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**Journal Title:** Journal of Cardiovascular Nursing  
**Volume:** Volume 33, Number 4  
**Publisher:** Lippincott, Williams & Wilkins | 2018-07-01, Pages 356-362  
**Type of Work:** Article | Post-print: After Peer Review  
**Publisher DOI:** 10.1097/JCN.0000000000000471  
**Permanent URL:** <https://pid.emory.edu/ark:/25593/tvbtw>

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Final published version: <http://dx.doi.org/10.1097/JCN.0000000000000471>

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*Accessed October 21, 2019 12:02 AM EDT*



Published in final edited form as:

*J Cardiovasc Nurs.* 2018 ; 33(4): 356–362. doi:10.1097/JCN.0000000000000471.

## Illness Uncertainty and Posttraumatic Stress in Young Adults with Congenital Heart Disease

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### Introduction

Young adults (YA), aged 19–35 years of age, diagnosed and treated for congenital heart disease (CHD) during infancy and childhood, experience premature onset of serious comorbid conditions attributable to their underlying disease or its treatment.<sup>1</sup> Prevalent among these comorbidities are arrhythmias,<sup>2</sup> stroke,<sup>3</sup> neuro-cognitive deficits,<sup>4</sup> and congestive heart failure.<sup>1</sup> Despite advances in the diagnosis and management of CHD, most congenital defects require lifelong cardiac care.<sup>1</sup> The long-term nature of CHD and the unpredictability of its course and outcome may result in high levels of uncertainty.<sup>5</sup>

Uncertainty has been defined as the inability of a person to determine the meaning of illness-related events.<sup>5,6</sup> According to Mishel's Uncertainty in Illness Theory (1981,1988), the four theoretically derived and empirically supported dimensions of uncertainty for adults have been shown to be, ambiguity about the state of the illness; lack of information about the disease, its treatment and comorbidities; complexity of the healthcare system and relationship with health care providers; and unpredictability of the illness course and outcome.<sup>5,6</sup> Previous research has found increased uncertainty to be associated with higher levels of psychological stress,<sup>7</sup> increased anxiety,<sup>8</sup> reduced quality of life,<sup>9</sup> decreased effective coping,<sup>10</sup> and lower perceived control.<sup>11</sup> Among YAs with chronic childhood health conditions, lack of experience independently managing their health care,<sup>12</sup> difficulty negotiating complex systems of care and communicating with providers,<sup>13,14,15</sup> lack of understanding of their disease,<sup>16</sup> and general developmental issues regarding autonomy and independence<sup>17</sup> can generate chronic uncertainty.

The perception and appraisal of uncertainty as described by Mishel<sup>5,6</sup> requires adult-like cognitions of illness and the future. Thus individuals with chronic childhood conditions can first come to perceive uncertainty during adolescence-young adulthood.<sup>17</sup> Adults tend to

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**Conflicts of interest:** The authors declare no conflicts of interest

appraise uncertainty as dangerous and manage it by taking action to eliminate its sources.<sup>5,6</sup> According to Mishel's (1990) Reconceptualization of Uncertainty in Illness Theory (RUIT), continual uncertainty, especially in the domain of unpredictability of the future, can be impossible or undesirable to eliminate.<sup>18</sup> By accepting continual uncertainty, individuals are able to move towards a new view of life which includes the reordering of priorities, and seeing multiple possibilities for their life.<sup>18</sup> Therefore, the reappraisal of uncertainty from a danger to an opportunity may lead to positive psychological changes and personal growth.<sup>18</sup>

Common strategies for managing uncertainty appraised as a danger include vigilance to symptoms and bodily changes, controlling cognitive awareness of upsetting information, and avoiding reminders that provoke intense somatic and emotional responses; these strategies resemble the characteristic symptoms (re-experiencing, avoidance, and arousal) seen in posttraumatic stress disorder (PTSD).<sup>18, 19</sup> In the absence of full-blown PTSD, moderate to severe levels of posttraumatic stress symptoms (PTSS) in one or more of the characteristic symptom clusters may interfere with day-to-day functioning.<sup>19</sup> Guidelines for the management of YAs with CHD recommend regular monitoring for co-morbid conditions.<sup>20</sup> However, avoidance of health care due to PTSS, can interfere with participation in ongoing monitoring. The purpose of this study is to explore how YAs with CHD appraise and experience uncertainty in the four domains described by Mishel<sup>5,6</sup> and to describe the relationship between PTSS and the appraisal and management process.

## Methods

### Design, Setting and Sample

We used an exploratory-descriptive design and mixed methods approach to conduct this study. Data were collected in person and via Skype. A sample of 25 participants were purposively chosen using postings in public places, a study recruitment website, Twitter, and Facebook. The study protocol was also posted on the Congenital Heart Information Network (C.H.I.N.) which included Facebook/Twitter and online discussion groups. Eligibility criteria included: diagnosed with CHD during childhood; current age between 19 and 35 years; and able to read and write English. Participants were excluded from the study if they had severe cognitive impairments. Of the 25 participants, eleven were interviewed face-to-face and fourteen were interviewed via Skype.

### Ethical Considerations

Prior to data collection, the study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill. Written informed consent was obtained from participants who were interviewed in person. For participants interviewed via Skype, a copy of the informed consent and information about the study were sent via e-mail. Verbal informed consent was obtained from the participants when they were called for their interview.

### Data Collection Measures

Data were collected at one time point using in-depth semi-structured interviews and standardized questionnaires. Interviews lasted 45 to 60 minutes and were audio-recorded.

The participant was asked to tell his/her story (e.g., “Tell me about how your heart condition is affecting your life now”). The collection and analysis of interview data was informed by the UIT and a review of related literature.<sup>7,8, 21–23</sup> The interview guide evolved as the study progressed and new questions arose. At the completion of the interview, participants were given a \$25 gift card.

## Measures

Socio-demographic and clinical data were collected from participants through self-report using an 11-item form. Complexity of cardiac defect was classified according to the criteria of the American College of Cardiology.<sup>24</sup>

The measure of PTSS was the 20-item University of California at Los Angeles Post Traumatic Stress Disorder-Reaction Index (PTSD-RI).<sup>25</sup> The items on the PTSD-RI relate to the three subscales of the characteristic symptom clusters (e.g., re-experiencing, avoidance, and arousal) seen in PTSD. The PTSD-RI has established reliability in studies of young adult survivors of childhood cancer ( $\alpha = .84–.88$ ).<sup>22</sup> For this study, participants were asked to think about their CHD, its treatment and potential co-morbidities and indicate the frequency with which they experienced each symptom using a 5-point Likert-type scale. PTSD-RI total scores were calculated by summing responses. Symptom severity levels were determined according to the following guidelines: RI total score 12 – 24 = mild, RI total score 25 – 37 = moderate and RI total score 38 = severe. RI total scores 38 are considered indicative of PTSD.<sup>25</sup>

## Data Management

Following each interview, the digital recording was transcribed verbatim and checked for accuracy. Questionnaire data were checked for completeness and entered into Excel computer files. To protect participants’ confidentiality, a 3-digit study identification number, rather than names were used to identify study materials.

The total PTSD-RI scores were calculated immediately after completion of the questionnaire. If a participant scored 38, the first author notified the second author to discuss the participant’s safety. If the participant was deemed to be safe he/she were encouraged to discuss the score with a primary care and/or mental health professional. If considered to be a safety risk, the participant was escorted to the emergency department.

## Data Analysis

Quantitative data was analyzed using descriptive statistics to calculate sample demographics, clinical variables, PTSD-RI scores and PTSD-RI symptom levels. Qualitative data was analyzed using the constant comparative method of Glaser and Strauss.<sup>26</sup> Interview transcripts were examined line by line for evidence of the domains of uncertainty, appraisal of uncertainty, and common uncertainty management strategies. To examine relationships between themes in the qualitative interviews and PTSD-RI severity levels, each theme was quantitized and an inter-respondent matrix (participant x theme) developed. Each textual passage labeled as a dimension of uncertainty (ambiguity, lack of information, complexity, and unpredictability) was further reviewed to identify the co-occurring subscales of PTSD

(e.g. 0=response to theme did not represent at least one of the subscales (re-experiencing, avoidance, and arousal); 1= response to theme represented at least one of the PTSD subscales; 3= theme was not represented in the participant interview. The final step of the analysis involved grouping the sample according to PTSS severity levels (mild, moderate, severe) then exploring the common themes of the appraisal and management of uncertainty in each respective group.

## Results

### Demographics of Study Sample

Table 1 presents demographic and illness characteristics of the sample. The mean age of participants was 25 years (range 19–34) and 84% were Caucasian. All participants had a high school education and 96% had medical insurance. The majority (60%) were taking cardiac medications, reported moderate and complex cardiac defects (96%), and had undergone two or more cardiac surgeries since birth (72%).

Table 2 provides descriptive statistics for the PTSD-RI total scores and severity levels. The mean PTSD-RI total score was 31.3 (SD  $\pm$  7.7, 19–47). Six participants (24%) had a total score that exceeded the cutoff point of 38, indicative of clinically significant PTSD.<sup>25</sup>

### Uncertainty Domains

**Ambiguity**—Participants described ambiguous, inconsistent symptoms such as dizziness, nausea, and fatigue. Their inability to discern the meaning of these symptoms in relationship to their CHD was a source of uncertainty. Participants found it difficult to distinguish between “different” and “wrong” and often perceived the need to remain vigilant for negative outcomes.

“Every time I get a headache, I think I am having a stroke...every time I get sick, I think what’s wrong with me now.”

**Lack of Information**—Lack of information regarding their CHD and its treatment, potential comorbidities, and means of preventing comorbidities was a source of uncertainty for many participants. For some the efficacy or longer-term complications of their current treatment was unknown.

“I have to worry about my future, because I’m one of the oldest with my heart condition, there is very little known about my lifespan or what’s going to happen as I grow older.”

**Complexity of the Health Care System**—Participants experienced uncertainty related to navigating the health care system, communicating with healthcare providers (HCPs), and transitioning to adult cardiology care.

“I feel like I don’t know them (adult cardiologist) and they don’t know me.”

**Unpredictability**—Unpredictability regarding the trajectory of their illness and whether they would ultimately succumb to CHD was a concern expressed by all participants. For

females, the most distressing and frequently mentioned uncertainties in the unpredictability domain, related to pregnancy, including whether their condition would worsen during pregnancy, whether their offspring would have CHD, and whether they would survive to raise their child. One young woman expressed the following concern:

“If I have children, will they be born with a heart defect and will I live long enough and be healthy enough to see my child grow?”

A visual representation of the tenuous nature of his condition was expressed by one participant:

“I feel like my life is hanging by a Gossamer thread.”

The sense of a foreshortened future was described as:

“I worry about dying. I didn’t really worry about that before but I guess I feel like I had a face to face with death.”

“If I want to put it in a darker way, I feel uncertain about how long I will hold on, for how many more years.”

### **Appraisal and Management of Uncertainty**

Narrative analysis indicated a relationship between PTSS severity levels (mild, moderate, severe) and the appraisal and management of uncertainty. Participants with mild PTSS scores appraised uncertainty as an opportunity that led to personal growth, a reevaluation of priorities and the development of a deeper appreciation of life. Management of uncertainty included seeking social support, establishing a trusting relationship with a healthcare provider, and belief in a higher power.

One participant described personal growth related to living with CHD:

“I think it’s made me a lot more sympathetic to people that have chronic conditions or illnesses.”

Narratives of participants with moderate PTSS scores appraised uncertainty as both a danger and an opportunity. For these participants, uncertainty appraisals co-existed. Overall, participants tended to focus on the opportunity appraisal. Management of uncertainty included focusing on the positive aspects of the present rather than the uncertainty of the future.

A participant in need of a heart transplant expressed the positive aspect of his disease:

“I would have a heart condition any day than to have a changed life and possibly not meet all the people that I care about...”

Narratives of participants with severe PTSS scores (indicative of PTSD) appraised uncertainty as a danger that generated distress and negative emotions. Re-experiencing symptoms were in the form of intrusive thoughts and recurring nightmares about disturbing aspects of their treatment. These intrusive thoughts often caused the YA to feel they were reliving the traumatic event. Arousal was in the form of excessive attention to and over interpretation of physical symptoms, resulting in the YA feeling constantly on guard to

protect themselves from and/or avoid further danger. Avoidance/numbing symptoms were in the form of blunting of emotional responses, not thinking of or talking about their condition, noncompliance with medications and routine medical appointments, and disregarding symptoms of illness.

Feelings of vulnerability and avoidance were expressed:

“What happens, happens...I feel numb to it...apathy is better than caring....”

“I have done everything in my power to ignore my heart condition and to put it in my past.”

Intrusive thoughts were described:

“I dream about my stroke. It happens in the dream like it did in real life, except I die.”

Feelings of arousal were expressed as:

“I have to really be sharp... you have to be a shark.”

## Discussion

Uncertainty was a central theme in the lives of YAs with CHD affecting their day-to-day decisions as well as their thoughts and plans for the future. Awareness of the seriousness of their childhood condition and the lingering effects increased as their cognitive functions matured.<sup>17</sup> Narratives revealed illness uncertainty in the four domains as described by Mishel.<sup>5,6</sup>

### Ambiguity

Uncertainty related to ambiguous, ever-changing illness symptoms, caused participants to perceive their body and condition as unpredictable. The inability to interpret these symptoms made some participants believe that their life was in constant danger. Uncertainty related to ambiguous symptoms has been described in patients with systemic lupus, rheumatoid arthritis, heart failure, hepatitis C, and advanced liver disease.<sup>27-30</sup> Bailey et al. (2009) found a strong relationship between the ambiguity component of the uncertainty scale and depressive symptoms, quality of life, and fatigue among patients with chronic hepatitis C.<sup>29</sup> These findings support the need for cognitive and behavioral interventions to assist ill individuals to redefine the meaning of illness-related symptoms to manage uncertainty.<sup>31</sup>

### Lack of knowledge

Acquisition of knowledge was described as a source of empowerment and a means of coping with uncertainty. These findings are consistent with previous studies among young women with breast cancer who relied on medical information to define themselves as either healthy or ill.<sup>32</sup> Similarly, patients with advanced liver disease related a poor understanding of their illness to increased uncertainty which impacted their ability to cope and plan for the future.<sup>30</sup> Providing developmentally appropriate education to YAs with CHD about the diagnosis, management and promotion of self-care behaviors during adolescence may decrease uncertainty and related co-morbidities.

## Complexity of the health care system

Transitioning to adult cardiology care was a source of uncertainty for many participants. Most YAs had attended the same pediatric cardiology clinic since childhood and felt unprepared to transition to the unfamiliar environment of adult care. Finding an adult cardiologist and developing a trusting relationship with their new provider was difficult for some YAs. Perceiving that the cardiologist was insensitive or lacked knowledge of their specific cardiac defect, and/or was unwilling to take the time to know them personally, created distrust and uncertainty. Studies among adolescents and young adults (AYA) with cancer have reported similar issues with patient-provider trust.<sup>33,34</sup> The inability to find an adult cardiologist resulted in some YAs not receiving appropriate follow-up care. Insufficiently coordinated cardiology care is associated with adverse health outcomes in patients with CHD.<sup>35</sup> Gurvitz et al. (2013) reported that 42% of 922 adults with CHD had a > 3-year lapse in cardiology care, commonly beginning at 19 years of age.<sup>36</sup> Coordinated transition to adult cardiology care and improving YA-provider communication is needed to engage and maintain YAs in ongoing cardiac care.

## Unpredictability

Unpredictability of the future, related to their disease course and ultimate outcome, was a source of uncertainty for the majority of participants. A significant theme to emerge within the unpredictability domain was uncertainty of female participants related to childbearing. This finding is consistent with studies among young women with cancer who describe a sense of loss related to pregnancy and their ability to conceive.<sup>32, 37–39</sup> Literature indicates that childbearing concerns are not consistently addressed among YAs with CHD.<sup>37–39</sup> Ngu et al. (2014), found that women with CHD had a poor understanding of the seriousness of their cardiac condition and the risks that may occur during pregnancy.<sup>40</sup> These findings underscore the importance of providing accurate and reliable information to support a woman's decision regarding childbirth in the context of CHD.

## Appraisal and Management of Uncertainty

As defined in Mishel's UIT, uncertainty is a neutral cognitive state that can be appraised as either a danger or an opportunity.<sup>5,6</sup> The majority of YAs in the current study believed that living with uncertainty caused them to re-evaluate life priorities and develop a new lifeview. This finding is consistent with the Mishel's RUIT that proposes the appraisal of uncertainty may change from being a threat to being an opportunity for personal growth.<sup>18</sup> Parry (2003) found that living with uncertainty was a catalyst for the development of resilience and optimism in AYA survivors of childhood cancer.<sup>41</sup>

Nevertheless, some participants appraised uncertainty as a danger and envisioned an unpredictable future which created psychological distress and the development of symptoms that resembled PTSD. The relationship between PTSD and uncertainty has been described in previous studies.<sup>7, 8, 21–23</sup> Lee's (2006) study among YA survivors of cancer, found uncertainty to be positively correlated with the PTSS of avoidance and arousal.<sup>7</sup>

## Practical Implications

This study highlights the importance of identifying PTSS/PTSD in YA with CHD and implementing developmentally appropriate interventions to reduce uncertainty and posttrauma symptoms as a means to promote treatment adherence and regular participation in health care.

## Limitations

The study results were limited to a small sample size that was predominately Caucasian. Results may be different for YAs of different ethnicities. The majority of YAs in the study were diagnosed with moderate to complex cardiac defects which may affect their perception of uncertainty and development of PTSS.

## Conclusion

Our findings suggest that YAs with CHD are at risk for the development of long-term psychological stress and PTSD in the setting of chronic uncertainty. Uncertainty management strategies, especially avoidance of reminders of CHD, can heighten the risk of CHD-related comorbidities.

## Acknowledgments

**Funding:** This research was supported in part by the National Institutes of Nursing Research T32 NR007091: Interventions to Prevent and Manage Chronic Illness and also by the American Nurses' Foundation.

## References

1. Ávila P, Mercier L, Dore A, et al. Adult congenital heart disease: A growing epidemic. *Can J Cardiol.* 2014; 30:S410–S419. [PubMed: 25432136]
2. Kumar S, Tedrow UB, Triedman JK. Arrhythmias in adult congenital heart disease. *Cardiol Clin.* 2015; 33:571–588. [PubMed: 26471821]
3. Lanz J, Brophy JM, Therrien J, Kaouache M, Guo L, Marelli AJ. Stroke in adults with congenital heart disease: Incidence, cumulative risk and predictors. *Circulation.* 2015; 132:2385–2394. [PubMed: 26597113]
4. Donofrio MT, Massaro AN. Impact of congenital heart disease on brain development and neurodevelopmental outcome. *Int J Pediatr.* 2010:1–13.
5. Mishel MH. The measurement of uncertainty in illness. *Nurs Res.* 1981; 30:258–263. [PubMed: 6912987]
6. Mishel MH. Uncertainty in Illness. *Image J Nurs Sch.* 1988; 20:225–232. [PubMed: 3203947]
7. Lee Y. The relationships between uncertainty and posttraumatic stress in survivors of childhood cancer. *Nurs Res.* 2006; 14:133–141.
8. Santacroce S. Uncertainty, anxiety, and symptoms of posttraumatic stress in parents of children recently diagnosed with cancer. *J Pediatr Oncol Nur.* 2002; 19(3):104–11.
9. Parker PA, Alba F, Fellman B, et al. Illness Uncertainty and quality of life of patients with small renal tumors undergoing watchful waiting: A 2-year prospective study. *Eur Urol.* 2013; 63:1–6. [PubMed: 22868670]
10. Caruso V, Giammanco DM, Gitto L. Quality of life and uncertainty in illness for chronic patients. *MJCP.* 2014; 2:2–10.
11. Eastwood JA, Doering L, Roper J, Hays RD. Uncertainty and health-related quality of life one year after coronary angiography. *Am J Crit Care.* 2008; 17(3):232–242. [PubMed: 18450680]

12. Van Deyk K, Pelgrims E, Troost E, et al. Adolescents' understanding of their congenital heart disease on transfer to adult-focused care. *Am J Cardiol.* 2010; 106:1803–1807. [PubMed: 21126624]
13. Morceri P, Goossens E, Hascoet S, et al. From adolescents to adults with congenital heart disease: the role of transition. *Eur J Pediatr.* 2015; 174:847–854. [PubMed: 25957970]
14. Meadows AK, Bosco V, Tong E, Fernandes S, Saidi A. Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease. *Curr Cardio Rep.* 2009; 11:291–297.
15. Heery E, Sheehan AM, While AE, Coyne I. Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: A systematic review. *Congent Heart Dis.* 2015; 10:413–427.
16. Harrison JL, Silversides CK, Oechslin EN, Kovacs AH. Healthcare needs of adults with congenital heart disease study of the patient perspective. *J Cardiovasc Nurs.* 2011; 26(6):497–503. [PubMed: 21372735]
17. Docherty SL, Kayle M, Maslow GR, Santacroce SJ. The adolescent and young adult with cancer: A developmental life course perspective. *Semin Oncol Nurs.* 2015; 31:186–196. [PubMed: 26210197]
18. Mishel MH. Reconceptualization of the Uncertainty in Illness Theory. *Image J Nurs Sch.* 1990; 22:256–262. [PubMed: 2292449]
19. Santacroce S. Parental uncertainty and posttraumatic stress in serious childhood illness. *J Nurs Scholarsh.* 2003; 35:45–51. [PubMed: 12701526]
20. Baumgartner H, Bonhoffer P, De Groot NM, et al. ESC Guidelines for the management of grown-up congenital heart disease: The Task Force on the management of grown-up congenital heart disease of the European Society of Cardiology. *Eur Heart J.* 2010; 31:2915–2957. [PubMed: 20801927]
21. Santacroce SJ, Lee YL. Uncertainty, posttraumatic stress, and health behavior in young adult childhood cancer survivors. *Nurs Res.* 2006; 55:259–66. [PubMed: 16849978]
22. Lee YL, Santacroce SJ. Post-traumatic stress in long-term young adult survivors of childhood cancer: A questionnaire survey. *Int J Nurs Stud.* 2007; 44:1406–1417. [PubMed: 16989835]
23. Tackett AP, Cushing CC, Suorsa KI, et al. Illness Uncertainty, global psychological distress, and posttraumatic stress in pediatric cancer: A preliminary examination using a path analysis approach. *J Pediatr Psychol.* 2016; 41(3):309–318. [PubMed: 26423322]
24. Warnes CA, Liberthson R, Danielson GK, et al. Task Force 1: The changing profile of congenital heart disease in adult life. *J Am Coll Cardiol.* 2001; 37(5):1170–1175. [PubMed: 11300418]
25. Steinberg AM, Brymer MJ, Decker KB, Pynoos RS. The University of California at Los Angeles Post-Traumatic Stress Disorder Reaction Index. *Curr Psychiatry Rep.* 2004; 6:96–100. [PubMed: 15038911]
26. Glaser, B., Strauss, A. The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine Transaction; 1967.
27. Cleanthous S, Newman SP, Shipley M, Isenberg DA, Cano SJ. What constitutes uncertainty in systemic lupus erythematosus and rheumatoid arthritis? *Psycholo & Health.* 2013; 28(2):171–188.
28. Dudas K, Olsson LE, Wolf A, et al. Uncertainty in illness among patients with chronic heart failure is less in person-centered care than in usual care. *Eur J CardiovascNurs.* 2012; 12(6):521–528.
29. Bailey DE, Landerman L, Barroso J, et al. Uncertainty, symptoms and quality of life in persons with chronic hepatitis C undergoing watchful waiting. *Psychosomatics.* 2009; 50(2):138–146. [PubMed: 19377022]
30. Kimbell B, Boyd K, Kendall M, Iredale J, Murray SA. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open.* 2015; 5:1–8.
31. Germino BB, Mishel MH, Crandell J, et al. Outcomes of an Uncertainty Management Intervention in Younger African American and Caucasian Breast Cancer Survivors. *Oncol Nurs Forum.* 2013; 40(1):82–92. [PubMed: 23269773]
32. Rees S. 'Am I really gonna go sixty years without getting cancer again?' Uncertainty and liminality in young women's accounts of living with a history of breast cancer. *Health.* 2017; 21(3):241–258. [PubMed: 28521649]

33. Decker CL, Haase JE, Bell CJ. Uncertainty in adolescents and young adults with cancer. *Oncol Nurs Forum*. 2007; 34(3):681–8. [PubMed: 17573327]
34. Phillips CR, Haase JE, Broome ME, Carpenter JS, Frankel RM. Connecting with healthcare providers at diagnosis: adolescent/young adult cancer survivors' perspectives. *Int J Qual Stud Health Well-being*. 2017; 12:1–10.
35. Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. *Int'l Journal of Cardiology*. 2008; 125:62–65.
36. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients (The Health, Education and Access Research Trial: HEART-ACHD). *J Am Coll Cardiol*. 2013; 61(21):2180–2184. [PubMed: 23542112]
37. Adams E, McCann L, Armes J, et al. The experiences, needs and concerns of younger women with breast cancer: a meta-ethnography. *Psycho-Oncology*. 2011; 20:851–861. [PubMed: 20597066]
38. Yeomanson DJ, Morgan S, Pacey AA. Discussing fertility preservation at the time of cancer diagnosis: dissatisfaction of young females. *Pediatr Blood Cancer*. 2013; 60:1996–2000. [PubMed: 23836521]
39. Halliday LE, Boughton MA, Kerridge I. Mothering and self-othering: The impact of uncertain reproductive capability in young women after hematological malignancy. *Health Care Women Int*. 35(3):249–265.
40. Ngu K, Hay M, Menahem S. Case studies of the perceptions of women with high risk congenital heart disease successfully completing a pregnancy. *Heart, Lung and Circulation*. 2014:252–255.
41. Parry C. Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qual Health Res*. 2003; 13:227–246. [PubMed: 12643030]

**Table 1**

## Socio-demographic and Clinical Variables

	<b>Participants n = 25 % n</b>
Mean age (years) $\pm$ SD, range	25 $\pm$ 4.3 (19–34)
Gender	
Male	36 (9)
Female	64 (16)
Race/Ethnicity	
White	84 (21)
African American	4 (1)
Asian	4 (1)
Anglo-Indian	4 (1)
Other	4 (1)
Education	
High school graduate	12 (3)
More than high school	88 (22)
Employed	
Yes	68 (17)
No	32 (8)
Medical insurance	
Parental policy	48 (12)
Individual policy	36 (9)
Spouse or domestic partner policy	8 (2)
Public policy	4 (1)
Uninsured	4 (1)
Income	
< \$25,000	60 (15)
\$25,000–\$50,000	24 (6)
>\$50,000	16 (4)
Prior cardiac surgery (Mean $\pm$ SD, range)	3.5 $\pm$ 3.75 (1–15)
Daily cardiac medications (Mean $\pm$ SD, range)	1.9 $\pm$ 1.83 (1–7)
CHD-related co-morbidities (Mean $\pm$ SD, range)	2.5 $\pm$ 1.6 (1–6)
Complexity of cardiac defect *	
Mild	4 (1)
Moderate	52 (13)
Complex	44 (11)

\* Warnes CA, Libertson R, Danielson GK, et al. Task Force 1: The changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001; 37, e1170–e1175.

Descriptive Statistics and Cronbach's Alpha Reliability for the UCLA PTSD-Reaction Index, N=25

**Table 2**

	% (n)	Mean	SD	Range	Cronbach's Alpha
Full PTSD	24 (6)			32-47	0.97
Severity Levels					
Mild	16 (4)	22.2	2.2	19-24	
Moderate	60 (15)	29.4	4.2	25-37	
Severe	24 (6)	42.3	2.9	40-47	