PATHS TO MOTHERHOOD FOR WOMEN WITH CYSTIC FIBROSIS

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Abstract

Purpose: Cystic fibrosis (CF) is no longer a disease limited to childhood. With medical advancements, many of those with CF live into adulthood and have similar life goals as their non-CF peers. Most women with CF want to become mothers. However, available options and the related decision-making process is not well understood. The purpose of this study was to explore the decision-making framework of women with CF to better understand the factors they consider when deciding on a path to motherhood.

Study Design and Methods: Qualitative interviews were performed using a grounded theory approach. Inclusion criteria were women with CF who became mothers through biological pregnancy, adoption, or gestational surrogacy.

Results: Twenty-five mothers with CF were interviewed. A distinct decision-making process was identified through which women started with a desire for motherhood, assessed several factors, then eventually took the path they felt was right for them and their family.

Clinical Implications: Our findings provide women with CF a framework that other women with CF have used to assist in making decisions about their reproductive options. Conversations about family planning should occur early and regularly between women with CF and their health care providers. The decision-making process to achieve motherhood for women with a chronic illness, such as CF, includes consideration of unique factors that should be included in clinical conversations.

Key words: Cystic fibrosis; Parenting; Patient-centered care; Qualitative research; Women's health.

Becoming a mother is a significant, life-changing milestone. Women become mothers many ways; biologically, biologically with medical assistance, via gestational surrogacy, or through adoption. When women who have a chronic, life-threatening disease, determination of which of these paths to take requires careful consideration.

Cystic fibrosis (CF) is a rare genetic disorder affecting approximately 30,000 people in the United States, and over 70,000 people globally (Cystic Fibrosis Foundation [CFF], n.d.-a). Historically, CF was considered a disease of childhood, as many individuals with CF did not survive to adulthood. However, with the average predicted survival age of a child born today with CF at 46 years, that is no longer the case (CFF, n.d.-a). Over 50% of individuals with CF in the United States are age 18 and older (CFF, n.d.-a), and they desire to reach life milestones such as experiencing motherhood similarly to their non-CF peers (Frayman & Sawyer, 2015; Tonelli & Aitken, 2007). Previous studies show that many women with CF want to become mothers (Kazmerski et al., 2018; Ladores et al., 2018).

Cystic fibrosis is an autosomal recessive, genetic disease. An individual must receive a copy of the CF producing gene from each parent; therefore, each parent must have at least one copy of the defective gene. Carriers are those with one copy of the defective gene, but do not have CF. For each couple with both partners having one copy of the genetic mutation, there is a 25% chance (1 in 4) the child will have CF, and a 50% chance (1 in 2) that the child will be a carrier but not have CF. There is a 25% chance (1 in 4) that the child will not be a carrier and will not have CF (CFF, n.d.-a).

Women with CF have noted CF affects the decision-making process involved in pregnancy and motherhood (Ladores et al., 2018). Pregnancy has been linked to an increase in CF-related health care visits and pulmonary exacerbations (Schechter et al., 2013). Women with CF face a number of additional challenges compared with non-CF peers, similar to those with other chronic conditions such as guilt and anxiety associated with feeling unwell, and decreased life expectancy (Jacob et al., 2021); challenges associated with balancing parental duties while also adhering to CF-related treatment regimen (Jacob et al.); concerns about achieving and maintaining a pregnancy; and having limited disease-specific information available to help inform decisions on pregnancy and motherhood (Holton et al., 2019).

Legislation and medical insurance coverage, which vary from state to state, can inform and influence this decision-making process. As of 2020, only 19 states in the United States have passed infertility insurance coverage laws with 13 of those containing *in vitro* fertilization coverage (Resolve, The National Infertility Association, 2021). Health insurance does not commonly cover gestational surrogacy, which can prompt the need to purchase a separate policy specifically for gestational surrogacy that can cost approximately $30,000 (Resolve, The National Infertility Association).

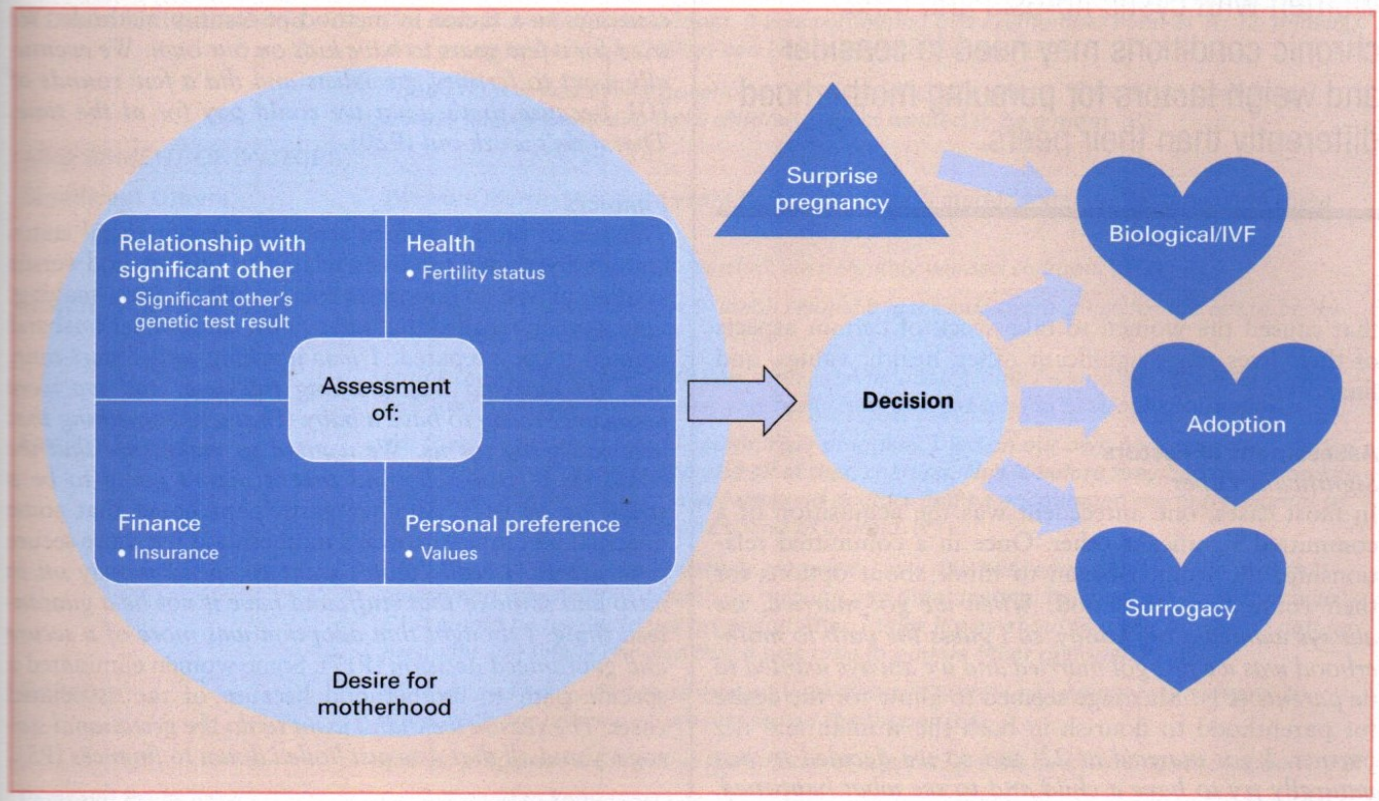
With advances in CF clinical care, women with CF generally experience healthy pregnancies. Analyses of several international patient registry data show that there was no significant difference in lung function decline between pregnant and nonpregnant women with CF when compared from baseline to follow-up visits (Ahluwalia et al., 2014; Gilljam et al., 2000; McMullen et al., 2006). For example, in a study of French patient registry, pregnant women with CF were stratified by lung function severity and were found to have no significant difference in FEV1 (a measure of pulmonary function) decline over a 4-year study period (Reynaud et al., 2020). The United States patient registry showed no difference in survival for women with CF who experienced pregnancy compared with those who did not (Goss et al., 2003). Schechter et al. (2013) found pregnant women with CF use more inhaled and intravenous antibiotics than their nonpregnant counterparts, as well as an increase in outpatient clinic visits and hospitalization rates. Managing weight and CF-related diabetes for pregnant women with CF requires close monitoring by the CF care team in collaboration with endocrinologists and nutritionists to follow American College of Obstetricians and Gynecologists (ACOG) guidelines (ACOG, 2018; Jain et al., 2021).

Although decision-making processes related to family planning in other chronic diseases (e.g., multiple sclerosis and human immunodeficiency virus) have been examined (Prunty et al., 2008; Wesley et al., 2000), there is scant evidence exploring the decision-making process of women with CF. Therefore, the purpose of our study was to explore the decision-making process for women with CF and determine how they arrived at their chosen path to motherhood and what factors they considered to reach their goal of becoming mothers. We chose the term *path* for the decision-making process and planning for motherhood because it is used commonly to denote the *process*, *journey,* or *road* to becoming mothers. For ease and clarity, the word *path* is used consistently in lieu of other synonyms.

Methods

Between January and August of 2020, women with CF were recruited to participate. They represented one of three potential paths to motherhood: biological (with or without reproductive assistance), adoption, or gestational surrogacy. Recruitment occurred in a CF center in the Southeast United States, at a summer camp for adults and children with CF, via social media postings within CF-specific Facebook groups, and through snowball sampling. Inclusion criteria were a woman diagnosed with CF, age 18 or older, resided in the United States, and achieved motherhood biologically, through adoption, or via gestational surrogacy. United States residence was used as one of the inclusion criteria because vast differences in opportunities and insurance coverage for adoption or gestational surrogacy in some countries compared with the United States. Participants were compensated $20 for their participation in a 30- to 60-minute audio-recorded telephone interview inquiring about their path

FIGURE 1. A GRAPHIC DEPICTION OF THE DECISION-MAKING PROCESS OF WOMEN WITH CYSTIC FIBROSIS IN OUR STUDY WHO DECIDED TO BECOME MOTHERS.



to motherhood. Questions were designed to explore significant factors that influenced their decision-making on how they chose to achieve motherhood. Table 1 contains the interview guide (Supplemental Digital Content at http://links.lww.com/MCN/A75). Audio recordings were transcribed verbatim by a transcriptionist service and uploaded into NVIVO 12 software for qualitative analysis.

To explore factors included in, and the process leading up to, the decision of a path to motherhood, we used a qualitative, grounded-theory approach (Charmaz, 2014). Data collection and analysis occurred concurrently. Analysis began by using line-by-line coding followed by focused coding to create categories using a constant comparative method documented through memoing (Charmaz). Memoing informed theoretical sampling to further clarify contextual factors and the decision-making process for the three paths to motherhood in women with CF. Consequently, the framework changed over time. Data collection was stopped when data saturation occurred, meaning no new properties of the decision-making framework were emerging (Charmaz).

We shared the preliminary framework with 12 participants who had indicated they would be willing to review our resulting framework to elicit feedback and validation to ensure that the framework we developed accurately reflected their experiences. We asked them to respond to the following questions: Do you feel like the model accurately represents your path to motherhood? Is the model easy to understand? Do you have any suggestions for improving the model? Five women provided their responses to these questions and represented all three paths (adoption, surrogacy, and biological). All five agreed that the model was accurate, easy to read. One participant provided minor feedback to improve the model. This study received institutional review board approval from the first author's university.

Results

Twenty-five women with CF who represented one of three potential paths to motherhood participated: biological (with or without reproductive assistance) (n = 10), adoption (n = 10), or gestational surrogacy (n = 5). A clear decision-making process about motherhood was identified (Figure 1). To explain this contextually, we present this decision-making process chronologically, similar to how the women in the study described their thought process. Table 2 contains the parts of the theory and additional supportive quotes not contained in the text.

A Desire for Motherhood

Women reported having the desire to become a mother. *I had always wanted to be a mother growing up. I just adored the idea of bringing kids into this world and helping raise good humans* (Participant 3[P3]). Another woman agreed. *I just knew overall that however it happened I desperately wanted to be a mom, and so it was just my goal* (P17). The desire for motherhood was a pivotal first step in the decision-making process, as it was this desire

Women with cystic fibrosis and other chronic conditions may need to consider and weigh factors for pursuing motherhood differently than their peers.

that caused the women to take stock of certain aspects of their lives (e.g., significant other, health, values, and finances).

Assessment of Factors

Significant Other

In most cases, one antecedent was the acquisition of a committed significant other. Once in a committed relationship, the women began to think about options for their route to motherhood. *When we got married, we always wanted a big family, so I guess the path to motherhood was we just got married and we always wanted to be parents* (P1). Marriage seemed to allow for the desire for parenthood to flourish in both the woman and her partner. *I got married at 22 and so we decided to just naturally try to have a child and to see what happened, stated* (P13). Women reported marriage was a deciding factor before trying to have children. *We got married in November of 2013. We had been talking the whole time about wanting to be parents and how we would go about that* (P16).

Most women wanted to know their partner's genetic testing results. Taking genetics into consideration, specifically whether their partner carried a CF genetic mutation, greatly contributed to their decision about whether to consider the biological route to motherhood. *If he had been a carrier, we probably would not have chosen to have any more kids biologically, but he was not, so we felt good about that* (P1). Another participant similarly stated, *If he was a carrier, we would have gone immediately to adoption* (P5).

Health

The women reported assessing their health. *I was healthy at that standpoint and was ready to start trying to become a mother* (P12). Alternatively, some women felt they were not healthy enough to pursue motherhood at a particular timeframe. *For those first three years of our marriage, I wasn't healthy enough* (P3). She recognized that she did not know what her health would look like in the future which influenced the timing of her pursuit of motherhood, *I knew in the back of my mind that I was running out of time...that my body was running out of time to healthily carry a child if I still want to do that* (P3).

Fertility Status. Several women discussed specifically assessing their fertility status and ability to conceive biologically. *A few years went by and we knew after two years, okay, this isn't happening so we probably should see a doctor* (P13). One participant included insurance coverage as a factor in method of fertility methods. *We tried for a few years to have kids on our own. We eventually went to fertility specialists and did a few rounds of IUI, because that's what we could pay for at the time. That didn't work out* (P20).

Finances

Thirteen of the 25 women reported their financial status and ability to pay for costs related to one method versus another played an important role in their decision-making. One woman recalled that financially, she and her husband wanted to be prepared. *I was working under part-time, and my husband was working full-time, and we were financially ready to have a baby. That was something that was really big for us. We wanted to make sure that we could do it financially and that it wasn't going to be a strain on us* (P7). Another participant noted that some financial investments toward motherhood felt more secure than others. *I really didn't want to spend money on in vitro and some of that stuff, and have it not be a guaranteed thing. I thought that adoption was more of a secure and guaranteed decision* (P17). Some women eliminated a specific path to motherhood because of the associated costs. *The reason we didn't want to do the gestational surrogacy and all that was just boiled down to finances* (P5).

Personal Preference

Women shared that considering the various options for motherhood was an immensely personal decision, involving ideals, values, and both the preferences of the woman and her partner. One participant explained how her partner's preferences helped determine the path she chose. *I was okay with adoption, and my husband just always dreamed of a biological baby. That was not very much my decision, more his* (P18). Another woman's partner also had a preference. *I told him that I would be interested in adoption, and he said that he was definitely not interested in that, so we didn't ever pursue it further* (P2).

A woman explained her personal decision as, *I think some people just feel led to do certain things for their family. I just never wanted to go that far into IVF and creating a child out of, I don't know. It just feels bizarre to me* (P13). Another participant also felt a particular route would not have been right for her. *I don't think we would've ever gone the surrogacy route. Not slamming anyone who does that, but I just don't think it would be right for our family* (P11). And one woman had an attitude of letting things happen on their own. *I couldn't become pregnant on my own, then it wasn't meant to be* (P10).

Decision

After the desire for motherhood and an assessment of some or all factors described, women arrived at a decision. *It really wasn't worth my health trying to get through this [physical work of carrying a pregnancy], so we pursued adoption* (P15). One participant did not want to

TABLE 2. ILLUSTRATIVE QUOTES FROM PARTICIPANTS

Theme	Supportive Quotes
A Desire for Motherhood	*I've always wanted to be a mom. It was something that I remember even at 11, 12, thinking, am I going to be a mom? What can I do to become a mom?* (P7)
	I don't think it was ever a question of if I wanted to be a mom... Ever since I was little, I always knew I wanted to have children... I just wanted to be a mom. (P6)
ASSESSMENT OF FACTORS	
Significant Others	*We were married for three years before we actually started trying so for those first three years of our marriage.* (P7)
	After my husband and I got married, we definitely wanted children. (P17)
Health	*We just realized with all of my health issues, It just made more sense for me not to be the one to carry the babies.* (P16)
	I think the fact that my health was pretty stable. I don't think I would've pursued it if my FEV [forced expiratory volume] was really low, or I was having a lot of exacerbations. (P2)
Fertility Status	*We tried for two years and I couldn't get pregnant. Tried on our own for a year then started doing the temperature taking and all of that, charting. This is before they had ovulation kits. Then after almost another year I changed doctors and he encouraged me to try Clomid so we got pregnant on the second round of Clomid.* (P1)
	After the first year, I wasn't getting pregnant. I saw a fertility specialist to make sure that everything was healthy. I didn't go through any other testing, because we knew that with CF it would be harder to get pregnant. After, I think it was about five years, I wasn't getting pregnant. We finally decided that it was time to pursue other options. (P17)
Finances	*My husband and I, we talked and we were financially stable and happy with where we were, with our careers, so we just pulled the trigger.* (P4)
	Are we prepared? Do we have the emotional support? Do we have the financial support? (P5)
Personal Preference	*I didn't need to know anything about that [assisted reproductive technology procedures] I felt like, if I couldn't become pregnant on my own, it wasn't meant to be. I wasn't going to go that route.* (P10)
	I had decided before of not giving birth myself. It was my individual decision due to the fact that A, I did not want to pass the disease onto my child, and B, I did not want to risk my health and how healthy I was. (P23)

miss out on the experience of pregnancy. *I seek items as much as I seek experiences, and it seemed like I should experience pregnancy* (P5). Another did not want to get caught up in a cycle of waiting. *I'm going to wait and wait and wait, and I might not be healthy enough to carry a pregnancy. I might not have all these years with my son or daughter that I want to have* (P7).

Surprise Pregnancy. A few women experienced an unplanned pregnancy, which circumvented the decision-making process and resulted in a biological child. One woman recalled when she first discovered she was pregnant. *I just walked into a walk-in clinic ... because I was sick. I had a cold. I was like, 'Something's not right.' They done a urine test. That was negative, and then he drew my blood. He was like, 'Congratulations.' I said, 'To what?... What are you talking about?' He said, 'You're pregnant.' I said, 'I can't be...I want to see my test result. I want a copy of the paper.' He gave it to me, so I come home. I called [CF Clinic], and I was like, 'What do I do?' I didn't believe it because I was like, 'Hm-mmm. After all these years? No. That can't be possible* (P10). Another woman experienced a similar surprise. *My path to motherhood was very unexpected because I was married but, I mean, I'm still married, but we weren't actively trying to have a baby... but we weren't using protection for a couple years at least, and then I missed a period, and took a pregnancy test, and I was pregnant* (P8).

Discussion

Findings from the interviews resulted in identification of a framework by which women with CF who participated in our study assessed and determined the path to motherhood that was best for them. The graphic of this framework (Figure 1) could be shared with women with CF, as well as women with other chronic conditions as a guide if no other resources are available for them, as an example of their family planning decisions.

Our study supports and extends findings from other studies involving non-CF chronic conditions. In a study of women with HIV who became mothers, Wesley et al. (2000) reported a desire for motherhood was a major influence in the decision to become a mother. Prunty et al. (2008) developed a decision-making aid for women with multiple sclerosis in Australia. Similar to our findings related to examination of the influence of significant others and personal preferences in the decision-making process,

Providers can assist women with cystic fibrosis to determine relevant factors in their personal decision by sharing the graphic based on the experiences of the women in our study.

Prunty et al. included comparable factors within their decision-making aid. Their decision aid was shown to be effective in promoting positive outcomes among users such as increased knowledge, improved self-efficacy, and decreased decision conflict (Prunty et al., 2008). Future research may apply our findings to a larger sample of women with CF who may be considering motherhood to see if they are helpful in describing this decision-making process. Sharing the experiences of women with CF as they decide the best options for them to grow their family may be of use to other women with CF.

Limitations

A limitation of our study is the inclusion of predominantly heterosexual women who had male partners. Despite our best efforts to recruit women who were single or those who may be part of the LGBTQ+ community via multiple CF-focused social media pages, we were only able to enroll one woman who identified as lesbian and had a female significant other. A single woman or someone who is not cisgender may experience a different decision-making process that would not have been captured by our data. Future research may explore these other groups' decision-making process to determine similarities and differences. Our sample was limited to women in the United States due to differences in available resources for fertility treatments and surrogacy.

Clinical Implications

Our findings support need for earlier and regular conversations on family planning in the CF community. Among patients with chronic conditions, women may need to consider and weigh factors for pursuing motherhood differently than their peers who do not have chronic conditions. Providers can assist women with CF determine relevant factors in their personal decision including relationship status, health, finances, and personal preferences. Revisiting the topic regularly (for example, annually) with baseline questions ensures that women know to expect the topic and that there will be an opportunity to discuss options if they become interested in pursuing motherhood. ACOG and the American Society for Reproductive Medicine's (2019) prepregnancy counseling recommendations on frequency, timing, and content of clinical care for women with chronic illnesses support our study conclusions and are consistent with clinical guidelines outlined by the CF Foundation (CFF, n.d.-b). Fertility and reproductive health discussions, regular assessments, and timely referrals to specialists would be critical to address the unique needs of these women.

Establishing a peer mentorship program may help women learn from others who have gone before them to determine what path to motherhood may be best for them and provide personal insight on what to expect. Peer mentorships have been demonstrated to be beneficial in providing tangible support and promoting health behavior changes across a variety of conditions and settings (Fisher et al., 2012). These conditions include gynecologic cancer (Moran et al., 2021), osteoarthritis (Lavender et al., 2021), lupus (Faith et al., 2018), and chronic kidney disease (Perry et al., 2005), among many others.

Based on our study on motherhood and CF, future research may focus on a phenomenological study of the experience of women with CF on becoming mothers. Further work could involve mixed methods study design to further investigate the experience. More research is necessary to explore the phenomenon of parenthood in people with CF, as medical and technological advances are enabling them to live into adulthood.

Many women with CF desire the opportunity to experience motherhood and can become mothers. To support them, we have described the decision-making framework of women with CF in our study for their consideration. As the predicted survival age of women with CF continues to increase with medical advances, the opportunities for them to experience motherhood increases as well. Equipping women with knowledge and points for consideration empowers them to make the best decision possible for both themselves and their families. ✣

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SUGGESTED CLINICAL IMPLICATIONS

- As the predicted survival age of women with cystic fibrosis continues to increase with medical advances, opportunities for them to experience motherhood increases as well.
- Unique family planning needs of women with cystic fibrosis and other chronic conditions should be taken into consideration in the clinical environment.
- Family planning should be discussed early and regularly (for example, annually) with baseline questions to ensure that women have the opportunity to discuss options for pursuing motherhood, if interested.
- Nurses can evaluate the needs of women with cystic fibrosis and other chronic conditions for information related to pregnancy and provide education if needed.
- Nurses can initiate conversations about family planning to provide opportunity for women with cystic fibrosis feel comfortable with the topic.
- Care providers can assist women with cystic fibrosis determine relevant factors in their personal decision.
- Using a decision-making framework in the clinical setting may be effective in promoting positive outcomes, such as increased knowledge of options and improved planning for women with cystic fibrosis.

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