Revised: 14 May 2018

ORIGINAL ARTICLE

WILEY Congenital Heart Disease

Narrative analysis of adults with complex congenital heart disease: Childhood experiences and their lifelong reverberations

Michelle Keir MD, FRCP(C)¹ Barbara Bailey NP, MSc^1 Angela Lee NP, MSc^1 Adrienne H. Kovacs $PhD^{1,2}$ S. Lucy Roche MB, ChB, MRCPCH, $MD^{1,3}$

¹Toronto Congenital Cardiac Centre for Adults, Peter Munk Cardiac Centre, University of Toronto, Toronto, Ontario, Canada

²Knight Cardiovascular Institute, Oregon Heath & Science University, Portland, Orgeon, USA

³The Hospital for Sick Children, Toronto, Ontario, Canada

Correspondence

S. Lucy Roche, Division of Cardiology, 5N-521 Toronto General Hospital, 585 University Avenue, Toronto, M5G 2N2, Ontario, Canada. Email: lucy.roche@uhn.ca

Funding information ACHD Fund for Excellence

Abstract

Background: With access to surgical care, >90% of today's infants with congenital heart disease (CHD) will reach adulthood. During childhood, survivors accrue a wealth of health care experience and develop strategies for navigating life with a chronic disease.

Methods: Seeking to learn from this individualized process, we invited adults with complex CHD to participate in narrative analysis-an established qualitative research method for studying how individuals derive meaning from their personal stories. Audio recordings of 2-4 hour free-form interviews were transcribed and iteratively analyzed to identify common themes and detect similarities or differences in language, viewpoint and interpretation. Recruitment continued until saturation was reached (n = 10). Results: While each narrative was unique, CHD had a pervasive effect on the autobiography of all participants. Seven themes were discussed consistently: (1) parental/sibling relationships, (2) physical limitations, (3) embarrassment/denial, (4) memories of pediatric health care, (5) transition to adult care, (6) education and career choices, and (7) relationship and reproductive choices. While some of the recalled experiences were negative, all participants also spoke positively about the effect of CHD on their lives. Conclusions: Adults with CHD provide the voices of expert witnesses; illuminating how the pediatric journey influences their identity, choices, personal relationships and adult health care interactions. These narratives could inform and improve the contemporary care of children with heart disease.

KEYWORD

adult congenital heart disease, pediatric cardiology, psychology, outcomes, narrative analysis

1 | INTRODUCTION

Advances over the past four decades mean that, with access to surgery, the majority of infants born with congenital heart disease (CHD) now live into adulthood. Excellent pediatric outcomes are expected even from those with complex anatomy.^{1,2} Survival usually requires major surgery in early life along with multiple cardiac catheterizations, hospitalizations, imaging studies and outpatient visits before the age of 18 years. Patients often also experience unpredictable acute events such as arrhythmia, infection, and heart failure episodes. We were interested to learn how a childhood permeated by these kinds of biographical disruptions influences the adult patient's understanding of who they are, how they relate to others (including health care professionals) and the choices they make. Insights would be of considerable interest, not only to the growing population of adults with CHD and those who care for them, but also to the next generation of pediatric cardiology patients, their parents, and care providers. Narrative analysis (NA) is an established qualitative research method for studying the way in which participants describe experiences.³ The method takes the story itself as its object of investigation and seeks to understand how participants "impose order on the flow of experience to make sense of events and actions in their lives."³ While oral narratives are inevitably imperfect recollections, their substance, structure, themes and language hold meaning. The teller makes decisions about which elements of an experience to include as well as how to order and describe them. Considering why participants choose to relate particular stories and analyzing them, permits a deeper understanding of what the teller considers most relevant and how they interpret events and interactions. The way in which a story is told also relates to how the teller envisages their current life and future potential.

We invited adults with complex CHD to narrate their disease course and reflect on a lifetime of illness experience. We wanted to gain insight into the strategies these patients use to make sense of their history and construct identity. A key objective was to learn how patients perceive childhood and adolescent health experiences to have affected their adult life.

2 | METHODS

With approval from our institutional research ethics board we conducted a prospective, narrative analysis study in adults (>18 years) with CHD of great complexity as per Task Force 1 classification.⁴ Because we were interested to learn not only about childhood experiences, but also about how patients with CHD make decisions related to advanced heart failure management options (data not included in this manuscript), we recruited patients with upcoming outpatient visits to our combined adult congenital heart disease-heart failure clinic who had made significant health care decisions in the previous 1-2 years. Patients with cognitive challenges, chromosomal defects and/or for whom English was not the preferred language were excluded. Potential participants were invited to take part by mail. Six responded. After the first interviews, our research team felt that we had not yet reached saturation. For that reason, we invited more patients to take part, all agreed to participate. Interview order was based on availability of participants.

Patients took part in a single NA interview after providing verbal and written informed consent. Demographic and clinical details were collected from the patient chart. Summary statistics are reported as median (interquartile range) or mean ± standard deviation as appropriate. Each interview was conducted by the study investigators (MK plus BB or AL) with audio recorded for later transcription. All participants had met at least one of their interviewers previously, in the context of either a routine outpatient visit or hospital inpatient stay.

Interviews were initiated with the broad, open-ended question: "Tell us the story of your heart." Participants were permitted to guide the interview with as little prompting as necessary Congenital Heart Disease -WILEY

and with free-form interplay with the interviewers. MK, BB and SLR met after each interview to analyze its transcript, primarily using a thematic approach but also considering the use of language and form. Emerging themes were fed back into the next interview until saturation was reached, at which point enrollment ceased. Transcripts were organized using NVivo (QSR International Pty Ltd. Version 10, 2014; Doncaster, Australia) and were coded based on identified themes.

3 | RESULTS

Ten participants were recruited and completed interviews. Table 1 details their demographic and clinical data. Median age was 44 (range: 38-49) years. Each had undergone at least one major cardiac surgery during childhood. Interviews lasted 2–4 hours with a transcribed word count of $15,644 \pm 3678$ words. All participants expressed that they found study participation positive and hoped that their experiences could improve care for those with CHD. Consistent themes were identified as follows:

3.1 | THEME 1: PARENTAL/SIBLING RELATIONSHIPS

Early in their interview, all 10 participants chose to recount examples of how their heart condition had affected family life. The priority, length of time and emphasis apportioned to this theme suggests a desire to convey the importance of making sense of these earliest relationships. All participants, including those who described problems in their family, displayed empathy toward their parents. Each acknowledged the difficulty of raising a child with CHD facing an uncertain future. Two felt over-protected but all remembered conscious efforts to treat them normally. Two participants believe their parents were relaxed about their physical activity and educational choices specifically because they didn't expect them to survive.

> Participant 6: At first, my parents were told I had a year at best, and then two years, and then four years. And then it became, if I survived, I would be severely mentally and physically stunted. I always joke that at least they got one right! When I was six and a half it was, "well, I guess we should do some surgery to correct things". I got away with whatever I wanted ... let him do what he wants, it doesn't make any difference.

Although all remembered a childhood awareness that their diagnosis was serious and potentially life-limiting, no participant recalled having an open conversation about this with their parents and most recounted that specifics were never discussed.

> Participant 7: ...it wasn't talked about a lot. I don't remember it being raised. I remember once asking how

		מו נוכולזמוונא							
Participant	Cardiac diagnosis	Age at interview	Sex	Age at 1st cardiac surgery	Number cardiac surgeries aged < 18 years	Number of cardiac surgeries ≥ 18 years	Married/cohabiting (Y/N)	Employed (Y/N)	# of Children
1	TGA-Mustard	37	Σ	13 months	1	1	≻	z	0
2	Fontan	36	ш	<1 month	2	2	×	z	0
S	TGA-Mustard	48	Σ	6 months	3	3	Y	×	1
4	TGA-Mustard	46	Σ	<1 month	2	4	×	z	2
5	Fontan	37	ш	<1 year	З	1	×	×	0
6	ccTGA with VSD and PS	39	Σ	8 years	1	4	×	z	1
7	TGA-Mustard	50	Σ	<1 month	2	5	×	×	2
8	TGA-Mustard	49	ш	<1 month	2	S	×	z	С
6	TGA-Mustard	53	Σ	<1 month	с	7	×	z	1
10	Palliated ToF with PA	42	ш	13 years	1	1	×	×	0
Abbreviations	: TGA, transposition of the g	(reat arteries; \	VSD, ven	itricular septal defeci	Abbreviations: TGA, transposition of the great arteries; VSD, ventricular septal defect; MA, mitral atresia; DORV, double outlet right ventricle; ccTGA, congenitally-corrected transposition of the great ar-	uble outlet right ventricle	e; ccTGA, congenitally-c	orrected transpositio	on of the great ar-

teries; PS, pulmonary stenosis; ToF, tetralogy of Fallot; PA, pulmonary atresia; MAPCAs, major aortopulonary collateral arteries

-WILEY- ... Congenital Heart Disease

much the surgery cost and being told it was paid for by the government and then wondering if I was worth it.

Four participants commented that they wished their parents had shared more.

> Participant 9: ... being a parent now I would do things differently.... I would be as open as possible, if my son or I had this disease, starting now.

We noticed participants seemed to feel a strong connection with the parent(s) who accompanied them to hospital appointments. Two male participants commented that attending doctor appointments was a positive experience because it felt special to spend alone time with their fathers.

> Participant 9: I would come to [major city] one day a year and that was the only day my Dad would take off from work when I was a kid ... it was our day together.

In contrast, one female participant felt distant from her father, in part because he did not attend clinic visits, which she remembers as momentous annual events.

> Participant 10: We're not close. My father was completely disconnected, he never came to any of those appointments, it was just me and my Mom ... every year, coming to the cardiologist ... it was a dose of reality, a very serious day, and the rest of the days I would live life.

Two participants believed their childhood illness contributed to breakdown of their parents' marriages although neither felt this was the only marital problem.

> Participant 2: I think it was the last, like the straw that broke the camel's back kind of thing. Because they got divorced or separated pretty much when I had my Fontan procedure. My Dad's opinion was kind of like, just let her be, let her be comfortable and happy and my Mom was like, nope, she wants to live, I want to do the surgery.

All 10 participants had siblings. The effects of CHD on sibling relationships seemed to vary greatly, perhaps influenced by birth order, gender, and also by parental attitudes.

> Participant 7: I was the first born. I had two brothers ... and my middle brother quickly became the leader of the family because while I had ideas, I couldn't actually execute any of them. And I definitely felt like my brothers wanted very little to do with me, especially in later childhood, and I think it's because I was weird. Different.

Participant 9: My siblings didn't treat me differently compared to my younger brother ... we would have piggy back fights and I would drop off my brother's shoulder, I fell out of a tree and broke my arm. I did all the child stupidity.

3.2 | THEME 2: PHYSICAL LIMITATIONS

Every participant mentioned exercise restrictions imposed by their pediatric cardiologists. There were varying levels of adherence. Four patients recalled purposely disobeying.

Participant 6: I was a little bit frustrated at being told I couldn't do things. I always pushed hard. My mom says she remembers, three weeks after leaving hospital [for cardiac surgery], looking out the front window and my friends and I had smoothed out the dirt and made a big bike jump off of it. She looked out and I was three feet up in the air on my BMX.

The majority of participants (n = 7) felt included despite having physical limitations.

Participant 2: I loved my childhood. I don't have any negative feelings toward it. I felt like I was really active.

Whereas three participants related feeling socially isolated because of their lack of sports participation during childhood.

Participant 3: In 1978, when the pacemakers began, then there was definitely no physical contact, right? No roughhousing, no tackle football, no hockey, none of those physical-kind of activities. So, that has, I think, a psychological impact on a young man because you're restricted from bonding, in that sense, with all the other males of your class.

Participant 7: My Mom told her friend who had a couple of boys in the school about me being physically retarded and she told her sons, perhaps to be nice to me, and in no time at all, the word physically dropped off ... so, that was extremely stigmatizing.

One participant was invited to an elite ski training camp as a preteen, but lost his place when the organizers learned of his heart condition. Nevertheless, he found alternative ways to pursue his interest and eventually had a career as an outdoor adventure guide.

> Participant 6: I was also angry that I was supposed to have these limitations that I didn't have. At 10 I was able to beat all the teams that were 16 and 18, things

Congenital Heart Disease

-WILEY

like that. And I got invited to [elite training], which was pretty cool, and then they denied me because of my heart—they said "you can't go"... there was no option. I was really angry about it ... it was pretty hard.... So I quit skiing and I started snowboarding. That was right at the beginning of snowboarding, there weren't any rules. I learned and could compete and do whatever I wanted. I was able to get sponsors and travel around.

3.3 | THEME 3: EMBARRASSMENT AND DENIAL

Participants described varying approaches to disclosing health issues to peers and dealing with questions about chest wall scars. Some developed strategies to make their scars "cool" while others lied out of embarrassment.

> Participant 4: I would have said, "Oh, my heart works backwards, it's kind of cool." But I've always, today, I still make it sound like everything's amazing. I could make the fact that I'm in here for a pleural effusion sound positive.

> Participant 6: I used to tell different people different things about the scar all the time—but never the truth.... I don't know, I guess you don't want people to know there's something wrong.

Two participants used the term "overcompensating" when describing childhood coping mechanisms for dealing with their condition. One recalled concealing the symptoms of a stroke while away from home on a school trip during her teenage years. As an adult retelling the incident, she emphasized that, at the time, she had lacked insight into the seriousness of her condition and symptoms.

> Participant 2: All of a sudden I couldn't, it was like I didn't have an arm anymore. I was walking with my friend. I was trying to say "My arm! My arm!" but I couldn't talk so I was just making weird noises and then I lost my vision. It didn't last long, though. And I remember my friend was freaking out, saying "We have to go see [adult in charge]," and I was like, "No, I don't want to, I don't want to tell people..." It's absolutely ridiculous. I guess maybe I didn't want people knowing I was different. I guess I thought it looked embarrassing. I don't know.

3.4 | THEME 4: MEMORIES OF PEDIATRIC HEALTH CARE

Three participants felt medical needs overtook and defined their childhood, vividly remembering events such as missing holidays due

to hospital admissions. Others remembered viewing their pediatric cardiac care as a side issue.

Participant 3: Santa Claus didn't come down the chimney, Santa Claus came down the elevator shaft at [children's hospital]

Participant 1: All my medical treatment would be just every six months, go to the doctor, or you know, go to the cardiologist, and check things out and then you'd get like, you know, a Holter monitor put on every now and then. And you know, stress tests and what not. And that went on for, until I was about 29 or 30. I mean, I led a normal life until then.

Participant 4: I went to [hospital] once a year. Great doctors but it was really just, check-check, great, ok. You're ... uh, we're happy

The majority (n = 8) had only positive things to say about their pediatric teams and all remembered their pediatric cardiologist, often known for many years.

> Participant 6: Dr. X was good ... it became amusing because I wasn't initially supposed to grow up and I got to be taller than he was. I always thought that was really entertaining. But he was good, he was calm, and he explained things well ... Whereas Dr. Y was really condescending, didn't really pay any attention to me. Talked to my parents. It was kind of like, I was the topic of discussion but didn't really matter as a person.

Fifty percent elected to relate stories of traumatic childhood experiences associated with procedures and hospitalization. One remembered witnessing the death of another child and described it as an "awful memory."

Participant 6: She passed away, pretty much as I was talking to her ... I remember everyone running in and my bed kind of got pushed to the side and I got taken out of the room. I was 7. So that was a pretty awful memory.

Participant 9: It was not a pleasant time. I felt lonely. I felt abused, because all of the needles, all of the tests. And I just wanted to get out of there.

Some participants who recounted suffering associated with medical procedures added that, at the time, they felt little control. For one woman, this feeling led to her avoiding adult health care for many years. Participant 10: I felt like I had no voice ... No, nobody discussed it with me. So, I was four, woke up on the table from my first cath, and that's when I ... like, my last cath was at thirteen and from then to when I was legally allowed to take over my own health care, at sixteen, when you can tell your parents not to come in for appointments. That's when I said, "No more caths" because at four, that was very traumatic.

For another, it wasn't a painful procedure or conversation that she chose to highlight, but something simpler, which nonetheless has affected her adult life.

> Participant 8: I came home and I couldn't walk and I had the Betadine all on my legs. I remember my mom putting me in the tub. Now I hate tub baths because of the, in my head, the vision of the orange coming off. I can't do tub baths.

3.5 | THEME 5: TRANSITION TO ADULT CARE

Only one of the study participants had experienced a period of being lost to specialist follow-up and few spontaneously chose to include reflections on transition to adult care. None mentioned transition as being a particularly traumatic or important event in their lives.

> Participant 5: So, I think I was 18 when I got transferred to [adult hospital], and I didn't like it. Because there was no more coloring—it was more bright and nice at [children's hospital] ... I got used to it after a year or two.

However, when discussing subsequent adult health events, participants universally mentioned feeling insufficiently educated regarding signs and symptoms of progression of their heart disease. They described being unprepared regarding what to expect in their future. Most felt that this had led to delays in diagnosis, mismanagement, or difficulty in participating in decisions about their care.

> Participant 1: I was like "Doctor, I said, is there something, I feel like there's something you're trying to tell me, but you're not doing a very good job." And she said "Well, has anyone ever told you that you are probably gonna need a transplant?" And I said "Never." It was the first time I ever heard of it. And it was like someone just shot me in the face. Probably not that extreme, but you know what I mean. It was just, 'cause I just thought I was, you know, one of these people with, you know, just a switched anatomy and everything would be fine.

One participant reported a misperception he remembered picking up in childhood that affected his adult choices:

Congenital Heart Disease – WILEY

Participant 7: I was told I couldn't drink. I was told I had a patch that dissolved in alcohol.

Another highlighted his challenges participating in adult health care decisions because he felt he hadn't been provided with enough information as a teenager.

Participant 9: It was hard to take ownership because I didn't know what my condition was. If someone asked me, if they saw my scar and they asked what is wrong with you, and I said, well my heart is upside down and backwards, that was my answer, sort of thing.

3.6 | THEME 6: EDUCATION AND CAREER

All participants remembered some degree of academic disruption, which they recognized as having impact on their adult lives.

Participant 3: Education was interrupted. I'd be in school; the heart would flutter or do something bizarre. My Dad would rush me to [children's hospital] and then, that's it, I'm there for a week or two, sometimes months, right? So, education was chopped up. I think I missed some things ... you miss a week of math, and you can't go back. It's like scaffold. You miss the foundation so it was very difficult.

One participant remembered consciously deciding not to prioritize education because he felt his life expectancy was limited.

Participant 6: I didn't do great in high school. I didn't go to class that often, I just messed around. It didn't matter ... because I wasn't going to have the long-term anyway so why would I bother working towards it. So, I did really well in the classes I enjoyed, and then the other classes, I usually didn't even go.

However, others felt CHD had some positive effects on education. One felt his parents made a good decision to stop speaking with him in their native tongue so he could adequately communicate with care providers.

> Participant 3: My, parents, right from the early get go, said "Well, if our son is going to be in and out of hospital, he's gonna learn English and that way, if he's hungry, he says he's hungry, and if he's got pain, he says he's in pain." So, that was a huge thing.

Another spoke about his parents using his cardiac limitations as a motivator for academic achievement.

Participant 9: My dad always said to me "you can't do construction, you are going to have to use your mind."

Despite the challenges, all 10 participants pursued post-secondary education. Two, both women with cyanotic heart disease, described consciously altering their preferred career choice because of their heart condition. One avoided becoming a teacher as she thought she was immune compromised and should not work around children. Another pursued psychology instead of medical school. Several others (n = 3) described avoiding stressful jobs as they worried about the impact on their hearts.

Participant 10: I knew I couldn't do med school. I knew, I'm not going to be here long enough and med school takes forever.... I'd be dead by the time I finished.

Six of our study subjects entered caring professions; working with children, vulnerable adults, or in health care. Each credited their childhood experiences with making them more empathetic adults. One participant, a high school teacher, gave multiple examples as to how his childhood health challenges enable him to communicate better with students and help them find a path through academic or emotional difficulties.

3.7 | THEME 7: RELATIONSHIPS AND REPRODUCTIVE CHOICES

Every participant chose to talk about their romantic/sexual relationships and the decision whether or not to have children. Half of the participants (all male) reported that their CHD had no bearing on their choice of partner. Two participants said they held onto relationships that were not healthy because of their heart disease and a sense of urgency.

> Participant 10: Well, I was never dumped because of it. ... It may have shifted things, it made things serious, for sure. ... I think I pulled them in even more. I tried to attach too much. Like, if this is all I'm going to have, let's get married.

Most participants remember choosing a definite point at which to disclose the seriousness their cardiac condition.

Participant 5: I kind of told him, that I knew I wouldn't live as long as everybody else, right? And then, he said something to the effect that "even if I had just 10 years with you, that's good enough for me." ...He's a great guy, he is. He also realized, just by us dating, that I couldn't keep up with him when we were walking, so, he kind of saw all that beforehand too.

All four female participants recalled advice that having children was dangerous or should be avoided. Each said this contributed to her relationship choices and, for one woman, cultural stigmatization was an added consideration:

Participant 5: I'm [visible minority]. So, how can I say this kind of nicely ... when I was born I think they were worried that I would never get married to a [visible minority] guy. Because, a lot of times, if you look at a mother-in-law, well, she wouldn't be willing to accept me because I wouldn't be able to give grandkids.

Despite the risks, one woman had three successful pregnancies. A large portion of her narrative focused on her obstetric experiences. She reflected on the effects of her pregnancies and children on both her health and spousal relationships. She seemed keen to impress that motherhood was as much a part of her identity as CHD. Another woman described undergoing tubal ligation at age 18 and her later life attempts at IVF surrogacy prior to exploring adoption.

> Participant 2: When I was 11, the doctor asked ... so, it was at a doctor's appointment with the cardiologist, and I left the room and he talked to my Mom and said, "She needs to have a tubal ligation 'cause she can't get pregnant." And at the time, my Mom thought, well, I want her to be a part of this decision and she's 11 ... The doctor was saying, "Well, you never know what could happen." And so, when I was 18, I had a tubal ligation. And that felt weird cause that felt like something somebody older should have. I found that was difficult.

4 | DISCUSSION

This study is the first report of NA undertaken in adults with CHD. It adds depth of detail and context to the existing quantitative literature regarding transition,^{5–7} disease knowledge, psychiatric disorders and physical limitations in this population.^{8–12} Addressing these nonsurgical, lifespan challenges is increasingly important as the distribution of complex CHD shifts from pediatric to adult practice.² It makes sense to inform our efforts with voices of "expert witnesses". Clinical reports constructed through the lens of the healthcare provider are heavily influenced by professional culture and language. They lack information about our patients' experiences, beliefs, hopes and fears that would be pertinent to the management of individual CHD survivors. We found allowing patients to narrate their own health care story both empowered participants and was of practical value to the clinical researchers who studied the transcripts. We agree with the suggestion that NA could be used as a medical education and clinical tool to build empathy.¹³

Previous qualitative CHD research has identified a dichotomy in the way adult patients feel about themselves, understanding that they are different and yet not wanting to define themselves as "sick"^{14–16} Our results support that conclusion and add another facet: health challenges and triumphs shape the lives of children with CHD and reverberate throughout adulthood. In their phenomenological study of young adult Fontan patients, Berghammer et al¹⁷ recognized commitment to life, hope for the future and identity as "a survivor" as major themes. Our participants similarly selfidentified as survivors and interestingly, did not view CHD as an entirely negative force in their lives. Many chose to speak about the positive effects growing up with CHD had on them; strengthening their personalities, clarifying their values and enhancing a sense of empathy. This observation requires us to recognize that CHD is neither a wholly negative nor positive experience but is, instead, a multifaceted part of the participant's biography.

Reflecting on the ways patients remember and make sense of events in their early lives provides insight as to how we might better counsel today's children and their families and partner with them through their lifelong healthcare journey. Specific suggestions stemming from our study include the need to involve teenagers in decision making regarding their cardiac care while acknowledging the trauma they may have experienced due to early hospitalizations. Discussing life expectancy and adult complications of their heart disease, including pregnancy considerations, seems important in helping young adult CHD patients plan for their future and make choices regarding education, career trajectory, and family planning.

5 | LIMITATIONS

Illness narratives are, by their nature, unique and although we felt that saturation was reached, there are inherent limits to the generalizability of a study with only 10 participants. Our participants all had complex CHD, were postsecondary educated, and had recently made major health care decisions. The study's findings may not directly translate to patients from the general CHD population with simpler disease or at a different life stage. Care should be taken applying the results to other cultural or socioeconomic groups. Also, presenting this research in the form of a journal article necessarily imposes constraints. The full transcripts of these interviews contain many insights about what it means to grow-up with a chronic and serious disease and the selected quotations can only convey a snapshot.

6 | CONCLUSION

Adults with complex CHD experience their "heart patient" role as a major component of their autobiography. Although it could be assumed that having life-threatening heart disease at a young age is an entirely negative occurrence, participants described their experiences as multifaceted and often spoke of the positive influence CHD had in their lives. The onus on care providers is to acknowledge the complexity of a CHD patient's feelings about their disease and its important effect on all aspects of their lives.

Congenital Heart Disease

CONFLICT OF INTEREST

The authors have no conflicts of interest relevant to this article to disclose.

AUTHOR CONTRIBUTIONS

Dr Keir conceptualized and designed the study, applied for institutional research ethics board approval, conducted and transcribed patient interviews, participated in meetings after each interview to analyze the transcripts. She drafted the initial manuscript and reviewed and revised the manuscript.

Dr Roche conceptualized and designed the study, applied for institutional research ethics board approval, participated in meetings after each interview to analyze the transcripts, reviewed and revised the manuscript.

Ms Bailey assisted in design of the study, interviewed study subjects, transcribed patient interviews, participated in meetings after each interview to analyze the transcripts, critically reviewed and revised the manuscript.

Ms Lee interviewed a study subject and also critically reviewed and revised the manuscript.

Dr Kovacs assisted in the design of the study and also critically reviewed and revised the manuscript.

All authors approved the final draft of the manuscript as submitted and agree to be accountable for all aspects of the work.

ORCID

Michelle Keir http://orcid.org/0000-0001-7354-0022 S. Lucy Roche http://orcid.org/0000-0003-1323-2196

REFERENCES

- Moons P, Bovijn L, Budts W, Belmans A, Gewillig M. Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation*. 2010;122(22):2264–2272.
- Khairy P, Ionescu-Ittu R, Mackie AS, Abrahamowicz M, Pilote L, Marelli AJ. Changing mortality in congenital heart disease. J Am Coll Cardiol. 2010;56(14):1149–1157.
- 3. Riessman CK. Narrative Analysis. London: SAGE; 1993.
- 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.

- Reid G, Irvine M, McCrindle B, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004;113(3 Pt 1):e197–e205.
- Bratt E, Luyckx K, Goossens E, Budts W, Moons P. Patient-reported health in young people with congenital heart disease transitioning to adulthood. J Adolesc Health. 2015;57:658–665.
- Gurvitz MZ, Inkelas M, Lee M, Stout K, Escarce J, Chang R. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. J Am Coll Cardiol. 2007;49(8):875–882.
- 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.
- Reid GJ, Webb GD, Barzel M, McCrindle BW, Irvine MJ, Siu SC. Estimates of life expectancy by adolescents and young adults with congenital heart disease. J Am Coll Cardiol. 2006;48(2):349–355.
- Jackson JJ, Tierney K, Daniels CJ, Vannatta K. Disease knowledge, perceived risk, and health behavior engagement among adolescents and adults with congenital heart disease. *Heart Lung.* 2015;44:39-44.
- White KS, Purdue C, Ludbrook P, Sodhi S, Esmaeeli A, Cedars A. Cardiac denial and psychological predictors of cardiac care adherence in adults with congenital heart disease. *Behav Modif.* 2016;40(1-2):29-50.
- Deng LX, Khan AM, Drajpuch D, et al. Prevalence and correlates of post-traumatic stress disorder in adults with congenital heart disease. Am J Cardiol. 2016;117:853–857.
- 13. Charon R. To render the lives of patients. Lit Med. 1986;5:58-74.
- Claessens P, Moons P, de Casterlé BD, Cannaerts N, Budts W, Gewillig M. What does it mean to live with a congenital heart disease? A qualitative study on the lived experiences of adult patients. *Eur J Cardiovasc Nurs*. 2005;4(1):3–10.
- Berghammer M, Dellborg M, Ekman I. Young adults experiences of living with congenital heart disease. Int J Cardiol. 2006;110(3):340-347.
- Shearer K, Rempel GR, Norris CM, Magill-Evans J. "It's no big deal": adolescents with congenital heart disease. J Pediatr Nurs. 2013;28(1):28–36.
- Berghammer M, Brink E, Rydberg A, Dellborg M, Ekman I. Committed to life: adolescents and young adults' experiences of living with Fontan circulation. *Congenit Heart Dis.* 2015;10:402–412.

How to cite this article: Keir M, Bailey B, Lee A, Kovacs AH, Lucy Roche S. Narrative analysis of adults with complex congenital heart disease: Childhood experiences and their lifelong reverberations. *Congenital Heart Disease*. 2018;13:740–747. https://doi.org/10.1111/chd.12647

WILEY