

Research Article

Taking a closer look at occupational/career development in young adults with a complex congenital heart defect: A secondary analysis

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ABSTRACT

This study re-analyzed a detailed aspect of the emerging adult developmental period among a small sample of participants living with a complex (chronic) heart defect. The purpose of this analysis was to explore narratives specific to work and career variables among people with chronic heart disease. A qualitative secondary analysis was conducted to extract work and career variables from existing qualitative telephone semi-structured interviews ($N=7$). Three themes were identified from the analysis: (a) *different from my peers*, (b) *restructure and reframe*, and (c) *trying to find my niche in life*. Congenital heart disease makes one reframe to approach life, 'disrupts' achieving developmental tasks. That would impact adult role expectations.

Keywords: Career Planning, Congenital Heart Disease, Developmental Tasks

Introduction

Young adults who live with a congenital heart defect face a unique circumstance. Particularly those individuals who have a history of a complex defect that has required multiple open-heart surgeries, heart catheterizations, prescribed medications (which may require close monitoring), and other procedures, such as a permanent pacemaker and/or internal defibrillator. In the original mixed-methods pilot study (2014), seven ($N=7$) young adults with congenital heart defects were interviewed. These individuals were between the ages of 24 and 25, ($n=3$ female, $n=4$ male), living in the Pacific Northwest (most in Washington state). All had been recommended to continue cardiac surveillance into adulthood by an Adult

Congenital Heart Disease (ACHD) certified provider. Results presented are from the data extracted focused solely on the young adult developmental task of 'establishing a career.'

The qualitative secondary analysis focused on exploring careers and work from the original sample of Congenital Heart Disease (CHD) young adults (age 24-25). It is important to analyze defined segments to the emerging adult developmental period to gain a greater understanding of factors, including facilitators and barriers that influence accomplishing these tasks. Young adults with a chronic health condition (e.g., complex CHD) function in the same society as do their healthy peers. Research shows employment and satisfaction with one's career promotes well-being; in fact, work

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promotes self-worth and gives one a sense of identity [1],[2]. Living with a chronic medical condition; however, potentiates a delay in achieving developmental milestones [3] and shares an inverse relationship with quality of life and overall well-being [4].

The analysis will shed light on participant perspectives recognizing that the original data were collected eight years ago (2014). A lot has occurred in our society that directly impacts early adult developmental tasks; tasks related to employment, education, socialization, and the opportunity for young adults to live independently.

Purpose

The purpose of this analysis was to explore narratives specific to work and career variables from existing semi-structured telephone interviews, conducted in 2014 as part of a mixed methods pilot study. Main ideas were consolidated to use as preliminary work in future research.

Original pilot work was used to re-analyze a detailed aspect of the emerging adult developmental period among a small sample of participants living with a complex (chronic) heart defect. It is this researcher's (KG) goal to add to the body of knowledge based on the findings of this secondary analysis. Findings that are guided by a development theoretical lens and what the current CHD literature tells us about adult congenital heart disease (ACHD).

Methods

A qualitative secondary analysis was conducted to extract work and career variables from existing qualitative telephone semi-structured interviews ($N=7$) conducted in 2014, from a mixed-methods pilot study.

For this analysis, the primary investigator (K.G.) collaborated with PhD faculty mentors from two academic institutions: Idaho State University (ISU) and the University of Oklahoma Health Sciences Center (OUHSC). K.G collaborated with the OU faculty (K.D.) in the original data collection.

The primary investigator (KG) downloaded each of the seven *original* transcribed semi-structured interviews (2014), free of notes. Separately, KG and co-investigator (G.C. - ISU)

read each to gain a general sense of the data. Line-by-line words/phrases relevant to work/careers were included based on the underlying assumptions from prior research in this patient population and guided by young adult developmental theory [1],[5].

K.G and G.C. discussed individual analyses to gain a sense of similarities and differences from the extracted data. For the quotes agreed upon, they were placed into a merged table. Subfolders were created via Google Drive so that K.G and G.C could share, which included thoughts/questions as they arose. The transcripts, in addition to the merged extractions, were then shared with the third investigator (K.D. - OUHSC) so that she too could extract data and share her analysis.

All three investigators convened via a Zoom meeting to create a coding structure with categories/themes. A final Word document was drafted to illustrate our 'group' coding scheme.' A subsequent meeting occurred to re-evaluate the shared extracted data for the final thematic table. This systematic approach enabled each to crucially unpack the data. The process included eliminating data that described other elements of developmental tasks to ensure the analysis focused solely on work/career planning.

An overarching narrative was created to reflect on the main levels and use as an outline to construct *their story* - across the group of individuals. The narrative captured the essence of our sample of individuals as they described work, jobs, and career planning. These direct quotes served as exemplars to the key variables.

Results and Discussion

Results presented draw from data extracted focused solely on the young adult developmental task of 'establishing a career.' Three themes evolved from the analysis: (a) *different from my peers*, (b) *restructure and reframe*, and (c) *trying to find my niche in life*.

Different

These individuals described themselves as different; different from others. Although all of them at the time of the interviews were medically stable, they detailed situations that made

them feel different from their peers. As one participant stated, *"I felt different from other people because I couldn't participate in certain things."*

Such statements materialized when it came to attending college, choosing a career, working, and enjoying the freedoms that come with young adulthood. They reported a lack of freedom to choose any job or profession. Here are a few exemplar quotes:

"It's not like I can bounce around from place to place and not worry about, Oh, I'm going to be fine!" And another stated, *"It's not like I can quit my job and find another one."* Job choice was also limiting because college was difficult for them to complete. For example, one individual needed cardiac surgery while attending college and then couldn't finish.

"I was going to school full-time until admitted into the hospital."

These individuals did not have the freedom to engage in activities without physical restrictions; unlike most of their peers. They described physically active jobs that limited their performance.

"I couldn't get a job where I had to stand up too much."

"Because of my anticoagulants, get bloody nose a lot."

"I'm treated like everyone else until I couldn't do the work."

They want to be treated like everyone else, but their heart condition disrupted developmental tasks. It [CHD] chooses where they live and where they work. One participant discussed difficulty approaching the boss to say, *"Hey, I can't mop. You need to find someone else."* They reported feeling winded, tired, and getting sick more often than others. As one interviewee said, *"I'm really skinny."*

This motivated them to stay in touch/close to home because it is there they are in their "comfort zone." *"Can move back home if I have another major surgery."* Despite potential barriers to gaining and maintaining full-time employment, health care benefits were their focus. This created a sense of feeling *stuck* in a job because they needed to maintain health insurance. *"I need a job that has health insurance. Good health insurance."*

There are limitations to what they can do, and they believe CHD, "chooses your job" and "affect[s] schooling." CHD chose their path for them because there are jobs that they cannot do, such as *"...a firefighter, or go into the Army, I wouldn't be able to do that."*

These individuals are different. Different because of their inability to normalize, to *"participate in certain things"* and they have a conscientious awareness of their health status. *"As long as I wasn't having complications, I was fine."* As they entered adulthood, they desired their independence and to begin shifting away from parents.

Differences also included the possibility of a future medical event. Uncertainty related to their heart could create setbacks to future planning. The group indicated that it is THEY who are most aware and reminded every time, *"I see my scar"*

while another shared, *"When I hear my heart, you'd think you'd get used to it."*

Restructure and Reframe

Although some participants focused on the negative, others appeared to be optimistic. Restructuring and reframing their lives in such a way to gain a sense of acceptance. Instead of 'illness,' these participants were born 'special.' They also never knew life to be different, and so having CHD is just the way things are. The following quotes exemplified this attitude:

"I just kind of take things as they are now."
Or, *"Go with the flow"*

This is also apparent in the individuals with a more positive attitude about work/career planning. They were more motivated and instead of focusing on what they could NOT do, they chose to focus on what one individual said, *"I can do."* This is further demonstrated by another's statement, *"I never had any situations where my heart condition affected my ability at school, or anything like at."*

And.....Now. Trying to find my "niche in life"

Despite reframing their perspective to live the life they desire, to *"go with the flow"* and *"go on with a positive attitude"*, there was a degree of uncertainty. Uncertainty is best captured as

one male put it, "What's going to happen to my future?" While another reported a constant fear that "something is going to happen." Some of our participants were doing well while others shared emotional disturbances (i.e., panic attacks). One of the individuals reported after experiencing a panic attack, "I'm going to have a heart attack." Another reported, "way more negative, negative thoughts."

Uncertainty was primarily driven by a fear of the unpredictability of CHD and its impact on their lives, and long-term planning. Life was okay until an event occurred. Events such as open-heart surgery or other cardiac procedures, when least expected. One participant tried not to think about the unexpected: "It really hasn't affected me too much except when my valve starts going out."

Other questions and thoughts arose as the individuals reflected on their future. Thoughts related to the need for time off work and the financial implications: "Medical bills come to my house now." A few indicated they had to quit their job or were even laid off. Requesting time off for illness or heart procedures made them feel like they could not, "venture out." And lacked choice because, "I was scared to move so far away from my doctors." Some individuals shared regrets about the decisions they made because of their heart condition:

"I wish I would have finished school." Another said, I took "time off for a surgery and never went back." While another individual candidly reported "In the realm of the education areas, I'm not very satisfied with it."

While some participants had regrets, others appeared to be goal driven. This is best exemplified by one of the female's statement about choosing a career in health care because she wanted to "give back", while another female excitedly reported following her "dreams," despite her heart defect. The participants appreciated a quality of life and not take anything for granted. One stated, "I want to be healthy enough to live life the way I want." This conscientious mindset about these individuals' present and future situation is paramount to survival; striving to live life to the fullest while never losing sight of the challenges that may come their way. This approach is best

exemplified by one's statement, "I just plan life decisions around heart procedures."

Conclusion

Understanding the challenges young adults face in the presence of complex CHD is important to designing interventions that help them achieve successful transition of developmental stages. There are limitations worth addressing. First, this was a secondary analysis from original data conducted eight years ago. Although a qualitative analysis, the small sample ($N=7$) and sampling from a single Heart Center minimized generalizability of our findings. However, the findings itself are a strength of the analysis. Considering there were variations in our participants' perceived abilities and satisfaction with work and/or their careers, it highlights the need for further inquiry. These findings will be used to inform a larger study.

Limitations to daily activities described by our participants extended beyond physical functioning. Emerging adulthood is a challenging time for CHD adults because of their innate desire for normalcy - to procure relationships and establish social roles *in addition* to an unknown chronicity. If transition from adolescence to adulthood is unsuccessful, individuals face isolation, which negatively impacts psychosocial experiences and overall development. Future work involving developmental variables at all stages of adulthood would reveal insight longitudinally. Even the emerging adult period generates such drastic changes that as a stand-alone stage, it cannot be approached in a uniform manner. The assumption that ALL emerging adults are similar is inconsistent with the current literature. Identifying this period for the rapid changes that incur, one approaches the individuals recognizing age differences within the same developmental stage. Similarly, ACHD, is unique, consisting of a heterogeneous group of individuals. No two individuals with the same diagnosed heart defect experience their CHD in the same way [6]. It is important that nurses understand individual patients at their current level, considering h/her developmental stage, and the long term sequela of their heart defect - sequela that is a *personal* experience.

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