

Family Planning and the Adult with Congenital Heart Disease: A Narrative Inquiry

Kathryn Osteen PhD, RN

College of Nursing, University of Texas Arlington

ABSTRACT

Congenital Heart Defects (CHD) affect 1% of all infants born in the United States.^{1,2}

Adults with CHD are living longer into adulthood

- Estimated 1 million adults living with CHD in the U.S.³
- Increased possibility of childbearing.^{4,5}

Family planning decisions include any decision about⁶

- Contraception
- Pregnancy
- Childbirth

Adults with CHD have specific concerns:⁷

- Pregnancy
- Surrogacy
- Adoption
- Sterilization

PURPOSE

The purpose of this qualitative narrative study is to describe the personal narrative experience of adult women with CHD, of childbearing age, and their struggle with family planning options.

METHODS

Narrative inquiry - guided by the Roy adaptation model

- Single in-depth, semi-structured interview.
- Structural and thematic analysis.
- Interviews continued until saturation of themes was obtained.

Recruited through a www.ACHAheart.org website study announcement.

Sample Description

Final sample

- N=17
- Age 24-41 years old.
- Women living in 10 U.S. states

Sample Characteristics

Mild	Moderate	Severe
ASD	Large ASD	Epsteins Anomaly
VSD	Complex VSD	Tricuspid Atresia
Mitral Valve Prolapse	Pulmonary Stenosis	Truncus Arteriosus
	Mitral Valve Regurgitation	Unicuspid Aortic Valve
		Tetralogy of Fallot
		Single Left Ventricle
		Double Inlet Left Ventricle
		Shone's Syndrome
		Transposition of the Great Arteries

Characteristic	Frequency
Age	
18-27	7
28-37	7
38-49	3
Number of Surgeries	
1-2	9
3-4	6
5 or more	2
Marital Status	
Married or Committed Relationship	12
Engaged	2
Single	3
Ethnicity	
African American	1
Asian	1
White	15
Number of Children	
0	10
1	5
2	2
Therapeutic Abortion	1
Surrogacy	1
Adoption	0
Sterilized	2

Contact Information

Kathryn Osteen

kcosten@sbcglobal.net

References available upon request

RESULTS

The participants described a continuous struggle with family planning decisions that occurred throughout their lives, from becoming sexually active to giving birth. Participants described experiences regarding several options for family planning including contraception, carrying a pregnancy, surrogacy, adoption, and sterilization.

Contraception

"My biggest fear is the blood clot risk that comes with all contraceptives."

"I used to live in a small town, so doctors were all really good about communicating with one another. That hasn't actually occurred in my adult life. I mean, no one actually cares to call and check on anybody else."

Carrying a Pregnancy

"I don't guess I really realized how much pregnancy would affect my heart."

"It was a traumatic experience. I had a lot of problems."

Surrogacy

"It's sad that women have to spend insane amounts of money to go through the process of having a child. Obviously, nothing's guaranteed, but this especially isn't guaranteed."

Adoption

"The thing with adoption is you have to be healthy; A its expensive, but B you can't have any health issues. And I just didn't want to be judged."

Sterilization

"I felt frustrated that it (sterilization) wasn't one of the options on the table that I was given. I think its hard given that no one ever wanted me to be pregnant, and yet they didn't really empower me to make the steps that felt right for me."

CONCLUSION

Findings support the need for more research on family planning and information communicated to the adult with CHD, and the effects of pregnancy on the adult with CHD. Individuals with CHD are emotionally attached to having a child. These women also had concerns about social, familial, and spousal expectation even though they were afraid of the potential of having decreased physical functioning after pregnancy and childbirth. To maximize the health of the adult with CHD, family planning should be incorporated into primary care.