Cystic Fibrosis-related Infertility: Thoughts and Experiences of Men in Romantic Relationships

Master’s Thesis

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Cystic fibrosis (CF) and congenital absence of the vas deferens (CAVD) are conditions caused by mutations in the CFTR gene. Ninety-five percent of men with CF and/or CAVD have infertility due to azoospermia. Until recently, men with CF were not likely to live into adulthood and because of this, issues surrounding CF-related infertility did not receive much attention. However, as improved care and treatments continue to extend the life expectancy for individuals with CF, the need to understand how affected men are feeling about issues surrounding CF-related infertility is becoming increasingly relevant. The purpose of this study is to explore the experiences of men with CF and/or CAVD in disclosing their infertility to romantic partners, the effects that both disclosure and associated infertility have had on their romantic relationships and their thoughts on reproduction. We used an anonymous online survey and received 37 responses. We found that nearly half of our participants (44.4%) desired more information at the time of learning about CF-related infertility, and that some wished they had learned this information at an earlier age. Almost all participants (97.2%) had disclosed CF-related infertility to their romantic partner and felt supported after doing so. While many men stated they were concerned that their romantic partners would react negatively to learning about CF-related infertility, few (21.4%) felt their partners actually had negative reactions after disclosure. In addition, the
majority of men (61.1%) in this study felt like CF-related infertility did not affect their ability to establish romantic relationships. Finally, 75% of men indicated they think about having or already have children, and most men discussed this with their romantic partner. This is one of the first studies to explore the issues men with CF and infertility face and the results provide valuable insight for other men affected by CF and CAVD, as well as the healthcare professionals who provide care for them.

Keywords: Cystic Fibrosis, infertility, male infertility, disclosure, romantic partners
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Introduction

Cystic fibrosis (CF) is the most common autosomal recessive disorder in Caucasians, with an incidence of one in every 2,500 livebirths (Scotet et al., 2012). This condition is the result of mutations in the CFTR gene, which is located on chromosome seven. Many individuals with CF have significant complications from pulmonary disease and pancreatic insufficiency, and over 95% of affected males have infertility because of azoospermia caused by congenital absence of the vas deferens (Hull and Kass, 2000). Additionally, men can have isolated congenital absence of the vas deferens (CAVD), resulting from one or more mutations in the same gene that causes cystic fibrosis. These individuals do not have other signs of CF, but also have infertility.

Historically, CF-related infertility in affected males was not a primary concern, due to the greatly shortened lifespan in affected individuals. Data from the 1980s demonstrated that individuals with CF had an average life expectancy of less than 20 years (Davis, 2006). However, with advances in treatments and a better understanding of how to care for affected individuals, people with CF are living longer lives, with the most recent Cystic Fibrosis Foundation Patient Registry (2015) projecting current life expectancy into the fourth decade. In addition, the Registry estimates that since 1994, the percentage of adults with CF who are married or live with a partner has increased by 10 percentage points and as of 2014, 50.7 %, or 16,345 affected individuals are over the age of 18 in the US. With a growing number of CF patients now living into adolescence and adulthood, the topic of male infertility becomes
increasingly important to address, yet there is little in the CF literature on this aspect of the condition.

Research exploring how men with CF learn of the associated infertility is very limited. Hull and Kass published a study in 2000 looking at how successful affected men felt their providers were in facilitating conversations around CF-related infertility. They found that the age at which participants found out about infertility varied significantly, and content of these conversations were highly inconsistent, even within the same clinic. Another study found that more than half of the participants felt they did not receive adequate information regarding reproductive options and that 30% of men reported that the personal significance of CF-related infertility changed over time (Saywer et al., 1998). Given the inconsistency with which affected men receive information about CF-related infertility and the increased relevance of this issue as more progress through adulthood, additional studies are needed to determine when and how to best talk about this issue with them.

Studies on disclosure have shown that people affected by genetic conditions have great anxiety over revealing their health status to romantic partners. Klitzman and Sweeney (2011) interviewed individuals at risk for, or affected by, Huntington’s disease, Alpha-1 antitrypsin deficiency, or hereditary breast and ovarian cancer syndrome (HBOC) and found that many factors influenced their feelings about disclosing their genetic condition. Past rejection, length in the relationship, and guilt were major contributors to participants’ decisions to disclose. Many study participants also stated they felt they were breaking the trust established with their partner by not telling them about their genetic condition, but delayed or avoided disclosure because of fear of rejection (Klitzman & Sweeney, 2011). One can imagine that this is further complicated when an individual is disclosing not only a genetic condition, but also associated infertility to a
romantic partner, given that this has implications for future children, and as such, the partner’s future as well.

Several studies have shown that males and females with CF differ on issues surrounding romantic relationships. A study by Abbott, et. al (2003) used a brief quantitative questionnaire to ask both male and female adolescents and adults affected with CF how their disease impacted both romantic and non-romantic relationships. Researchers found that men had greater difficulty establishing and maintaining relationships because of their CF compared to women, however they were not able to determine what factors were responsible for this difference. A separate study found that women with CF were more likely than affected men to disclose their condition to romantic partners, and that some of these female-reported disclosure experiences were negative (Modi et al., 2010). While this research suggests that men with CF face greater challenges in disclosing their diagnosis than women, these studies provide little insight into the issues men face discussing the infertility component of their condition.

The aim of this study will be to explore the experiences of men affected by cystic fibrosis or CAVD in disclosing their infertility to their partners, the effects that both the disclosure and associated infertility have had on their romantic relationship(s), and their thoughts on having children. As life expectancy for individuals with CF increases, this will become a more important and frequent topic of conversation for affected men. We hope that the insight gained by this study will help the CF and medical communities to facilitate more productive and supportive conversations about the disclosure of CF-related infertility in romantic relationships.
Methods

Brandeis University’s Institutional Review Board approved this study.

Study design

We created an anonymous online survey through Qualtrics, which included multiple choice questions with single and multiple answers, Likert-scale and open ended questions. We gathered demographic information such as age, state or country of residence, level of education completed and current relationship status, as well as details about participants’ initial diagnosis of CF, medical complications and the time at which they learned of their CF-related infertility. We then asked participants about their experiences with disclosure of infertility to a romantic partner, how they felt infertility has affected their romantic relationships, thoughts on having children and ideas about self-perception. Finally, we solicited advice for other men affected by CF/CAVD and their healthcare providers. At the conclusion of the survey we asked participants if they would like to share anything else that they did not feel was captured in the survey. Respondents had the option to not answer any of the survey questions. We collected the data online to allow for easy access to the survey and to maximize the number of respondents.

Recruitment

We recruited participants through notices posted on cystic fibrosis social media pages, with permission from page administrators, as well as through snowball sampling. We asked participants to share the survey link with other individuals who they thought might also be interested in participating in the study. The eligibility criteria included men who: were 18 years or older, had a diagnosis of cystic fibrosis or CAVD, were aware of CF-related infertility, had
been in at least one romantic relationship and spoke English. At the end of the survey, we asked subjects if they would like to enter a drawing for one of three $50 Amazon.com gift certificates. If subjects were interested, our study directed them to another Qualtrics survey that asked for their email address. We made the survey for four weeks.

**Data collection and analysis**

We analyzed quantitative data using SPSS Statistics Version 23, a statistical software package available through Brandeis University. We first analyzed the data using descriptive statistics; we also performed bivariate and multivariate statistical analyses to determine relationships between independent and dependent variables. We manually analyzed responses to the open-ended questions using an inductive approach to identify themes.
Results

We had 45 respondents participate in our survey. We removed six participants from our analysis due to incomplete responses for the majority of the questions in the survey, and an additional two because the participants indicated they were female. We based our analysis on 37 respondents who had a diagnosis of CF and/or CAVD and fit the rest of the inclusion criteria.

Demographics

Respondents were between 19 and 52 years of age, with a mean age of 33.5 years. The majority of participants were from the United States (59.5%, n=22); we further categorized participants’ US state residencies into regions as defined by the US census. An overwhelming majority of men who responded indicated they had completed some level of college/vocational school or higher (81.1%, n=30), and almost half had a college or professional degree (45.9%, n=17). Thirty men (81.1%) indicated they were either in a relationship or married, six men were single (16.2%) and one man was divorced/separated (2.7%). Table 1 contains a summary of demographic data on the study population.

Men with Cystic Fibrosis

All but one of the men who participated in the study (97.3%) indicated that they had a diagnosis of cystic fibrosis. Pulmonary disease (94.4%, n=34) and pancreatic insufficiency (91.6%, n=33) were the most frequent complications affected men experienced because of their condition. Less frequent medical issues noted by respondents included congenital absence of the vas deferens (CAVD) (n=19), CF-related diabetes (n=10) and liver disease (n=8) (Figure 1). Four participants (11.1%) indicated they have received a double lung transplant, with these
surgeries taking place between the ages of 31-40 years for two participants, and 41 years or older for the other two participants.

We then asked participants at what age they received their diagnosis of cystic fibrosis and when they first learned of CF-related infertility. Over 94% stated they had received their CF diagnosis at younger than five years of age (n=34) and over 66% received their CF diagnosis at age one or younger (n=24). In contrast, when asked at what age they first learned about CF-related infertility, over 83% of respondents said this occurred between 11-20 years of age (n=30) (Figure 2). Of the 35 respondents who provided information regarding who they first learned about CF-related infertility from, the majority stated they had learned from either a medical professional (37.8%, n=14) or a parent (29.7%, n=11). Other, less frequent responses included learning from the internet (16.2%, n=6) and written material (10.8%, n=4). When discussing cystic fibrosis-related infertility, over 43% (n=16) did not feel their healthcare providers offered enough information on the subject. Seventy-five percent (n=12) of those who felt they were not provided with adequate information about CF-related infertility wished they would have received more information specifically about assisted reproduction options. Other areas that respondents frequently felt lacked adequate discussion were causes of CF-related infertility and its psychological impact.

When asked about their level of comfort with discussing CF-related infertility, 81.8% (n=27) of participants indicated they were comfortable or very comfortable discussing this topic with their primary care provider or CF care team. Similarly, 83.3% (n=30) indicated they were comfortable or very comfortable discussing this with their family and friends. One respondent who indicated he was uncomfortable discussing CF-related infertility with his primary care provider stated that having “a proper system set up to deal with cf related infertility” would make
him more comfortable. A few respondents stated that there was nothing that would make them more comfortable discussing CF-related infertility with any of the afore mentioned groups, with one stating,

“I am a tad prudish; so any discussion of sexual nature makes me uncomfortable.”

When asked about support they received after learning about CF-related infertility, about half of respondents stated they were satisfied or very satisfied with the support given by their primary care providers, CF care team, family and friends.

All but one respondent with cystic fibrosis indicated that they had disclosed their CF-related infertility to a romantic partner. These disclosure conversations occurred most frequently within one month of establishing a relationship (40%, n=14), but ranged from less than one month to greater than one year. Figure 3 summarizes participants’ reasons for disclosing their CF-related infertility to romantic partners. Fourteen respondents stated they were concerned their partner would have a negative reaction to their disclosure about CF-related infertility, yet of these, only 21.4% (n=3) said their partner actually had a negative reaction. Across all participants, 71.4% (n=25) stated their romantic partners did not react negatively when they were told. Similarly, 71.4% (n=25) stated they felt supported by their romantic partner after disclosing their CF-related infertility. The one respondent who did not disclose his CF-related infertility felt he would burden his romantic partner if he discussed infertility.

When asked if it was difficult to establish romantic relationships because of CF-related infertility, 22 men (61.1%) responded that it was not. When men who indicated that having CF made it difficult to establish a romantic relationship elaborated on why they felt this way, themes included the respondent wanting a family, pressure from the woman to have children naturally and the stressful nature of the situation. One respondent said,
“It is a shadow constantly hanging over things.”

Another stated,

“Most women want children. I do as well, but know adoption is my only option. I’ve found that most women want to experience the pregnancy/childbirth first hand.”

**Men with CAVD**

There was only one participant who indicated he has isolated CAVD without other symptoms of cystic fibrosis. This respondent learned of his infertility at 25-29 years of age and indicated that his romantic partner was with him at the time he learned of his diagnosis. He also indicated he is still with this partner. At the time of diagnosis, the respondent felt his doctor provided enough information regarding CAVD. He indicated that he felt comfortable discussing CAVD with and felt supported by his primary care provider, infertility specialist, family, friends and romantic partner. The respondent also indicated he did not believe CAVD caused tension in his romantic relationships.

**Participants’ thoughts on having children and sexuality**

We asked participants about their thoughts on having children and over 59% (n=22) indicated that they think about having children, approximately 24% (n=9) indicated they did not, and nearly 16% (n=6) indicated that they had children. Of the 22 men who stated they think about having children, 21 (95.5%) said that this was a conversation they had had with their romantic partners. Of the 28 respondents who either thought about or had children, 22 (84.6%) said they either discussed or used ART, 15 (57.7%) discussed or used adoption, 4 (15.4%) were able to have children naturally and 3 (11.5%) said they did not discuss or use any options (Figure 4). Explanations for wanting children but not discussing or using options to do so included being in same sex relationships and gaining stepchildren. For those participants who indicated they do
not think about having children themes in their reasons why included not wanting children, no particular reason, and fear that their child would witness the natural decline of their health due to CF, along with not being able to watch their child grow up. One participant explained,

‘... there's a lot I want to do with my life. I love adventure. Exploring. Doing crazy things. With CF, I don't know how long I have [...] I feel the responsibility of a Father is basically being SuperMan to your son/daughter. SuperMan doesn't die a slow death in a hospital bed. SuperMan doesn't need help showering or feeding himself. I wouldn't want any son/daughter of mine to have to witness that and carry those memories.”

Some men felt their CF-related infertility was a positive thing for their sexuality. One participant stated,

“It is incredibly sexually liberating to know I can have sexual intercourse with my wife, or in theory whomever [...] without having to fear paternity.”

Another stated,

“being infertile gives an element of control to the situation.”

A number of participants in the study also mentioned the topic of safe sex. One participant explained how providers never discussed this topic in a clinical setting:

“My cf care team never had a conversation with me about safe sex... Just because most adolescent men with cf are infertile doesn't decrease the risks of stds. Further, having cf does not mean that we can't form lasting, deep relationships.”

We asked participants if there was any advice they would give to couples who are dealing with CF-related infertility and desire children. Themes from open responses included exploring all your options, remaining optimistic, considering adoption, and having open/honest communication with your romantic partner. One respondent illustrated these, stating,

“Be open and honest. There are a lot of options available, and the right partner will be supportive. If she isn't, then she's not the right person for you anyway.”

Another participant said,

“There's always adoption or other means of conceiving so don't give up.”
**Advice to Medical Professionals**

Finally, we asked participants what advice they would give to medical professionals on how to improve the care of other men with CF/CAVD. Themes in their responses included medical professionals giving more information, discussing CF-related infertility at an earlier age and being aware of the psychological impact it has on the patient. One participant explained the importance of clear information;

“**distinguish between infertility and its effects with sexual desire and function. As a young male I was disturbed/very worried that infertility meant problems with having sex. be open about cf & its fertility effects earlier.**”

Another participant illustrated the lack of sensitivity regarding the psychological aspect, stating,

“**I should have been told at a much younger age. I would recommend around 12-14. I was 18, my pediatrician had never talked about it because it wasn't viewed as a peds issue, and on my first visit to an adult cf clinic, was asked/told 'you know you are mos[t] likely infertile, right? ’ It was terrible.**”

Another stated,

“**Try not to equate fertility with masculinity. For many man this problem is emasculating, and the last thing you want is to feel that from a medical professional.**”

One participant stressed that medical professionals need to,

“**provide more information, especially about adoption options. I don’t even know if i am infertile because none of my doctors have ever discussed the topic with me.**”
Table 1. Demographic information of participants

<table>
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<th>Respondents</th>
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<tr>
<td></td>
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<td>UK</td>
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<td>Canada</td>
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<td>Relationship Status (n=37)</td>
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</table>
Figure 1. Clinical features reported by participants

Clinical features of CF (n=36)

- Pulmonary disease: 34
- Pancreatic insufficiency: 33
- CAVD: 19
- Cystic fibrosis-related diabetes mellitus: 10
- Liver disease: 8
- Other*: 4

*other responses included: gastrointestinal issues, nasal polyps, diabetic neuropathy, high blood pressure and gall bladder removal.

Figure 2. Age at diagnosis of CF and age when participants first learned of CF-related infertility

Age Difference in CF Diagnosis vs. Infertility Diagnosis

- CF
- Infertility

Younger than 1 year: 25
1-5: 10
6-10: 5
11-15: 15
16-20: 20
21-25: 25
Older than 25: 30
Figure 3. Reasons why individuals with CF disclosed CF-related infertility to romantic partners

<table>
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<th>Reason</th>
<th>Count</th>
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</thead>
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<td>Wanting to maintain trust</td>
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<tr>
<td>Perceived acceptance by partner</td>
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<tr>
<td>Wanting to share</td>
<td>15</td>
</tr>
<tr>
<td>Previous conversations about children with partner</td>
<td>14</td>
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<tr>
<td>Length in relationship</td>
<td>12</td>
</tr>
<tr>
<td>Guilt of not disclosing</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
</tbody>
</table>

Figure 4. Options discussed or used by men with CF who think about or have children

- Adoption: 34%
- ART: 50%
- None: 7%
- Able to have children naturally: 9%

Options Discussed/Used to have Children
**Discussion**

This study aimed to explore the experiences, feelings and thoughts of men affected by cystic fibrosis (CF) and/or congenital absence of the vas deferens (CAVD) surrounding disclosure of their infertility to romantic partner(s), along with the effects it has had on their romantic relationship(s). As care and treatment for individuals with cystic fibrosis continues to improve, affected adolescents and adults will face new considerations pertaining to romantic relationships and reproduction. Our hope is that results from this study provide insight for both the CF community and their healthcare providers on how best to approach and discuss this issue.

The mean age and education levels of participants in this study were slightly higher than those reported in the 2015 Cystic Fibrosis Foundation Patient Registry. The eligibility criteria could account for the age discrepancy since we excluded men under the age of 18 from this study. Participants also had to have internet access and be involved with social media, which could explain the slightly higher levels of education. It was of no surprise that the most frequently reported clinical features among men with cystic fibrosis were pulmonary disease and pancreatic insufficiency. However, of note, only 53% of men indicated that congenital absence of the vas deferens was among their list of clinical features. This is interesting given that no participants stated they were unaware of CF-related infertility, and could be explained by participants not knowing the actual cause of their infertility or not knowing what CAVD meant. Another explanation could be that participants did not choose CAVD because, in comparison to complications like pulmonary disease and pancreatic insufficiency, they view CF-related infertility as a less significant clinical feature.
A theme that emerged when we asked affected men to give advice to healthcare providers was participants wanting to learn of CF-related infertility at an earlier age. Some even indicated they were unaware of CF-related infertility until it came as a surprise when they were older and planning families. This is consistent with previous studies in which some men with CF did not learn about their likely infertility until they were entering romantic relationships, sexually active and may have been thinking about having children (Sawyer, 1996 and Hull & Kass, 2000). There are a number of potential explanations for the delay in healthcare providers having these discussions. One may be that providers did not believe their patients would live to an age at which infertility would be an issue. A second possibility could be that these discussions did not happen because of the transition of care from pediatric to adult CF clinics, with one clinic assuming the other would address this issue. Finally, it is possible that providers did not want to initiate these conversations, so they delayed them. This explanation would be consistent with previous research that showed, while many physicians stated they would be comfortable discussing reproduction relating to CF if patients initiated the conversations, they themselves would not typically initiate it, or would simply avoid it (Sawyer, 1996 and Hull & Kass, 2000).

This is particularly interesting given that most men in the current study felt comfortable discussing CF-related infertility with their CF care team and other medical professionals. Given these findings, it seems that provider-initiated conversations at an earlier age are warranted and would be well-received. Open discussions regarding CF-related infertility would empower patients as they begin to plan for their future, something that was not a reality for young men with CF until recently.

Another finding from our research is that some men with CF feel there is a lack of adequate explanation surrounding CF-related infertility. Over 43% of participants in our study
said that they wanted more information at the time they learned of CF-related infertility, with specific topics including assisted reproduction options, the cause of CF-related infertility and its psychological impact. This finding is similar to a study done in 2000, where researchers found that while CF care providers thought they were having adequate conversations about reproductive and sexual health with their affected teenage patients, men with CF in the same clinic felt they had not been provided enough information (Hull & Kass, 2000). The perceived lack of education, around assisted reproduction options in particular, is illustrated by one participant who stated that he desired children but knew that adoption was his only option. This current study demonstrates that the findings from 15 years ago are still not being adequately addressed, as men with CF who desire children are not being provided information on all of their reproductive options. It is becoming increasingly important for parents and healthcare providers to prepare for and facilitate these conversations. This will result in future generations of men with CF who enter adolescence and adulthood armed with the information needed to make informed decisions about their future.

One of the goals of this study was to gain insight into the process of infertility disclosure to a romantic partner(s) by men with CF and/or CAVD. Of the 36 participants in this study who stated they had CF, 35 men had previously disclosed their likely infertility to at least one romantic partner. We found that these disclosure conversations mostly took place within the first 6 months of establishing a romantic relationship, with the majority happening within the first month. These relatively early disclosures could be explained by participants stating that wanting to maintain trust with their partner was the most frequent reason for disclosing CF-related infertility. While some participants stated that they were concerned that their partners would have a negative reaction to their disclosure, only three men actually agreed that the reaction was
negative and further, 25 men said they felt supported by their partner after disclosing. The one man who had a diagnosis of isolated CAVD also indicated that he felt supported by his romantic partner after learning of his infertility. These findings are crucial for men with CF or CAVD who have concerns about disclosing their infertility, as they can provide reassurance that most men feel comfortable disclosing their infertility and few experience negative reactions from their partners.

Over a third of study participants said they felt that that CF-related infertility affected their ability to establish romantic relationships. When asked why they thought this was the case, two themes emerged. The first was men’s concern about not being able to have biological children. Some participants expressed sadness over the thought of having a romantic relationship without biological children, which may have resulted in a reluctance to either pursue or maintain a romantic relationship. The second theme identified was the pressure that participants felt from women surrounding the ability to have children naturally. In fact, some men stated that previous romantic partners had left them because of this. This pressure, either perceived or real, may create a barrier for men with CF and related infertility, making it more difficult to enter into romantic relationships. While these concerns were not true for a majority of our participants, they are still important in illustrating the psychological distress that men with CF-related infertility may experience in forming romantic relationships. Discussions with young men about the issues surrounding CF-related infertility should therefore include potential difficulties establishing relationships.

Another goal of this study was to explore affected men’s thoughts on having children. We found that 75% of participants in the current study indicated that they think about or have children. This finding alone is a major historical shift in the CF community given that until
recently, affected individuals were not typically living long enough to consider having children. Nearly all participants said they discussed having children with their partner. This may suggest that it is not only the men with CF and CAVD who are wanting children while coping with infertility, but may be that the couple as a unit are also dealing with these challenges. Therefore, education about CF-related infertility needs to extend beyond the affected man and include the partners who may be coping with this as well.

Reproductive options available to men with CF-related infertility/CAVD include assisted reproductive technologies (ART), via testicular biopsy for sperm extraction or sperm donation and in vitro fertilization, as well as adoption. For those men who said that they think about having or have children, the majority indicated that they had either discussed or used ART to do so. Some participants also discussed or pursued adoption and four men stated they were able to have children naturally. The frequent consideration or use of ART is not a surprise given that the number of pregnancies reported by couples, where one partner has CF, has increased by over 79% since 2004 (Cystic Fibrosis Foundation Patient Registry, 2015). When asked to give advice to other couples who desire children and are dealing with CF-related infertility, two themes emerged. First, many men stated that remaining optimistic about being able to have children and exploring all reproductive options were very important. One participant stressed never taking no for an answer and taking time to make such a decision. The second theme that emerged was suggesting couples in this situation consider adoption. This is consistent with the options participants reported discussing or using most frequently, suggesting that they would recommend options that they themselves were comfortable using to have children.

A subset of participants indicated that they do not think about having children. Five men stated that either they did not desire children, or the thought of having children had never crossed
their mind before. Some men also stated that they did not consider having children because they feared their children would witness the eventual decline of their health and have to experience the death of a parent. One participant illustrated this when explained that his infertility was a relief because he feared his life-limiting condition would prevent him from watching his children grow. These responses provide a different perspective on CF-related infertility and should also be included in discussions with young men with CF so they realize that, while having children is something some men think about, it is not universal.

Finally, while exploring thoughts on sexual activity was not a specific aim of this study, many men commented on this in relation to CF-related infertility. Although it is not surprising that this topic came up in discussions about romantic relationships, it was particularly interesting that some participants had similar statements without any prompting. First, several men stated the CF-related infertility was not a negative thing at all, and that the ability to have “consequence-free” sexual activity was extremely liberating. It gave some men a sense of control over when, or if, they wanted to start a family, given that almost all men with CF and CAVD require the use of ART to have biological children, a process that cannot happen without active planning. This may be somewhat unexpected, as the medical community typically views infertility negatively, and this perspective could be the same even when infertility is associated with CF. Another interesting theme regarding sexuality was the lack of discussions about practicing safe sex. Some men stated that their CF care team never had conversations about safe sex and the risk for sexually transmitted diseases (STDs) with them. One man also said that he wished his providers had made the distinction between infertility and sexual function when he learned about CF-related infertility, as this was something that caused him worry as he became sexually active. It seems that men who did not have sufficient education from their healthcare
providers had to learn, on their own, that CF-related infertility does not impact sexual function and that they are still at risk for STDs just like anyone else who is sexually active. This again becomes part of the bigger issue of educating young men about CF-related infertility. While it is evident from our study that not all men with CF or CAVD may view their infertility negatively, it is essential that young men receive accurate and comprehensive information about it so that they are able to form these opinions themselves.

Limitations

Our analysis focused on data from a small sample of men with CF and CAVD. Further, only one respondent indicated he had a diagnosis of CAVD without other manifestations of CF. Our findings therefore represent those of a limited population, and may not be generalizable to men with CF or CAVD as a whole. Recruitment through CF pages on social media and snowball sampling may have created unintended bias in the data we collected. Men who are a part of such pages may be more inclined to share their thoughts and experiences, more likely to have support from others with CF, and more adjusted to living with CF and having romantic relationships. In addition, since data was collected from an online survey, this may have narrowed the population of willing participants to those who had internet access and were technologically savvy. Most men stated that they learned about CF-related infertility at 11-20 years of age. Given that this survey asked questions about initially learning about CF-related infertility, and that the average age for our participants was 33.5 years, recall bias is another potential limitation to this study. Finally, one researcher was responsible for the qualitative analysis of free-response questions. This may have led to subjectivity in the identification of themes.
**Future research**

Further studies on a larger sample size would allow us to determine if the results from the current study are consistent with thoughts and experiences from a larger population of men affected by CF and CAVD. Men in the current study seemed to want to share their thoughts on or experiences with having children; a follow-up study asking how these men feel about having a child who either has CF or is a CF carrier may produce further insight for future generations of men with CF or CAVD that desire biological children. It would also be interesting to repeat a study similar to this one in a younger population of men with CF and CAVD to see if more recent conversations and experiences surrounding CF-related infertility are improving. Finally, our study showed that many men felt supported by their romantic partners after disclosing, while others stated their partners left them. Interviewing or surveying romantic partners of men with CF or CAVD may provide insight into experiences and reactions to learning about their partner’s CF-related infertility and how they have coped if children were desired.
Conclusion

This study assessed the experiences of men with CF surrounding the infertility associated with their condition. We found that men with CF and CAVD often feel they are not getting adequate information from their healthcare providers about CF-related infertility and wish to learn about the subject at an earlier age. Ninety-seven percent of men disclosed their likely infertility to their romantic partners, and most were well-received and felt supported after doing so. We also found that 75% of men indicated they think about having or already have children, and that most men discussed this topic with their romantic partner. Men who did not think about having children either did not desire them, had not thought about it, enjoyed participating in sexual activity without the consequence of pregnancy, or feared their children would witness the eventual decline of their parent’s health. Some men even stated that they viewed their CF-related infertility as a positive aspect of their condition.

These findings provide important insight from men with CF and CAVD about experiences that, until very recently, affected men were not living long enough to face. We hope that these results will provide valuable information to future generations of men with CF and/or CAVD in romantic relationships, as well as to their providers, who can use these findings to improve the quality of their care. Facilitating conversations and education around CF-related infertility from an early age seems to be essential in empowering men with CF or CAVD to make important decisions about their increasingly bright future.
References


Appendices

Appendix A: Recruitment notice

Hello, my name is Megan Sikes and I am a graduate student in Brandeis University’s Master’s Program in Genetic Counseling. I am conducting a survey on males affected with cystic fibrosis or CAVD. The purpose of this study is to explore the experiences, feelings and thoughts of men with cystic fibrosis and/or CAVD surrounding infertility and romantic relationships. I would like to invite you to please take this anonymous and confidential survey. Those who complete the survey will be eligible to win one of three $50 amazon gift card.

This study is open to any men who fit the following criteria:

- 18 years or older
- Have a diagnosis of cystic fibrosis or congenital absence of the vas deferens
- Are aware of cystic fibrosis/CAVD related infertility
- Have been in at least one, or are currently in a romantic relationship
- Speak fluent English

If you are interested, please click the following link: (link to Qualtrics survey)

If you know of any other men who might be interested in completing this survey, please share this posting and/or link with them.

Thank you for your time,
Megan Sikes
Appendix B: Survey instrument

Cystic Fibrosis-related Infertility: thoughts and experiences of men in romantic relationships

Q1 You are being asked to participate in this study because you are either a male with cystic fibrosis or congenital absence of the vas deferens (CAVD) and have been in at least one romantic relationship. The purpose of this study is to explore the experiences, feelings and thoughts of men with cystic fibrosis or CAVD surrounding disclosure of infertility with their romantic partner(s), along with the effects infertility has had on their romantic relationship(s). We hope that this study will provide valuable insight that can be shared with other men who have cystic fibrosis/CAVD as well as the healthcare professionals that provide services to them.

Your responses to this online survey will be anonymous. This survey is estimated to take approximately 20 minutes to complete. Participation in this survey is voluntary. You may skip any question you are not comfortable answering, and you may exit the survey at any time.

This survey is being distributed through social media. Please only complete this survey once.

Participants may benefit from feeling like they are contributing useful information to other men with CF/CAVD or their healthcare providers. There are minimal risks to participants. Some participants may feel distress when recalling unpleasant encounters.

Participants who complete this survey can enter a raffle to win one of three $50 Amazon.com gift cards. If you enter the drawing, you will be directed to a separate survey to provide your email address. Your contact information will not be linked to your survey responses.

If you have any questions regarding this study please contact the student researcher, Megan Sikes at sikesm@brandeis.edu or the study's principle investigator, Gretchen Schneider at gretchen@brandeis.edu.

This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have any questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133.

Please feel free to pass this survey link on to anyone whom you feel would be interested in participating.

By clicking Next, you acknowledge that you have read the information above and you consent to participate in this survey.
○ Next (1)
○ I do not wish to participate (2)
If I do not wish to participate Is Selected, Then Skip To End of Survey
**BLOCK 1**

Q2 Are you a male?
- Yes (1)
- No (2)

If No Is Selected, Then Skip To End of Survey

Q3 How old are you?
If How old are you? Is Less Than or Equal to 17, Then Skip To End of Survey

Q4 What level of education have you completed?
- Some high school (1)
- High school degree (2)
- Some college/vocational school (3)
- College degree (4)
- Professional/graduate degree (5)

Q5 Where do you live?
- [Drop down of 50 states]
- Outside the US

Q5b Answer If Where do you live? Outside the US Is Selected
You indicated you live outside the US. What country do you live in?

Q6 What is your current relationship status?
- Single (1)
- In a relationship (2)
- Married (3)
- Separated/divorced (4)
- Widower (5)

Q7 Cystic fibrosis is often identified in childhood because of pulmonary/gastrointestinal issues, and likely infertility is a secondary diagnosis. However, some men find out they have CF or CAVD at an older age because they first are diagnosed with infertility. Did you receive a diagnosis of cystic fibrosis or CAVD because you were first having infertility issues?
- No (1) (GO TO Q21/BLOCK 3)
- Yes (2) (GO TO Q 8/BLOCK 2)

**BLOCK 2 (only for those who answer yes to Q7)**

Q8 The next set of questions ask about your initial diagnosis and romantic relationships.
Q9 At what age did you first learn about congenital absence of the vas deferens (CAVD)?
- 19 years or younger (1)
- 20-24 (2)
- 25-29 (3)
- 30-34 (4)
- 35-39 (5)
- 40 years or older (6)
- Don't remember (7)

Q10 Was your partner at that time in the room with you when you found out about your CAVD infertility?
- Yes (1)
- No (2)

Answer If Q10 Yes Is Selected
Q11 Are you still in a romantic relationship with that partner?
- Yes (1)
- No (2)

Q12 Did you feel your health care provider supplied you with enough information about CAVD infertility at the time of diagnosis?
- Yes (1)
- No (2)

Answer If Q12 No Is Selected
Q13 What kind of information do you wish was discussed in more detail by your healthcare providers?
- Assistive reproductive options (1)
- Adoption options (2)
- Cause of CAVD infertility (4)
- Psychological impact of infertility (6)
- How other men with CAVD have coped with infertility (7)
- Other (5) ____________________
Q14 How comfortable are you with discussing the topic of CAVD infertility with... (If you have not discussed infertility with people in a particular category, please leave blank)

<table>
<thead>
<tr>
<th></th>
<th>Very uncomfortable (1)</th>
<th>Uncomfortable (2)</th>
<th>Neither (3)</th>
<th>Comfortable (4)</th>
<th>Very Comfortable (5)</th>
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<tr>
<td>Infertility specialists</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Family</td>
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<tr>
<td>Friends</td>
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<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Romantic partner(s)</td>
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<td>○</td>
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</tr>
</tbody>
</table>

Answer Q14 Primary care physicians – Very uncomfortable Is Selected Or Primary care physicians - Uncomfortable Is Selected Or Infertility specialists - Very uncomfortable Is Selected Or Infertility specialists - Uncomfortable Is Selected

Q15 You indicated you were never or rarely comfortable with discussing CAVD related infertility with primary care physicians or infertility specialists. What would make you more comfortable?

Answer Q14 Family - Very uncomfortable Is Selected Or Family - Uncomfortable Is Selected Or Friends - Very uncomfortable Is Selected Or Family - Uncomfortable Is Selected Or Romantic partner(s) - Very uncomfortable Is Selected Or Romantic partner(s) - Uncomfortable Is Selected

Q16 You indicated you were never or rarely comfortable with discussing CAVD related infertility with family, friends or romantic partners. What would make you more comfortable?

Q17 After learning about CF-related infertility, how satisfied were you with the level of support provided by...

<table>
<thead>
<tr>
<th></th>
<th>Very unsatisfied (1)</th>
<th>Unsatisfied (2)</th>
<th>Neither (3)</th>
<th>Satisfied (4)</th>
<th>Very Satisfied (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care physicians</td>
<td>○</td>
<td>○</td>
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<td>○</td>
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<tr>
<td>Fertility specialists</td>
<td>○</td>
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<td>Family</td>
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<tr>
<td>Friends</td>
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<tr>
<td>Romantic partner(s)</td>
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</tr>
</tbody>
</table>
Q18 How strongly do you agree with the following statements? (These questions ask about any romantic relationships where you have disclosed CAVD infertility)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neither Agree nor Disagree (3)</th>
<th>Agree (4)</th>
<th>Strongly Agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related infertility has caused tension in my relationship(s) that otherwise wouldn't be there (1)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel like I am putting a burden on my partner by having CAVD infertility (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I felt my relationship(s) changed after discussing CAVD infertility as compared to before (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am less satisfied with my romantic relationship(s) because of CF-related infertility (4)</td>
<td>○</td>
<td>○</td>
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<td>○</td>
</tr>
</tbody>
</table>

Q19 Is it harder to establish a romantic relationship because of CF-related infertility?
- Yes (1)
- No (2)

Answer If Q19 Yes Is Selected
Q20 Please explain.

BLOCK 3 (only for those who answered no to Q7)
Q21 This next set of questions ask about your initial diagnosis of cystic fibrosis.

Q22 What clinical features do you have as a result of cystic fibrosis (CF)? (choose all that apply)
- Pulmonary disease (1)
- Pancreatic insufficiency (2)
- Cystic fibrosis-related diabetes mellitus (3)
- Liver disease (4)
- Congenital Absence of the Vas Deferens (CAVD) (5)
- Other: (6) ____________________

Q23 Have you ever had a lung transplant?
- Yes (1)
- No (2)
Q24 Did you receive a double lung transplant?
- Yes (1)
- No (2)

Q25 At what age did you receive a lung transplant? (If more than one, please answer for your first transplant)
- 15 years old or younger (1)
- 16 - 20 years old (2)
- 21 - 25 years old (3)
- 26-30 years old (4)
- 31-35 years old (5)
- 36 - 40 years old (6)
- 41 years old or older (7)

Q26 At what age did you receive a diagnosis of cystic fibrosis?
- Younger than 1 year (1)
- 1-5 (2)
- 6-10 (3)
- 11-15 (4)
- 16-20 (5)
- 21-25 (6)
- Older than 25 years (7)
- Don't remember (8)

Q27 At what age did you first learn about CF-related infertility?
- 1-5 (1)
- 6-10 (2)
- 11-15 (3)
- 16-20 (4)
- 21-25 (5)
- 26-30 (6)
- 31-35 (7)
- Older than 35 years (8)

Q28 From whom did you first learn about CF-related infertility?
- Medical professional (1)
- Parents (2)
- Internet (3)
- Written material (4)
- Other (5) ____________________
Q29 Did you feel like you have been provided enough information about CF-related infertility by your healthcare providers?
☐ Yes (1)
☐ No (2)

Answer If Q29 No Is Selected

Q30 What kind of information do you wish was discussed in more detail?
☐ Assistive reproductive options (1)
☐ Adoption options (2)
☐ Infertility support services (3)
☐ Cause of CF infertility (4)
☐ Other (5) __________________

Q31 How comfortable are you with discussing the topic of CF-related infertility with... (If you have not discussed infertility with people in a particular category, please leave blank)

<table>
<thead>
<tr>
<th></th>
<th>Very uncomfortable (1)</th>
<th>Uncomfortable (2)</th>
<th>Neither (3)</th>
<th>Comfortable (4)</th>
<th>Very comfortable (5)</th>
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<tbody>
<tr>
<td>Primary care physicians (1)</td>
<td>☐</td>
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<td>☐</td>
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<td>☐</td>
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<tr>
<td>CF care team (2)</td>
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<tr>
<td>Family (3)</td>
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<tr>
<td>Friends (4)</td>
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</tbody>
</table>

Answer If Q31 Primary care physicians - Very uncomfortable Is Selected Or Primary care physicians - Uncomfortable Is Selected Or CF care team - Very uncomfortable Is Selected Or CF care team - Uncomfortable Is Selected

Q32 You indicated you were never or rarely comfortable with discussing CF-related infertility with primary care physicians or CF care team.

What would make you more comfortable?

Answer If Q31 Family - Very uncomfortable Is Selected Or Family - Uncomfortable Is Selected Or Friends - Very uncomfortable Is Selected Or Friends - Uncomfortable Is Selected

Q33 You indicated you were never or rarely comfortable with discussing CF-related infertility with family or friends.

What would make you more comfortable?
Q34 After learning about CF-related infertility, how satisfied were you with the level of support provided by...

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied (1)</th>
<th>Dissatisfied (2)</th>
<th>Neither (3)</th>
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<th>Very satisfied (5)</th>
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<tbody>
<tr>
<td>Primary care physicians (1)</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>CF care team (2)</td>
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<tr>
<td>Family (3)</td>
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<td>o</td>
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<tr>
<td>Friends (4)</td>
<td>o</td>
<td>o</td>
<td>o</td>
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</tbody>
</table>

Q35 Have you disclosed possible or confirmed CF-related infertility to a romantic partner(s)?
- Yes (1)
- No (2)

If No Is Selected, Then Skip To BLOCK 4

Q36 The following questions pertain to the first relationship where you disclosed CF-related infertility. How far into the romantic relationship did you start thinking about disclosing possible or confirmed CF-related infertility?
- less than 1 month (1)
- 1-3 months (2)
- 4-6 months (3)
- 7-9 months (4)
- 10 months- 1 yr (5)
- greater than 1 yr (6)

Q37 How far into the romantic relationship did you actually disclose possible or confirmed CF-related infertility?
- less than 1 month (1)
- 1-3 months (2)
- 4-6 months (3)
- 7-9 months (4)
- 10 months - 1 yr (5)
- greater than 1 yr (6)

Q38 What factors influenced your decision to disclose to your partner? (choose all that apply)
- Length of your relationship (1)
- Wanting to share (2)
- Previous conversations with your partner about having children (3)
- Wanting to maintain trust with your partner (4)
- Guilt of not disclosing (5)
- Perceived acceptance by your partner (6)
- Other (7) ____________________
Q39 These questions pertain to your concerns surrounding disclosure to your first romantic partner. Please rate how much you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neither Agree nor Disagree (3)</th>
<th>Agree (4)</th>
<th>Strongly Agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was concerned my partner would have a negative reaction to the disclosure (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before disclosing to my romantic partner, I was concerned my relationship would change (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>After disclosing to my romantic partner, I was concerned my relationship would change (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>My partner had a negative reaction to the disclosure (4)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>I felt supported by my partner after disclosing (5)</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
</tbody>
</table>

**BLOCK 4 (only for those who answered no to Q35)**

Q40 The next set of questions will ask about your experience in romantic relationships.

Q41 What factors have kept you from disclosing infertility to a romantic partner(s)?
- Conversation of infertility was/is too serious for relationship (1)
- Previous conversations with my partner have swayed my decision not to share (3)
- Lack of trust in relationship (4)
- I believe my partner would react negatively (5)
- I do not desire children, so it is not relevant (8)
- Other (6) ____________________
Q42 How strongly do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neither Agree nor Disagree (3)</th>
<th>Agree (4)</th>
<th>Strongly Agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related infertility has caused me anxiety about relationship(s) that otherwise wouldn't be there (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel like I would be putting a burden on my partner if I discussed infertility (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel my relationship(s) would change after discussing CF infertility (3)</td>
<td>○</td>
<td>○</td>
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<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am less satisfied with my romantic relationship(s) because of CF-related infertility (4)</td>
<td>○</td>
<td>○</td>
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<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Q43 Do you believe it is difficult to establish a romantic relationship because of CF-related infertility?
○ Yes (1)
○ No (2)

**Answer If Q43 Yes Is Selected**

Q44 Please explain.

**BLOCK 5 (for all participants)**

Q45 The next set of questions will ask about your thoughts on parenting.

Q46 Do you think about having children?
○ Yes (1)
○ No (2)
○ I have children (3)

If No Is Selected, Then Skip To Please explain why

**Answer If Q46 Yes Is Selected**

Q47 Is this a topic that you discuss with your partner(s)?
○ Yes (1)
○ No (2)
Answer If Q47 Yes Is Selected OR I have children Is Selected
Q48 What, if any, options have you discussed/used to have children?
☐ Adoption (1)
☐ Assisted reproductive technology (2)
☐ Able to have children naturally (4)
☐ None (please explain) (5) ____________________

Answer iF Q46 No Is Selected
Q49 Please explain why

Q50 Has the possibility of not having biological children ended any romantic relationships?
☐ Yes (1)
☐ No (2)

Answer If Q47 Yes Is Selected OR I have children Is Selected
Q51 What advice would you want to share with another couple dealing with CF-related infertility who desired children?

Q52 This last set of questions will ask about self-awareness and advice.

Q53 What impacts has CF-related infertility had on your...

<table>
<thead>
<tr>
<th></th>
<th>Not at all (1)</th>
<th>Minor (2)</th>
<th>Moderate (3)</th>
<th>Serious (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-image (1)</td>
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<tr>
<td>Sense of masculinity (2)</td>
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<tr>
<td>View on romantic relationships (3)</td>
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<td>View on parenting (4)</td>
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</tbody>
</table>

Q54 Please share any advice you would give to medical professionals (doctors, nurses, infertility specialists or anyone else who is involved in CF care) to improve the care of other men affected with CF or CAVD.

Q55 Please share anything else that you feel was not captured in this survey

The end of survey response had a link to the second survey, where the participant could enter an email address to be eligible to receive one of three $50 Amazon.com gift cards if they choose to.
Appendix C: Permission letters

Permission from Facebook page/group administrators to allow posting the recruitment notice and survey link.

Cystic Fibrosis Foundation:

Cystic Fibrosis Foundation

Hi, Megan --

Thank you for taking the time to let us know about your survey -- it sounds like it will be very interesting!

We receive many requests from our Facebook fans asking us to share their surveys on our page. Unfortunately, due to the high volume, we cannot accommodate these. However, we invite you to share your survey on our timeline so others in the CF community can see it.

Take Care,
Katrina, CFF Community Manager

Cystic Fibrosis Canada:

Cystic Fibrosis Canada

Hi Megan! If you'd like to share on our page, that would be great. Thanks so much for reaching out.

Cystic Fibrosis Worldwide:

Cystic Fibrosis Worldwide

Hi Megan, apologies for the delay in responding. CFW is happy to promote research that focuses on all aspects of CF. We would be able to have the recruitment page notice on our page. Our organization is focused on CF and access to care and information and does not generally work at the individual basis, so posting the link would be the best option. Regards Mitch
CFW Board member
DearCF:

Grant Montague
1/28, 8:41pm
Hi Megan, no probs. Feel free to join the group and post. Thanks for asking in advance.

Cystic Fibrosis group:

Candice Dexter
1/28, 12:48pm
Hi Megan, Yes please feel free to post about your study on the group. Good luck and let me know if you have any other questions! --Candice