

Development and Validation of a Scale to Measure Person-Centered Care in Fetal Care Centers

Abigail Wilpers^{a,b} Marney White^{c,d} Mary T. Austin^e Mert Ozan Bahtiyar^{f,g}
Katie Francis^h Stephen P. Emeryⁱ Diane Wall^{f,g} Lonnie Somers^j
Charlotte Wool^k

^aDepartment of Family and Community Health, University of Pennsylvania School of Nursing, Philadelphia, PA, USA; ^bResearch Institute, Children's Hospital of Philadelphia, Philadelphia, PA, USA; ^cDepartment of Psychiatry, Yale School of Medicine, New Haven, CT, USA; ^dDepartment of Social and Behavioral Sciences, Yale School of Public Health, New Haven, CT, USA; ^eDepartment of Pediatric Surgery, McGovern Medical School, University of Texas Health Science Center, Houston, TX, USA; ^fDepartment of Obstetrics, Gynecology, and Reproductive Sciences, Yale School of Medicine, New Haven, CT, USA; ^gFetal Care Center, Yale New Haven Hospital, New Haven, CT, USA; ^hSt. Louis Fetal Care Institute, SSM Health Cardinal Glennon Children's Hospital, St. Louis, MO, USA; ⁱDepartment of Obstetrics, Gynecology, and Reproductive Sciences, University of Pittsburgh, Pittsburgh, PA, USA; ^jFetal Health Foundation, Littleton, CO, USA; ^kSchool of Nursing and Health Professionals, York College of Pennsylvania, Philadelphia, PA, USA

Keywords

Fetal diagnosis · Fetal care center · Perinatal care · Reproductive health · Scale development · Delphi study

Abstract

Introduction: Fetal care centers (FCCs) in the USA lack a standardized instrument to measure person-centered care. This study aimed to develop and validate the Person-Centered Care in Fetal Care Centers (PCC-FCC) Scale. **Methods:** Initial items were developed based on literature and input from clinicians and former patients. A Delphi study involving 16 experts was conducted to validate the content and construct. Through three rounds of online questionnaires using open-ended questions and Likert scales, consensus on item clarity and relevancy was established. The resulting items were then piloted with former fetal care

center patients via a web-based survey. The instrument's reliability and validity were validated using Cronbach's α and exploratory factor analysis, respectively. Concurrent validity was assessed by comparing scores with the Revised Patient Perception of Patient-Centeredness (PPPC-R) Questionnaire. **Results:** 258 participants completed the 48-item pilot PCC-FCC survey, categorized into six domains. Factor analysis yielded a 2-factor, 28-item scale. Internal consistency of the final scale had good reliability ($\alpha = 0.969$). Data supported content, construct, and concurrent validity. **Conclusion:** The PCC-FCC Scale is a reliable and valid measure of person-centered care in U.S. FCCs. It can be used to enhance services and begin connecting person-centered care to maternal-child health outcomes.

© 2024 S. Karger AG, Basel

Introduction

Person-centered care is essential to achieving positive care experiences and optimal health outcomes in maternal-child care [1, 2]. Person-centered care is defined by The National Academy of Medicine as care that is “respectful of and responsive to individual people’s and their families’ preferences, needs, and values” [1]. Recently, researchers have identified gaps in the delivery of person-centered care in specialized fetal diagnosis and treatment settings [3–5].

The discovery of severe and complex fetal conditions, such as congenital heart disease, can be a traumatic and life-changing experience for pregnant women and their families [6]. Over the last four decades, fetal care centers (FCCs) have evolved to serve this patient population [7]. Although the outcome of care may not always be the discharge of a healthy baby, it is still possible to have a positive care experience, which can help individuals cope with their grief, set realistic expectations, and actively participate in their care [3]. However, a growing body of qualitative research has identified FCC experiences that left patients and families feeling confused, disrespected, or abandoned [3–5]. For example, Eyerly-Webb et al. [5] conducted a prospective multicenter qualitative patient experience study at three FCCs and found that the transition from prenatal to postnatal care was a pain point for many patients. As one of their participants said of her care post-birth, “Where are my [fetal care center] doctors? Why am I not seeing my doctors? I needed closure. I lost my baby, I lost my care team, I lost everything that we were building up for” (page 16) [5]. These findings and other concerns about person-centered care (e.g., access to abortion care, inconsistent messaging from large multidisciplinary teams) were echoed in a recent metasynthesis on patients’ experiences in FCCs [3]. These preliminary warning signs merit further investigation into the delivery of person-centered care in these relatively new and growing specialized high-risk settings.

Building upon this foundation of qualitative evidence, standardized quantitative measures of person-centered care in FCCs will generate comprehensive and generalizable evidence to improve care. A standardized instrument will enable monitoring experiences across different populations and settings over time and allow for the measurement of patient experiences as predictors of health outcomes [8, 9]. An instrument focused on capturing the quality of person-centered care in FCCs will also enable the investigation of health disparities that may be experienced by marginalized individuals [10, 11].

The concepts of person-centered perinatal care are incorporated in scales such as the Person-Centered Maternity Care Scale (PCMC) and the Person-Centered Prenatal Care scale for People of Color (PCPC) [8, 11]. While scales like the PCMC and the PCPC measure certain aspects of person-centered perinatal care, they may not fully capture the unique complexities of patients’ experiences in FCCs, where care involves collaboration with large, multidisciplinary specialist teams, and the intense focus on the fetal condition may impact the overall patient experience. There is a need for a comprehensive instrument that includes all aspects of person-centered care tailored for pregnant women receiving care from specialized fetal diagnosis and treatment centers. The purpose of this research is to generate a psychometrically sound instrument that identifies and measures quality indicators of person-centered care in FCCs across the USA.

Materials and Methods

About Our Language

We use terminology such as “pregnant women” throughout our paper to indicate sex (a reproductive category), rather than gender identity (an inner sense of self) [12, 13]. Our sexed language is meant to be respectful and inclusive of all individuals who experience a pregnancy complicated by a fetal condition, while acknowledging the significant implications to desexing language when referring to reproductive care [14]. We recognize that not all people with the capacity for pregnancy identify as women and recommend addressing individuals with their preferred terms for gender identity [15].

Study Design

Developing an instrument is an iterative, multistep, and multimethod process [16]. In this research, we approached it in two distinct phases: (1) initial item generation and a Delphi study to establish content validity, and (2) a pilot study to conduct psychometric evaluation of the instrument.

Initial Item Generation

In scale development, the process of determining which items (i.e., survey questions) to include begins with identifying the content domain. This involves specifying the aspects of a concept that the instrument aims to assess, essentially defining the boundaries of exploration for the scale. We defined an FCC as a multidisciplinary practice specialized in providing coordinated fetal diagnosis and consultations for pregnant women in a tertiary care setting. Next, we drew from the National Academy of Medicine’s defining characteristics of person-centered care and the World Health Organization’s (WHO) dimensions of care experience in their vision for quality of maternal and newborn health [1, 2]. We also examined existing perinatal person-centered care scales [8–11, 17], relevant health policy [18], FCC guidelines [7, 19, 20], and qualitative evidence from FCC patients’ about their care

experiences [3–5, 21–23]. This qualitative evidence represented the voices of over 250 FCC patients. These data were reviewed and organized by our interprofessional and multidisciplinary research team, which included FCC leaders from across the USA and a coinvestigator with lived experience who cofounded and leads the Fetal Health Foundation (FHF) – a 501(c)(3) nonprofit charity that provides medical information and unconditional support to families dealing with fetal conditions (FHF, 2018). Data were examined for relevance to patient-level measurements (i.e., measurements that rely on parents' self-report). This kind of measurement does not include clinical outcomes, clinician- or administrator-level measures, or systems-level measures.

The goal is for this instrument to be suitable for as many FCC models of care as possible (e.g., adult hospital-based, children's hospital-based, free-standing, etc.). Based on the literature and our team's clinical experience, the most shared services across FCCs are coordinated diagnostic care, interprofessional and multidisciplinary specialist consultations, care planning (from the prenatal to the postnatal period), and prenatal treatments (i.e., medical and surgical fetal therapy) [24]. Therefore, our item generation focused on those services and included only a few broader questions outside this scope. After an iterative process of item generation and discussion, we concluded this process with 51 initial items designed by the research team. All items are at the sixth-grade level as scored in the Flesch-Kincaid readability test. We concluded that the instrument should be administered at the conclusion of FCC care (i.e., discharge from the hospital, or transfer of care back to local prenatal provider).

Content Validity – The Delphi Study Design

We employed the Delphi method to achieve consensus from experts, ensuring that both individual items and the overall instrument possess content validity – a measure of how well the items represent the intended construct [25]. The Delphi method involves gathering data from a panel of diverse experts through multiple rounds to reach consensus [26].

Sample

We aimed to recruit a panel of experts with lived and professional experience [27]. Experts with lived experience represented members of the instrument's target population (patients of FCCs) who have familiarity with the construct through direct personal experience. We aimed to recruit one person to represent each of the following types of FCC care experiences: maternal-fetal surgery, postnatal/neonatal intervention, and perinatal palliative care (i.e., prenatal care in the setting of a life-limiting fetal anomaly). Former FCC patients were eligible for the panel if they received care in the USA between 1 and 5 years prior, were over the age of 18, regularly accessible via email, and possessed sufficient knowledge of the English language. Lived experience panelists were recruited via email by the Director of Patient Services (DPS) at the FHF.

Professional experts represented fetal diagnosis and management specialists with recognized clinical, research, and/or community advocacy expertise from major fetal diagnosis and treatment centers across the USA. We used maximum variation sampling to recruit a professional expert panel to represent the foundational composition of an FCC including experts in maternal-fetal medicine, nursing, pediatric surgery, pediatric

subspecialties, neonatology, psychosocial care, genetic counseling, and FCC administration. In addition, we aimed to recruit at least one community advocacy expert, such as a leader in a nonprofit organization dedicated to supporting people and families who experienced fetal complications. Professional expert panelists were recruited via the North American Fetal Therapy Network and the Fetal Therapy Nurse Network.

Potential participants were contacted via email and provided with further information about the study. Written informed consent took place through Qualtrics software (2018, Provo, UT) on a secure internet site. We collected no identifying participant information, and there was minimal to no risk to the participants; thus, the research was deemed exempt from [institution masked for blind review] Institutional Review Board review (Protocol ID 2000031494). No compensation was provided to participants.

Data Collection and Analysis

We collected data in three consecutive rounds via Qualtrics questionnaires that were emailed to panelists through a secured electronic link. In each round, panelists were oriented to the instrument (e.g., where, when, how, why would it be used) and provided definitions of key words and concepts (e.g., FCC, person-centered care). Round 1 was designed to elicit qualitative data in response to the initial 51-items. We requested that panelists share their feedback including whether any concepts were missing from our initial items. Content analysis was used to examine, organize, and present Round 1 findings to the research team for discussion, item revision, and approval of newly generated items.

In Round 2, we asked panelists to vote on whether each item was relevant (yes/no) and clear (yes/no). Comment boxes were provided after each item for additional explanation of panelists' feedback. We calculated item-level content validity index (I-CVI), which expresses the proportion of agreement on the relevancy and clarity of each item between zero and one and is calculated by dividing the number of experts voting yes on each item by the total number of experts on the panel [28]. Consensus that an item was relevant and clear was defined as an I-CVI higher than 79% – a widely accepted cutoff for scale development and Delphi studies [29]. Items were revised for clarity if they scored an I-CVI of less than 80% or panelists' comments indicated the need for modification. If items scored an I-CVI of less than 70% on relevance, they were removed from the scale.

In Round 3, we sent panelists the items that required modification from Round 2. Panelists were able to see the original item, the revised item, panelists' comments (anonymized), and the I-CVIs from Round 2. They were then given the opportunity to vote again on item relevance and clarity and were given space to comment. The same process from Round 2 was used to determine the final items included in the instrument.

Psychometric Evaluation – The Pilot Study Sample

We aimed to recruit a pilot sample of approximately 250–500 participants (5–10 respondents per item) [30]. Through convenience sampling, we recruited female individuals who experienced care at an FCC in the USA between 2017 and 2021 and were over the age of 18, had access to the internet, and were able to read English. Inclusion criteria were purposefully broad to capture the largest sample possible.

Notices recruiting former patients were placed on Internet discussion boards, blogs, informational websites, social media, and online support communities relevant to fetal diagnosis and treatment (e.g., The FHF, The Spina Bifida Association). Study information was also sent through the North American Fetal Therapy Network and Fetal Therapy Nurse Network so that members of these groups could help advertise the study at their sites or engage in targeted recruitment. A total of eight sites contributed to targeted recruitment (UPMC Magee-Women's Hospital; Riley Children's; Miller Children's & Women's Hospital Long Beach; University of California, Davis; Children's Minnesota; Children's Mercy Kansas City; Yale New Haven Health; and Children's Wisconsin). Targeted recruitment involved screening electronic medical records to identify eligible former patients who were then directly notified about the study via email, phone call, letter, or MyChart messaging. Internal Review Board approval was obtained from [blinded for review] and approval or exemption was obtained from sites participating in targeted recruitment (protocol # 2000032383). No compensation was provided to participants.

Data Collection and Analysis

Data were collected at a single time-point for each participant via secure web-based self-administered survey on Qualtrics. Study information was provided to potential participants on the initial page of the survey. A participant screening tool was used to determine eligibility, including a comprehensive list of sites that met our definition of an FCC. Written informed consent was then obtained followed by a sociodemographic questionnaire. Participants then completed the pilot Person-Centered Care in Fetal Care Centers (PCC-FCC) survey. Participants answered questions from the PCC-FCC on a Likert scale (1 = disagree strongly, 2 = disagree, 3 = agree, 4 = agree strongly) and were also given an option of "does not apply." The majority of the survey items were framed positively (e.g., "I felt satisfied with . . .") and so higher Likert responses represented a higher degree of person-centered care. Finally, to gather evidence toward concurrent validity, participants completed the Revised Patient Perception of Patient-Centeredness (PPPC-R) Questionnaire [31]. The PPPC-R is an 18-item validated instrument used to measure patients' perception of patient-centeredness in care. The PPPC-R has been used in studies with primary care populations and with specialized patient populations in the USA and internationally. The reliability of the questionnaire, as indicated by Cronbach α values, was found to be high in these studies [31].

Fit indices were examined to confirm that the data were appropriate for analysis. Exploratory factor analysis (EFA) was conducted to reduce the items to smaller subsets of measurement variables (i.e., factors) and establish construct validity. EFA is a way to find patterns in the data that help group similar items together and understand which factors, or underlying ideas, are most important [16]. Cronbach's α was used to assess internal reliability of the factors and the overall instrument. Cronbach's α ranges between 0 and 1, where higher values indicate greater internal consistency [16]. To establish concurrent validity, or the extent to which the instrument's scores correlate with an established external criterion of the same construct assessed simultaneously, we used Pearson's correlation coefficient to identify

Table 1. Delphi panelist characteristics

Characteristics	n (%)
Role	
Lived-experience experts (n = 4)	
Former patient and advocacy leader	2
Former patient	2
Professional experts (n = 12)	
Advanced practice provider – CNM*	1
Advanced practice provider – PA**	1
Genetic counselor	1
MD – maternal-fetal medicine	2
MD – pediatric surgery	2
MD – pediatric cardiology	1
MD – neonatology	1
RN – care coordinator	1
RN – administrator	1
Social worker	1
Gender	
Female	13 (81)
Male	3 (19)
Race and ethnicity	
Asian	1 (6)
Black or African American	4 (25)
Hispanic or Latino	1 (6)
Non-Hispanic White	10 (63)
Region	
Midwest	5 (31)
Northeast	4 (25)
Southeast	2 (13)
Southwest	3 (18)
West	2 (13)
*CNM, certified nurse midwife. **PA, physician assistant.	

correlation between our total score and the total score of the Revised Patient Perception of Patient-Centeredness (PPPC-R) Questionnaire.

Results

The Delphi Study

We conducted the Delphi study from June 2021 to September 2021. Our panel was comprised of four experts with lived experience and 12 experts with professional experience. Panelists represented experience and recognized expertise from at least 12 different major FCCs across the USA. The characteristics of our panel can be seen in Table 1.

All panelists participated in Round 1 and provided qualitative feedback on the initial 51 items. Based on panelist feedback, items were revised and additional

Table 2. Pilot PCC-FCC survey

Survey questions
FCC referral and access
1. My prenatal care provider/s helped me understand why I was referred to the FCC <i>Prenatal care providers may be the physician (e.g., obstetrician or maternal-fetal medicine specialist) or the advanced practice nurse (e.g., midwife) who provided prenatal care prior to your FCC visit</i>
2. Someone from my prenatal care providers' office helped me get an appointment with the FCC If you contacted the FCC yourself (without a referral), please respond to question #3. Otherwise select NA.
3. It was easy to get in touch with someone from the FCC to request an appointment
4. The wait time between my referral or first contact with the FCC and my first appointment at the FCC was reasonable
5. Someone from the FCC contacted me to help me prepare for my first visit
6. I was given enough information and directions for travel to the FCC
FCC physical and emotional environment
7. The FCC environment supported my physical needs <i>The FCC environment may include the waiting room, exam rooms, consult rooms, and/or areas related to surgical care. Physical needs may include space for a support person(s), easily accessible rest rooms, comfortable temperature, etc.</i>
8. The FCC environment supported my emotional needs <i>This may include a sense of privacy and sensitivity towards your unique needs or challenges</i>
9. The FCC team cared about my health as well as the health of my fetus/baby
10. Someone from the FCC explained the reasons for the care that I received <i>Care may include examinations (e.g., ultrasounds, MRIs, physical assessment), consultations with specialists, and interventions (e.g., fetal therapy)</i>
11. Clinical care at the FCC was done with compassion <i>Clinical care may include examinations (ultrasounds, MRIs, physical assessment) and procedures (e.g., amniocentesis or fetal intervention)</i>
12. I felt like I had to fight for my needs and wishes
13. I felt discriminated against during my care <i>For any reason including race, ethnicity, culture, sex, gender, sexual orientation, language, immigration status, religion, income, education, age, marital status, past perinatal losses, past prenatal decisions, number of children, insurance status, or other attributes)</i>
FCC communication
14. The FCC team called me by my preferred name
15. The FCC team used words that was respectful of my pregnancy or baby/babies
16. The FCC team listened to me
17. During my visit, the FCC team took time to learn about me and my story
18. The FCC team explained things in a way that I could understand
19. The FCC team checked that I understood information that was given to me
20. The FCC team delivered the amount of information that was right for me personally (e.g., not too much, not too little)
21. The information I was given was consistent across providers and staff at the FCC
22. The FCC team gave me resources to help me learn about the condition(s) diagnosed <i>These could include trusted websites with diagnosis information, scientific literature, or national associations related to the diagnosed condition(s) (e.g., the Spina Bifida Association)</i>
23. I felt that I could ask the FCC team about any questions I had
24. If you disagree with the question above, please describe why you did not feel that you could ask any questions that you had <i>Open-ended question (for pilot only)</i>

Table 2 (continued)

Survey questions
25. The FCC team answered my questions
FCC support
26. I had a member of the FCC team I could contact when I had a question or problem
27. My support person(s) was included in my care at the fetal center at my request <i>Support people may include a partner, family member, friend, or a professional support person like a doula</i>
28. The FCC team asked me about emotional health concerns <i>Emotional health concerns may include depression, anxiety, lack of support network, or past traumatic experiences</i>
29. The FCC team gave me resources to help with my emotional health <i>Resources may include a mental health provider (e.g., social worker within or outside of the FCC) or support groups</i>
30. The FCC team helped me learn how to talk to family and friends about my pregnancy <i>This may include how to talk to children (e.g., siblings) about the diagnosed condition(s)</i>
31. I faced financial challenges related to my care at the FCC
If agree, or strongly agree to question above. . .
32. The FCC gave me resources to help address financial challenges
Decision making
33. At the FCC, I was told about all the possible options for my pregnancy
34. Members of the FCC team told me about the options for my pregnancy in a compassionate way
35. The FCC team helped me make decisions that were best for me and my family
36. When possible, the FCC team gave me the time I needed to make decisions
37. I felt supported in my decisions by the FCC team
38. I felt pressured into a decision by the FCC team
Care continuum
39. I was able to speak with all the people that I felt were important to my care
40. The FCC team worked with me to create a plan of care
41. The FCC team followed through on my plan of care
42. My visits with the FCC team were well coordinated
43. If I wanted, the FCC worked with my local prenatal care provider/s during my care <i>Prenatal care providers may be the physician (e.g., obstetrician or maternal-fetal medicine specialist) or advanced practice nurse (e.g., midwife) who provided prenatal care prior to your FCC visit</i>
44. Members of the FCC team knew my story, so I did not have to repeat it often
45. The FCC team asked me about my expectations and hopes throughout my care
46. The FCC team prepared me for changes in my care <i>Changes may include a change in monitoring regularity, postintervention care, childbirth, and NICU stay</i>
47. The counseling from the FCC prepared me well for my care experience
48. I felt satisfied with the amount of interaction I had with the FCC team after I left their care

clarifications and instructions for patients were added. For example, in Question 1 patients are asked if their prenatal care providers helped them understand why they were referred to the FCC. Following feedback from Round 1, we

clarified in this question that “prenatal care providers may be the physician (e.g., obstetrician or maternal-fetal medicine specialist) or advanced practice nurse (e.g., midwife) who provided prenatal care prior to your fetal care center

Table 3. Participant characteristics (*n* = 258)

Characteristics	<i>n</i> (%)
Age	Range 19–43, mean = 31±4.5
Gender by pronouns	
She/her/hers	253 (98.2)
They/them/theirs	3 (1)
He/him/his	1 (0.4)
Other	1 (0.4)
Race and ethnicity	
Non-Hispanic White	232 (89.9)
Hispanic or Latino	5 (1.9)
Hispanic or Latino, White	5 (1.9)
Asian	4 (1.6)
Black or African American	4 (1.6)
Black or African America, White	4 (1.6)
Asian, White	3 (1.1)
Other	1 (0.4)
Relationship status	
Married	224 (86.8)
In a relationship, not married	30 (11.6)
Single	4 (1.6)
Insurance type	
Private	208 (81)
Public	47 (18)
No insurance	3 (1)
Employment status	
Full time	176 (68.2)
Homemaker	49 (19)
Part time	18 (7)
Unemployed	13 (5)
Student	2 (0.8)
Combined household income	
>100,000 USD	104 (40.3)
50,000–99,999 USD	97 (37.5)
20,000–49,000 USD	46 (17.9)
<20,000 USD	11 (4.3)
Education level	
Bachelor's degree	93 (36)
Graduate or postgraduate degree	75 (28.7)
Some college or associate degree	53 (20.9)
High school graduate or equivalent	24 (9.3)
Trade/technical/vocational training	10 (3.9)
Some high school, no diploma	3 (1.2)
Primary language	
English	255 (98.8)
Other	3 (1.2)
Region care was received	
Midwest	157 (60.9)
Northeast	39 (15.1)
West	25 (9.7)
Southeast	22 (8.5)
Southwest	15 (5.8)

Table 3 (continued)

Characteristics	n (%)
Year care was received	
2020	73 (28.3)
2021	63 (24.4)
2018	48 (18.6)
2019	48 (18.6)
2017	26 (10.1)
Type of care received	
Fetal intervention	73 (28.3)
Fetal intervention + neonatal intervention	49 (19)
Expectant management (no intervention)	44 (17.1)
Neonatal intervention	31 (12)
Perinatal palliative care (expected loss)	22 (8.5)
Consultation only	10 (3.9)
Fetal intervention + neonatal intervention + palliative care	10 (3.9)
Fetal intervention + palliative care	7 (2.7)
Neonatal intervention + palliative care	5 (1.9)
Termination of pregnancy	5 (1.9)
Fetal intervention + termination of pregnancy	2 (0.8)

visit”). In Round 2, 94% of panelists participated. Of the 51 items, 44 met consensus for inclusion (i.e., I-CVI >79% for relevance and clarity) and three items were removed (i.e., I-CVI <80% for relevance). Four items scored an I-CVI <80% for clarity and were thus revised and returned to panelists for final feedback. Thus, the Delphi process concluded with 48 items to be piloted (Table 2). Based on the literature, panelist feedback, and the expert opinion of the research team, the items on the scale were categorized into 6 domains: referral and access (6 items), physical and emotional environment (7 items), communication from providers and staff (12 items), support (7 items), decision-making (6 items), and care continuum (10 items).

The Pilot Study

A total of 258 people completed the pilot study from January 2022 to May 2023. The sociodemographic and care characteristics of the sample are summarized in Table 3. Participants were primarily White (89.9%), married (86.8%), held private insurance (86.8%), and received care in the Midwest (60.9%).

Exploratory Factor Analysis

Participants’ data were included in the EFA if they responded to at least 70% of the items in each factor and in the total scale. The Kaiser-Meyer-Olkin index (a measure of sample adequacy) of 0.952 confirmed that our sample was suitable, and the significant Bartlett’s test ($p <$

0.0001) signaled that item correlations were not random, affirming the suitability of factor analysis to reveal meaningful patterns in the data structure. The data were subjected to maximum likelihood extraction with an orthogonal (Varimax) rotation, a technique to simplify and interpret the data structure. Items were considered for retention if they exhibited a factor of 0.5 or higher. In EFA, factor loading values, ranging from -1 to 1 , indicate the strength of individual item relationships with the underlying factor, with values above 0.5 suggesting a moderate to strong connection. These values aid in pinpointing items more strongly linked to the measured construct. An iterative process was employed, removing nonloading and poorly loading items individually and sequentially.

This process resulted in 2 factors explaining 61% of the variance (Table 4). Scores were calculated by generating the sum of all items comprising each factor and the sum of all items in both factors represented participants’ total score on the PCC-FCC. Higher scores represent a higher degree of person-centered care. Factors 1 and 2 highlight different aspects of the overall person-centered care experience, with factor 1 focusing on the patient’s experience with the care received, and factor 2 emphasizing emotional support and education. Total scores for the 2-factor solution can range from 28 to 112. In this sample, scores ranged from 37 to 112 with an average of 96.45 (SD = 15.84).

Factor 1 explained 36.4% of the total variance and had a Cronbach’s α of 0.963. This factor consisted of 19 items

Table 4. EFA results

Items	Loadings
Factor 1 "Cared For" (n = 19)	
The FCC team listened to me	0.775
Clinical care was done with compassion	0.768
The team used words that were respectful of my pregnancy/baby/babies	0.763
The FCC environment supported my physical needs	0.731
I felt supported in my decisions by the team	0.720
The team helped me make decisions	0.719
The team answered my questions	0.710
The team cared about my health as well as the health of my fetus/baby	0.705
The team told me about all the possible options for my pregnancy	0.692
When possible, the team gave me the time I needed to make decisions	0.679
The team checked that I understood information	0.675
I was told about the options for my pregnancy in a compassionate way	0.671
The team explained things in a way that I could understand	0.670
The team took time to learn about me and my story	0.656
Someone from the FCC explained the reasons for the care I received	0.621
I felt like I had to fight for my needs and wishes	0.617
I felt pressured into a decision by the team	0.615
My visits were well coordinated	0.604
The team followed through on my plan of care*	0.561
Factor 2 "Cared About" (n = 9)	
The team gave me resources to help with my emotional health	0.857
The team helped me learn how to talk to family and friends about my pregnancy	0.830
The team asked me about my emotional health concerns	0.809
The team asked me about my expectations and hopes throughout my care	0.671
FCC counseling prepared me well for my care experience	0.660
The team prepared me for changes in my care	0.657
I felt satisfied with the amount of interaction I had with the FCC team after I left their care	0.567
The team gave me resources to help me learn about the condition(s) diagnosed	0.558
I had a member of the team I could contact when I had a problem	0.514

*This item crossloaded onto factor 2 at 0.559. We chose to keep the item in factor 1, due to the higher loading value.

pertaining to the experience and quality of FCC services such as being listened to, receiving compassionate clinical care, respectful language, physical support, feeling supported and involved in decision-making, receiving information about options and understanding explanations, having the reasons for care explained, coordination of visits, and the team following through on the plan of care. Scores for factor 1 can range from 19 to 76. In this sample, the scores ranged from 26 to 76 with an average of 68.21 (SD = 20.29).

Factor 2 explained 24.5% of the total variance and had a Cronbach's α of 0.934. This factor consisted of 9 items focused on the emotional aspects of care and the resources and education provided to the patients such as addressing emotional health concerns and receiving resources for emotional health, receiving resources for learning about diagnosed conditions, learning how to communicate with family and friends about the fetal condition, discussing expectations and hopes, being well-prepared for care ex-

periences and changes, having a contact person for problem-solving, and satisfaction with follow-up. Scores for factor 2 can range from 9 to 36. In this sample, scores ranged from 9 to 36 with an average of 28.52 (SD = 6.49).

Reliability Analyses and Tests of Concurrent Validity

The reliability of the 28-item two-factor scale was very high (total α = 0.969, factor 1 α = 0.963, factor 2 α = 0.934). The concurrent validity of the PPC-FCC was assessed using the PPPC-R. The PCC-FCC total score was highly and significantly correlated with the PPPC-R (r = 0.889, p < 0.001).

Discussion

Results from the development of this scale indicate that the construct of person-centered care can be defined and characterized for FCCs. Although models of care may differ,

our findings suggest that there are fundamental questions that all centers should ask to reliably and meaningfully measure how well they are providing care that is respectful of and responsive to individual people's and their families' preferences, needs, and values.

Although the items in factor 1 and factor 2 initially seemed very similar, our team conceptualized their differences as measuring whether a person felt "cared for" versus "cared about" during their FCC experience. Factor 1 and the concept of feeling "cared for" focus on the active performance of respectful and compassionate caregiving tasks necessary to the immediate physical health of the patient [32, 33]. Caring for someone involves aspects such as the technical competence of the health care team and effective communication. On the other hand, factor 2 and feeling "cared about" involve clinicians interacting with patients in a manner that may not be directly required or expected as part of treatment [32, 33]. This often requires a deeper emotional connection and a sense that clinicians genuinely value and understand the patient as an individual. It entails recognizing and addressing the patient's emotional and psychological needs, fostering trust, and demonstrating empathy and compassion to meet their greatest health-related quality of life needs (e.g., asking the patient about their hopes throughout their care, helping them explain the diagnosis to friends and family, providing resources for their emotional health, interacting with the patient after they leave FCC care). Factor 2 scores were lower than factor 1 in this sample, which underscores the significant challenges of providing "expert compassion" [34].

Evidence to define and characterize "caring for" and "caring about" patients can be found in research on nursing practice, palliative care, and informal caregivers [32–35]. Although this evidence is limited, it closely resembles the prior qualitative findings that informed this study, as highlighted by the quote in our introductory section – "Where are my (FCC) doctors? Why am I not seeing my doctors? I needed closure. I lost my baby, I lost my care team, I lost everything that we were building up for" (page 16) [5]. This patient who felt abandoned after their FCC care could be expected to have a low factor 2 score, independent of their factor 1 score. In other words, their need for emotional closure that extended beyond the clinical care they received may be an essential element to closing the loop on comprehensive person-centered FCC care. In a similar vein, we are observing a parallel distinction between being "cared for" and "cared about" in the preliminary analysis of qualitative data that was provided by participants at the end of the PCC-FCC in response to the prompt "Is there any other information about your care experience that you feel is important to share to help us measure and enhance care quality?" Initial findings indicate

that some patients who felt very satisfied with their care perceived the FCC team's approach as akin to being part of a family. Further analysis to confirm the significance of these findings and their relationship to the 2-factor scale is ongoing.

It is a critical time for the field of fetal diagnosis and treatment to establish consistent patient-level measurement of person-centered care. FCCs are rapidly expanding across the globe and novel prenatal treatments continue to be introduced [36, 37]. In addition, since the Supreme Court overturned federal protection for abortion in its *Dobbs v. Jackson Women's Health Organization* ruling, FCCs' ability to provide person-centered care to patients who desire a termination of pregnancy is in question [38]. Finally, increasing evidence suggests that the effects of individual and structural racism play major roles in how people of color experience perinatal care [39–41]. For that reason, we incorporated items into our scale that directly address pregnancy-related health care experiences of people of color (e.g., not feeling listened to, feeling the need to advocate for oneself) [10].

Strengths and Limitations

The development of this instrument builds on the work of researchers in areas of care that intersect in FCCs (e.g., perinatal palliative care, maternity care, neonatal care, etc.). Thus, starting with a collection of validated instruments and qualitative data from 232 former FCC patients created a rigorous, theory-based foundation from which to build a person-centered care scale for FCCs. We also enhanced our understanding and scientific rigor by engaging people with lived experience and care community members throughout the scale development process. In addition to our pilot sample, we included people with a variety of lived experiences in FCCs on our research team and Delphi panel.

This study must be understood in the context of the following limitations. This instrument is based on the patient's experience and is designed to allow for some interpretation and subjectivity. Although patients' answers may not provide complete or detailed information for FCCs, they should indicate areas where an FCC may want to follow up with a patient to gain a better understanding of their responses. In order to be inclusive of as many models of care as possible, we sacrificed some specificity for higher generalizability in our approach to item generation. For example, rather than specifically asking about maternal-fetal surgery the items address prenatal procedures more broadly, as many FCC patients are ineligible or choose not to undergo fetal intervention.

In addition, our Delphi panel and pilot sample were relatively homogeneous, with most participants identifying as non-Hispanic White. While this observation may accurately portray the current lack of diversity in both FCC clinician and patient populations, our commitment lies in enhancing representation across various socio-demographic characteristics in future research. This involves ongoing translation of the PCC-FCC into additional languages and employing alternative data collection methods that do not rely on participants having internet access. Finally, self-selection bias may have influenced the characteristics of our Delphi and pilot samples, and their experiences may not represent the entire population.

Conclusion

By embracing the principles of person-centered care, FCCs can optimize both the clinical outcomes and the overall care experience for pregnant people. Through a comprehensive approach that integrates medical expertise with individualized support, FCC teams can provide a compassionate environment where patients feel heard, understood, and respected during this challenging and pivotal period of their lives. The PCC-FCC Scale is a valid and reliable measure of person-centered care in U.S. FCCs. It can be used to enhance services and begin connecting person-centered care to maternal-child health outcomes.

Acknowledgments

The authors would like to thank the Fetal Therapy Nurse Network and the North American Fetal Therapy Network who provided the infrastructure for this collaborative study. They would also like to thank Dr. Katie Donohue, Executive Director at Yale New Haven Hospital and Director of Women's Health, for her support of the National Clinician Scholars Program. Thanks to Barbara Eichhorn (UPMC Magee-Womens Hospital), Rachel LeEllen Tullar (Riley Children's), Annie Petteys (Miller Children's & Women's Hospital Long Beach), Srikar Shrikantham (University of California, Davis),

Stephanie Eyerly-Webb (Children's Minnesota), Kara Hansen (Children's Mercy, Kansas City), Marin Karsmarski (Yale New Haven Health), Elizabeth Awe (Children's Wisconsin), and their teams for their contributions to targeted recruitment.

Statement of Ethics

This study protocol was reviewed and approved by the Yale Internal Review Board under 45CFR46.104 (2)(ii) Delphi (2000031494), pilot (2000032383). Written informed consent was obtained from participants prior to the study. See Methods section for details.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Funding Sources

This study was made possible by the Yale National Clinician Scholars Program and by CTSA Grant Number TL1 TR001864 from the National Center for Advancing Translational Science (NCATS), a component of the National Institutes of Health (NIH). Its contents are solely the responsibility of the authors and do not necessarily represent the official view of NIH.

Author Contributions

Abigail Wilpers, Marney White, Mary Austin, Mert Bahtiyar, Katie Francis, Stephen Emery, Diane Wall, Lonnie Somers, and Charlotte Wool all made substantial contributions to the conception of the work; analysis of the data; and drafting, revising, and final approval of the version to be published.

Data Availability Statement

The data that support the findings of this study are not publicly available due to their containing information that could compromise the privacy of research participants but are available from the corresponding author A.B.W. upon reasonable request.

References

- Richardson WC, Berwick DM, Bisgard J, Bristow L, Buck C, Cassel C. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academy Press; 2001.
- Tunçalp Ö, Were WM, MacLennan C, Oladapo OT, Gülmezoglu AM, Bahl R, et al. Quality of care for pregnant women and newborns-the WHO vision. *BJOG*. 2015;122(8):1045–9.
- Wilpers A, Bahtiyar MO, Stitelman D, Batten J, Calix RX, Chase V, et al. The parental journey of fetal care: a systematic review and meta-synthesis. *Am J Obstet Gynecol MF*. 2021;3(3):100320.
- Blumenthal-Barby JS, Krieger H, Wei A, Kim D, Olutoye OO, Cass DL. Communication about maternal-fetal surgery for myelomeningocele and congenital diaphragmatic hernia: preliminary findings with implications for informed consent and shared decision-making. *J Perinat Med*. 2016;44(6):645–53.

- 5 Eyerly-Webb SA, Beh M, Lim FY, Liechty K, Velasco P, Dion E, et al. Understanding the care journey and needs of advanced fetal care center patients. *Pern J*. 2022;26(21):1889.
- 6 Sandelowski M, Barroso J. The travesty of choosing after positive prenatal diagnosis. *J Obstet Gynecol Neonatal Nurs*. 2005;34(3):307–18.
- 7 Baschat AA, Blackwell SB, Chatterjee D, Cummings JJ, Emery SP, Hirose S, et al. Care levels for fetal therapy centers. *Obstet Gynecol*. 2022;139(6):1027–42.
- 8 Afulani PA, Feesser K, Sudhinaraset M, Aborigo R, Montagu D, Chakraborty N. Toward the development of a short multi-country person-centered maternity care scale. *Int J Gynaecol Obstet*. 2019;146(1):80–7.
- 9 Afulani PA, Sayi TS, Montagu D. Predictors of person-centered maternity care: the role of socioeconomic status, empowerment, and facility type. *BMC Health Serv Res*. 2018;18(1):360.
- 10 Afulani PA, Altman MR, Castillo E, Bernal N, Jones L, Camara TL, et al. Development of the person-centered maternity care scale for people of color. *Am J Obstet Gynecol*. 2021; 225(4):427 e1–3.
- 11 Afulani PA, Altman MR, Castillo E, Bernal N, Jones L, Camara T, et al. Adaptation of the person-centered maternity care scale in the United States: prioritizing the experiences of black women and birthing people. *Wom Health Issues*. 2022;32(4):352–61.
- 12 Sullivan A. Sex and the census: why surveys should not conflate sex and gender identity. *Int J Soc Res Methodol*. 2020;23(5):517–24.
- 13 Oliver D, Klugman B, Bewley M. David Oliver: lack of PPE betrays NHS clinical staff. *BMJ*. 2021;372:n438.
- 14 Gribble KD, Bewley S, Bartick MC, Mathisen R, Walker S, Gamble J, et al. Effective communication about pregnancy, birth, lactation, breastfeeding and newborn care: the importance of sexed language. *Front Glob Womens Health*. 2022;3:3.
- 15 Society for Maternal-Fetal Medicine SMFM Electronic address smfm@smfmorg, Brandt JS, Eichelberger KY, Wong MS. Society for Maternal-Fetal Medicine Special Statement: commitment to excellence in obstetrical care, research, and education for people with diverse sexual and gender identities. *Am J Obstet Gynecol*. 2022;226(4):B10–2.
- 16 DeVellis RF, Thorpe CT. Scale development: theory and applications. Sage publications; 2021.
- 17 Sheferaw ED, Mengesha TZ, Wase SB. Development of a tool to measure women's perception of respectful maternity care in public health facilities. *BMC Pregnancy Childbirth*. 2016;16:67.
- 18 Texas Department of State Health Services, Centers of excellence for fetal diagnosis and therapy. Available from: [https://texreg.sos.state.tx.us/public/readtac\\$ext.TacPage:sl5R&app59&p_dir5&p_rloc5&p_tloc5&p_ploc5&p_pg51&p_tac5&ti525&pt51&ch5133&rl5225](https://texreg.sos.state.tx.us/public/readtac$ext.TacPage:sl5R&app59&p_dir5&p_rloc5&p_tloc5&p_ploc5&p_pg51&p_tac5&ti525&pt51&ch5133&rl5225). (accessed November 18, 2021).
- 19 Moon-Grady AJ, Baschat A, Cass D, Choolani M, Copel JA, Crombleholme TM, et al. Fetal treatment 2017: the evolution of fetal therapy centers: a joint opinion from the International Fetal Medicine and Surgical Society (IFMSS) and the North American Fetal Therapy Network (NAFTNet). *Fetal Diagn Ther*. 2017;42(4):241–8.
- 20 American College of Obstetricians and Gynecologists Committee on Ethics; American Academy of Pediatrics, Committee on Bioethics. Maternal-fetal intervention and fetal care centers. *Pediatrics*. 2011;128(2):e473–8.
- 21 Denny E, Quinlan-Jones E, Bibila S, Kilby M. The experience of pregnant women with a diagnosis of fetal lower urinary tract obstruction (LUTO). *Midwifery*. 2014;30(6):636–42.
- 22 Colicchia LC, Snowise S, Wunderlich W, Schulte A, Sidebottom AC. Maternal decision-making about intrauterine myelomeningocele repair: a qualitative exploration. *Am J Obstet Gynecol*. 2022;226(1):S522–3.
- 23 Colicchia LC, Snowise S, Wunderlich W, Taghon J, Sidebottom AC. 178: maternal decision-making about fetal therapy for complicated monochorionic twin gestations: a qualitative exploration. *Am J Obstet Gynecol*. 2020;222(1):S126.
- 24 Kett JC, Woodrum DE, Diekema DS. A survey of fetal care centers in the United States. *J Neonatal Perinatal Med*. 1 2014;7(2):131–5.
- 25 Zamanzadeh V, Ghahramanian A, Rassouli M, Abbaszadeh A, Alavi-Majid H, Nikanfar AR. Design and implementation content validity study: development of an instrument for measuring patient-centered communication. *J Caring Sci*. 2015;4(2):165–78.
- 26 Keeney S, McKenna H, Hasson F. The Delphi technique in nursing and health research. John Wiley & Sons; 2011.
- 27 Grant JS, Davis LL. Selection and use of content experts for instrument development. *Res Nurs Health*. 1997;20(3):269–74.
- 28 Davis LL. Instrument review: getting the most from a panel of experts. *Appl Nurs Res*. 1992; 5(4):194–7.
- 29 Lynn MR. Determination and quantification of content validity. *Nurs Res*. 1986;35(6):382–6.
- 30 Floyd FJ, Widaman KF. Factor analysis in the development and refinement of clinical assessment instruments. *Psychol Assess*. 1995; 7(3):286–99.
- 31 Ryan BL, Brown JB, Tremblay PF, Stewart M. Measuring patients' perceptions of health care encounters: examining the factor structure of the revised Patient Perception of Patient-Centeredness (PPPC-R) questionnaire. *J Patient Cent Res Rev*. 2019; 6(3):192–202.
- 32 Manderson L, Warren N. "Caring for" and "caring about": embedded interdependence and quality of life. Reframing disability and quality of life: a global perspective. 2013. 179–93.
- 33 Henderson A, Van Eps MA, Pearson K, James C, Henderson P, Osborne Y. "Caring for" behaviours that indicate to patients that nurses "care about" them. *J Adv Nurs*. 2007;60(2):146–53.
- 34 Bobinac A, Van Exel NJ, Rutten FF, Brouwer WB. Caring for and caring about: disentangling the caregiver effect and the family effect. *J Health Econ*. 2010;29(4):549–56.
- 35 Funk LM, Peters S, Roger KS. Caring about dying persons and their families: interpretation, practice and emotional labour. *Health Soc Care Community*. 2018;26(4):519–26.
- 36 Sacco A, Simpson L, Deprest J, David AL. A study to assess global availability of fetal surgery for myelomeningocele. *Prenat Diagn*. 2018;38(13):1020–7.
- 37 Tomiyoshi T. World's first stem cell treatment for spina bifida delivered during fetal surgery. UC Davis Health News [Internet]. 2022 [cited 2022 Oct 12]. Available from: <https://health.ucdavis.edu/health-news/newsroom/worlds-first-stem-cell-treatment-for-spina-bifida-delivered-during-fetal-surgery/2022/10>.
- 38 Rader B, Upadhyay UD, Sehgal NKR, Reis BY, Brownstein JS, Hsuen Y. Estimated travel time and spatial access to abortion facilities in the US before and after the Dobbs v Jackson Women's Health Decision. *JAMA*. 2022;328(20):2041–7.
- 39 Altman MR, Oseguera T, McLemore MR, Kantrowitz-Gordon I, Franck LS, Lyndon A. Information and power: women of color's experiences interacting with health care providers in pregnancy and birth. *Soc Sci Med*. 2019;238:112491.
- 40 McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L. Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Soc Sci Med*. 2018;201:127–35.
- 41 Ebert L, Bellchambers H, Ferguson A, Browne J. Socially disadvantaged women's views of barriers to feeling safe to engage in decision-making in maternity care. *Women Birth*. 2014;27(2):132–7.