Sexual and Reproductive Health of Young Women With Cystic Fibrosis: A Concept Mapping Study

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ABSTRACT

OBJECTIVE: Adolescent and young adult (AYA) women with pediatric-onset chronic diseases, such as cystic fibrosis (CF), face disease-specific sexual and reproductive health (SRH) concerns. Using concept mapping (CM), this study aimed to identify the SRH topics and outcomes valued by AYA women with CF and their parents.

METHODS: Women with CF who were 13 to 30 years of age and parents of 13- to 30-year-old daughters with CF participated in an online CM study. Participants individually brainstormed, rated, and sorted SRH topics important for AYA women with CF. Using multidimensional scaling, hierarchical cluster analyses, and *t* tests to assess rating differences, multidisciplinary stakeholders interpreted results during in-person meetings.

RESULTS: Twenty-four participants (13 AYAs and 11 parents) generated 109 statements around SRH in CF; 88% completed rating and sorting. Sixteen stakeholders named 6 main clusters of concepts: fertility and pregnancy, deciding to have children, birth control, navigating life, sex, and gynecologic concerns. Participants rated birth control as highest in importance for adolescent women (mean = 3.9 ± 0.1 on a 5-point scale) and fertility and pregnancy as highest for young adult women (mean = 4.2 ± 0.04). Parents provided higher importance ratings for all clusters than patient participants. Stakeholders identified patient-centered outcomes for each cluster and focused on how to improve SRH knowledge, decision making, and patient-provider communication in the subspecialty setting.

CONCLUSIONS: Eliciting patient-centered outcomes using CM can inform improvements in the care of AYAs with pediatric-onset chronic diseases. The SRH topics and patient-centered outcomes identified in this study should inform enhancements to comprehensive clinical care delivery for these populations.

KEYWORDS: chronic disease management; concept mapping; cystic fibrosis; sexual and reproductive health

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WHAT'S NEW

Concept mapping (CM) allowed young women with cystic fibrosis and their parents to identify key sexual and reproductive health topics and patient-centered outcomes. Using CM to elicit patient and family perspectives can inform improvements in comprehensive healthcare.

MANY ADOLESCENT AND young adult (AYA) women with pediatric-onset chronic diseases have seen major improvements in their life expectancy and health outcomes over the past several decades.[1−3] As these women live longer and healthier lives, they increasingly face a variety of general and disease-specific concerns around their sexual and reproductive health (SRH).[4,5]

Cystic fibrosis (CF) is an example of a pediatric-onset chronic disease where AYA women face both general and disease-specific SRH concerns.[6] A recent multisite survey identified and compared SRH experiences and behaviors of 15- to 24-year-old women with CF to the general US population using data from the Centers for Disease Control and Prevention's National Survey for Family Growth.[7] Despite similar levels of sexual activity, AYA women with CF reported significantly lower contraceptive use, sexually transmitted infection (STI) testing, cervical screening, and pregnancy rates than the general US population. In addition, many young women reported disease-specific concerns, including pubertal delay, yeast

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infections due to frequent antibiotic use, urinary incontinence, and sexual dysfunction.[7] CF also impacts fertility and childbearing due to effects on cervical mucus and respiratory function during pregnancy.[6,8] AYA women with CF report experiencing major gaps in SRH care access and utilization.[9]

The American Academy of Pediatrics recommends that confidential SRH discussions and counseling be completed by primary care providers (PCPs) at yearly health maintenance visits beginning in adolescence for all patients.[10] Importantly, PCPs should not ignore this aspect of comprehensive care for AYA women with disabilities and should focus on it as a key piece of the transition of care to adulthood.[11,12]

However, when asked who they view as their "main physician," many AYA women with pediatric-onset chronic diseases (eg, CF and sickle cell disease) name their subspecialist as a de facto PCP and thus may not receive SRH care in a primary care setting.[13] Girls with CF also name their parents as key resources for SRH information.[14] Although prior work has shown that patients and providers view the CF multidisciplinary team as having a key role in SRH, this aspect of comprehensive care is not standardized and is rarely discussed in the CF care setting.[6,9]

A necessary step in improving SRH care is identification of the facets of SRH prioritized by AYA women with CF and their parents. Knowing what outcomes patients and parents consider important can help guide subspecialists in their SRH discussions and care. This study aimed to identify SRH topics and outcomes valued by AYA women with CF and their parents using a concept mapping (CM) approach. With this method, important concepts are generated around a particular theme, and stakeholders discuss their relevance for clinical practice and research.[15] CM has been used in programmatic planning and evaluation and increasingly in the exploration of complex interactions in health care.[16] Findings from this study may help guide development of future interventions to improve SRH care for AYA women with CF.

METHODS

CM is a semistructured, participatory research method that generally includes 3 steps: 1) brainstorming, 2) rating and sorting, and 3) interpretation.[15] We have detailed our chosen approach to the following CM methodology.

SETTING AND PARTICIPANTS

The principal investigator or a research coordinator recruited a convenience sample of AYA women with CF 13 to 30 years of age and parents with 13- to 30-year-old daughters with CF from the Boston Children's Hospital Cystic Fibrosis Center during hospitalization or a routine CF clinic visit to participate in the brainstorming and the rating and sorting steps. Given our interest in exploring a range of topics from puberty to pregnancy, we selected a wide age range, from the teens up to 30 years.[17] Participants utilized the online Global MAX software (Concept Systems, Ithaca, NY) to individually complete the brainstorming and the rating and sorting steps. Patients and parents participated separately and were not treated as dyads during recruitment. Each participant provided an electronic informed consent and completed a demographic survey; an honorarium of $30 was offered for completion of these steps. Typically in CM, participants who complete the brainstorming and the rating and sorting steps also meet to interpret results; however, due to infection control concerns and technology limitations, the patients were unable to participate in an in-person group meeting. Instead, and given our interest in exploring the implications of these patient-centered concerns with service delivery providers, a heterogeneous group of key stakeholders participated in an in-person interpretation meeting (including a patient and a parent who completed the prior steps). The stakeholder group included all major members of the multidisciplinary CF team (dietitians, social workers, physicians, and nurses). Figure 1 details the CM approach. The study was approved by the Institutional Review Board of Boston Children's Hospital (IRB #P00023462).

BRAINSTORMING

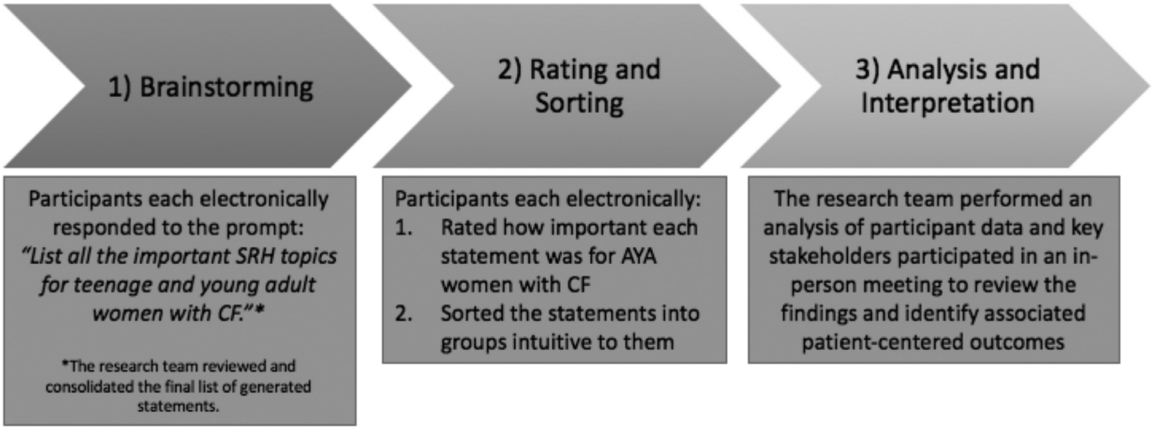
During brainstorming, participants individually responded to the following prompt: "List all the important SRH topics for teenage and young adult women with cystic fibrosis." After all participants had generated and submitted ideas, the research team consolidated all statements by eliminating duplicates and similar statements.

RATING AND SORTING

For the sorting activity, participants electronically sorted the refined list of brainstormed ideas into groups intuitive to them and provided a name for each group. They were instructed to assign each statement to only 1 group and to refrain from creating fewer than 3 groups or groups containing only 1 statement. Participants rated the importance of each SRH statement using a 5-point Likert scale, from 1 (relatively unimportant) to 5 (extremely important), for 2 populations: 1) adolescent women with CF (ages 13 to 17 years) and 2) young adult women with CF (ages 18 to 30 years).

ANALYSIS AND INTERPRETATION

The research team performed an analysis using the quantitative techniques of multidimensional scaling and hierarchical cluster analyses in the Concept Systems statistical package. Multidimensional scaling generated simple point maps wherein each statement was represented as a point on a map. Point proximity represents how often participants grouped certain statements together. Using hierarchical cluster analysis, boundaries were created between points that reflected similar concepts on a cluster map. The research team began with a 10-cluster solution and increased or decreased the number of clusters by 1 successively to identify a cluster configuration where



Participants each electronically responded to the prompt: *"List all the important SRH topics for teenage and young adult women with CF."**

*The research team reviewed and consolidated the final list of generated statements.

Participants each electronically:
1. Rated how important each statement was for AYA women with CF
2. Sorted the statements into groups intuitive to them

The research team performed an analysis of participant data and key stakeholders participated in an in-person meeting to review the findings and identify associated patient-centered outcomes

Figure 1. *Concept mapping approach. SRH indicates sexual and reproductive health; CF, cystic fibrosis; AYA, adolescent and young adult.*

separation or merger of clusters appropriately represented the data. After reviewing different configurations, the research team determined that a 6-cluster solution provided the optimal balance between sufficient detail and meaningful interpretation.

To visualize the SRH topic importance ratings, point and cluster maps illustrating variations were created. The overall rating of each cluster was derived from the mean of the participants' ratings of all statements in the cluster, and *t* tests were used to assess differences in cluster ratings of topics for young adult women with CF compared to adolescents. Finally, a rating bridge map was created to compare cluster rating differences between parent and patient participants.

During the interpretation session, stakeholders examined the individual statements, cluster content, and maps through group discussion facilitated by the principal investigator. Based on this evaluation, they provided cluster labels, identified outlier statements in clusters, and compared ratings of importance across participant groups through group discussion and consensus. Stakeholders also discussed and identified SRH patient-centered health outcomes relevant to each cluster. The research team verbally defined patient centeredness as "measurable outcomes viewed as important to patients and those who care for them" for the stakeholder group. A research assistant took written notes of the interpretation session discussions.

RESULTS

PARTICIPANTS

Twenty-four participants completed the brainstorming step: 13 young women with CF (mean age = 18.9 years; range, 14–26) and 11 parents (mean age = 50.9 years; range, 40–60). Rating and sorting of generated statements was completed by 88% of participants (21 of 24). Sixteen multidisciplinary stakeholders participated in the interpretation step: 4 CF physicians, 1 adolescent medicine physician, 3 CF social workers, 1 CF nurse practitioner, 1 CF dietitian, 1 young adult woman with CF, 1 parent of an adolescent woman with CF, 1 CF psychologist, and 3 research coordinators. Two of the participating CF physicians were male; the rest of the stakeholder group was female.

CLUSTER MAPS AND CONTENT

Participants generated 109 unique response statements to the brainstorming prompt. Six clusters of statements were ultimately drawn and named by the stakeholders: 1) fertility and pregnancy, 2) deciding to have children, 3) birth control, 4) navigating life, 5) sex, and 6) gynecologic concerns (Fig. 2). The stress value of this cluster configuration (with a lower value indicating better fit for the configuration[18]) was 0.22. The interpretation stakeholder group felt strongly on 5 of 6 primary clusters of items but less confident on the cohesiveness of the navigating life cluster. Statements contained in each cluster are presented in Supplementary Table S1 online.

The largest cluster was fertility and pregnancy (32 items). It included several subthemes identified by the research team: 1) fertility in CF (eg, physiologic mechanisms of decreased female fertility, options for fertility testing, discussion of fertility with health care providers and/or partners), 2) the interplay of pregnancy and CF (eg, effect of pregnancy on CF health, effect of CF on maternal-fetal health, CF disease parameters considered "safe" for pregnancy, effect of CF during unplanned pregnancies, abortions, role in miscarriage), 3) CF medication interactions or teratogenic effects (eg, antibiotics, mucolytics, antidepressants), and 4) options for becoming a parent (eg, fertility treatments, adoption, surrogacy).

The deciding to have children cluster (8 items) included statements pertaining primarily to the genetics of CF, including fetal genetic testing and CF carrier status. Additionally, participants included statements centered on the decision to have a family or pursue pregnancy and how to discuss this topic with partners. Stakeholders did not identify any major outliers in this cluster.

Birth control (15 items) included statements related to types and side effects of contraception, interactions between contraceptive methods and CF medications

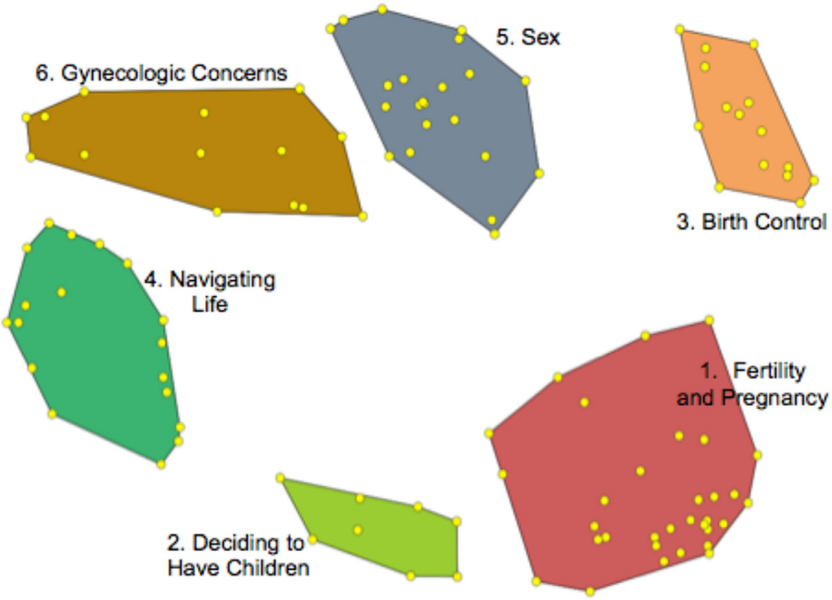


Figure 2. *Cluster map: 6 clusters of participant-generated statements and named by key stakeholders.*

(including new CF transmembrane conductance regulator modulator therapies), and emergency contraception. Although many statements focused on personalized contraceptive choice, stakeholders identified that participants did not include the noncontraceptive benefits of contraceptives (ie, for gynecologic concerns or as a treatment modality for potential negative effects of female hormonal shifts on CF health).

The navigating life cluster (18 items) was subtitled "adulting" by stakeholders during the interpretation meeting. Adulting is defined by the *Oxford Dictionary* as "the practice of behaving in a way characteristic of a responsible adult, especially the accomplishment of mundane but necessary tasks."[19] A major subtheme of this cluster focused on relationships and included disclosure of CF status and discussion of CF complications with partners and decisions to marry and/or have a family as someone with CF. Several statements raised questions around how to deal with the ambiguity about life expectancy in CF, or, as a stakeholder in the interpretation session articulated, "Do I have a 401 (k) or do I just spend the money?" Other statements raised questions around balancing aspects of teen life and CF, such as school, major social events (eg, prom), and experimentation with drugs and alcohol. The effect of CF on puberty was included in this cluster and was felt by stakeholders to be an outlier. It was theorized during the interpretation step that its inclusion might have been the result of the older ages of participants, who viewed puberty as a past issue and something that they had already dealt with.

The sex cluster had 22 items, and subthemes included 1) STIs, 2) sexual functioning (ie, general sexual desire/fulfillment and CF-specific concerns, including coughing, hemoptysis, and presence of a gastrostomy tube), 3) the human papillomavirus vaccine, and 4) discussing sexual functioning with partners. Stakeholders commented on how specific accommodations for those with CF, such as information about sexual positions that improved dyspnea during sex, were highlighted.

The final cluster, gynecologic concerns, had 14 items and included statements regarding the effects of hormonal shifts on CF symptoms, yeast infections, and menstrual periods. Several items on sexuality, sexual orientation, and sexual functioning were felt to be outliers and fit more appropriately in the sex cluster.

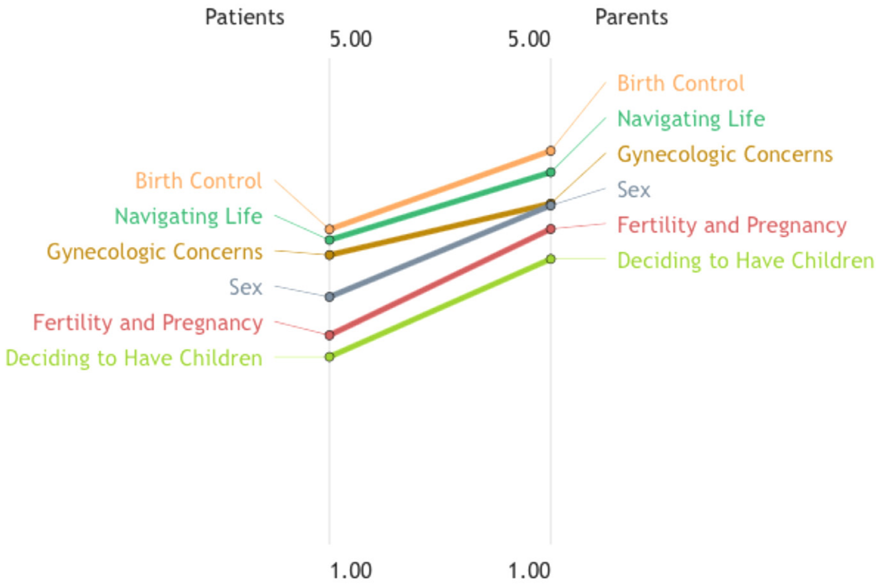
CLUSTER RATING

Participants rated the birth control cluster highest in importance for 13- to 17-year-old adolescent women with CF (mean rating = 3.9 ± 0.1 of 5). Navigating life was also rated highly for this group (mean = 3.8 ± 0.22). The remaining clusters were rated as follows: gynecologic concerns, mean = 3.6 ± 0.13; sex, mean = 3.4 ± 0.18; fertility and pregnancy, mean = 3.2 ± 0.02; and deciding to have children, mean = 3.0 ± 0.13.

Participants rated the fertility and pregnancy cluster highest in importance for 18- to 30-year-old young adult women with CF (mean rating = 4.2 ± 0.04 of 5). Also ranked highly by all participants were deciding to have children (mean = 4.0 ± 0.03) and birth control (mean = 4.1 ± 0.03). The remaining clusters received the following mean ratings: navigating life, mean = 3.7 ± 0.24; sex, mean = 3.6 ± 0.08; and gynecologic concerns, mean = 3.4 ± 0.29.

The fertility and pregnancy and the deciding to have children clusters were viewed by all participants as significantly more important for young adult women with CF compared to adolescents (both with $P < .001$). Compared to patient participants, parents provided higher average

For Adolescent Women:



For Young Adult Women:

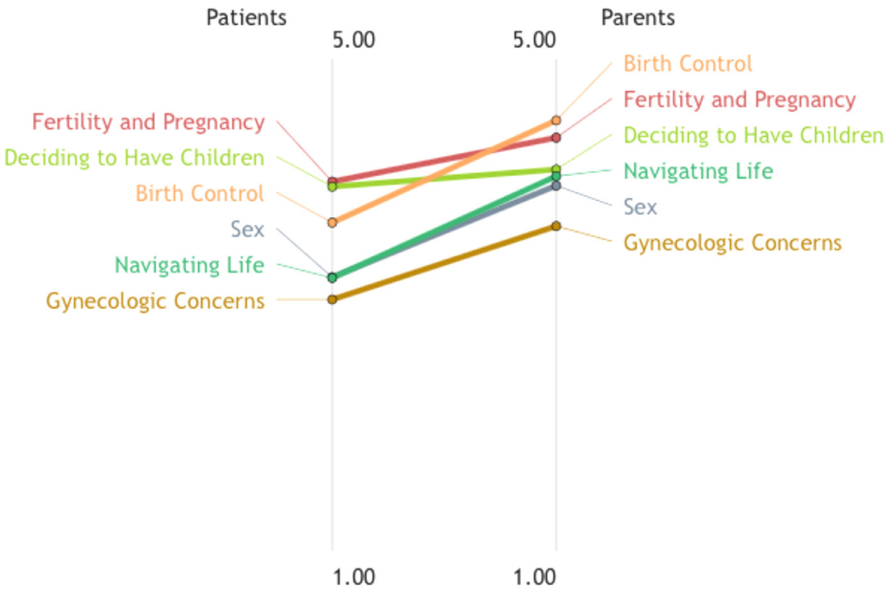


Figure 3. *Cluster ratings for adolescent and young adult women with cystic fibrosis by participant group (with 1 being "not at all important" and 5 being "very important" to address).*

importance ratings for all 6 clusters for both adolescents and young adults (Fig. 3).

SRH PATIENT-CENTERED OUTCOMES

During the interpretation meeting, stakeholders identified numerous potential patient-centered outcomes for each cluster (Table 1). For all clusters, improved SRH knowledge and the ability to make informed SRH decisions were viewed as major outcomes for AYA women with CF. An additional focus included the importance of enhancing the frequency and quality of patient-provider communication around SRH and shared decision making in the CF care setting. For the fertility and pregnancy cluster, stakeholders identified pregnancy testing, the need for fertility testing and/or treatments, receipt of tailored preconception counseling, and routine assessment of patients' family planning desires as important outcomes. Stakeholders also believed patients' ability to talk with partners, family, and friends regarding decisions to have children was important.

Contraceptive use, receipt of contraceptive counseling, pregnancy rates, and pregnancy outcomes were viewed as important outcomes related to the birth control cluster. Stakeholders named a range of outcomes related to the navigating life cluster, including rates of depression and anxiety, substance use and abuse, patient satisfaction regarding SRH care, transition readiness, and quality of life. STI testing, counseling, prevalence, and treatment rates and measures of SRH care utilization, including

Table 1. Patient-Centered Outcome Clusters Identified by Stakeholders

General
- Patient knowledge regarding general and CF-specific SRH concerns
- Patient ability to make informed SRH decisions
- Patient-provider communication around SRH in the CF setting
- Shared decision making around SRH in the CF setting

1. Fertility and pregnancy
- Pregnancy testing
- Need for fertility testing and/or fertility treatments
- Receipt of tailored preconception counseling
- Routine assessment of patients' family planning desires

2. Deciding to have children
- Detailed patient knowledge regarding CF genetics and genetic testing
- Patient ability to talk with partners, family, and friends regarding decisions to have children

3. Birth control
- Contraceptive use
- Receipt of contraceptive counseling
- Pregnancy rates and outcomes

4. Navigating life
- Rates of depression and anxiety
- Substance use and abuse
- Patient satisfaction regarding SRH care
- Transition readiness
- Quality of life

5. Sex
- STI testing and counseling
- STI prevalence and treatment rates
- HPV vaccination rates
- Receipt of SRH care services by health care providers (CF setting, obstetricians/gynecologists, adolescent medicine specialists, primary care providers)

6. Gynecologic concerns
- Vulvovaginal candidiasis patient burden and treatment rates
- Urinary incontinence patient burden and treatment rates

CF indicates cystic fibrosis; SRH, sexual and reproductive health; STI, sexually transmitted infection; and HPV, human papillomavirus.

delivery of SRH care by PCPs or women's health specialists, were viewed as important outcomes for the sex cluster. Treatment and patient burden of yeast infections and urinary incontinence were viewed as important outcomes related to gynecologic concerns.

DISCUSSION

CM is a novel and powerful tool that can be used to generate patient-centered concerns and to inform improvements in the complex care of patients with pediatric-onset chronic diseases. Using this method, AYA women with CF and parents identified a multitude of important SRH topics ranging from general to highly specific CF-related concerns. Both patient and parent groups rated these topics as important to address in AYA women with CF, with parents assigning overall greater importance to all SRH topics identified. During the interpretation step, stakeholders generated a variety of patient-centered outcomes related to specific SRH topics and highlighted the importance of improving overall knowledge, decision making, and patient-provider communication around SRH in the subspecialty setting.

CM encourages shared understanding among participants as they contribute to data generation, analyses, and interpretation alongside the researcher.[20,21] CM has been used in a variety of settings to further explore health concerns and design interventions, including public health initiatives. CM can be an important tool in the co-production of health care during which patients, families, and providers are invited to directly participate in the design and delivery of services.[22] Through the interpretation, both provider and patient stakeholders can help uncover mechanisms underlying complex health problems and collaborate in the design of innovative and practical policies and solutions. This process can be extremely helpful when attempting to address novel aspects of care, such as SRH, with health care providers who do not routinely discuss such issues.

In our study, participants appeared to be future oriented, as many statements were generated around fertility and pregnancy and deciding to have children. Consistent with our findings, reproductive planning is challenging and highly valued among AYA women with a variety of chronic health conditions.[23,24] Recent advances in therapeutics and care have increased optimism for the CF community,[25] but they have also led to increased uncertainty around individual life expectancy for many AYA patients. With new medications that improve survival and quality of life, many may find it difficult to plan further ahead than once anticipated. This uncertainty extends to SRH and reproductive planning and may even be heightened by the lack of discussion of these concerns by CF care teams.[26]

Participants viewed SRH as a key part of emerging adulthood and assigned high importance ratings to navigating life, or adulting. This is not surprising, as SRH services are often the first type of health care that many adolescents seek independently (eg, for contraception, STI or pregnancy testing, general gynecologic care). However, as noted earlier, AYA women with CF may selectively seek care with their subspecialist.[13] Thus, the multidisciplinary CF care team should serve a central role in coordinating SRH care delivery with PCPs and women's health specialists. Building collaborative models that harness the expertise of all health care providers may help with SRH education, outcomes, and the transition process.[6,27] Optimizing SRH care for those with pediatric-onset chronic disease may lead to improvements in this population's overall transition readiness and ownership over other disease-specific aspects of their health.

This study generated key SRH patient-centered outcomes for this population. Development of patient educational resources for AYA women with CF is ongoing, and content can be supplemented by targeting outcomes identified in this work.[28] Adult women with CF have also clearly stated that they desire tailored discussions around SRH concerns; results of this study reaffirm the importance of patient-provider communication and shared decision making related to SRH. Unfortunately, adolescent-physician communication regarding SRH is infrequent[29] and is rarely addressed by subspecialists.[30,31] A national survey of subspecialty providers found a significant discrepancy between the level of importance given to many SRH topics and routine discussions with AYA female patients with CF in clinical practice.[32]

This study has several limitations. First, this is a single-site, exploratory study and may not be generalizable. The locality of the study may limit the transferability of findings to other settings, such as different countries or regions of the United States. The richness of responses in the brainstorming and the rating and sorting steps may have been reduced due to the inability to conduct in-person sessions because of infection control. That said, CM studies often include the use of an electronic platform in the first 2 stages to allow more individuals to participate and to encourage generation of a range of ideas, which may be less likely to emerge in a live discussion. As participation in the interpretation session was similarly constrained, it is likely that the range of possible perspectives of AYA women with CF and their parents may not be fully captured in these findings. Multidisciplinary providers only participated during the interpretation meeting and thus did not offer their perspectives regarding SRH topic generation or rating. This study also did not ask participants to assess the feasibility of integrating generated SRH topics into CF care. Nevertheless, CM is a unique approach that combines qualitative data with quantitative analysis and visual maps for participant feedback. This method allowed for the identification of a variety of SRH topics of vital importance to CF patients and their parents and facilitated discussion about a rarely discussed, but increasingly important, aspect of CF care.

Optimal patient-provider communication and shared decision making require all participants to be informed of general and disease-specific SRH concerns.[33] An important next step is to engage the range of health care providers for this population (CF subspecialists, women's health providers, and PCPs) and identify factors crucial to improving SRH care delivery that take these patient-centered outcomes into account. These may include education of both PCPs and subspecialists with regard to the unique SRH concerns faced by AYA women with CF, the development of communication skills around discussing SRH (including shared decision making), and systemic changes necessary to provide SRH care in the subspecialty setting. Patient, parent, and provider stakeholders should be key informants in the development of future health service delivery interventions that address SRH as a part of CF care. In addition, parental resources on this topic are needed and should also be informed by key stakeholders. Using CF as a model, future projects should strive to enhance communication and improve SRH care delivery between AYA patients with a variety of pediatric-onset chronic diseases and their PCPs, subspecialty providers, and parents.

SRH is complicated for patients with pediatric-onset chronic disease. Understanding what stakeholders value is an important first step in designing improved interventions or care delivery models. This CM study identified SRH concerns and outcomes shared by AYA women with CF and parents. Results can be used to guide the content and focus of future SRH interventions and scientific inquiries.

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at https://doi:10.1016/j.acap.2018.08.011.

REFERENCES

1. Cystic Fibrosis Foundation. *Cystic Fibrosis Foundation Patient Registry: 2012 Annual Data Report*. Bethesda, Md: Cystic Fibrosis Foundation; 2014.
2. Ivy DD, Abman SH, Barst RJ, et al. Pediatric pulmonary hypertension. *J Am Coll Cardiol*. 2013;62:D117–D126.
3. Strauss D, Shavelle R, Reynolds R, et al. Survival in cerebral palsy in the last 20 years: signs of improvement? *Dev Med Child Neurol*. 2007;49:86–92.
4. Finer LB, Zolna MR. Shifts in intended and unintended pregnancies in the United States, 2001−2008. *Am J Public Health*. 2014;104 (suppl 1):S43–S48.
5. Centers for Disease Control and Prevention. *2010 Sexually Transmitted Disease Surveillance: STDs in Adolescents and Young Adults*. Atlanta, Ga: Centers for Disease Control and Prevention; 2010.
6. Frayman KB, Sawyer SM. Sexual and reproductive health in cystic fibrosis: a life-course perspective. *Lancet Respir Med*. 2015;3:70–86.
7. Kazmerski TM, Sawicki GS, Miller E, et al. Sexual and reproductive health behaviors and experiences reported by young women with cystic fibrosis. *J Cyst Fibros*. 2018;17:57–63.
8. Goss CH, Rubenfeld GD, Otto K, et al. The effect of pregnancy on survival in women with cystic fibrosis. *Chest*. 2003;124:1460–1468.
9. Kazmerski TM, Sawicki GS, Miller E, et al. Sexual and reproductive health care utilization and preferences reported by young women with cystic fibrosis. *J Cyst Fibros*. 2018;17:64–70.
10. Breuner CC, Mattson G, Committee on Adolescenceet al. Sexuality education for children and adolescents. *Pediatrics*. 2016;138: e20161348.
11. Houtrow AJ. Addressing the sexual health needs of youth with disabilities. *AAP News*. 2014;35:15.
12. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128:182–200.
13. Britto MT, Garrett JM, Dugliss MA, et al. Preventive services received by adolescents with cystic fibrosis and sickle cell disease. *Arch Pediatr Adolesc Med*. 1999;153:27–32.
14. Nixon GM, Glazner JA, Martin JM, et al. Female sexual health care in cystic fibrosis. *Arch Dis Child*. 2003;88:265–266.
15. Kane M, Trochim W. *Concept Mapping for Planning and Evaluation*. Thousand Oaks, Calif: Sage Publications; 2007.
16. Trochim WMK. An introduction to concept mapping for planning and evaluation. *Eval Program Plann*. 1989;12:1–16.
17. Hardin AP, Hackell JM. Committee on Practice and Ambulatory Medicine. Age limit of pediatrics. *Pediatrics*. 2017;140:e20172151.
18. Trochim WMK. Pattern matching, validity, and conceptualization in program evaluation. *Eval Rev*. 1985;9:575–604.
19. Oxford Dictionary. Adulting. Available at: https://en.oxforddictionaries.com/definition/adulting. Accessed January 7, 2018.
20. Burke JG, O'Campo P, Peak GL, et al. An introduction to concept mapping as a participatory public health research methodology. *Qual Health Res*. 2005;15:1392–1410.
21. O'Campo P, Burke J, Peak GL, et al. Uncovering neighborhood influences on intimate partner violence using concept mapping. *J Epidemiol Community Health*. 2005;59:603–608.
22. Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf*. 2016;25:509–517.
23. Tong A, Brown MA, Winkelmayer WC, et al. Perspectives on pregnancy in women with CKD: a semistructured interview study. *Am J Kidney Dis*. 2015: 951–961. 66.

24. Lateef A, Petri M. Systemic lupus erythematosus and pregnancy. *Rheum Dis Clin North Am.* 2017;43:215–226.
25. Kazmerski T, Gmelin T, Slocum B, et al. Attitudes and decision making related to pregnancy in young women with cystic fibrosis. *Matern Child Health J.* 2017;21:818–824.
26. Pollack A. F.D.A. approves new cystic fibrosis drug. *New York Times.* February 1, 2012, B2.
27. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics.* 2002;110:1315–1321.
28. Kazmerski TM, Hill K, Prushinskaya O, et al. Perspectives of young women with cystic fibrosis and parents on sexual and reproductive health educational resources. *Pediatr Pulmonol*. doi:10.1002/ppul.24015.
29. Fuzzell L, Shields CG, Alexander SC, et al. Physicians talking about sex, sexuality, and protection with adolescents. *J Adolesc Health.* 2017;61:6–23.
30. Ashoor IF, Dharnidharka VR. Sexually transmitted infection screening and reproductive health counseling in adolescent renal transplant recipients: perceptions and practice patterns. A study from the Midwest Pediatric Nephrology Consortium. *Pediatr Transplant.* 2015;19:704–708.
31. Gray SH, Wylie M, Bloom Z, et al. Reproductive health education received by women with cerebral palsy. *J Pediatr Adolesc Gynecol.* 2017;30:286–287.
32. Kazmerski T, Borrero S, Sawicki GS, et al. Provider attitudes and practices toward sexual and reproductive health care for young women with cystic fibrosis. *J Pediatr Adolesc Gynecol*. 2017;30:546–552.
33. Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med.* 2012;366:780–781.