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The Beat Goes On: Perceptions of Covid-19 as a Young Adult with Congenital Heart Disease

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Abstract

Purpose: The purpose of this paper is to describe the effects of the Covid-19 pandemic on young adults with chronic congenital heart disease. Relevant findings evolved from an existing unpublished study. The study's aim was to qualitatively interpret individuals' illness representation and how the uncertainties of a cardiac condition fit into their role development during the Emerging Adult (EA) stage.

Background: The life expectancy for complex CHD has improved. However, CHD survivors face multiple adverse outcomes as they age. It is not well understood how those with chronic pediatric heart disease perceived their health and the social determinants of health throughout the Covid-19 pandemic. In line with the developmental psychology, major life events may impair one's ability to engage and focus on developmental tasks. The EA developmental period is characterized by a transition to independent living that is marked by profound change.

Methods: 13 young adults (age 22-25) with chronic CHD were recruited from a cardiac clinic in Washington State to participate in a semi-structured interview between November 2022 and February 2030. Data were analyzed via interpretative analysis.

Results: Findings revealed the effects of Covid-19 arose without interview prompts. Example participant quotes include, (a) "I didn't really want to work with people" ('Lena'), (b) "I was told people with my condition had an 84% rate of survival, and that's pretty crazy!"... "they [providers] recommended I get vaccinated and I thought, 'you know. I'll bet on the immune system that I built up'..." "It worked out!" ('Steve').

Conclusion: The experiences of young adults with chronic CHD elucidated meaningful data relevant to the Covid 19-pandemic. Longitudinal data are evolving as scholars analyze the psychological and social implications of the pandemic in the U.S. Findings relevant to Covid-19 from this original research can be used to inform future developmental psychology and public health research.

Keywords: Adult Congenital Heart Disease; Congenital Heart Disease; Coronavirus; Emerging Adulthood

Introduction

Adult Congenital Heart Disease (ACHD) comprises two thirds of the CHD population [1]. Prevalence estimates for adults 18 years of age or older with Congenital Heart Disease (CHD) is 1.4 million (cdc.gov). Advancements in the care and management of congenital heart disease has created improved lifespans. However, life as a young adult with a pediatric heart condition poses challenges. These challenges are multifaceted - physical, psychological, and psychosocial [2-7]. Any setback in adults with CHD potentiates their risk to disengage from expected developmental tasks. Disengagement may exist without an acute event. Circumstances may be related to collective personality changes or a collective identity [8] in the presence of an historical event - or associated with a changing world trend in economic and moral systems [9]. Guided by empirical evidence, the primary investigator posited that the Covid-19 pandemic would have an adverse effect on participants' structure to the point that they disengage from their developmental tasks; thereby impeding role development.

Significance

Anytime individuals disengage from their life tasks, it results in a lower perceived quality of life, efficacious behaviors [10,11], and constructed meaning to make sense of the associated experiences [12]. When faced with an external catastrophic event, it is not well known if such a circumstance would motivate the young adult with chronic CHD to disengage to the point that daily functioning is markedly impaired, and which factors may be facilitators or barriers to successful role transition.

Following the global impact of the Covid-19 pandemic (2020), every age group was adversely affected. Evidence demonstrates a positive correlation between psychological maladjustment and emotional and behavioral difficulties. Additionally, when the social network or human connection renders to virtual platforms, it creates a dissonance between one's perceived identity and the newly "emerging reality" [13]. Negative events impact emerging adults tremendously because it is such an unstable and vulnerable stage. Disruptions to self-development are concerning. In a study by Mather and Carstensen cited in Keil [11], it was found that in the presence of a negative event, healthy older and young individuals shifted their focus and goals to emotional regulation for the present (now) instead of the future. Future planning is at the core of the young adult developmental stage. Therefore, the pandemic is germane to human development, particularly during the Emerging Adult transitional stage and those deemed vulnerable (i.e., chronic conditions). The collective effects of social isolation, mandatory masking, and the global economic shutdown created a public health crisis.

Findings

Although not included as an interview item directly, the effects of Covid-19 on one's life arose in the semi-structured interviews. Topics relevant to wearing masks, school and work restrictions, and the health risks associated with contracting the virus emerged. A surprising finding, however, was that our group of individuals did not reveal financial insecurities during this time. Financial stability may be influenced by one's strong support system, which many reported positive relationships because of growing up with a heart defect. Sample interview items are presented in Appendix A.

The recognition of self occurs within the social and cultural context by which one lives. Therefore, when Covid hit, 'Lena' described, "I didn't really want to work with people as much like I wanted to do more of the back-end stuff (working in a restaurant), so they provided me with a note because it made me feel more comfortable". And now I mean, I've been vaccinated, vaccinated twice, gotten a booster. So I feel pretty OK". 'Steve' discussed leaving college to move back home since all the classes were transferred to online learning. He further shared, "I guess I was worried about it when it first started happening because I knew it was going to affect your heart". "I was told people with my condition had an 84% rate of survival, and that's pretty crazy!" ...However, "they [providers] recommended I get vaccinated and I thought, 'you know. I'll bet on the immune system that I built up'..." "It worked out". Conversely, 'Lena' reported that her doctor wasn't "super worried about me, or like MY type of defect. I would be fine, or semi-OK if I did have caught Covid." 'Nicole's' doctor recommended she stay close to home while recovering from heart surgery to minimize public exposure: "He would rather have had me stay home than being out in the public". The topic of Covid also arose regarding its impact on scheduling medical procedures. 'Lena' was advised to complete a stress test early in 2020, but "it got weird with like getting tested for Covid and stuff", so she never followed up. Discussions relevant to wearing masks, 'Steve' emphatically stated, "That's the only kind of moderate discomfort I have to basically be reminded that Covid exists". "It affected how I breathe, for sure!"

Conclusion and Discussion

Common topics relevant to the Covid-19 pandemic arose in this study among young adults with chronic congenital heart disease. These findings are in line with Moons, et al. [7] in their longitudinal work measuring outcomes from the various waves of the Covid-19 outbreak in the U.K. Their findings [7] revealed that overall, 91.2% reported Covid had a negative effect on their lives. Included in their findings was that there were no differences in PROs (patient reported outcomes) between those who had, and those who had not, contracted Covid. Such outcomes were not quantitatively measured in this study nor were comparison data between the U.S. and U.K. analyzed.

The long-term outcomes of the Covid-19 pandemic in the United States are not known. One could surmise dissonance between perceived reality and the newly "emerging reality" postulated by Godinc, et al. [13] at the height of the pandemic would commence following the loss of the social network. Based on this study's findings, however, the Covid-19 pandemic did not appear to have a deleterious effect on the participants. The economic and social ramifications; however, have yet to fully materialize. The deleterious effects of such coercive policy will likely be observed for years to come. Longitudinal data will provide the evidence to substantiate such a claim. Perhaps many of the economic ills that are felt even by our young adults are an unintended consequence of the Pandemic response. According to the Bureau of Labor Statistics, the U.S. inflation rate was reported to be 6.4% in January 2023. That rate was 1.5% at the end of January 2021. Although total wages have increased, they are not enough to match the inflationary rate. Therefore, Americans face a higher cost of living. Young adults, with or without chronic disease, are no exception.

Regardless of one's current health status and health risk profile, a global pandemic has great implications to every facet of life. As a young adult already living with a pediatric heart condition in the presence of other age-related medical conditions, concerns manifest that may not be faced by healthy young adults. The findings relevant to Covid-19 that emerged from this study can be used to inform future research on disease management throughout the life cycle; and further advance the psychological sciences and public health policy.

References

1. Marelli A, Ionescu-Ittu R, Mackie AS, et al. (2014) Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. *Circulation* 130: 749-756.
2. Cateight B, Samuel M, Laplante L, et. al. (2021) Atrial arrhythmias and patient-reported outcomes in adults with congenital heart diseases: An international study. *Heart Rhythm* 18: 793-800.
3. Moons P, Apers S, Kovacs A, et al. (2020) Sense of coherence in adults with congenital heart disease in 15 countries: Patient characteristics, cultural dimensions and quality of life. *European Journal of Cardiovascular Nursing* 11: 1-11.
4. Moons P, Luyckx K, Thomet C, et al. (2021a) Physical functioning, mental health, and quality of life in different congenital heart defects: Comparative analysis in 3538 patients from 15 countries. *Canadian Journal of Cardiology* 37: 215-223.
5. Thomet C, Moons P, Schwerzmann M, et al. (2018) Self-efficacy as a predictor of patient-reported outcomes in adults with congenital heart disease. *European Journal of Cardiovascular Nursing* 17: 619-626.
6. Van Bulck L, Goossens E, Apers S, et al. (2021) Illness identity in adults with congenital heart disease: Longitudinal trajectories and associations with patient-reported outcomes and healthcare use-Van Bulck-2021-Journal of Advanced Nursing-Wiley Online Library. *Journal of Advanced Nursing* 77: 743-754.
7. Moons P, Goossens E, Luyckx K, et al. (2021b) The COVID-19 pandemic as experienced by adults with congenital heart disease from Belgium, Norway, and South Korea: Impact on life domains, patient-reported outcomes, and experiences with care.
8. Dawson P, Sykes C (2019) Concepts of time and temporality in the storytelling and sensemaking literatures: A review and critique. *International Journal of Management Reviews* 21: 97-114.
9. Erikson E (1980) Identity and the life cycle. W.W. Norton & Company.
10. Bandura A (1989) Human agency in social cognitive theory. *American Psychologist* 44: 1175-1184.
11. Keil F (2013) Developmental Psychology: The Growth of Mind and Behavior: International Student Edition. W. W. Norton & Company.
12. Mills JH, Thurlow A, Mills AJ (2010) Making sense of sensemaking: The critical sensemaking approach. *Qualitative Research in Organizations and Management: An International Journal* 5: 182-195.
13. Godinic D, Obrenovic B, Khudaykulov A (2020) Effects of economic uncertainty on mental health in the covid-19 pandemic context: Social identity disturbance, job uncertainty and psychological well-being model. *International Journal of Innovation and Economic Development* 6: 61-74.
14. Arnett J (2000) A theory of development from the late teens through the twenties. *American Psychologist* 55: 469-480.