



Navigating life with single-ventricle CHD: psychosocial needs across adulthood

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Original Article

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Abstract

Objective: The population of adults with single-ventricle congenital heart disease (CHD) is growing. This study explores their lived experiences through an adult developmental psychology framework. **Methods:** Individuals aged 18 and older with single-ventricle CHD participated in Experience Group sessions and 1:1 interviews. Sessions were transcribed and analysed thematically. Themes were categorized by developmental domains and age group. **Results:** Of the 29 participants, 18 (62%) were female, 10 (35%) were emerging (18–29 years), 13 (45%) were established (30–45 years), and 6 (21%) were midlife adults (46–60 years). Emerging adults expressed reluctance to initiate romantic relationships and fear of burdening partners, while established adults reported strong relationships with partners deeply involved in caregiving. Emerging adults struggled with finding fulfilling work that meets their health needs, whereas established and midlife adults faced unemployment or early retirement due to health limits. Family dynamics shifted, with established and midlife adults educating their children to become caregivers. Physical limitations and low self-rated health were consistent across life stages, and midlife adults did not worry about traditional chronic conditions. Mental health concerns, including anxiety and depression, persisted across all life stages, but resiliency and positive affect were also evident. **Conclusion:** Adults with single-ventricle CHD experience developmental milestones differently, indicating the need for early anticipatory guidance in these domains to achieve optimal outcomes in adulthood.

Introduction

With advances in congenital heart disease (CHD) care, a growing population of individuals with CHD has reached adulthood.^{1–4} Since the development of the Fontan procedure in 1968 for treating complex CHD, the treatment and prognosis for single-ventricle lesions have significantly improved due to advancements in medical and interventional strategies.⁵ As these patients transition to adulthood, they now face unique physical and psychosocial challenges.⁶ However, the understanding of the challenges faced by individuals with single-ventricle CHD and their families is limited, particularly outside the realms of medical care.⁷

Given today's shifting societal dynamics, the traditional life course theory proposed by Erikson on adult developmental psychology in 1950 no longer fully aligns with the richness and complexity of contemporary adulthood.⁸ His theory assumes individuals progress through a rigid sequence of psychosocial stages at specific ages. However, modern adulthood is shaped by diverse cultural, societal, and economic factors, with life expectancy and ageing extending far beyond what the model anticipated.⁹ To address this gap and change the unidimensional focus on adulthood, Clare M. Mehta, Jeffery Arnett, and colleagues collaborated to propose a novel adult developmental framework that divides adulthood into life stages: emerging adulthood (18–29 years), established adulthood (30–45 years), and midlife (45–60 years).^{10,11} The framework categorises six domains that evolve during these stages: romantic relationships, career, caregiving/family, physical health, cognitive development, and overall wellbeing (Supplement 1). These domains are influenced by individual and contextual factors and transform as individuals progress through the various life stages.¹⁰ This study explores the lived experiences of adults with single-ventricle CHD, and how they converge and diverge from Mehta et al.'s framework.

Materials and method

This study is a component of a broader investigation on the lifelong experiences of individuals with single-ventricle CHD and their families. The methodology for the primary findings of the larger study was published by Mery et al. in 2023.¹² In summary, individuals with single-ventricle CHD aged 7 years and older, as well as parents of children of any age, were recruited to participate in Experience Group sessions and 1:1 interviews. Participants were also invited to complete an optional sociodemographic survey.

Experience group sessions

This original study uses a qualitative research methodology known as Experience Group sessions to understand the lived experiences of people who share similar health circumstances. Through lightly moderated group discussions by non-clinical facilitators of 60–90 minutes, usually consisting of small groups of 3–8 people, participants may openly share their lived experiences and health needs, as they engage with each other.^{13,14} Examples of open-ended questions to encourage discussion included “*What does a good day look like for you? What does a bad day look like? What are your goals? What are your fears?*” Experience Group sessions aim to gain insights into what is most important to participants around their journey living with a particular condition. If participants were unable to participate in a session, they were invited to complete a 1:1 interview.

These sessions were conducted in person and virtually with facilitators guiding the conversation to discuss daily experiences, aspects of care delivery as an adult, and how their condition has impacted other domains of life. Audio recordings from Experience Group sessions were transcribed and underwent systematic coding utilising deductive thematic analysis using NVivo software (QSR International, Victoria, Australia). In qualitative research, thematic data analysis is based on grouping overarching ideas, patterns, or concepts into “themes,” representing a key recurring idea that ties together different aspects of the data collected. Codes are labels assigned to specific parts of data to identify key concepts.¹⁵ In our methodology, an a priori codebook was developed using Mehta et al.’s developmental domains as codes, known as deductive thematic analysis. Themes that did not fit into the six codes were coded as “Other emerging themes” and coded inductively, where coders read through transcripts to generate initial codes. A team of five coders independently reviewed all transcripts collected for the study, with each transcript being assessed by two coders. Deductive and inductive themes were discussed with other coders before being categorised by life stage.

Study population

This study utilises data from a subset of adult single-ventricle CHD patients who participated in the original study. It includes all patients aged 18 and older who were diagnosed with single-ventricle CHD and spoke either English or Spanish. For the original study, patients had provided informed consent prior to participation in survey responses and Experience Group sessions.

Results

A total of 29 adults with single-ventricle CHD participated in the Experience Group sessions and 1:1 interviews. Of the participants, 18 (62%) were female. In terms of life stages, 10 (34%) were emerging adults, 13 (45%) were established adults, and 6 (21%)

were midlife adults. A total of six Experience Group sessions were conducted, along with two 1:1 interviews. Group sizes ranged from 2 to 6 participants, and included participants of all life stages. All Experience Group sessions and one of the 1:1 interviews were conducted in English. The only session in Spanish was one 1:1 interview (Table 1). Participant ages ranged from 19 to 56 years old.

Deductive thematic analysis

Example quotes for each code in the different life stages are presented in Table 1.

Romantic relationships

Emerging adult participants reported feeling pressure from traditional gender roles to be providers and helpers in relationships, which conflicted with their health status. Fearing they would burden their partners, some hesitated in pursuing relationships due to financial worries. Concerns about future family roles and parenting were also common. The diagnosis of CHD influenced relationship choices and family planning, leading to difficult conversations about the expectations of family and childbearing. This contrasts with normative experiences, where emerging adults typically focus on exploring long-term relationships without the added pressure of health-related considerations.

In established adulthood, participants with partners described them as supportive in managing their health. Despite this, participants expressed ongoing concern for their partners, feeling guilty about the emotional burden their condition might impose, particularly during hospitalisations. Many participants doubted their worth as partners, fearing that they might be perceived as burdens or poor investments due to the unpredictability and demands of their health condition. This internal conflict often led to feelings of inadequacy and anxiety about their relationships’ long-term viability. Disclosure about their condition remained a pivotal moment in relationships, often occurring early to ensure partners were fully aware of potential future challenges. Planning for the future, including decisions about marriage and family, remained complex over time. Participants also emphasised the importance of balancing present enjoyment with planning for the future, striving to ensure both they and their partners had fulfilling experiences.

Even though romantic relationships were not commonly discussed in midlife patients, there were allusions to experiences through past life stages that involved fears of rejection and romantic marginalisation due to their cardiac conditions. This contrasts with normative experiences, where individuals in midlife often focus on strong, long-term commitments or potentially entering second relationships.

Career

Emerging adults expressed a desire to maintain regular employment despite their health challenges, valuing the ability to work a typical nine-to-five job. Health considerations, such as taking medication that requires vigilant monitoring, and avoiding physical activities, led some to shift career paths, and in extreme cases, resign from their positions. Access to adequate health insurance was a significant concern, with participants noting the high costs of medical care and the difficulty of choosing suitable insurance when transitioning from their parents’ coverage. Financial concerns related to healthcare costs influenced career

Table 1. Example quotes and themes per adult developmental domain in adult single-ventricle CHD through life stages

Code	Life stages		
	Emerging adulthood	Established adulthood	Midlife
Romantic Relationship	<p>Initial resistance to serious relationships: “Yo no quería que una persona se encariñe de mí porque no quiero que en un futuro, no sé, que fallecer, ella se quede sufriendo . . . hubo un tiempo en que me cerré mucho en eso, de no quiero tener una relación” (“I didn’t want a person to get attached to me because I didn’t want that in the future, I don’t know, if I die, she will be left suffering . . . there was a time when I closed myself a lot on that, that I don’t want to have a relationship.”)</p> <p>Fear of becoming a burden “I still struggle with feeling like a burden to him half of the time or most of the time, I would say, which is really difficult because he’s very understanding, he’s very easy going and I’m like a high-strong type A anxious person.”</p>	<p>Strong involvement of partners in medical care journey “My wife is really supportive as well. I mean, to the point . . . It’s kind of like . . . I don’t know. There’s that feeling too of when you feel kind of bad for the people around you. If you end up in the hospital something, you spend a lot of time just like arrgghh. It seems like it’s almost worse for them kind of.”</p>	<p>“And if you’re dating and you tell someone [about the SV condition] and then you don’t get no calls anymore or I had one guy, he called me damaged goods.”</p>
Career	<p>Life-shaping career choices based on insurance coverage and physical condition “But then with this job, they had a health insurance plan and I looked at it very thoroughly and I noticed that if I added everything up, I would make less money than I would be working part-time. So it’s actually affected my employment decisions because I have to weigh all of my options.”</p>	<p>Concerns for ability to perform in current role and potential option of retirement “I’m updating my will. I am freaking out. My husband and I, I was like, “Damn, we worked so hard to try to retire and I’m only in my 40s.” “. . . if I wear oxygen, it impedes me on my job. If I don’t wear oxygen, I’m impeded on my job . . . So do I want to get retirement, but yet I’m not nearly old enough to retire. So what are my options here</p>	
Caregiving/ Family	<p>Decision-making about childbearing “I’m getting closer towards that age where’s going to either happen or not happen type thing. But . . . if I have kids and I can’t provide for them and I pass on due to heart condition, is that something I really want to do?”</p> <p>Family providing emotional support “I can’t even imagine trying to do that without a good family or an adult behind you, especially when you’re young.”</p> <p>Conflict of wanting to be a contributing member of the household “I’d say for me the biggest roadblock that I guess I’ve come across is the medical bills. I mean, I’ll never get away from that for my entire life . . .”</p>	<p>Prepare children for being involved in my own care taking “Both of my kids can outrun me and neither one of them know that and they never will. They can’t know that they could probably get away from mommy.” “For me as a mother, it’s being around long enough to care for my kids. I don’t know . . . it’s getting them to a point where I feel like they can survive without me.”</p>	
Physical	<p>“. . . I go on periods of gains like working out, eating right and I’d say it just gets harder. The more I weigh, the longer it goes on, the harder it gets.”</p>	<p>Acknowledgement of physical limitations and challenges with diet and exercise “. . . it’s not clearly visible on us that we’re limited in any way except if you look close you might notice that our fingertips, our lips are a little blue or if you strap the monitor on us”</p>	<p>Concerns about hepatic complications “I pretty much didn’t know about the liver issues until recently as well. I think it’s because the health community didn’t really know. It wasn’t like they were keeping a big secret.”</p>
Cognitive	<p>“I think intellectually if I was to take a test and let’s say I grew up without a heart condition and I studied, as opposed to growing up with a heart condition . . . I’d make the same score on the test.”</p>	<p>Fear of cognitive decline associated with diagnosis “You’re always wondering what you would be like if you didn’t have this kind of situation going on and it can take your brain a bunch of different ways.” “. . . as I’m getting older, of course age has something to do with it and maybe my oxygen has dropped a little bit, I’m having a little more issues with clarity of not just memory, but comprehension sometimes. Of course I’m thinking dementia, but I don’t want to go there either.”</p>	

(Continued)

Table 1. (Continued)

Code	Life stages		
	Emerging adulthood	Established adulthood	Midlife
Wellbeing	Higher positive affect		
	<p>“I feel like every bad thing that has come with my condition, there’s been something great that came with it.”</p> <p>“I just feel like I want to live life instead of focusing on it. But it is hard when I put my life out there with CHD to so many, it is hard to balance. So sometimes I need to take a break. You don’t want one thing to overwhelm you.”</p> <p>“But there’s a lot of hope, and there’s going to be a lot of blessings and there’s going to be a lot of “normal” and a lot of great. So as much as there will be downs, there will be a lot of highs and that everyone has challenges in life.”</p>		

decisions, with some opting for jobs with better health insurance benefits or weighing the cost of insurance against potential earnings. Frequent job changes and information gathering about career alternatives is a component shared with the normative framework.

Many established adults were surprised by their ability to achieve educational and career milestones at their life stage. Even though health concerns persisted into adulthood, influencing long-term planning, such as updating wills and questioning retirement goals, support from family was crucial to fulfilling career ambitions. Financial considerations continued to be prevalent in this life stage, affecting decisions about medical care and work-life balance. Some participants reported career satisfaction being important, prioritising engaging in meaningful daily activities over adhering to traditional retirement plans and focusing on a fulfilling and balanced life despite their health challenges. These adaptive strategies to achieve occupational stability, part of the normative framework, are highlighted through this life stage.

Midlife adults described navigating significant health challenges while maintaining their careers, feeling caught between health needs and job performance. Despite these obstacles, participants highlighted their ability to achieve professional success, as Mehta et al. state in midlife career findings. They credited their upbringing, which encouraged independence and high expectations, for their accomplishments. Balancing health and career remained a central theme, with participants striving to live their lives to the fullest despite ongoing health issues.

Caregiving/Family

Emerging adults shared varied experiences regarding caregiving and family planning. Participants reported having different recommendations and warnings in the past regarding pregnancy risks and family planning, yet some shared the surprise of having safe and uneventful pregnancies. There was a recurring theme of concern about passing on CHD to future children and the responsibilities and challenges it might entail. Despite these challenges, the desire to start a family was strong, though tempered by practical considerations of health and financial stability. Participants also emphasised the importance of having a supportive family structure in coping with their condition. The support of friends and faith was highlighted as crucial, particularly in managing the burden of disease and medical expenses. Though decision-making about childbearing typically appears in later life stages, individuals with single-ventricle CHD can experience this before it appears in the normative framework. Nonetheless, the emotional and instrumental support that parents of individuals with single-ventricle CHD provide during this life stage was shared by both groups.

Established adults continued to share how faith played a role in comfort and family coping strategies. Participants reported a sense of guilt about burdening family members financially, especially older parents and partners during hospitalisations during this life stage. Despite physical limitations, participants were driven to continue working and caring for their families, often pushing through health challenges. Those who were parents maintained an open communication about their condition with their children, while preparing them for the complexities that their health would entail in the near future.

Midlife adults shared concerns about medical interventions that would come during this life stage related to complications from their single-ventricle diagnosis. Evaluations for transplant, surgical reinterventions, and other palliative measures and their implications for family life were discussed. These participants had to prepare their children to be vigilant about their health, adding to the emotional burden. The support of friends and family was crucial, and the desire to see their children grow up and succeed was a powerful motivator. Despite uncertainties, they hoped to teach their children essential life lessons and ensure their wellbeing. When compared to Mehta et al.’s framework, established and midlife adults still rely on parental care, or shift their focus to educating younger generations and caring for them, rather than having the ability to care for ageing parents as discussed in the normative framework.

Physical

Throughout emerging and established adulthood, Mehta et al. highlighted the overall high self-related health perception in normative development. For single-ventricle CHD, emerging adults shared how they learned to recognise their physical limitations before reaching this life stage, which was often guided by supportive care team members and family members. Situations of overexertion, visible symptoms during physical activities, and struggling with weight management were described by several participants. Despite these challenges, many strive to excel in physical activities, determined not to let their condition define them. Established and midlife adults struggled with weight management and complications associated with the single-ventricle CHD diagnosis. Differences were seen regarding the medical recommendations on physical exertion between life stages. Emerging adults were encouraged to be active and self-monitor as needed, while established and midlife adults were advised in the past to avoid vigorous exercise. Despite this, individuals at all life stages continue to seek ways to improve their quality of life through physical activity that aligns with their abilities and preferences. No allusions were made to the other high-risk chronic conditions that tend to rise during normative midlife development such as obesity,

cancer, or other non-related single-ventricle heart diseases. Yet, concerns over comorbidities related to single-ventricle CHD were mentioned in midlife adults. Hepatic complications were the most common comorbidity reported in this life stage.

Cognitive

Discussion of the cognitive domain was limited among emerging adults. However, some participants expressed a desire to prioritise intellectual pursuits over physical prowess when considering career paths or lifestyle choices. Additionally, some individuals emphasised the importance of continuous learning and exploring new skills, viewing hands-on trades as engaging opportunities for personal growth.

Similar to the decline in processing speed stated in Mehta et al.'s framework, established and midlife adults shared how their condition has affected their cognitive functioning and life trajectory and wondered about their cognitive abilities if they didn't have their health condition. Participants reported that the demands of managing their health, including medications and treatments, can affect their cognitive sharpness and memory, which in turn influences their daily interactions and activities. More in line with the normative framework, single-ventricle emerging, and established adults reflected on the achievement of long-term goals, acquisition, and narrowing of the knowledge base in the context of their cognitive ability and health condition. Midlife participants recognised that ageing, chronically low oxygenation levels, and physiologic cognitive deterioration could all be plausible causes for these declines in function, yet exploration of this cause generated apprehension.

Wellbeing

Mehta et al.'s framework describes a transition from low to high positive affect across the three life stages. However, findings from individuals with single-ventricle CHD suggest that their wellbeing is influenced by their health condition in a more complex manner.

Emerging adults reported a mix of positive affect and mental struggles. Many experienced feelings of isolation, self-harming thoughts, and a lack of understanding from both their community and medical professionals. Struggles with acceptance and finding support were common, with some facing resistance from family members on seeking psychological help. Nonetheless, many found meaning in connecting with others who share their condition, offering a sense of community and understanding. Participants recognised the importance of staying positive, advocating for themselves, and finding gratitude in everyday moments. This stage was marked by a search for identity and purpose, influenced by their experiences with single-ventricle CHD.

Established adults' reflections on wellbeing become more clinically oriented. Early encounters with medical professionals and the ongoing challenges of living with a chronic condition often shaped their perspective. Many recall feeling different from their peers, with memories of surgeries and medical interventions dating back to childhood. This early awareness of mortality led to anxiety and a sense of isolation. However, many established adults drew strength from their faith and advocacy for themselves. They focused on maintaining a positive outlook, finding meaning in their experiences and seeking to live life to the fullest. That being said, they still acknowledged the mental health toll, including anxiety, depression, and post-traumatic stress disorder, exacerbated by their condition. The uncertainty about their future health

and the limitations imposed by their condition added to their challenges.

In midlife, participants reflected on their wellbeing with a mixture of acceptance and frustration. They had generally adapted to living with their condition, managing their health through preventative measures and self-care practices. However, they continued to face stigma that can affect their social lives and relationships. Psychological changes, such as decreased mental function and mood shifts after certain procedures, contributed to a sense of uncertainty about the future. Navigating the healthcare system, especially with insurance issues, added to their stress. Having said this, many emphasised the importance of listening to their bodies, advocating for their own health needs, and finding ways to cope with the unknowns of their condition (Figure 1).

Despite the complexity of wellbeing experienced across all life stages, individuals with single-ventricle CHD consistently maintained a high positive affect, with the development of the ability to find meaning and positivity even in the face of significant challenges through all life stages.

Other emerging themes

Other themes that did not align with Mehta et al.'s framework but were prevalent across all life stages included the challenges of transferring care from pediatric to adult providers and the medical attention received from new providers unfamiliar with managing single-ventricle CHD. Participants frequently reported needing to explain their condition to new providers or during emergency department visits, often leading to setbacks and prolonged delays in receiving care. Many participants preferred continuing with their paediatric care team well into adulthood rather than engaging in receiving their care from an adult medical team. Some even kept their paediatric cardiologist on speed dial for emergencies into midlife. Additionally, physical health issues that appeared unrelated to their condition – such as migraines, tachycardia linked to panic attacks, and brain fog – were often dismissed by medical teams and not fully addressed in the pathophysiology or understanding of their condition.

Discussion

The overall findings of this study unveiled that individuals with single-ventricle CHD face life challenges that transcend the traditional developmental stages. Even when exposed to typical developmental issues, the decision-making process they go through becomes more nuanced and complex. When compared to Mehta et al.'s framework, adults with single-ventricle CHD tend to prioritise different aspects in domains like career, cognitive, and wellbeing, yet experience an accelerated timeline with themes like retirement, mortality, and financial planning. Consistent struggles were observed across all life stages in the physical domain, yet this domain exhibited the most variation in clinician advice on physical exertion due to evolving medical knowledge on recommendations for individuals with single-ventricle CHD. This could be explained by the fact that our knowledge in this area has grown with time.¹⁶

There is no widely recognised application of Mehta and Arnett et al.'s framework specifically in the context of chronic diseases, which highlights an important gap in how we understand and address the life course of individuals with long-term health conditions. This framework, which was designed to describe typical developmental trajectories in otherwise healthy individuals, assumes a relatively linear progression through life stages such as

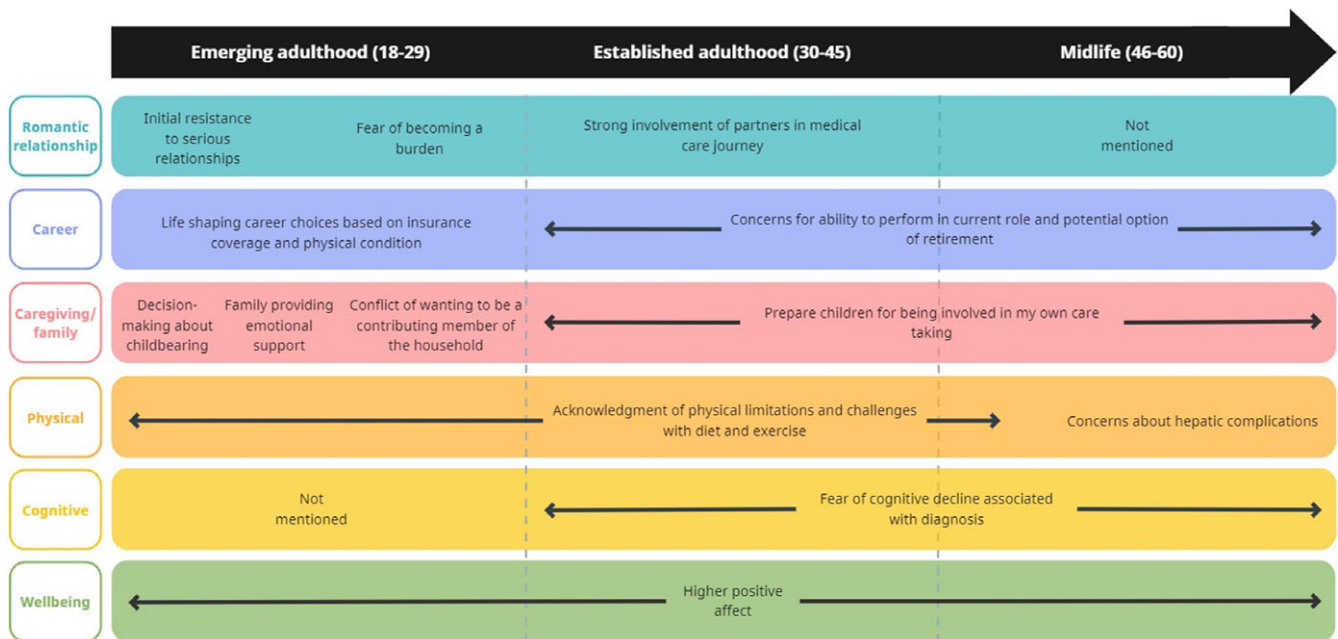


Figure 1. Distinctive features of participants with single-ventricle CHD within Mehta et al.'s adult developmental framework.

education, career, family building, and retirement. However, for individuals with chronic diseases, such as single-ventricle CHD, this linear model is often disrupted or altered in ways that the current framework does not adequately capture. To more accurately reflect the lived experiences of adults with chronic diseases, the framework could involve introducing new domains that consider the medical, psychological, and social complexities of chronic disease management, such as the need for ongoing medical decision-making, navigating healthcare systems, and the emotional toll of living with a long-term condition. A lack of knowledge about the physical changes that might arise throughout adulthood with single-ventricle CHD was clear, and consequently, affected the ability to fully prepare patients for these unforeseen changes. Participants raised awareness around the need for consistent and educated recommendations on the management of pregnancy, family planning, and expectations before and during childbearing ages. Flocco et al. studied the lived experiences of pregnancy and early motherhood with CHD, and highlighted the need for specific intervention programmes to understand the challenges endured by women with CHD who desire and have experienced pregnancy despite the risks and complications caused by their illness.¹⁷ Finally, the wellbeing domain in all three life stages provided insights into the undertreatment of anxiety and depression in this patient group throughout their lifespan and the need for community support systems. Simultaneously, resilience and positive affect were portrayed in all life stages, highlighting the dynamic nature of living with single-ventricle CHD.

These findings align with previous studies that highlight the complex interplay between physical health and psychosocial wellbeing in adults with CHD. Andonian et al. examined how illness identity was a mediator between self-rated health and psychological outcomes, highlighting the need to study modifiable risk factors that predict emotional distress in adult CHD.¹⁸ The correlation between domains and psychosocial wellbeing has also been studied. Pelosi et al. evaluated the relationship between

education, occupational level, and employment rate in adults 40-53 years after surgery, demonstrating an overall better quality of life and psychological functioning despite their lower employment rates.¹ Our study uniquely applies Mehta and authors' developmental framework, offering a nuanced understanding of how these challenges evolve across different life stages. This perspective reveals that while some concerns are consistent throughout adulthood, how individuals prioritise and manage these issues shift significantly as they age.

An important consideration is how medical advances have reshaped the experiences of younger adults with single-ventricle CHD. The initial cohort of patients who survived the single-ventricle palliation pathway coincides with the final life stage outlined in Mehta et al.'s framework. These patients encountered a distinctly different life experience, as their primary focus was survival, with limited attention to long-term quality of life considerations.¹⁹ Uncertain prognoses often translated into more cautious expectations for their future. In contrast, younger patient groups are likely to expect longer and more active lives, with the possibility of engaging in careers, family planning, and managing long-term health. This shift requires care models to adapt to the distinct nuances that come with increased longevity in chronic conditions such as single-ventricle CHD.

These Experience Group insights call attention to crucial factors affecting psychological development outside of medical care in adults with single-ventricle CHD. Healthcare providers are uniquely positioned to enhance relationship-centered care and facilitate communication that addresses specific needs of individuals with single-ventricle CHD, even before they reach adulthood. This approach may involve recognising the stressors these patients face at different life stages, validating them, and inquiring about or offering available resources. Emerging adults may need more guidance on navigating romantic relationships and career planning, while for established and midlife adults, the focus may shift toward managing the emotional burden of chronic illness and planning for future health declines.

Furthermore, key elements identified in the “Other emerging themes” thematic analysis could be interpreted as a distinct domain tailored specifically for individuals with single-ventricle CHD. Considering the dynamic and often unpredictable medical journeys that chronic disease patients experience can profoundly influence decisions around career, family planning, and cognitive and emotional wellbeing. The framework could treat physical health as an ever-present and evolving concern that shapes nearly all aspects of their life decisions.

To enhance the success of adults with single-ventricle CHD in achieving the goals that matter most to them, several key interventions should be considered. Engaging romantic partners in the patient’s care or helping patients learn to talk to their romantic partners about their care can create a supportive environment and ensure partners are well-informed about the patient’s health needs, thereby improving adherence to treatment plans and providing emotional stability. Discussing career aspirations with patients could allow for tailored support and resources that align with their professional ambitions, including managing health conditions in the workplace and accessing career development opportunities.

Providing comprehensive information on family planning and pregnancy is essential, given the specific health considerations associated with single-ventricle CHD.¹⁷ Addressing physical limitations and new symptoms through regular discussions can lead to timely adjustments in treatment and management plans, helping to mitigate the impact of these challenges on daily life. Constant emotional support, including counselling and support groups, is vital for coping with the psychological aspects of living with a chronic condition.^{18,20} This also ensures patients make informed decisions about their reproductive health.

Future research should focus on exploring the long-term trajectories of adults with single-ventricle CHD, examining how their needs and experiences evolve. This includes studying how different life stages affect health management, quality of life, and wellbeing. Additionally, evaluating the effectiveness of targeted interventions such as peer support groups and integrated care models could offer valuable insights into which strategies are most beneficial. Research should also explore innovative support strategies and interventions to further enhance the quality of life for adults with single-ventricle CHD, involving new technologies or approaches in patient education and support. By addressing these areas, we can develop more effective strategies to support this population throughout their adulthood and care journey.

Limitations

Several limitations were noted in this study. First, the Experience Group methodology, which encourages participants to share their lived experiences and health needs while engaging with one another, may introduce the risk of groupthink or conformity, potentially biasing the results. To mitigate this, the study team incorporated 1:1 interviews to complement the focus group findings. Moderators encouraged diverse perspectives, managed dominant voices, and lightly guided conversations to avoid influencing the discussions.

Another limitation to consider was potential inclusion bias within the study’s framework, particularly regarding cognitive ability. Individuals with limited cognitive function may face challenges in learning about or participating in the study, which could restrict the diversity of perspectives and limit the generalizability of the findings. The study team made efforts to simplify

recruitment materials and provide any needed support during the sessions, yet further Experience Group sessions should incorporate an array of accommodations for varying participant cognitive abilities.

A further issue to address is that some elements in the Experience Group transcripts may not align well with the established framework by Mehta et al., potentially leading to misinterpretation or omission of important domains relevant to this patient group. However, the study team identified emergent themes outside of the established framework, grouping these findings in their own domain to better encompass chronic care conditions. Regarding the various care recommendations participants received throughout their care journey, the differences in these recommendations could pose a challenge when comparing domains across life stages. Study participants were skewed towards those who were employed to some capacity, which could introduce sampling bias and limit the generalizability of findings regarding single-ventricle CHD experiences in the career domain. Additionally, the participants that were recruited for the original study that fit our segment were all English-speaking, limiting the scope of lived experiences of Spanish-speaking population insights.

Conclusion

Evaluating the differences and similarities between Mehta et al.’s adult developmental framework and the life experiences of adults with single-ventricle CHD helped identify unmet healthcare needs and challenges faced throughout adulthood. Individuals with single-ventricle CHD experience lifespan development differently and dynamically. Even though individuals with single-ventricle CHD share the same needs as the norm, the prioritization and relevance of each theme varies throughout different life stages. This denotes the need for anticipatory guidance in these domains earlier in care to achieve the best possible outcomes in adulthood. It is crucial to advance efforts encouraging the medical community to incorporate these questions into their standard care protocols.

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Competing interests. The authors declare none.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional review board of the University of Texas at Austin Dell Medical School.

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