data in this population are even more limited: one interview study of 14 participants focused on decision-making around pregnancy alone [17], and the other interviewed 12 participants and focused solely on how information is obtained about puberty and motherhood [18]. There are no qualitative studies that specifically address issues of contraception and

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decision-making in this patient cohort. Given this dearth of data and the low utilization of contraceptive methods relative to peers, we sought a deeper understanding of pregnancy intentions, fertility awareness and health status and how these concepts contribute to contraception decision-making among women with CF.

2. Methods

2.1. Study design

We conducted a qualitative study using semistructured interviews of female patients within the Penn Adult CF Center. The University of Pennsylvania Institutional Review Board (IRB) approved the study.

2.2. Interview guide development

We developed the interview guide with two qualitative experts (C.M. and J.S.) and established content validity with CF and family planning experts (C.S. and D.H.). The guide underwent pilot testing with four female CF patients to assess understandability, flow and omissions.

Content of the interview guide consisted of a semistructured, open-ended format focusing on three major domains: (1) attitudes about contraception, (2) attitudes about pregnancy and pregnancy experience, and (3) perceptions of fertility. Additional prompts were included to expand discussion on themes.

2.3. Recruitment of participants

Study recruitment took place between November 2014 and April 2015. English-speaking females between the ages of 18 and 45 with CF were eligible to participate. We anticipated needing up to 30 participants to reach thematic saturation [19].

Approximately 100 women of reproductive age attended the Adult CF Program at Penn Medicine during that period. Thirty-five patients provided informed consent to be interviewed. Twenty-eight (80%) consented and completed interviews by phone. Interviews ranged approximately 30 min to 1 h in duration.

2.4. Analysis

Research assistants, who worked for the Penn Family Planning research program and had been trained to conduct interviews for previous qualitative data collection, conducted all interviews over the phone. The interviews were recorded; transcribed by ADA Transcription Service, a professional transcriptionist service; and deidentified according to standards required by the IRB and the Health Insurance Portability and Accountability Act. We uploaded transcripts into NVivo 10.0 software to facilitate systematic coding and analysis.

Two independent investigators (S.T. and V.C.), trained in thematic analysis under direct supervision of a qualitative methods expert (C.M.), read through transcripts to identify common themes. Investigators met frequently and used iterative processes consistent with modified grounded theory with a focus on sequence, framing and relationships of themes [20]. We discussed emerging themes openly to develop a codebook.

The two primary coders (S.T. and V.C.) used the codebook to assign codes to 5 (20%) transcripts and used NVivo to quantitatively determine intercoder reliability. We discussed code assignments with mediation by the qualitative expert (C.M.). When we reached intercoder reliability with a Kappa statistic >0.65 and agreement >90%, we determined consensus and coded the remaining transcripts. Analysis occurred in tandem with coding as an iterative process until we reached thematic saturation.

3. Results

3.1. Participants

Twenty-four (86%) of 28 interviews were used for final analyses due to significant changes to the interview guide after pilot testing with 4 participants. Participants ranged in age from 22 to 43 with a mean age of 30.4 years (Table 1).

3.2. Primary themes

Participant responses revealed three distinct domains pertaining to the impact of CF on family planning: (1) future pregnancy intentions, (2) beliefs about fertility and contraception and (3) medical provider influence on decision-making. Themes from within each of these domains emerged as significant contributors to decision-making about family planning, and representative quotes are provided in the table as well as in text (Table 2).

3.3. Future pregnancy intentions

Every participant expressed opinions about pregnancy regardless of whether or not they had been pregnant. Patients who had not been pregnant expressed beliefs that pregnancies should be strategically planned because of physiologic stress associated with pregnancy: "…you need to be very careful with your body…and make sure that you're taking good care of it…getting pregnant unintentionally is potentially much more serious than if you get pregnant and you're perfectly healthy…taking steps to be careful that that doesn't happen is very important in CF."

Many women who desired future pregnancies expressed attitudes of urgency and stated that CF was the impetus for having children sooner rather than later: "I think [CF] has influenced me. I definitely would like to try a little bit sooner than I would if I didn't have CF. Because I want as much time with my kids as possible, and I want to have kids before my health degenerates anymore."

Conversely, women who did not desire pregnancy expressed aversion to pregnancy based on beliefs about protection of their own health: "I don't feel optimistic about [having kids] at all and I have absolutely no interest in it. None. Zero. Being wary of the adverse health impact of pregnancy."

For women who had children, their prior pregnancy experience in the setting of chronic disease influenced plans for future pregnancies: "[CF] definitely affected the number [I want], especially after doing it once, I do have concerns that I don't know if my body would be able to handle it a second time. Or any other time after that."

Table 1
Demographic characteristics of participants with CF who were interviewed about contraceptive decision-making*[a]

Age, mean in years	30.4	-
Caucasian	24	100
Education (at least HS)	24	100
Marital status		
- Married	11	46
- Never married	7	29
- Partnered	6	25
Birth history		
- Gravid	9	37.5
- *Parous*	*6*	*25*
- Nulligravid	15	62.5
Self-reported disease severity		
- Mild	15	62.5
- Moderate/Severe	9	37.5
Health insurance[a]		
- Private	16	67
- Public	12	50

[a] Some participants had both private and public health insurance.

Table 2
How having CF affects family planning decision-making

Theme	Representative quotes
Future pregnancy intentions	
Deliberately planned pregnancies	"Yeah, it would definitely be a step-by-step process in terms of…we're just talking about starting a family, not even that we're trying yet. So it would be a very slow process like oh, we'd like to have a family, so what treatments should I go through? Anything else that I should consider? Definitely getting my husband tested to see if he's a carrier."
Beliefs about personal health status and impact on pregnancy intentions	"I don't want to have one because I know my body can't handle it physically…I couldn't imagine having to take care of a kid…I just don't think it would be fair to the baby or to me…I'd have to pick one or the other, the baby or me. And it's just not very fair." "I'm going to start with one [child] and see how that goes…Because caring for my condition and caring for a child would be more than enough."
Consequences of CF on a potential child	"Not to mention that baby — it may have CF. It may have to go through what I have to go through. It might be a carrier. It's like, why keep progressing the bad gene down if you don't have to?"
Fertility and contraception	
Perceptions of a woman's own fertility and its role in use of contraception	"I feel like I don't even need [birth control]. Terrible to say, but I almost feel like it's really hard to get pregnant. I feel like I'm not going to get pregnant, even if I tried without help or seeing a fertility clinic. So I guess it's made me think that it's just going to be really difficult to get pregnant. So it made me feel safe having sex without any protection." "…when I was younger, I think I was a bit careless because I was convinced that I couldn't get pregnant. I mean, if you read about CF, it tells you, you might not be able to get pregnant, so I was like, oh, I probably can't get pregnant. This is fine…on some level, I'm still kind of convinced that I won't get pregnant…a little part of my brain still thinks that I just would never get pregnant even if I tried."
Consideration of simultaneous use of contraception and other medications	"I stopped taking the birth control pill because I was concerned that there might be interaction with antibiotics and its efficacy would be less predictable. So I actually had an IUD placed…like six years ago so that I had a predictable, reliable form of birth control that did not depend on what other medication I was taking at the time." "I'm on and off antibiotics so much that it would cancel [the Pill] out, and it would be just so useless — a useless way for me to prevent — I just think it would be more dangerous than using condoms."
Hesitation and lack of knowledge about LARC methods	"I didn't feel necessarily comfortable with having something implanted in me. You never know, you hear recalls of things all the time. Things seem great and then a year or two later, oh, no, the thing that's implanted in you is now releasing whatever toxic chemicals inside of you. I was trying to avoid that."
Medical provider influence	
Consideration of provider input when making decisions about pregnancy	"Before I became pregnant, I had been tipped off by another CF patient that [pregnancy] might not be well-received…rumor had it that they weren't super-thrilled about patients getting pregnant. So I kind of didn't talk too much about it, just to not have to deal with that." "…when I had a ring on and everyone noticed it, the diabetes doctor, my CF doctor, both said, you know, if you're planning on becoming pregnant, come talk to us first. So I think they…wanted to make sure if I was going to be pregnant, that it would be planned through them."
Medical providers as key informants in contraceptive decision-making	"It's mostly from my gynecologist…who I was able to get the information from in regards to what the pill or what the actual contraceptive device did. Whether if it was a shot or a pill, as far as side effects, or how it would affect my period, or how long it lasted for, the doctor was the one that really provided that information to me."
Belief that medical providers lack knowledge to make recommendations	"I think the biggest [barrier] would be lack of expertise in CF and birth control…any other gynecologist I'd seen had a very basic understanding of CF, but no idea of any effects that it could have on contraception…I had some questions, and [the providers] weren't even really equipped to answer them."
Transitions in care and gaps in communication about family planning	"I was in pediatrics with my same doctor, who'd been taking care of me from the age of two. When I was in high school, they would ask me if I was sexually active. But it never went beyond that, because I would always say no. Even when I was, I would still say that I wasn't, because I didn't want to tell them…because they were almost like family and I didn't trust that they wouldn't tell my mom."

In nulliparous women, pregnancy planning depended on health status: "I definitely want to use [contraception] because I'm not ready. I mean, I am at the healthiest point that I've ever been…I know that going through a pregnancy with CF can…take a toll on your lungs. I don't want to jeopardize my health at all at this point. So it plays a really big part in making sure that I'm protected."

All but three participants described their dilemma regarding consequences of CF for potential children: "I want to be around, if I were to have children, to spend time with them…CF is a disease that shortens your life span…I haven't been able to come to a firm decision that rectifies that concern about not being able to be there to raise my children or be healthy for my children, versus a very deep seated human desire to have children."

Some participants with pregnancy plans discussed partner carrier status and felt that having a CF-carrier partner would influence willingness to have biological children: "Just a lot of concerns about, especially passing on the CF gene…We don't know if [my husband] is a carrier for CF. So it's like if he's a carrier, our child would definitely have CF…we would actually probably not have a biological child, but would consider adopting if he's a carrier."

3.4. Beliefs about fertility, contraception and contraception uptake

Contraception use varied widely for this cohort. Combined hormonal methods (21%) and condoms (38%) were the most commonly reported types ever used. Perception of one's own fertility, interactions with other medications and misconceptions about LARC seemed to impact the type of contraception utilized based on participants' reports.

Respondents often described a belief that at least subfertility persists for women with CF: "…if you read about CF, it tells you, you might not be able to get pregnant, so I was like, oh, I probably can't get pregnant." Moreover, perception of one's own fertility seemed to influence type of contraception for participants. In our cohort, those women who had been pregnant before expressed a belief that they could become pregnant again and utilized moderately to highly effective methods of contraception when they were trying to avoid pregnancy: "because my pregnancies were so difficult for me…I didn't think I could do it again. And that was the ultimate decision for [getting my tubes tied]." Conversely, women who had never been pregnant before expressed doubts about their fertility and tended to use less effective methods of contraception (or none) even if they were trying to avoid pregnancy: "I guess I'd use [an IUD] if it were something I felt that I really had to do…I just feel secure that I'm not gonna get pregnant, even though that's probably a falsity…" (Figure 1).

Participants described concern about interactions with other medications and decreased efficacy of oral contraceptive pills: "…I was concerned that the interaction between the two [medications] would negate the effectiveness of the pill."

Few participants reported ever-use of LARC methods. All other women reported knowing nothing about LARC, described inaccurate information about them or expressed doubts about ever using them: "I feel like you have to be older to get [IUDs]. Or maybe just planning on not having children. And they can be removed. I know the Mirena, you take it out every month, I think it is. Then there's also a risk for infection with those."

3.5. Medical provider influences

All but one participant identified providers as important in shared decision-making about all health-related matters, but especially when making complex family planning decisions: "I think about other things that CF women consider, because if [my provider] told me…you have to take this pill three times a day, but it'll be better overall for…regulating your hormones and make you less prone to flare-ups… I'd absolutely do it."

All respondents identified medical providers as main sources of information and recommendations about contraception. Participants described conversations with CF providers and their willingness to communicate about pregnancy prevention but reported that, frequently, discussions with CF providers lack information: "Probably I would want to talk to my gynecologist about the risks…Because obviously there's risks with every medication, or type of contraception…that's the first thing I would do, is talk to [my doctor] about it…then I would make my decision based on that."

All women recognized gynecologists as the provider they saw most for issues related to contraception and family planning, but several expressed apprehension about providers' lack of knowledge regarding a relationship between CF and contraception: "I don't feel like a lot of OB/GYNs have experience with CF even. So I'm not sure they completely understand why some people would choose a certain method over a different method…"

A few participants identified transition from pediatric to adult care as a critical time when they wanted to talk about reproductive health. For two respondents, sexual activity commenced prior to this transition, and they reported experiencing worry that confidentiality may be compromised by intimate parental involvement. One woman felt less comfortable bringing it up with providers because of lack of trust:"I didn't really talk to my CF doctor about it because I was in transition from — because I was 18, changing from…a kid doctor to an adult doctor, so I didn't really know my new doctor too well from the CF side."

4. Discussion

Our findings are consistent with four previous surveys in which participants reported plans to become pregnant but cited concerns about its impact on their health and reported wanting to know partner

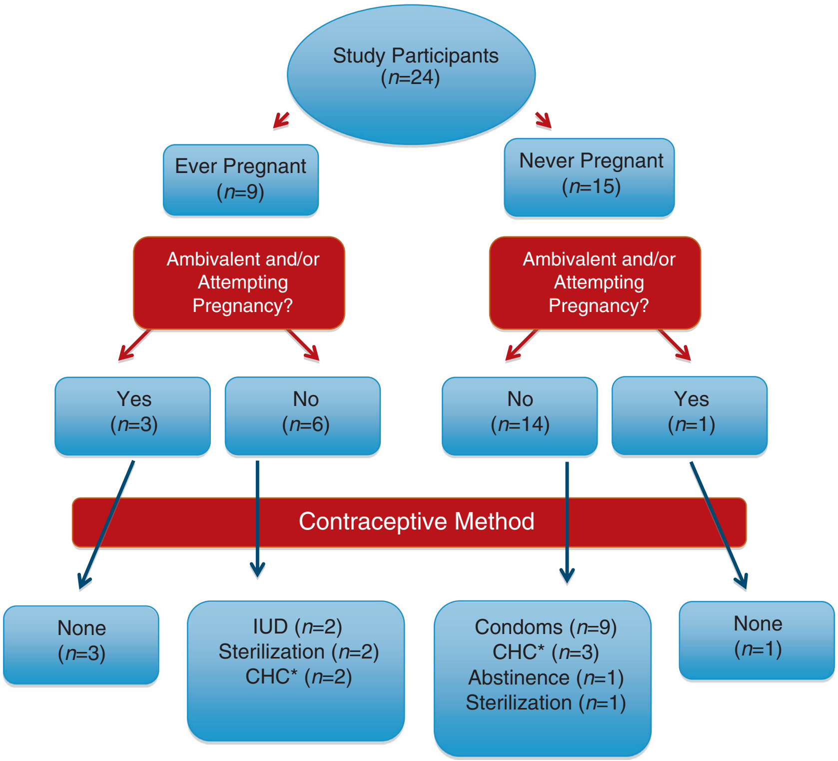

Figure 1. Pregnancy intentions and contraceptive uptake.

carrier status prior to pregnancy [5,6,15,16]. These data, as well as two interview studies, indicated that participants lacked knowledge about fertility and CF; and while participants reported use of all contraceptive method types similar to the general US population, participants reported use of condoms and natural family planning more often [5,6,15,16,17,21]. Again, consistent with our findings, participants in three surveys and two interview studies indicated health care providers as the main source of information regarding reproductive health yet reported that these discussions were inadequate [6,15,16,17,21].

Unlike previous studies, our in-depth interviews, specific to contraception decision-making, allowed respondents to expand on themes that had additional impact on family planning decisions, such as personal health status, barriers to use, shortened lifespan, provider level of knowledge and perceived fertility. Personal health status significantly influenced the need for deliberately planned pregnancies. Our cohort almost universally utilized contraception but expressed significant barriers to optimal use, such as misinformation about concomitant use of other medications and misconceptions about contraception, especially long-acting reversible contraception. Additionally, respondents relied on medical providers to guide them appropriately but expressed concerns about providers' level of knowledge. Concerns about pregnancy and shortened lifespan were considered with both urgency and aversion. Disease heritability was taken into account and caused some women to avoid pregnancy altogether where others made decisions based on partner status. Universally, a woman's perception of her own fertility and her pregnancy intentions influenced contraception utilization. Women who did not desire pregnancy but had been pregnant more often used moderately and highly effective contraceptive methods (IUDs, sterilization) relative to women who had never been pregnant but were trying to avoid pregnancy.

This study had limitations. While the sample size was appropriate for the methods, the small sample impacts generalizability. We conducted interviews at a single academic institution with a homogenous population in a single geographic area. However, based on statistics from the Cystic Fibrosis Foundation Patient Registry, 90%–95% of CF patients are Caucasian, 93% have completed at least a high school education, and 41% are married or partnered [1]. Thus, our population appears representative of the general adult CF population.

Furthermore, the knowledge, attitudes and beliefs around pregnancy and contraception decision-making reported by our participants with CF parallel those expressed in studies with women who have other chronic medical conditions. A study of women with diabetes showed that over one-third reported never having contraceptive counseling and had misconceptions about what types of contraception were available to them [22]. Similarly, two studies of women with systemic lupus erythematosus showed that 30%–59% reported not receiving contraceptive counseling in the year prior to questioning by researchers [23,24]. Data from a survey in women with congenital heart disease indicated that a physician is the primary contact for information about contraception; however, participants reported feeling uninformed about sexuality, contraception and risks of pregnancy [25]. And finally, in a qualitative study of women with a history of breast cancer, participants reported an overall paucity of information about family planning from their providers and lacked fundamental understanding of impacts of their disease and treatment on fertility [26].

Three separate interviewers conducted interviews, which may have interfered with consistency and depth of theme emergence, introducing bias into data collection. Variation from the interview guide between interviewers may have occurred, which would provide more or less in-depth discussion by the interviewee. Based on the interview transcripts, all interviewers followed the script; however, of note, some interviews varied in length, which may correlate with a differential relation to the interviewer. Additionally, interviewers may inadvertently probe for answers that affirm their own assumptions, also introducing bias into the data. In this study, however, only one interviewer (V.C.) acted as both data collector and data analyzer.

Women with CF think deliberately about family planning and prioritize planned pregnancies at times when health is optimized. Most women factor in attitudes about personal health status, ethical issues around reproduction with a heritable disease, and knowledge and beliefs about contraceptive methods when considering pregnancy prevention. Women with CF consider the recommendations and expertise of their medical providers as vital pieces in shared decision-making with regard to choice in contraception use and pregnancy planning. However, there are identifiable gaps in knowledge for the women themselves and the medical providers who care for them, potentially adversely affecting a woman's ability to make the most informed family planning choices. Furthermore, gaps in communication about sexual activity and pregnancy intentions around the times of transitions in care may negatively impact a woman's ability to make informed family planning decisions.

Understanding how best to meet the family planning needs of this population is complex. As for any provider caring for women with complex, chronic medical conditions, it is important for clinicians caring for women with CF to share knowledge, communicate expertise across disciplines and create spaces for collaborative provision of care. Development of interdisciplinary clinics that combine care for chronic conditions as well as family planning expertise can improve care delivery for women not only with CF but other chronic conditions as well.

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