Measuring Knowledge of Fertility Preservation in Women with Cystic Fibrosis: Instrument Development and Psychometric Analysis

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Abstract

Objective: To describe the development, evaluation, and psychometric properties of a new instrument that measures fertility preservation (FP) knowledge in women with cystic fibrosis (CF) titled Knowledge of FP in Women with CF Instrument (KFP-WCFI).

Design: The 10-item KFP-WCFI was developed and evaluated through a cross-sectional survey.

Setting: Participants were recruited nationally from CF Foundation-accredited CF clinics and via snowball sampling.

Participants: Fifty women with CF ages 18 through 35 completed the instrument.

Measurements: Construct validity was assessed using confirmatory factor analysis (CFA). In the CFA, the model fit was evaluated using standardized root mean square residual (SRMR), root mean square error of approximation (RMSEA), and comparative fit index (CFI). Cronbach's α was used to examine internal consistency reliability. The criterion validity was assessed using inferential statistics.

Results: The CFA with two subscales "General Fertility Knowledge" and "Transplant-related Fertility Knowledge" demonstrated good fit with SRMR of .07, RMSEA of .06, and CFI of

Conflict of Interest

The authors report no conflicts of interest or relevant financial relationships.

.97, indicating good construct validity of the instrument. This instrument demonstrated internal consistency reliability with Cronbach α's of .91 for the "General Fertility Knowledge" subscale, and .64 for the "Transplant-related Fertility Knowledge" subscale. Women who reported a pregnancy scored higher than women who did not report a pregnancy ($p = .02$) suggesting criterion validity.

Conclusion: The newly developed KFP-WCFI appears to be a valid and reliable instrument that can be used to measure self-assessed FP knowledge in women with CF.

Precis

A newly developed instrument appears to be valid and reliable for measuring self-assessed knowledge of fertility preservation in women with cystic fibrosis.

Keywords

cystic fibrosis; fertility preservation; instrument development; psychometric analysis

Cystic fibrosis (CF) is a genetic, life-limiting, multi-system disease. With advances in early diagnosis and management, people with CF are living into adulthood with an average survival age into the mid-40s (Cystic Fibrosis Foundation, 2017). Many individuals with CF want to engage in parenthood, but researchers have found that women with CF have limited knowledge about the influence of their disease on reproductive health (Kazmerski et al., 2018; Ladores, Raju, & Bray, 2016). Furthermore, many are dissatisfied with the content and timing of reproductive health-related discussions with their CF providers (Kazmerski et al., 2018; Ladores et al., 2016). Women with CF have normal to near normal reproductive structures and can become pregnant naturally, but about 20% may need to utilize assisted reproductive technology due to thickened cervical mucous and ovulatory disturbances caused by CF-related malnutrition (Ahmad, Ahmed, & Patrizio, 2013; Edenborough, 2001).

Fertility preservation (FP), the process of retrieving and preserving eggs and/or embryos for future use, may be necessary for individuals with fertility difficulties as well as those with severe CF disease who may need to undergo lung transplantation but would like the opportunity to have a biological child post-transplantation. Recent (< 2 years) post-transplant pregnancy or egg retrieval is not advised because of the potential teratogenic effects of immunosuppressant therapy and the risk for acute graft rejection (De Pinho, & Sauer, 2014). Graft rejection in pregnancy post lung-transplant is the biggest risk, with an estimated pulmonary graft loss of 21% within 2 years postpartum (Wu, Wilt, & Restaino, 2007). Additionally, acute rejection during pregnancy is higher with lung transplant than with other solid organ transplants (lung: 36%; heart: 20%; liver: 10%; kidney: 9%; Coscia et al., 2009). There are also known teratogenic effects, including fetal demise with common anti-rejection medications (e.g., sirolimus and everolimus) such that these medications should be discontinued prior to pregnancy for individuals post-transplant. Risks to the newborn include a 50% increase in prematurity and low birth weight and a 40% to 50% miscarriage rate (Armenti et al., 2004). Fertility preservation procedures should ideally occur pre-lung transplant in individuals with CF to preserve healthy eggs. Fertility

preservation procedures include: 1) ovarian hyperstimulation with oocyte retrieval, and 2) oocyte or embryo cryopreservation (Holland, Walker, Ladores, & Meneses, 2015).

Questionnaires and other survey instruments are developed to gather standardized information from an identified group to better understand and make generalizations to the broader population (Kalucy, Hordacre, & Patterson, 2008; Rattray & Jones, 2007). In health-related research, new instruments are designed regularly due to a lack of available instruments to measure a particular phenomenon or when current instruments lack validity and reliability for specific populations (Kumar, 2015). Instrument development is a multi-step process that requires rigor in design to yield valid conclusions about a population (Rattray & Jones, 2007). Questionnaire and survey development should be grounded in literature and follow a well-documented systematic approach to improve rigor and reproducibility (Kumar, 2015; Rattray & Jones, 2007). While instruments measuring FP knowledge and treatment options are routinely delivered within the oncology population, there are no valid and reliable instruments available to measure FP knowledge for women with non-malignant conditions (Balthazar, Fritz, & Mersereau, 2011; Jukkala, Meneses, Azuero, Cho, & McNees, 2012; Woodard et al., 2018). The purpose of this article is to describe the systematic instrument development process and evaluation of the psychometric properties of an exploratory, quantitative survey examining self-assessed FP knowledge in women with CF.

Methods

Instrument Development

We used the fertility instrument by Jukkala et al. (2012), which measures self-assessed fertility knowledge in women with oncological disorders, as a framework for developing the Knowledge of FP in Women with CF Instrument (KFP-WCFI). Our instrument differs in that its purpose is to measure self-assessed FP knowledge in a population of women with CF. Considerable modifications and additions were made to develop the KFP-WCFI. The instrument modifications were made based on current literature regarding general FP knowledge and transplant-related FP knowledge. Using these two constructs, as well as data from prior qualitative interviews (Ladores et al., 2016; Ladores et al., 2018a; Ladores et al., 2018b), we developed a new instrument to measure FP knowledge.

During development, the instrument was assessed by stakeholders in the CF patient population (two adult women with CF and two partners of women with CF) as well as experts in CF and women's health (one CF pediatric/adolescent pulmonologist, one director of an adult CF clinic, one PhD-prepared nurse scientist whose research is on CF health-related quality of life, two undergraduate nursing Honors students, and three PhD students whose dissertations are on CF sexual and reproductive health, adolescent and young female adults' sexual health education, and global health disparities in reproductive health, respectively). These stakeholders came from diverse racial and ethnic backgrounds as well as geographic locations. The majority were women, but we did obtain feedback from two male partners of women with CF and a male CF clinic director.

The initial KFP-WCFI items were proposed by two authors and sent out to the stakeholders asking for feedback on essentialness, relevance, and clarity. Based on the feedback, we retained, eliminated, or modified items and then sent the instrument out for another evaluation. We repeated the above step for several rounds and obtained the final instrument in which every item was agreed on by all stakeholders on essentialness, relevance, and clarity. Because we chose a conservative method requiring universal agreement among experts, we did not calculate the content validity ratio (CVR) or content validity index (CVI) in each round; however, we did reach CVR=1 and CVI=1 in our final instrument.

The KFP-WCFI was created on a web-based platform, Qualtrics (Qualtrics, 2019). Readability was initially assessed and determined to be above an 8th grade reading level. The instrument was edited to achieve a 7th grade reading level based on the Flesch-Kincaid grade level score. After all modifications, the final version of the instrument contained two subscales with ten total items (see Table 1). The KFP-WCFI measures self-assessed knowledge of fertility preservation on a four-point Likert-scale. Scores ranged from 10 to 40 with higher scores indicating a higher perception of personal FP knowledge. University IRB approval was obtained prior to the start of this study.

Testing

A national sample of 50 women with CF ages 18 through 35 were recruited either in-person or by email to complete the KFP-WCFI. IRB approved flyers were shared with CF clinics in the United States and CF-specific social media platforms. The inclusion criteria for this study included being a woman between the ages of 18 and 35, having a diagnosis of CF, not having a prior lung transplant, and being proficient in English. Interested potential research participants were encouraged to conduct snowball sampling, the process of sharing the study information with friends who met eligibility criteria. Interested participants responded to the flyer by contacting the principal investigator to request additional information or volunteer to participate in the study. The survey included basic demographic questions (e.g., age, race, employment, and education history) as well as the KFP-WCFI. Participants received $20 for completing the survey that included the KFP-WCFI. Initially, 56 women began the survey, but six women closed their web browser prior to completing the KFP-WCFI. The six partial responses were not included in the analyses. The 50 completed surveys, which included the KFP-WCFI, were used for analysis. The 50 surveys had no missing data.

Data Analysis

Confirmatory factor analysis (CFA) was used to assess the construct validity of the KFP-WCFI. In the CFA, two-factor structures, representing "General Fertility Knowledge" and "Transplant-related Fertility Knowledge", were evaluated using standardized root mean square residual (SRMR), root mean square error of approximation (RMSEA), and comparative fit index (CFI). Table 2 displays the factor loadings for the CFA for the 10-item instrument. Cronbach's alpha was used to examine the internal consistency reliability of each subscale, and criterion validity was assessed using inferential statistics. Descriptive statistics were used to generate average, minimum, and maximum scores. Spearman's rho correlation coefficient was used to assess the relationship between FP knowledge scores

and satisfaction of fertility discussions. Independent t-tests were used to measure group differences. All statistical analyses were conducted using R (R Core Team, 2019).

Results

Table 3 describes the characteristics of the study sample. Almost half of the participants were married (n=23), and about one-third reported experiencing a pregnancy (n=15). A CFA was conducted on the final 10-item KFP-WCFI. The CFA confirmed the two-factor structure with a SRMR of .07, a RMSEA of .06, and a CFI of .97, indicating good construct validity. The KFP-WCFI also demonstrated internal consistency reliability with Cronbach α's of .91 for the "General Fertility Knowledge" subscale and .64 for the "Transplant-related Fertility Knowledge" subscale (Taber, 2018).

Table 4 displays the descriptive statistics. Reponses ranged from 1= "not at all knowledgeable" to 4= "very knowledgeable" for a minimum total score of 10 and a maximum total score of 40. Overall, the mean composite score was 19.04 with a standard deviation (SD) of 5.76. Participants reported knowing the least about "reproductive options after transplant" (38 reported "not at all knowledgeable" while none reported "very knowledgeable") and "impact of immunosuppressive therapy on fertility and pregnancy" (36 reported "not at all" while two reported "very knowledgeable"). Items that participants reported being most knowledgeable about were "planning for pregnancy with CF" with 12 participants reporting "very knowledgeable" and 11 participants reporting "moderately knowledgeable." Participants reported similarly about the item "fertility" with 11 participants reporting "very knowledgeable" and 16 participants reporting "moderately knowledgeable."

Women who reported a pregnancy scored higher on the KFP-WCFI than women who did not report a pregnancy (24.27 ± 6.69 vs 19.40 ± 5.57; p= .02), and women who had received a specialist referral for reproductive counseling scored higher than women who had not received a specialist referral (26.86 ± 4.91 vs 19.88 ± 5.96; p< .01). Additionally, women who were married scored higher than women who were single (24.22± 6.76 vs 17.94 ± 4.72; p< .01). There was a moderate correlation between composite KFP-WCFI score and FP discussion satisfaction score (r_s=0.43, p<0.01). Overall, these results suggested the KFP-WCFI demonstrated high criterion validity.

Discussion

To our knowledge, this is the first instrument of its kind developed to assess FP knowledge in women with CF. Similar instruments have been developed to measure fertility and FP knowledge in the oncology population (Balthazar, Fritz, & Mersereau, 2011; Jukkala et al., 2012; Woodard et al., 2018), but work in non-malignant, chronic illnesses that may require organ transplantation, such as CF, is lacking. Generally, our sample reported low FP knowledge, suggesting that more work is needed to address this critical knowledge gap for women with CF. As individuals with CF are expected to live full lives into adulthood, the discussions of fertility and reproductive health must be integrated into comprehensive health care within the CF model to fully meet their needs (Kazmerski et al., 2018; Ladores

et al., 2018b). These discussions must include FP as well as lung transplantation and how that impacts FP options in the future. Individuals with CF should be informed of all their FP options prior to needing a lung transplant.

Our findings that women who had received a referral to see a fertility specialist scored higher than women who had not received a referral are consistent with findings from Balthazar, Fritz, and Mersereau, (2011). In their study, higher FP knowledge scores in women with cancer correlated with prior exposure to FP information. In the study by Balthazar, Fritz, and Mersereau, (2011), they found no difference in FP knowledge score by relationship status or prior pregnancy. Our findings indicated a statistically significant difference in score by relationship status and prior pregnancy status. This difference could be due to the inherent differences in an acute cancer diagnosis versus a chronic genetic condition. When a woman with CF gets married or discusses pregnancy, CF health care providers may be more likely to bring up fertility and FP options or refer the patient to a women's health care provider versus when a previously healthy women gets married and then acutely develops cancer. In women with cancer, the fertility and FP discussions were not triggered by the change in relationship status but by the new cancer diagnosis (Balthazar, Fritz, & Mersereau, 2011).

In our study, women who were married or reported a prior pregnancy scored higher on the KFP-WCFI suggesting that at some point they were exposed to FP information either through seeking out the information themselves or facilitated by a health care provider. A qualitative study by Simcox, Hewison, Duff, Morton, and Conway (2009) examining fertility discussions in women with CF, found similarly that fertility and pregnancy discussions were not initiated by the healthcare team until the women was married. Interestingly, in our study age was not associated with higher scores suggesting that increased age was not a factor that triggered FP conversations, but marital and pregnancy status did trigger the conversation in this group of women with CF.

Our findings suggest that FP discussions are happening around marriage and pregnancy, and that for many women with severe CF these FP discussions may occur too late (Simcox et al., 2009). Delaying fertility and FP discussions with individuals with CF can have severe consequences in decreasing or removing options for creating biological children. These findings highlight the need for CF and women's and gender-related health care providers to discuss fertility and FP options with individuals with CF early and regardless of their marital or pregnancy status.

Limitations

Because of the cross-sectional nature of this study, reliability was only assessed using internal consistency reliability. Test-retest reliability should be assessed in future studies with the KFP-WCFI. Another limitation was the small and homogenous sample size in this study. More than 95% of our study population identified as White. CF primarily affects people of European descent, but prevalence is increasing in racially and ethnically diverse populations. However, these genetic variants are considered rare and current testing capabilities may not be able to fully identify them. Another limitation of this study was

the use of snowball sampling to recruit participants. Given the relatively rare nature of CF, recruiting 50 women of childbearing age with CF to complete this survey was challenging and thus convenience sampling techniques were used to ensure adequate participation. The use of snowball sampling may limit generalizability. However, measuring FP knowledge is warranted for this subgroup because these women are now meeting adult milestones, including parenthood, that were previously not possible.

Implications for Practice

The KFP-WCFI was developed and assessed in women with CF but could easily be adapted and tested in individuals with other disease processes that require organ transplantation. Thus, the KFP-WCFI has broader implications for use by women's and gender-related health care providers who treat individuals with any condition at risk for needing organ transplantation. Health care providers who care for patients with chronic, nonmalignant conditions should discuss fertility and options for creating a biological family to ensure they have all the information needed to make informed decisions regarding their reproductive options. Medications and gene therapies for people with CF are increasing lifespan and improving health, making parenting possible, but critical discussions regarding FP are not occurring (Kazmerski, Gmelin, Slocum, Borrero, & Miller, 2017).

Nurses, advanced practice nurses, and midwives play a vital role in assessing and discussing fertility and FP options with all individuals, but especially those at increased risk for needing FP procedures. We encourage nurses to use the KFP-WCFI to assess FP knowledge in women at risk for disease- or transplant-related fertility issues to quickly assess knowledge deficits and tailor conversations to best meet their FP educational needs. Creating a valid and reliable instrument to measure FP knowledge is the first step in understanding and improving FP knowledge and outcomes for women with CF. Women's and gender-related health care providers should work to create standards for discussing and preserving fertility for all individuals who have the possibility of losing fertility due to medical conditions or procedures.

Due to the chronic nature of CF, health care providers can discuss FP options and procedures at several time points throughout adolescence and early adulthood. However, literature suggests fertility knowledge is lacking, and conversations around fertility are not occurring until after people are married (Kazmerski et al., 2018; Ladores et al., 2016; Simcox et al., 2009). Nurses can improve FP knowledge among their patients by recognizing the importance of and advocating for FP discussions with both health care providers and with individuals with CF. People with CF should have discussions about all their reproductive options in adolescence to ensure that all options are explored if it is desired.

Conclusion

The KFP-WCFI is a 10-item instrument with two subscales developed from an existing instrument, recent literature, and prior qualitative findings, to measure self-assessed FP knowledge in women with CF. The content validity was established by an intensive discussion with experts in the field. To evaluate the instrument's reliability, construct

validity, and criterion validity, we obtained 50 completed surveys from women with CF. The results from the CFA suggested good construct validity. The Cronbach α for each of the subscales indicated good internal consistency reliability. Because of the lack of a 'gold' standard for this specific phenomenon in CF, the criterion validity of the instrument was assessed by the associations of knowledge scores with potential influential factors, indicating reasonable criterion validity. In summary, this newly developed KFP-WCFI appears to be a valid and reliable two-dimensional instrument that can be used to measure self-assessed FP knowledge in women with CF. The KFP-WCFI may be used in future studies and in practice to quickly and accurately assess perceived FP knowledge in women with CF.

Funding

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References

Ahmad A, Ahmed A, & Patrizio P (2013). Cystic fibrosis and fertility. Current Opinion in Obstetrics and Gynecology, 25(3), 167–172. [PubMed: 23429570]

Armenti VT, Radomski JS, Moritz MJ, Gaughan WJ, Hecker WP, Lavelanet A, … & Coscia LA (2004). Report from the National Transplantation Pregnancy Registry (NTPR): outcomes of pregnancy after transplantation. Clinical transplants, 103–114. [PubMed: 16704142]

Balthazar U, Fritz MA, & Mersereau JE (2011). Fertility preservation: a pilot study to assess previsit patient knowledge quantitatively. Fertility and sterility, 95(6), 1913–1916. doi:10.1016/j.fertnstert.2011.02.016 [PubMed: 21392750]

Coscia LA, Constantinescu S, Moritz MJ, Frank A, Ramirez CB, Maley WL, … & Armenti VT (2009). Report from the National Transplantation Pregnancy Registry (NTPR): Outcomes of pregnancy after transplantation. Clinical transplants, 103–122. [PubMed: 20524279]

Cystic Fibrosis Foundation. (2017) About cystic fibrosis. Retrieved from https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/

De Pinho JC, & Sauer MV (2014). Infertility and ART after transplantation. Best Practice & Research Clinical Obstetrics & Gynaecology, 28(8), 1235–1250. doi: 10.1016/j.bpobgyn.2014.07.017. [PubMed: 25240422]

Edenborough FP (2001). Women with cystic fibrosis and their potential for reproduction. Thorax, 56(8), 649–655. 10.1136/thorax.56.8.649 [PubMed: 11462069]

Hirshfeld-Cytron J, Gracia C, & Woodruff TK (2011). Nonmalignant diseases and treatments associated with primary ovarian failure: An expanded role for fertility preservation. Journal of Women's Health, 20(10), 1467–1477. doi:10.1089/jwh.2010.2625.

Holland AC, Walker DK, Ladores S, & Meneses K (2015). Fertility preservation for young cervical cancer survivors. Journal of Women's Healthcare, 3(2): 40–45.

Jukkala A, Meneses K, Azuero A, Cho J, & McNees P (2012). Development of the knowledge of fertility and fertility preservation scale. Nursing: Research and Reviews, 2, 1–7.

Kalucy E, Hordacre A-L, & Patterson S (2008). Going online: Experiences with a web survey. Australian Health Review, 32(2), 366–370. doi:10.1071/AH080366 [PubMed: 18447828]

Kazmerski TM, Gmelin T, Slocum B, Borrero S, & Miller E (2017). Attitudes and decision making related to pregnancy among young women with cystic fibrosis. Maternal and child health journal, 21(4), 818–824. [PubMed: 27531009]

Kazmerski TM, Sawicki GS, Miller E, Jones KA, Abebe KZ, Tuchman LK, … & Pilewski JM (2018). Sexual and reproductive health behaviors and experiences reported by young women with cystic fibrosis. Journal of Cystic Fibrosis, 17(1), 57–63. doi:10.1016/j.jcf.2017.07.017. [PubMed: 28774749]

Kumar A (2015). Review of the steps for development of quantitative research tools. Advanced Practice Nurse, 1,103. doi:10.4172/APN.1000103

Ladores S, Raju D, & Bray LA (2016). Fertility and reproductive health implications of targeted therapeutics for cystic fibrosis. Reproductive System and Sexual Disorders, 5(4): 1–10. doi:10.4172/2161-038X.1000194.

Qualtrics. (2019). Try the top-rated survey tool. https://www.qualtrics.com/research-core/

R Core Team (2019). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. http://www.R-project.org/.

Rattray J, & Jones MC (2007). Essential elements of questionnaire design and development. Journal of Clinical Nursing, 16(2), 234–243.

Simcox AM, Hewison J, Duff AJ, Morton AM, & Conway SP (2009). Decision-making about pregnancy for women with cystic fibrosis. British Journal of Health Psychology, 14(2), 323–342. [PubMed: 18718108]

Taber KS (2018). The use of Cronbach's alpha when developing and reporting research instruments in science education. Research in Science Education, 48(6), 1273–1296. 10.1007/s11165-016-9602-2

Woodard TL, Hoffman AS, Covarrubias LA, Holman D, Schover L, Bradford A, … & Volk RJ (2018). The Pathways fertility preservation decision aid website for women with cancer: Development and field testing. Journal of Cancer Survivorship, 12(1), 101–114. 10.1007/s11764-017-0649-5 [PubMed: 29034438]

Wu DW, Wilt J, & Restaino S (2007). Pregnancy after thoracic organ transplantation. In Seminars in perinatology (Vol. 31, No. 6, pp. 354–362). WB Saunders. [PubMed: 18063119]

Clinical Implications:

- Some individuals with cystic fibrosis (CF) may need to undergo fertility preservation (FP) procedures to have a biological child.

- Women's and gender-related health care providers should discuss FP with all individuals who are at risk for losing fertility due to disease process or medical treatment.

- The Knowledge of FP in Women with CF Instrument appears to be a valid and reliable 10-item instrument that can quickly measure FP knowledge to help clinicians identify knowledge gaps and tailor FP discussions to the unique needs of women with CF.

Callouts

Fertility preservation may be necessary for individuals with fertility difficulties as well as those with severe cystic fibrosis disease who may need to undergo lung transplantation but would like the opportunity to have a biological child post-transplantation

Due to the chronic nature of cystic fibrosis, health care providers can discuss fertility preservation options and procedures at several time points throughout adolescence and early adulthood

Table 1.

Knowledge of FP in Women with CF Instrument (KFP-WCFI)

How knowledgeable do you feel you are regarding each of the fertility and fertility preservation topics below? Please rank on a scale from 1 to 4 with 1 being not at all knowledgeable and 4 being very knowledgeable.

	1 Not at all knowledgeable	2 Slightly knowledgeable	3 Moderately knowledgeable	4 Very knowledgeable
Subscale- General Fertility Knowledge				
1. Fertility	◦	◦	◦	◦
2. Planning for pregnancy with CF	◦	◦	◦	◦
5. Assisted reproductive technology procedures (medical procedure to help you become pregnant)	◦	◦	◦	◦
6. Ovarian hyperstimulation (using medication to make ovaries work better)	◦	◦	◦	◦
7. Embryo cryopreservation (freezing an egg fertilized with sperm for future)	◦	◦	◦	◦
10. Referral to a fertility specialist	◦	◦	◦	◦
Subscale- Transplant-related Fertility Knowledge	◦	◦	◦	◦
3. Impact of immunosuppressive therapy (medicines taken after a lung transplant to prevent rejection of the lungs) on fertility and pregnancy	◦	◦	◦	◦
4. Reproductive options after transplant	◦	◦	◦	◦
8. Risks during pregnancy after transplant	◦	◦	◦	◦
9. Use of gestational surrogate (using another person to carry your fertilized egg)	◦	◦	◦	◦

Table 2.

Factor Loadings for the Confirmatory Factor Analysis

Item Number	Factor	
	1- General Fertility Knowledge	**2- Transplant-related Fertility Knowledge**
Item 1	**0.761**	
Item 2	**0.693**	0.234
Item 3		**0.402**
Item 4	0.160	**0.745**
Item 5	**0.811**	0.231
Item 6	**0.908**	
Item 7	**0.814**	0.110
Item 8		**0.716**
Item 9	0.206	**0.432**
Item 10	**0.725**	0.318

Table 3.

Characteristics of Study Sample

Characteristics	Participants (*N*=50)	
	n	*n%*
Age		
18–21	3	6
22–25	12	24
26–30	19	38
31–35	16	32
Marital Status		
Single/never married	17	34
Married	23	46
Divorced	3	6
Living with partner	7	14
Race		
White/Caucasian	48	96
Black/African American	0	0
Hispanic	1	2
American Indian or Alaskan Native	1	2
Other	0	0
Education		
Some high school or less	0	0
High school graduate or GED	4	8
Some college	16	32
Vocational school	2	4
College degree	22	44
Professional or graduate degree	6	12
Region		
Northeast	12	24
Mid-Atlantic	2	4
Southeast	25	50
Northwest	4	8
Midwest	3	6
Southwest	4	8
Self-assessed Health Status		
Excellent	7	14
Very Good	17	34
Good	13	26
Fair	13	26
Poor	0	0
Have an OB/GYN		
Yes	38	76

Characteristics	Participants (*N*=50)	
	n	*n%*
No	12	24
Ever Experienced a Pregnancy		
Yes	15	30
How did you become pregnant		
Naturally	9	60
Required Medical Help	6	40
No	35	70

Table 4.

Knowledge of FP in Women with CF Instrument (KFP-WCFI) Descriptive Statistics

10-item KFP-WCFI						
Scale	Cronbach's Alpha	Mean	SD	Minimum	Maximum	Score Range
Complete Scale 10-items	0.86	19.04	5.76	11	34	10–40
FP Subscale 6-items	0.91	12.96	4.89	7	24	6–24
Transplant Subscale 4-items	0.64	6.08	5.76	4	11	4–16