The Lived Experiences of Adults with Congenital Heart Defects – A qualitative pilot study

Abstract

Background: The number of adults living with congenital heart defects in the United Kingdom is increasing, yet little qualitative research has explored their lived experiences within a National Health Service context.

Aim: This study utilised interpretative phenomenological analysis to explore how adults living with congenital heart defects in the UK make sense of their condition in everyday life.

Findings: Three themes were identified: (1) loss and mortality, with participants describing a heightened awareness of death shaped by peer and family bereavement; (2) mental health and congenital heart defects, including emotional strain, feelings of burden and inadequate psychological support; and (3) post-surgical support, marked by inconsistent follow-up, variable access to rehabilitation and gaps in continuity of care.

Conclusion: This exploratory study highlights how adults with congenital heart defects may be medically visible but psychosocially overlooked. While services address physical health needs, participants reported unmet psychological and social needs. These findings underscore the importance of proactive psychosocial support across the lifespan and the need for further UK-based research.

Introduction

Congenital heart defects are structural anomalies present from birth that require lifelong management (Houyel and Meilhac 2021). Advances in medical treatment now mean that more than 90% of children with congenital heart defects survive into adulthood (Brida and Gatzoulis 2020), creating a growing population of adults with congenital heart defects.

Understanding the psychosocial impact of living with congenital heart defects in adulthood is therefore increasingly important.

Research has shown that adults with congenital heart defects experience high levels of psychological distress, with between one third and almost half reporting symptoms of anxiety and depression (Khanna et al. 2019; Gleason et al. 2019). Contributing factors include repeated medical interventions, uncertainty about prognosis, and a heightened awareness of mortality (Livecchi and Morton 2022; Hoyos et al. 2024; Steiner et al. 2021). Difficulties with identity, future planning and social participation are also common, as living with a lifelong condition shapes self-concept and expectations (Wang et al. 2023). International studies highlight further challenges, including fragmented care, limited access to tailored rehabilitation, and inadequate psychological support (Lloyd et al. 2025). Despite these difficulties, some individuals demonstrate resilience, drawing strength from family, peers and personal coping strategies (Wang et al. 2023).

Most existing studies are based outside the UK, which limits their applicability to the NHS context. While UK guidance specifies that adult congenital heart defect centres should include specialist psychological services and that next-day support should be available for those in acute distress (NHS, 2016), provision often falls short in practice. For example, Chaudhry et al. (2024) found that access to psychological services is frequently delayed unless patients are in crisis. This creates barriers for those experiencing ongoing psychosocial challenges that may not be judged as urgent.

Aims

This study aimed to explore how adults living with congenital heart defects in the UK make sense of their condition in everyday life. Particular attention was given to how participants understand their identity, mental wellbeing and future in the context of living with a lifelong cardiac condition.

Design

This study employed a qualitative research design, using semi-structured interviews to explore the lived experiences of patients living with congenital heart defects. Interpretative phenomenological analysis, with its foundations in health psychology, provides a methodological approach designed to capture the richness and complexity of individual experiences (Smith et al. 2022), aligning with the study's focus on understanding the personal and subjective impact of congenital heart defects in everyday life. Rooted in idiography, it prioritises detailed engagement with participants lived experiences, supporting this study's focus on generating rich, nuanced accounts rather than breadth across a large sample. As Interpretative Phenomenological Analysis is a double hermeneutic approach, the researcher is sense making of both their own experiences and of the participant's experience. This relates to the researcher's lived experiences as an adult with congenital heart defects; with the researcher having the ability to interpret the data differently to a researcher with no lived experience. However, this poses risks such as selective interpretation.

An interview schedule was developed following the guidance of Smith et al. (2022), with questions designed to encourage reflection and narrative sharing. The benefits of this schedule were that it allowed the interviews to stay focused, as well as keeping interviewees on track, minimising the risk of potential distress. Some questions were adapted from

previous literature to broaden their relevance across different congenital heart defect presentations. (Appendix 1).

Participants

Three adults were recruited through opportunity sampling via the British Heart Foundation's Heart Voices network. Participants were required to be over 18, reside in the UK, and have a formal congenital heart defect diagnosis. Individuals currently experiencing mental health difficulties were excluded in order to minimise the risk of exacerbating psychological distress during discussions of potentially sensitive topics such as mortality and illness experiences. Mental health difficulties were self-reported by participants via asking on the participant demographics form if they selected yes to either "Are you currently experiencing any mental health issues?" or "Are you currently undergoing counselling?". If participants declared yes to either of these questions, they were automatically ineligible to participate. This approach was taken to ensure participant wellbeing while still enabling exploration of psychosocial experiences within a non-crisis context.

The participants represented a range of ages (27-74) Pseudonyms were assigned to all participants to protect confidentiality. Additional identifying details were minimised to reduce the risk of identification within the relatively small congenital heart defects community. Participants included Tom in his 20's, Anna in her 70's and Margaret in her 60's (See table 1) They also presented with conditions associated with different complexities (from simple to complex). Whilst participants shared living with as adults with congenital heart defects, there was heterogeneity in life experiences and treatment. One participant experienced surgery in childhood, another experienced surgery in childhood and adulthood

and the final participant experienced surgery exclusively in adulthood. Consistent with IPA methodology, a small sample size was used to allow for in-depth, idiographic analysis of each participant's account. This enabled detailed exploration of individual experiences before identifying patterns across cases, prioritising depth and meaning over generalisability. Recruitment through the British Heart Foundation Heart Voices network may have resulted in a sample that was more engaged with healthcare services and patient advocacy communities. Individuals not connected to such networks, including those from lower socio-economic backgrounds or with limited digital access, may therefore be underrepresented.

Methods

Ethical approval was obtained by the ethics committee at University of Wolverhampton. Ethics number 1025HFUOWPSY. Given the potentially sensitive nature of discussing illness experiences and mortality, procedures were implemented to support participant wellbeing. Participants were informed that they could pause or stop the interview at any time without explanation. If distress occurred during interviews, the researcher planned to pause the discussion and offer participants the option to discontinue participation. Participants were also provided with information about relevant support services, including their GP and cardiac patient support organisations.

Participants were invited to express interest via email. Upon confirming participation, they were provided with a participant information sheet, consent form, and demographic questionnaire. Participants also had the option of viewing the interview schedule

beforehand to ensure they were satisfied with what would be asked during the interview. Interviews were conducted by the primary researcher and undertaken via Microsoft Teams. Each lasted approximately 25–60 minutes, with a total of 119 minutes of data collated. As the researcher has lived experience of congenital heart disease, careful attention was given to managing the insider position. Reflexive journaling and supervisory discussions were used to ensure that professional boundaries were maintained during recruitment, interviewing and analysis.

Data Analysis

Interviews were transcribed verbatim and analysis followed the six stages of interpretative phenomenological analysis described by Smith et al. (2022). Each transcript was analysed individually before cross-case comparison in order to maintain Interpretative Phenomenological Analysis's idiographic commitment. Initial analysis involved repeated reading of each transcript and detailed exploratory noting, including semantic, linguistic and descriptive content.

From these notes, emergent themes were developed for each individual case. Connections between themes were then examined to generate case-level thematic structures. Only after completing individual analyses were patterns explored across cases to identify shared experiential themes. Themes were not treated as fixed but were iteratively reviewed and refined through repeated engagement with the data. This involved moving back and forth between individual transcripts and developing themes, ensuring that interpretations

remained grounded in participants' accounts while also capturing shared patterns across cases. Where themes overlapped or diverged, these were revisited and reorganised to ensure clarity, coherence, and distinctiveness.

To enhance analytic rigour, developing themes were discussed regularly with the research supervisor to explore alternative interpretations and challenge potential bias arising from the researcher's insider position. Reflexivity played an ongoing role in shaping interpretation. The researcher actively considered how their own experiences and assumptions may influence analytic decisions, using reflexive journaling and supervisory discussions to question interpretations and remain attentive to alternative meanings within the data. This process supported a more nuanced and critically engaged analysis. Rigour was also enhanced by the usage of an audit trail, which enabled the supervisory team to assess where findings were made by the primary researcher. Furthermore, peer debriefing was vital to the process, allowing the primary researcher to seek feedback from your supervisor at key stages in the data-analysis process, affirming the rigour of the work by checking the consistency and veracity of the analysis. This further helped reconcile competing/conflicting interpretations.

Reflexivity

Reflexivity was a critical component throughout the research process, particularly given the researcher's own lived experience with congenital heart defects. This personal connection offered valuable insight and empathy during interviews, potentially enhancing participant rapport and openness. However, it also required careful reflection to ensure that interpretations remained in participants' narratives rather than the researcher's own experiences or assumptions. A reflexive journal was maintained to examine how the

researcher's perspectives, emotions, and positionality influenced data collection and analysis, in alignment with best practices in Interpretative Phenomenological Analysis. Frequent discussions with the project supervisor addressed how the researcher's lived experience could influence the research.

Results

Theme one – Loss and mortality

The theme of loss and mortality constructed as a central aspect of participants' lived experiences, reflecting how the presence of a congenital heart defects extends beyond physical health to influence emotional and existential dimensions of life. Participants described a heightened awareness of mortality, shaped by both personal reflection and experiences of bereavement within their social and familial circles.

Experiences of peer loss were particularly significant for those engaged in congenital heart defect communities or peer support networks. For Tom, these groups provided connection and understanding, but also carried the emotional burden of witnessing the decline or passing of others with similar conditions. As Tom had purposefully settled himself within a community with others with CHD, this set a higher chance of losing fellow individuals with Congenital Heart Defects.

It is mentally tough and we found a lot of times where people have passed away and there's no support to losing that friend, that person that you have grown up with. [Tom].

The frequency of such losses contributed to a persistent sense of vulnerability and reinforced the potentially life-limiting nature of congenital heart defects. Whereas Anna recalls an experience of losing her friend, with what she presumes is a cardiac-related death.

Apart from losing my one of my very, very best friends at only 55, knowing that she had been very tired and they thought it was a heart related thing. […] I was never told if it was her heart, but I'd take take it for granted, it was her heart. [Anna].

Arguably, Anna's experience of having a heart condition and knowing signs and symptoms may have led to speculation surrounding her friend's cause of death and conceptualisation of a heart related death narrative.

In addition to peer bereavement, **losses within the family** played a formative role in participants' perceptions of their own condition. Where congenital heart defects had a genetic component, the death of relatives with the same diagnosis led to deeper contemplation of personal prognosis.

I had my grandfather die[...], but we don't think he had it. So, I don't know anybody who's going there, but it's meant to be in the family because that's how you inherited it [Margaret].

However, Anna recalls outliving family members, which brought both a sense of resilience and a confrontation with the unpredictability of the condition's trajectory. There is an implication that congenital heart defects have nothing to do with odds of survival, and that whilst this is recognised, it does appear that there is a certain level of surprise about this.

kind of got used to people (laugh) die from time to time actually. And it doesn't always have to do anything, have anything to do with congenital heart [defects]. [Anna].

All participants engaged in **reflections on their own mortality**, though their responses varied. Margaret articulated anxiety stemming from a lack of clarity around life expectancy and an absence of consistent information from healthcare professionals.

I don't think you have as many years as you would have as I thought I read you have a not, not as many years as I thought I had when you've had an operation for the heart, I I was reading, I don't know if that's true?[Margaret]

However, for Anna, a congenital heart defect related death is not feared and there is little impact from the condition on the viewing of death. This accepting stance, integrates the presence of congenital heart defects into their broader understanding of life and death.

When it's actually congenital heart related. I don't fear that [Anna].

Tom expressed concern when hearing about a peer passing away, and a sense of concern that he could be the next in his peer group to die. This sense of ending could potentially reinforce the idea that a congenital heart defect death is inevitable.

There is that what if factor. What if it's me? What if I'm next? [Tom].

Across the sample, mortality was not a distant or abstract concept, but a lived reality that shaped daily life, long-term planning, and emotional wellbeing.

Across the sample, mortality was not a distant or abstract concept, but a lived reality that shaped daily life, long-term planning, and emotional wellbeing. Repeated exposure to loss, particularly within peer networks, appeared to both normalise mortality and reinforce vulnerability, creating a complex emotional landscape in which acceptance and anxiety coexist. This suggests that awareness of mortality becomes embedded within everyday life, shaping how individuals understand their future and position themselves in relation to others.

Theme two – experiences of mental health and congenital heart defects

The theme of mental health and congenital heart defects was constructed as prevalent to participants, highlighting how the presence of a congenital heart defects extends to feelings of financial burden on healthcare systems and family networks. Insufficient mental health support, often exacerbated by congenital heart defects, was a common challenge. Difficulties with exercise and hobbies were highlighted illustrating challenges faced with doing these activities while living with congenital heart defects.

Experiences of burdensome were reported across participants in a multitude of formats. Conceptualisation of status appeared intertwined into the lived experiences with Anna describing the feeling that they should be on a lower priority due to being of an older age and being of a better financial status.

I think a younger, poor person actually is more important than me [Anna].

Tom contemplated financial burden on their family who experienced time off work along the participant's congenital heart defects journey.

if they didn't come with me to the appointments, could we be better off? [Tom]

Further concerns centred being overbearing on medical staff and feeling a hesitancy to contact them. This came with elements of hesitating contacting even with the occurrence of new symptoms due to feeling a burden.

having a feeling that I'm bothering him. You know, I know that his queues are endless. [Anna]

Furthermore, participants explored their experiences surrounding accessing mental health support. Margaret described how she felt support after surgery was minimal, with no support being offered – in hindsight indication of a safe space to talk was indicated to be appreciated.

Oh someone who could have talked to me about it more and why, why this happened [Margaret]

Whereas for Anna, support was offered by a nurse, after an incident where Anna was visibly distressed. However, in this circumstance Anna was required to self-refer to psychological support.

I came out to my husband in floods of tears and one of the nurses said I think you need help for this So what I did, I had, I contacted self referred to this talking therapy. [Anna].

Furthermore, there is an element that general psychological interventions were not best suited for Anna, as there came a sense that it was unhelpful with the daily challenges of living with congenital heart defects; which was the initial reason for accessing psychological support.

actually a lockdown started, and err, I suppose it helped in that respect, but it hasn't really helped the day-to-day congenital heart thing. [Anna]

All three participants expressed a relationship between physical health and mental health. Whilst all participants experienced a preferred style of exercise, congenital heart defects can lead to a sense of frustration with exercise including that it can be hard to keep up with others. This may lead to a sense of frustration with one's limitations. In both Anna and Tom's experiences, they describe how walking with others can highlight one's limitations.

I mean they have to wait for me all the time, but we always say the most important is that at least I'm out uh walking. [Anna]

I find that limitation can be quite hard as well, where my family we're all quite outdoorsy [Tom]

Whereas for Margaret, she felt difficulties when it came to clinicians imposing restrictions and highlighted the choice to reject medical restrictions. Implications came from experiencing symptomology when performing restrictions. The choice to reject medical restrictions was also poignant to Margaret's experience, due to the exercise of choice being central to Margaret's identity.

I would just skate and I don't get any symptoms. Of course I've got it now, oh I feel that and I know I've got had something done. [Margaret]

These findings highlight how participants appear to internalise responsibility for both their health and its wider impact, positioning themselves as potential burdens to family and services. This may shape how individuals engage with support, with a tendency to minimise needs or delay help-seeking in order to protect others. Experiences of limitation, particularly in relation to physical activity, also suggest an impact beyond functional capacity, influencing how individuals perceive themselves in comparison to others and navigate everyday life. In this way, managing a congenital heart defect becomes intertwined with identity and daily decision-making, while distress may remain present but not always visible within routine care.

Theme three – support after surgery

This theme conceptualises participant's experiences surrounding the support they received after surgery. Medical support appeared vital after surgery, with participants reporting negative experiences with practitioners after surgery. Cardiac rehabilitation had considerable impacts on participants with mixed experiences of the accessing and participation of sessions.

Medical treatment appeared poignant to an individual post-surgical congenital heart defects surgeries. In some cases, participants had fallen through the cracks and experienced long delays to receive medical care again. One participant describing how she had not seen a clinician in forty-seven years. This led to a sense of upset and dismay at the realisation that this should not have been the case.

I'm trying to find excuses. I'm trying to find explanations [Anna]. This led to a sense of upset and dismay at the realisation.

Furthermore, Margaret found herself making excuses for their treatment as they expressed issues with physiotherapy services seeing her once and never again inexplicably.

I saw the physios once in that year up there and they never saw me again. Sometimes I think they were quite busy or I don't know if I fell through the net [Margaret].

This experience led to a sense of confusion and uncertainty as to why there was a lack of follow-up and may have been a barrier in their recovery process. Furthermore, this led to a sense of trying to excuse why this may have been the case.

Further experiences also highlight how lack of follow-ups have been barriers in the recovery process with Anna not receiving regular blood pressure checks from a clinician.

my GP. He insisted on me seeing him every six months for blood pressure. Since erm since he left […]. I do it here (stuttering) on my own [Anna].

Whereas Margaret describes being asked to remove surgical bandages at home.

she had said "can't you take the dressing off yourself?" and I hadn't seen the scar. I thought that was awful [Margaret].

Both experiences led to distrust and frustration between patients and doctors – which leads the question of considering how this may ultimately rupture the clinical relationship between both patients and clinicians.

Overall, these data highlight how inconsistent follow-up and continuity of care may contribute to feelings of neglect and erode confidence in healthcare professionals, with potential implications for long-term engagement with services.

Experiences in accessing cardiac rehabilitation appeared mixed, particularly in accessing it. accessing it. Margaret describes how she was not offered it after surgery in adequate time and how she was not able to participate at the hospitals version due to work commitments. Therefore, by having commitments in her daily life - this led to her attending an external cardiac rehabilitation.

when I asked about it, they said I could go to one, I said well I've gone back to work now so I couldn't go to it [Margaret].

However, this contrasts Anna's experience, who undertook cardiac rehabilitation through her local hospital. She did not report any concerns surrounding attending her cardiac rehabilitation appointments. Furthermore, Anna described how unspecific information for congenital heart defects was provided at cardiac rehabilitation.

you went for exercises and more sort of information about it. That was not specifically for err for err congenital heart [defects] [Anna]

Participants appeared to have a mixed consensus on the benefits of cardiac rehabilitation socially, with Margaret reporting that it was helpful for meeting others with similar conditions, and those who had undergone similar experiences to herself.

Cause it's nice having some other people who've got a heart thing, you know, even if it's not yours, you feel the same [Margaret]

However, Anna reported feeling behind her peers – and in turn, turned into a somewhat negative experience for her.

I always felt I was doing worse than anyone in that class. [Anna]

These experiences suggest that inconsistencies in follow-up extend beyond practical gaps in care, contributing to uncertainty in how individuals navigate healthcare systems over time. A lack of continuity may shape how patients understand their place within services, with some accounts reflecting attempts to rationalise or make sense of being overlooked. This may influence trust in healthcare professionals and affect future help-seeking behaviours. Experiences of cardiac rehabilitation further indicate that when support is not aligned with individual needs, it can impact both engagement and confidence, highlighting how recovery is shaped not only by clinical input but by how care is experienced in everyday life.

Discussion

This study explored the lived experiences of three adults with congenital heart defects in the UK, identifying three themes: loss and mortality, experiences of mental health, and post-surgical support. Participants described a heightened awareness of death, shaped by peer and family bereavement, as well as personal reflections on their prognosis. These findings reflect previous research highlighting mortality as a salient concern within the adult congenital heart defect population (Hoyos et al. 2024; Steiner et al. 2021).

Psychological needs were a recurring challenge. Participants reported feelings of burden towards family and health services, alongside frustration with exercise limitations and barriers to mental health support. In line with existing evidence of high anxiety and

depression rates with congenital heart defects in adulthood (Khanna et al. 2019; Gleason et al. 2019), our findings suggest that support is often reactive, offered only when distress is evident, rather than proactively embedded in care. Some participants described reluctance to seek help, reflecting a desire not to overuse resources or create concern. Such self-regulation has been reported in other chronic conditions (Ivynian et al. 2024) and may contribute to unmet needs in adult congenital heart defects. It is also important to note that individuals with pre-existing mental health conditions were excluded from this study; therefore, the psychological burden identified here is likely underestimated, and the true extent of unmet need may be greater in the broader adult congenital heart defect population.

Experiences of post-surgical support were mixed. Participants reported gaps in follow-up, a lack of continuity, and inconsistent access to cardiac rehabilitation. Where rehabilitation was available, it was not always tailored to congenital conditions, leaving some participants feeling unsupported or out of place. This aligns with literature suggesting that current rehabilitation models are primarily designed for acquired heart defects and do not address the lifelong and complex needs of adult congenital heart defect patients (Kovacs et al. 2018).

Overall, the findings highlight how psychosocial concerns may remain invisible within a system that prioritises medical monitoring. While services often respond to acute needs, participants described vulnerabilities that extend across the lifespan. This underscores the need for greater integration of psychosocial care within adult congenital heart disease services. Cardiac nurses, often the professionals with the most consistent patient contact, are well placed to identify emerging both hidden and visible psychological distress. They are also well situated in recognising key points of vulnerability, such as bereavement, surgery, or

functional limitations. Integrating routine psychosocial assessment into follow-up care, alongside screening for anxiety and depression, could support earlier identification of need. Strengthening referral pathways to psychological services, improving signposting, and developing CHD-specific cardiac rehabilitation programmes throughout the lifespan -though with particular considerations surrounding the period after surgical interventions - are important steps toward addressing the unmet psychosocial needs described by participants.

These findings contribute to the limited UK-based qualitative literature on adults living with congenital heart defects, offering insight into how psychosocial needs are experienced within an NHS context. While previous international research has identified similar challenges, this study highlights how gaps in continuity of care, access to psychological support, and provision of tailored rehabilitation may persist despite existing NHS guidelines. In doing so, the findings extend current understanding by illustrating how patients may remain medically monitored yet psychosocially underserved, emphasising the need for more consistent integration of psychosocial care within routine cardiac services.

Implications for cardiac nursing

Cardiac nurses play a key role in addressing the psychosocial needs of adults with congenital heart defects. Routine follow-up should incorporate proactive psychosocial assessment, with attention to identifying less visible distress, such as reluctance to seek help or feelings of burden. Ensuring consistent post-surgical follow-up and clear points of contact may reduce gaps in care. Earlier referral to psychological services, alongside access to congenital-specific cardiac rehabilitation, may better support patients' long-term adjustment and wellbeing.

Conclusion

This study highlights how adults with congenital heart defects may be medically visible yet emotionally overlooked within the healthcare system. Participants described vulnerabilities linked to mortality, mental health, and post-surgical experiences, illustrating how psychosocial needs are not consistently addressed in routine care. These findings suggest that beyond managing physical health, there is a clear need for proactive psychosocial support across the lifespan. For cardiac nursing, this includes recognising distress at key points in the ACHD lifespan such as death of a peer or undergoing medical tests. This factor may also be of consideration to nurses who organise or are involved in peer support groups. It may also be of consideration to embed psychosocial assessment into follow-up – through doing this, this can ensure timely referral pathways to psychological services.

Limitations/weaknesses/considerations for future literature

This study involved a small, heterogeneous sample, which limits generalisability. However, the use of Interpretative Phenomenological Analysis was appropriate, as its idiographic focus prioritises depth of individual accounts over breadth (Smith et al. 2022). The variation in age and congenital heart defects complexity provided a wide lens on experiences across the lifespan, though it also reduced consistency in shared patterns. Recruitment via the Heart Voices network may have favoured participants already engaged with support systems, meaning the perspectives of more isolated individuals are under-represented.

The researcher's lived experience of congenital heart defects enhanced rapport and depth of insight but also introduced potential interpretative bias. Reflexive journalling, supervisory input and critical reflection were used to mitigate this influence. Future research could build on these findings with larger, more diverse samples, including those not connected to

support networks, to explore how psychosocial needs are addressed or overlooked within UK services.

Furthermore, it is acknowledged that the exclusion criteria surrounding those who experienced mental health difficulties may have limited the inclusion of individuals experiencing psychological distress. As mental health was raised as a significant theme within the findings, this criterion may have shaped the experiences captured and represents a limitation of the study.

Keywords:

Congenital Heart defects, psychosocial needs, emotional impact, patient experience, patient needs, adult congenital heart defects

Key points:

Congenital heart defects have an impact on a large proportion of adult population within the United Kingdom – of which there has been limited literature in understanding the psychosocial impact on the lived experiences of these adults. Through interviewing three participants, there has been the identification of three common themes: loss and mortality, experiences of mental health, and post-surgical support. Loss and mortality discussed how participants viewed death as an individual as well as deaths to those around them, whereas mental health looked at the impact and intersection between their CHD and mental health. Post-surgical support identified topics such as cardiac rehabilitation and difficulties with accessing follow-up post-surgery.

Reflective questions:

- Are there any considerations to the community when an individual with CHD passes away?
- Could embedding a proactive approach to assessing for psychosocial needs improve the speed of mental health support for an individual?
- Could future research support individuals with ACHD to receive specialised information in cardiac rehabilitation? How would this support patients?

Acknowledgments:

I would like to extend my gratitude to the British Heart Foundation for allowing permission to publish my research advertisement in their Heart Voices.

References:

Baumgartner H, et al. *2020 ESC Guidelines for the management of adult congenital heart disease*. European Heart Journal. 2020;41:4153–4154. doi:10.1093/eurheartj/ehaa554

Brida M, Gatzoulis MA. Adult congenital heart disease: Past, present, future. International Journal of Cardiology Congenital Heart Disease. 2020;1:100052. doi:10.1016/j.ijcchd.2020.100052

Chaudhry I, Ghassani A, Wray J, Chaudhry B, Coats L. Outpatient care of adults with congenital heart disease in the UK: a qualitative appraisal of the clinician perspective. Open Heart. 2024;11(1):e002420. doi:10.1136/openhrt-2023-002420

Gleason LP, Deng LX, Khan AM, Drajpuch D, Fuller S, Ludmir J, Mascio CE, Partington SL, Tobin L, Kim YY, et al. Psychological distress in adults with congenital heart disease: focus beyond depression. Cardiology in the Young. 2019;29(2):185–189. doi:10.1017/S1047951118002068

Houyel L, Meilhac SM. Heart Development and Congenital Structural Heart Defects. Annual Review of Genomics and Human Genetics. 2021;22(1):257–284. doi:10.1146/annurev-genom-083118-015012

Hoyos ME, Well A, Van Diest H, Lopez H, Morris M, Carberry KE, Johnson G, Fraser CD, Mery CM, Lamari-Fisher A. Navigating life with single-ventricle CHD: psychosocial needs across adulthood. Cardiology in the Young. 2024;34(11):2341–2348. doi:10.1017/S1047951124036084

Ivynian SE, Ferguson C, Newton PJ, DiGiacomo M. The role of illness perceptions in delayed care-seeking in heart failure: A mixed-methods study. International Journal of Nursing Studies. 2024;150:104644. doi:10.1016/j.ijnurstu.2023.104644

Khanna AD, Duca LM, Kay JD, Shore J, Kelly SL, Crume T. Prevalence of Mental Illness in Adolescents and Adults With Congenital Heart Disease from the Colorado Congenital Heart Defect Surveillance System. The American Journal of Cardiology. 2019;124(4):618–626. doi:10.1016/j.amjcard.2019.05.023

Kovacs AH, Kaufman TM, Broberg CS. Cardiac Rehabilitation for Adults With Congenital Heart Disease: Physical and Psychosocial Considerations. Canadian Journal of Cardiology. 2018;34(10):S270–S277. doi:10.1016/j.cjca.2018.07.016

Livecchi T, Morton L. 2022. Healing Hearts and Minds. Oxford University Press.

Lloyd L, Ruban S, Badal T, Strange G, Celermajer DS, Bonner C. Living with congenital heart disease: a qualitative study to explore psychosocial impacts in adulthood. International Journal of Cardiology Congenital Heart Disease. 2025;21:100610. doi:10.1016/j.ijcchd.2025.100610

NHS England. Congenital Heart Disease Standards & Specifications. 2016. Available from: https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf

Smith JA, Flowers P, Larkin M. 2022. Interpretative phenomenological analysis: theory, method and research. SAGE Publications Ltd 240 p.

Steiner JM, Dhami A, Brown CE, Stout KK, Curtis JR, Engelberg RA, Kirkpatrick JN. It's part of who I am: The impact of congenital heart disease on adult identity and life experience. International Journal of Cardiology Congenital Heart Disease. 2021;4:100146. doi:10.1016/j.ijcchd.2021.100146

Table 1

Participant (Pseudonym)	Age Group	Had surgery	Condition Complexity*	Key Contextual Features
Tom	20s	Yes	Complex	Actively engaged in peer support networks; frequent exposure to peer loss; concerned about burden on family; experiences frustration with physical limitations
Anna	70s	Yes	Moderate	Long-term lived experience; relatively accepting of mortality; feelings of being a burden; gaps in long-term follow-up care; mixed experiences with psychological and rehabilitation support
Margaret	60s	Yes	Simple	Later-life surgical intervention; uncertainty about prognosis; values independence; challenges medical advice at times; reports inconsistent follow-up and rehabilitation access

*As assessed via Baumgartner et al. (2020)