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A qualitative exploration of the experiences of adults living with congenital heart disease.

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Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology.

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Table of Contents

List of Tables

Systematic Review

Major Research Project

List of Figures

Systematic Review

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Chapter 1 Systematic Review

A systematic review of the psychological experiences of adults living with congenital heart disease: a thematic synthesis of the qualitative literature.

Prepared in accordance with the author requirements for

Qualitative Health Research

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Abstract

Due to advancements in cardiac medicine, more people with congenital heart disease (CHD) are surviving into adulthood. CHD poses challenges for mental health and quality of life. Existing reviews summarising the psychological impact of living with CHD in adulthood focus solely on quantitative research and exclude qualitative studies about lived experiences. An updated systematic review synthesising findings from qualitative studies about the psychological experiences of adults living with CHD (ACHD) is needed to better understand the mental health needs of this population. This review aims to appraise, synthesise, and summarise the findings from qualitative studies that have explored the psychological experiences of ACHD.

A systematic search of five electronic databases was performed. Ten eligible studies were identified, and thematic synthesis was used to develop analytical and descriptive themes. Six analytical themes were generated: determination to live a normal life, feeling different, living with uncertainty, fear of being negatively judged by others, positive outlooks, and traumatic memories.

Participants reported challenging psychological experiences associated with living with CHD. However, positive experiences were also reported, conveying hope and inspiration. Psychological care should focus on early identification and intervention of psychological difficulties for people living with CHD, which may lead to better health and quality of life outcomes.

Keywords: congenital heart disease; qualitative systematic review; qualitative research; thematic synthesis.

Background

Congenital heart disease (CHD) is a medical term which refers to heart conditions that develop in the womb (Centers for Disease Control & Prevention, 2023). It is usually diagnosed during pregnancy, or early childhood, although some individuals may be diagnosed later in life. CHD is present in approximately one in 150 births, which equates to approximately 13 babies per day in the United Kingdom (UK) (British Heart Foundation (BHF), 2025). The prevalence of CHD in the UK is estimated to be between one to two percent (BHF, 2025). Prior to the 1950s, CHD was a fatal diagnosis. However, due to advancements in cardiovascular medicine, eight out of 10 infants diagnosed with CHD will now survive until adulthood (Wu et.al., 2020).

Living with CHD poses many challenges, which can impact negatively on psychological wellbeing and quality of life (QoL) (BHF, 2023). A recent large-scale study of a global sample of adults with CHD (ACHD) found that almost one-third of participants reported clinically elevated symptoms of depression and/or anxiety, which was associated with lower QoL and health status (Kovacs et al., 2024). In 2023, Health Improvement Scotland (HIS) published the first standards of care for CHD in Scotland (HIS, 2023). The standards recommend that NHS health boards should provide psychologically informed services to ensure the mental health needs of people with CHD are identified and met. Kovacs et al. (2022) highlighted that, despite strong advocacy from patients and health care professionals, there has been slow progress in implementing mental health care into CHD services. They emphasised the urgency for large scale research studies examining psychological experiences, outcomes, and interventions tailored to this population.

Currently, there is a paucity of qualitative systematic reviews exploring the psychological impact of CHD on adults. Many of the existing qualitative reviews are focused on the psychological experiences of children and adolescents with CHD, or their parents (Dandy et al., 2024; Potterton et al., 2024). Interestingly, existing qualitative systematic reviews tend to emphasise females' experiences with CHD, compared to males. For example, there are several qualitative reviews focusing on women with CHD's experiences of pregnancy and childbirth (Dawson et al., 2018; Harris et al., 2020; Nakamura et al., 2018). Comparatively, there is a dearth of qualitative research focusing on the experiences of males with CHD. One explanation for this is that females with CHD may be more drawn to participating in qualitative research due to wishing to discuss and explore their experiences. However, it may also indicate an inherent bias within the research towards females with CHD.

Existing systematic reviews focusing on the mental health of ACHD are typically based on quantitative studies. For example, Moons et al. (2023) reviewed the quantitative literature on mental health in ACHD and reported that there is a high prevalence of mental health conditions (e.g. anxiety and depression) in this population. By only focusing on quantitative studies and excluding qualitative studies, the recognition and reporting of lived experiences of ACHD is limited. Consequently, this inhibits our understanding of *why* ACHD are more vulnerable to mental health difficulties and how this relates to their experience of living with CHD.

Qualitative research enables a nuanced and detailed exploration of experiences and perspectives (Saunders et al., 2023). It is particularly useful for identifying and exploring new research topics that have not previously been examined. The findings from qualitative research can be used to inform and improve person-centred healthcare interventions, policy, and service development.

To date, and to the author’s knowledge, there are no published systematic reviews that have synthesised qualitative research on the psychological experiences of ACHD. The current review aims to critically appraise, synthesise, and summarise the findings from qualitative studies using thematic synthesis to answer the following research question: “What are the psychological experiences of adults living with congenital heart disease?” It is hoped that the findings will inform and improve clinical practice and future research.

Methods

Registration and Reporting

This systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on the 21st of May 2024 (ID: CRD42024546489). To enhance transparency, the author completed the ENTREQ checklist for the reporting of this review (Tong et al., 2012). The completed checklist is in Appendix A.

Inclusion Criteria

- Primary qualitative studies using phenomenological methods of data collection (e.g., interviews and/or focus groups).
- Studies that recruited adults (aged 16 years and older) with a diagnosis of CHD (any sub-type). No upper age limit.
- Published in English language.
- Published a peer reviewed, academic journal.
- Published at any time (no year limits).

The rationale for setting the lower age limit at 16 was determined through discussions with specialist clinicians in the Scottish Adult Congenital Cardiac Service (SACCS) in the Golden Jubilee University National Hospital, and a review of the literature. Transfer of medical care from paediatric to adult services usually begins at age 16-18 years old for CHD patients in Scotland (Scottish Paediatric Cardiac Services et al., 2022).

Exclusion Criteria

- Studies that used only quantitative methods.
- Studies that included participants with illnesses, other than CHD.

- Studies not published in the English language.
- Unpublished, non-peer reviewed articles or book chapters.

Information Sources

The following databases were systematically searched by the author from their inception to 26th April 2024:

- CINAHL (EBESCOhost).
- MEDLINE (EBESCOhost).
- APA PsycInfo (EBESCOhost).
- Psychology and Behavioural Sciences Collection (EBESCOhost).

Embase (Ovid) was searched two days after the other databases, from inception to 28th April 2024. A search of Google Scholar was also performed, and the reference lists of key articles were hand searched by the author. An updated search of the above databases and Google Scholar was performed on 10th of February 2025. However, no new eligible articles were retrieved. A search of unpublished literature was not conducted. Searching for unpublished literature is recommended to reduce publication bias and enhance the rigour of systematic reviews (Siddaway et al., 2019). However, it can be argued that unpublished studies may be of a lower methodological quality due to not having undergone a peer review process. Furthermore, it can also be difficult and time consuming to access unpublished literature (Korevaar et al., 2020). A search for grey literature was not performed as this was not deemed relevant to the research question.

Search Strategy

The search strategy was developed using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) (Cooke et al., 2012). The search terms related to congenital heart disease, psychological experiences, and qualitative methodology. The search terms were developed through consultation with clinicians who are specialists within the field of CHD and via discussion with a university librarian. The terms were also reviewed by the author's research supervisors. The combination of search terms was designed to achieve a balance between sensitivity and precision to locate articles that were relevant to the inclusion criteria (Higgins et al., 2024). An iterative approach was taken to revise the search strategy, once initial scoping searches were completed. The terms were adapted to suit each database and MeSH/subject headings were used. The terms were searched using the boolean operator "OR" and then combined with the boolean operator "AND". Truncation (*) was used to find plural and singular variations of the search terms. The following limiters were applied: peer reviewed and English language.

An example of the full search conducted in CINAHL is in Appendix B. The following key word search terms were used:

1. congenital heart disease OR congenital heart defect* OR congenital heart malformation.
2. psychological OR experience* OR perspective* OR impact.
3. qualitative OR interview* OR semi-structured interview* OR focus groups* OR qualitative research.

Screening and Selection

The articles retrieved from the databases were exported to End Note referencing software and de-duplicated. The author independently screened titles, abstracts, and full-text articles by applying the inclusion and exclusion criteria. There was no second reviewer involved in this stage. The author attempted to minimise error by repeating the screening and selection process a few days later to check for discrepancies of which there were none. Uncertainties regarding the eligibility of studies was discussed with the author's research supervisors. The author acknowledges that when conducting a systematic review, the gold standard is to have at least two people involved in the screening and selection of articles to minimise the risk of bias and omitting relevant studies (Higgins et al.,2024). However, it is recognised that when dealing with a large volume of articles, limited resources and time constraints, a decision may be made to utilise a single reviewer (Nama et al., 2021).

Data Extraction

The author independently extracted relevant characteristics from the included studies using a data extraction form adapted from a template provided by Cochrane (Noyes & Lewin., 2011) (see Appendix C). The focus and range of the data extraction was informed by the research question, quality appraisal, and synthesis. A second reviewer cross checked a random sample of 50% of the included studies using the same data extraction form. This proportion was determined through discussion with the author's research supervisors. No disagreements arose regarding the data extraction.

Quality Appraisal

Quality appraisal is crucial to assessing the credibility and trustworthiness of research studies. It is important that the appraisal assesses the appropriateness and congruence of the study objectives, research design, methodology, and results (Williams et al., 2020).

The author used the Joanna Briggs Institute (JBI) checklist for qualitative research which is a 10-item critical appraisal tool (Lockwood et al., 2015). This tool was selected because it allowed for congruence in the research methodology to be assessed, as well as other key elements (e.g. transparency, reflexivity, and ethical issues). A copy of this tool is in Appendix D. 50% of the included studies were co-rated by a second reviewer. Inter-rater reliability (as calculated using Cohen's Kappa) was 92%. Disagreements were discussed and resolved to reach a consensus.

Thematic Synthesis

Thematic synthesis was used to synthesise the qualitative evidence gathered in this review. It is an interpretative approach to synthesising qualitative research evidence and was developed by Thomas and Harden (2008) to address questions regarding perspectives and experiences. It involves three-stages: 1) line by line coding of the text, 2) developing descriptive themes, 3) generating analytical themes.

Thematic synthesis is one of Cochrane's recommended methods of qualitative evidence synthesis due to it being a "flexible, systematic, and transparent approach" (Cochrane, 2025). This approach was selected due to its ability to produce descriptive themes that remain close to the original data and broader analytical themes. This allows new concepts and theories to emerge, beyond that which was initially reported in the primary studies (Maeda et al., 2022). However, a criticism of thematic synthesis is that it can sometimes produce a simplified, descriptive account of themes, rather than an analytical explanation (Flemming & Noyes, 2021).

Qualitative data analysis software (NVivo, version 14) was used to assist with coding and organising the synthesis (Jackson & Bazeley, 2019). An inductive approach was taken to the synthesis. The author imported each of the included articles into NVivo. The reported themes, interpretations and quotations from each of the studies were coded in NVivo and used for the thematic synthesis. A code list was formed and revised. The final code list was used to form the descriptive themes and analytical themes. The author recognises that it is best practice for thematic synthesis to be conducted in pairs or by a small team (Cochrane, 2025). However, due to restrictions on time and resources, the thematic synthesis was conducted independently by the author. The resulting themes were peer reviewed by the author's research supervisors.

Researcher Reflexivity

The author is a female trainee clinical psychologist who has direct clinical experience in working with individuals with long-term conditions (LTCs) and mental health difficulties. The author maintained an awareness of this, particularly when conducting the thematic synthesis. The author's theoretical position is underpinned by interpretivism, which is concerned with understanding subjective meanings and interpretations behind social phenomena (Creswell & Poth, 2024). The author recorded beliefs, assumptions, and preconceptions in a reflective journal and discussed this in research supervision.

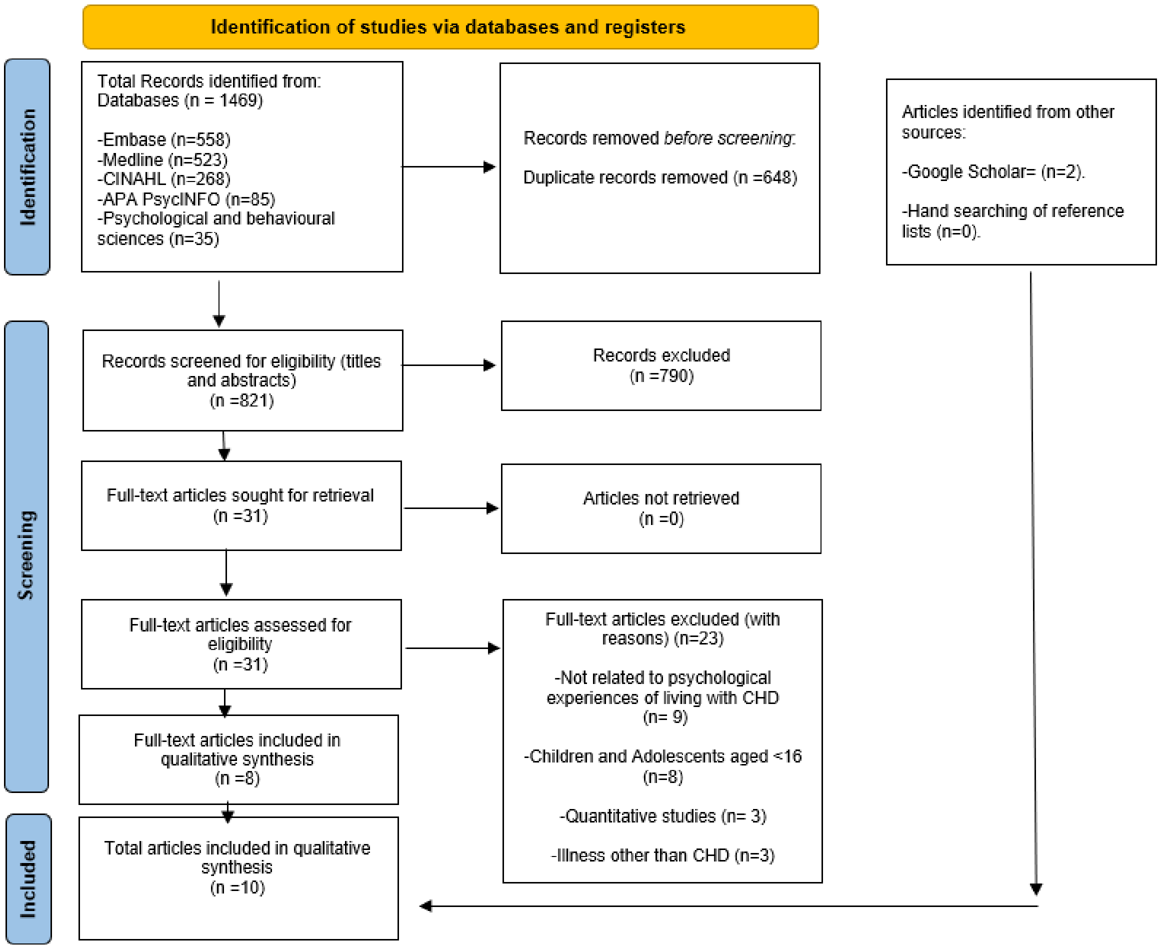
Results

Study Screening and Selection

A total of 1469 articles were identified from the database search strategy and exported to EndNote. After 648 duplicates were removed, 821 articles remained. The titles and abstracts of these articles were screened independently by the author. Thirty-one articles remained for full-text review. The author independently screened these full-text articles by applying the inclusion and exclusion criteria and eight articles were deemed eligible for inclusion. The author hand searched the reference list of these articles, but no eligible articles were identified. A search of Google scholar retrieved two eligible articles. A total of 10 studies were included in the thematic synthesis. The study screening and selection results are depicted in the PRISMA flow diagram (Page et al., 2021) in Figure 1.

Figure 1

PRISMA 2020 Flow Diagram



Study Characteristics

The study characteristics, including core themes and sub-themes, can be viewed in Table 1. The studies were published between 2005-2023 and they originated from a variety of countries: UK, USA, Canada, Italy, Sweden, Denmark, Belgium, Norway and Pakistan. All studies sought to explore the experiences of adults living with CHD. Sample sizes ranged from 6-25. The age range of participants was between 16-76 years. Most participants were female. No studies reported on the ethnicity of participants. Six studies (4,5,6,7, 9, 10) reported relationship status, and three studies (4, 5, 10) reported employment status. Eight studies (1,2,3,5,6,7,9,10) used semi-structured interviews and two studies (4, 8) used unstructured interviews for data collection. The following analytical approaches were used: Interpretative Phenomenological Analysis (IPA) (n=2) (1,10), Grounded Theory (n=2) (8,9), Phenomenological-Hermeneutic Method (n=2) (4,5), Thematic Analysis (n=1) (2), Systematic Text Condensation Method (n=1) (3), Narrative Analysis (n=1), (7) and Phenomenological Methodology (n=1) (6).

Table 1

Study Characteristics

Study ID	First Author, Year & Short Title.	Country	Sample Characteristics.	Data Collection & Analysis.	Core Themes & Sub Themes.
1	Yaseen, M. (2023). Experiences of Adults with CHD.	Pakistan.	• N=6 • Age range=18-21 (mean age=20). • Female=83%; Male=17% • Ethnicity=NR • Relationship status=NR • Employment status=NR	• Semi-structured interviews. • Interpretative Phenomenological Analysis.	**1. Social factors and self-identity.** a) Loss of self. b) Social loss. **2. Physical and future concerns.** **3. Psychological factors.** a) Negative emotions. b) Negative thoughts. **4.Coping styles.** a) Adaptive. b) Support seeking c) Maladaptive. d) Avoidance. e) Religious.
2	Steiner, J.M. (2021). The impact of CHD on adult identity and life experience	USA	• N=25 • Age range=21-63 (mean age=38). • Female=52%; Male=48% • Ethnicity=NR • Relationship status=NR • Employment status=NR	• Semi-structured interviews. • Thematic Analysis.	**1. Impact on identity.** **2. Source of psychological distress.** **3. Influence on adult decisions.**
3	Andersen, J. (2008). Living with Long QT syndrome: Coping with Increased Risk of Sudden Cardiac Death.	Norway	• N=7 • Age range=23-76 (mean age=NR) • Female=57% Male=43% • Ethnicity=NR • Relationship status=NR • Employment status=NR	• Semi-structured interviews. • Systematic text condensation method.	**1. Positive responses to the diagnosis.** a) Initial relief. b) Early and gradually acquired information. **2. Causes of anxiety and worry.** a) Uncertainty and loss of control. b) Untreated emotions and dramatic events. c) Concern for others

Abbreviations: NR = Not reported. CHD=congenital heart disease

Table 1
Study Characteristics

					3. Limitations and loneliness. a) Limitations in daily life. b) A need for someone with whom to talk. c) Difficult choices re: pregnancy and childbirth **4. Risk and existentiality.** a) A normal and fulfilled life b) Death as an acceptable aspect of life. c) Trust and incompetence in healthcare.
4	Berghammer, M. (2006). Young adults' experiences of living with CHD.	Sweden	• N=6 • Age range=22-39 (mean age=31) • Female =83% Male=17% • Ethnicity=NR • Relationship status= Married/in a relationship= 67%, single=33% • Employment status= Working or studying full time =83%, working part time = 17%	• Unstructured interviews. • Phenomenological-hermeneutic method.	**1. Ambivalence.** **2. Having the disease.** a) Like-unlike. b) Sick-healthy. c) Tell-not tell. d) Invisible handicap. **3. Living with the illness.** a) Wish for a "normal life". b) Mastering the disease. c) Expected gratefulness-not being grateful. d) Accepting-not accepting the situation. d) Feeling of suffering. e) Thoughts and fears about the future. f) Security-insecurity.
5	Berghammer, M. (2015). Adolescents' and Young Adults' Experiences of Living with Fontan Circulation.	Sweden	• N=7 • Age range= 17-32 (mean age=22). • Female=71%, Male=29% • Ethnicity=NR • Relationship status= Married/in a relationship= 29%. • Employment status=Studying=71%, working=29%	• Semi-structured interviews. • Phenomenological-hermeneutic method.	**1. Happiness over being me.** a) Feeling proud and mature. b) Being humble and accepting other people. c) Feeling healthy and special.

Abbreviations: NR = Not reported. CHD=congenital heart disease

Table 1
Study Characteristics

					d) Feeling normal and the same as one's friends. e) Belief in oneself. **2. Focusing on possibilities.** a) Dealing with physical restrictions. b) Mastering medical procedures. c) Trying to control the heart defect. **3. Being committed to life** a) Holding on to life and creating meaning. b) Being in uncertainty. c) Making the most out of life.
6	Overgaard, D. (2013). Experiences of Young Adults With Single Ventricle Physiology.	Denmark	• N=11 • Age range=16-48 (mean age=26). • Female=55%, Male= 45% • Ethnicity=NR • Relationship status= Married=27%. • Employment status=NR	• Semi-structured interviews. • Phenomenological methodology.	**1. The family network: The mother embraces while the father lets go.** a) One who is always there for me **2. Physical limitations** a) Coping with all the challenges and finding my own pace **3. “One values life more if one has fought for it”.** a) Life perspectives
7	Keir, M. (2018). Narrative analysis of adults with complex CHD: Childhood experiences and their lifelong reverberations.	Canada	• N=10 • Age range= 36-53 (mean age=44). • Male=60%; Female=40% • Ethnicity=NR • Relationship status=Married/cohabiting=100% • Employment status=NR	• Semi-structured interviews. • Narrative analysis.	**1. Parental/sibling relationships.** **2. Physical limitations.** **3. Embarrassment and denial.** **4. Memories of paediatric healthcare.** **5. Transition to adult care.**

Abbreviations: NR = Not reported. CHD=congenital heart disease

Table 1
Study Characteristics

					6. Education and career. **7. Relationships and reproductive choices**.
8	Callus. E. (2013). Life Experiences and Coping Strategies in Adults with CHD.	Italy	• N=11 • Age range= 20-56 (mean age=35). • Male=64%; Female=36% • Ethnicity=NR • Relationship status=NR • Employment status=NR	• Unstructured interviews. • Grounded Theory.	**1. Being different**. **2. Limitations and resources when having CHD.** a) Dealing with physical limits in childhood and adolescence. b) Rejection, humiliation isolation and perceiving oneself as a burden. c) Shame due to rejection and visible signs of the illness and it's limitations. d) Sexual and reproductive issues. e) Positive outcomes: feeling more mature and being pampered. **3. Hospitalisation experiences.** a) Difficult moments during hospitalisation: experience of intense suffering. b) The relationship with the medical staff. c) "Colluding" with the patients' (implicit) requests. d) Insensitivity of the medical staff. e) Misdiagnosis and its catastrophic consequences.

Abbreviations: NR = Not reported. CHD=congenital heart disease

Table 1
Study Characteristics

					4. Cognitive approach coping. a) Not being alone with this condition and comparing oneself with others in worse situations. **5. Cognitive avoidance coping.** a) Accepting the inevitable. b) Utilisation of irony and humour. c). Trust in faith. d) Downplaying the condition: minimisation to complete denial. **6. Behavioural approach coping.** a) Getting support from family, partners and friends. **7. Behavioural avoidance coping.** a) Defying limits and its consequences.
9	Claessens, P. (2005). The lived experiences of adult patients with CHD.	Belgium	• N=12 • Age Range= 23-37 (mean age=31) • Female=50%, Male=50% • Ethnicity=NR • Relationship status= • Single=33%; Co-habiting=33%; Married=34% • Employment status= NR	• Semi-structured interviews. • Grounded Theory.	**1. Feeling different and the process of normalisation.** **2. Influencing factors.** a) Environment. b) Healthcare. c)Personality attributes. d) Consequences.
10	Cornett, L. (2014). An exploration of the psychological impact of living with CHD in adulthood.	UK	• N=7 • Age range= 21-36 (mean age=30). • Female=71%; Male=29% • Ethnicity=NR • Relationship status= Married= 43%, Single=43%, Divorced=14%	• Semi-structured interviews. • Interpretative Phenomenological Analysis.	**1. A constant, limiting presence.** a). Living with CHD in adulthood. b) Living with uncertainty. **2. The psychological experience.**

Abbreviations: NR = Not reported. CHD=congenital heart disease

Table 1
Study Characteristics

	• Employment status= Employed=86%, Student=14%	a) Depression. b) Shame. c)Trauma. d) Life and death. **3. Impact on view of the self.** a) Being different. b) Self-image. **4. Impact on relationships.** a) Protection. b) Telling others. **5. Coping.** a) Denial. b) Overcompensating. c) Knowledge. **6. Help and support.** a) Received. b) Needed.

Abbreviations: NR = Not reported. CHD=congenital heart disease

Quality Appraisal Results

Table 2 presents the results of the quality appraisal. Five studies (1,4,5,8,10) were rated as having congruity between the philosophical perspective and research methodology, four studies (2,3,6,9) provided a lack of detail about the philosophical underpinnings of the research, and one study (7) did not report on the philosophical perspective at all. Nine studies (1,2,4,5,6,7,8,9,10) were rated as having compatibility between the research methodology and research objectives. Andersen et al. (2008) did not explicitly state the research methodology being used and only referred to it as being a “qualitative method”. Therefore, an assessment for congruity between the methodology and the research objectives, data collection methods, analysis, and interpretation of the results could not be made. All other studies were assessed as being consistent in their stated methodological approach to data collection, analysis, and interpretation of results.

In terms of reflexivity, only three studies (5,6,10) made some attempt to convey this, but they were rated as “unclear” due to a lack of transparent reporting. One study (10) explicitly reported on the researcher’s influence by declaring that one of the authors was born with complex CHD and had undergone two open heart procedures. However, the authors did not elaborate on reflexivity or phenomenological bracketing. Berghammer et al. (2015) reported that the researcher kept reflective notes about the interviews and rapport between interviewer and participant. However, there was no mention of whether this was used to critically examine the researcher’s personal influence on the research. Overgaard et al. (2013) stated that the team “strived” to set aside preconceptions when analysing the data by “distancing themselves” from the phenomenon. However, it was unclear what was meant by this and how they prevented their preconceptions from influencing the analysis. All studies ensured that the participants’ voices had been adequately represented by supporting their themes with quotations from participants. However, the relationship between the conclusions, interpretations, and participant quotations was deemed not to be concordant in four studies (2,4,5,8).

Six studies provided a clear statement about the research being ethical and having received ethical approval by an approved body (2,3,4,5,6,10). Two studies (7,8) stated that ethical approval had been granted, but did not provide further details. Two studies (1,9) did not state that ethical approval had been received.

The author decided not to exclude any from the thematic synthesis based on the results of the quality appraisal. All studies were therefore included in the final synthesis. A criticism of quality appraisal tools, such as the JBI checklist, is that there is no clear consensus regarding the essential core criteria that studies must meet to be included within an evidence synthesis (Small, 2023). It is therefore at the discretion of the researcher to decide whether studies should be included or excluded, which is subjective and open to bias.

Quality appraisal checklists have been criticised for taking a ‘broad brush’ approach to quality appraisal because they do not differentiate between the methodological approaches used in qualitative research (Williams et al., 2020). The JBI checklist has been criticised because it does not include criterion to assess external validity (Hannes et al., 2010). However, the JBI checklist has also been praised for its emphasis on assessing congruity within the study methodology, which is why it was selected for use in this review. The Critical Appraisal Skills Programme (CASP) checklist was also considered for use. However, it has been criticised for being less sensitive to assessing validity compared to the JBI checklist (Hannes et al., 2010).

Furthermore, the CASP does not assess the congruence of the theoretical underpinnings of the chosen methodology, which is good practice in qualitative research (Long et al., 2020).

Secondly, the lack of transparency in reporting about philosophical/theoretical stance and reflexivity has been identified as a recurring issue in qualitative research (O'Brien et al., 2014). Attempts have been made to address this by introducing checklists for reporting qualitative research (e.g. the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007)). The reporting of reflexivity is important in qualitative research because of the potential for biases to influence the data collection and analysis (Olmos-Vega et al., 2023). It is therefore best practice for researchers to include a statement about reflexivity and acknowledge how biases were addressed in the interests of enhancing the credibility of the results.

Table 2

Quality Appraisal of Included Studies

ID	First Author & Year.	JBI Checklist Item										
		Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation of the data?	Overall Quality Rating
1	Yaseen, M. (2023).	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Include
2	Steiner, J.M. (2021).	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Unclear	Include
3	Anderson, J. (2008).	Unclear	Unclear	Unclear	Unclear	Unclear	No	No	Yes	Yes	Yes	Include
4	Berghammer, M. (2006).	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Unclear	Include
5	Berghammer, M. (2015).	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Unclear	Include
6	Overgaard, D. (2013).	Unclear	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Include
7	Keir, M. (2018).	No	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include
8	Callus. E. (2013).	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Unclear	Include
9	Claessens, P. (2005).	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Include
10	Cornett, L. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include

Thematic Synthesis Results

Six overarching analytical themes emerged from the thematic synthesis, with descriptive themes underpinning each of these. A sample of quotations have been used to illustrate the themes below. Table 3 (see Appendix E) displays the full list of analytical and descriptive themes and supporting quotations. Table 4 (see Appendix F) shows the prevalence of the analytic and descriptive themes across studies.

Theme 1: Determination to Live a Normal Life

This analytical theme encapsulates a common psychological experience reported by participants across five studies (3,4,5,6,10) which relates to their determination to live a "normal" life. Participants spoke of choosing to view themselves as healthy as a way of ensuring that the CHD did not control or define their lives. This theme encompasses two descriptive themes: denial/refusal to see oneself as unwell and not letting it control me.

Denial/Refusal to See Oneself as Unwell.

Across four studies (3,4,5,10), participants shared their psychological experiences of choosing to believe that they are healthy instead of unwell. For some, this helped them to master the condition by continuing to do things that are important to them:

> *"...I have to feel and think that I'm healthy and fine all the time...if you start thinking that you are sick and you have a chronic disease, you have to take it easy...then it's like you live in the disease and you restrain yourself from doing things you probably would have been able to manage...you live in the disease...you get ill...but if you think that you are healthy and that you can manage things you try and you want to be healthy."* (Berghammer et al., 2006, p. 343).

For other participants, not thinking about themselves as being ill or having CHD allowed them to feel the same as their peers and invoked a determination to do the same as everyone else:

> *"I will do everything that everyone else does and I am not ill, but I think I have become more determined . . . Yes, that I am healthy and that's the way it should be…"* (Berghammer et al., 2015, p. 408).

One participant indicated that there was a downside to denying the presence and impact of the illness, describing it as a "mask":

> *"It's a mask, it's your alter ego ... I'm normal just like everyone else, you know the denial part, you are completely sick ... you're in complete denial and try to be something that you're not".* (Cornett & Simms, 2014, p. 401).

Not Letting it Control Me.

In two studies (5, 6), participants spoke of their determination not to allow CHD to control their lives or prevent them from doing things:

> *'I'm not sick. I have a heart defect, and I have symptoms every day, but I don't feel sick. This is how I choose to view things and cope with having a chronic heart defect. I think my heart defect is important, but it shouldn't dominate my life".*
>
> (Overgaard et al., 2013, p. 192).

Theme 2: Feeling Different

A second analytical theme which emerged from seven studies (1,2,6,7,8,9,10) related to 'feeling different'. Participants spoke of their psychological experiences of feeling different, being treated differently and/or being bullied and excluded by peers and family members. This theme is underpinned by two descriptive themes: experiences of being bullied and excluded and internalisation of negative feelings about oneself.

Experiences of Being Bullied and Excluded.

A theme expressed by participants across six studies (1,2, 6,7,9,10) was about being excluded or bullied because of their CHD condition. Exclusion by peers often occurred due to being unable to participate in or keep up with physical activities (e.g. sports):

> *''I can't really do anything physical. When I was 10 years old, I had to quit football and couldn't really do any sports. So, I was naturally excluded because I couldn't keep up with the others. I felt different.'* (Overgaard et al., 2013, p. 192).

One participant described their experience of being excluded from high school sports as a "little traumatic". This highlights the lasting psychological impact of the exclusion on this individual:

> *"[I was] excited to be able to go to high school and join the team. And then as my friend group was going to do that, I was clearly not allowed to do it, so it was a little traumatic."* (Steiner et al., 2021, p. 2).

Internalisation of Negative Feelings About Oneself.

The psychological impact of being excluded and treated differently by others because of their CHD condition was described by participants across four studies (2,7,8,10). They spoke of a feeling of being different, which manifested in negative self-beliefs such as "weird", "a bad person", and "faulty":

> *"… I definitely felt like my brothers wanted very little to do with me, especially in later childhood, and I think it's because I was weird. Different."* (Keir et al., 2018. p. 742).

Theme 3: Positive Outlooks

A prevalent theme which emerged across eight studies (1,2,3,5,6,7,8,10) related to positive outlooks and associations with having CHD. Participants spoke about positive and meaningful ways in which the condition had impacted on their life and sense of identity. This analytical theme was supported by five descriptive themes: inner strength and maturity, part of me, greater appreciation of life, motivation to achieve goals, and optimism.

Inner Strength and Maturity.

Across three studies (5,6,8), participants shared that their experiences of living with CHD had resulted in a greater sense of maturity and a feeling of being able to handle challenges and problems:

> *"I have been able to experience things that not so many people around me have experienced . . . I feel more mature and experienced than others because of my heart defect and my other illnesses, and I see that as a positive thing . . . I feel proud of both myself, and my heart defect."* (Berghammer et al., 2015, p. 406).

Part of Me.

In two studies (2,5), several participants reflected that CHD had become an important part of their identity and life story, with one person stating that they could not imagine themselves without the scars from previous surgeries:

"I'm not ashamed of it, nor of my scars, it has kind of become a part of me, or part of my personality, and it would feel very empty without it. My chest would have been very bare without the scar . . . I don't really know who I would have been in that case. I can't imagine my chest with no scars, it would have looked dull and ordinary . . ." (Berghammer et al., 2015, p. 406).

Greater Appreciation of Life.

Participants across four studies (3,5,6,10) reflected that their experiences of living with CHD had made them more appreciative of life:

"Your life is precious and until something like that happens to you, you just take it for granted ... It has made everything make sense, it makes me feel I can do anything." (Cornett & Simms, 2014, p. 399).

Motivation to Achieve Goals.

Within three studies (2,6,7), participants spoke of how living with CHD had motivated them to achieve their goals:

"*Sometimes I get sad, but sometimes it will also motivate me to do this, do that, check things off the bucket list … I regularly do re-evaluations of my life and myself of, 'this is what I want to be doing with what's left on the clock'".*

(Steiner et al., 2021, p. 2).

Optimism.

A sense of optimism and determination to survive was expressed by participants in two studies (1,6) who spoke about feeling hopeful, despite the physical challenges they faced:

> *“I was not worried about the disease; I was hopeful for the recovery. I even did not think about the physical limitations that will be stopping me in daily routine functioning. And I even do not care about the comorbidity that the heart disease can affect the kidney, lungs or others.”* (Yasseen et al., 2023, p. 1599).

Theme 4: Living With Uncertainty

This analytical theme was present across eight studies (1,2,3,4,5,6,9,10), with participants sharing their angst and frustration about the uncertainty surrounding their condition and their future. Three descriptive themes relating to: worry about pregnancy and having children, uncertainty regarding one’s own future and life expectancy, and worry about prognosis and the possibility of future health problems underpin this theme.

Pregnancy and Having Children.

In two studies (3,6), participants spoke about their worry regarding having pregnancy and having children. Some of this worry related to the possibility of children inheriting CHD, whilst other worries related to the possible risks associated with pregnancy and childbirth. There appeared to be a lack of clarity relating to this for one participant who spoke of not getting a clear answer:

> *“And I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt and all those things…then you think about having a child, it is very frustrating not to get a clear answer as to whether you might die or not…If I choose to take the risk, because it is a hard burden on the heart, it is entirely up to me. No one can say whether it will work out well or not.”*
>
> (Andersen et al., 2008, p. 494).

Future and Life Expectancy.

Across five studies (2,4,5,6,9) participants shared their concerns about the future, specifically regarding their own life expectancy and mortality:

> *".. I think it's more like when you think about the future and that you have had a transplant...that you might not be able to think about the future like everybody else...you know that a transplant is not a solution for life.....I will live with it as long as I live but it's probably not something that will make me have a normal long life...."* *(*Berghammer et al., 2006, p.344).

For some participants, this uncertainty impacted on decision making, with one person choosing to make better lifestyle choices and another being afraid to make important life decisions:

> *"I do make plans and that sort of thing, but I don't dare to carry them out.... I must start something independently ... but I'm scared, because ... you start to think how it is going to be 10 years from now if I make that decision now .... I want to make lots of plans but making an important decision ... I do not dare make."*
>
> (Claessens et al., 2005, p. 7).

Prognosis and Future Health Problems.

In two studies (1,10), participants shared their frustrations regarding the uncertainty and a perceived loss of control about the possibility of becoming unwell:

> *"I was angry at not being warned, it was the fear of it happening again, and I know it could happen again ... It's the not knowing I can't deal with."*
>
> (Cornett & Simms, 2014, p. 398).

Two participants spoke of feeling fearful and depressed due to the uncertainty about whether their condition was treatable, the outlook for recovery, and possibility of comorbid health difficulties:

> *"I was worried about the disease; I was fearful for the recovery and the level of death anxiety enhanced. I was totally concerned about the physical limitations that will be stopping me in daily routine functioning. And I was afraid of the comorbidity of other physical or psychological disease/disorder*." (Yasseen et al., 2023, p.1599).

Theme 5: Fear of Being Negatively Judged by Others

This analytical theme relates to the fears of participants across five studies (2,4,7,8,10) about being negatively judged by others for having CHD. Some participants spoke of feeling reluctant to disclose their condition to others and hiding it because of their concerns about how others may react. This theme is supported by two descriptive themes: worry about the reactions of others and reluctance to tell.

Worry About the Reactions of Others.

In two studies (4,10), participants expressed concerns about the reactions of others when being informed about their CHD condition. One participant alluded to feeling judged by friends due to the invisibility of the illness and being unable to do certain things:

> *"...you are forced to explain sometimes...yes...and…. even my friends who know about my congenital heart disease...forget...they think it's strange when I can't manage different things just because...I don't know... it can't be seen on the outside..."* (Berghammer et al., 2006, p. 343).

Other participants spoke of how the fear of others' reactions has affected their confidence and they worry that others may not wish to spend time with them once they know about the condition:

> *"I felt like, I tell you, you won't want to hang out with me anymore*".
>
> (Cornett & Simms, 2014, p. 401).

Reluctance to Tell.

Participants across four studies (2,7,8,10) reported that they were reluctant to tell others the truth about their CHD condition, with some refusing to disclose to others and hiding it from them:

> "*I used to tell different people different things about the scar all the time—but never the truth…. I don't know, I guess you don't want people to know there's something wrong."* (Keir et al., 2018, p. 743).

Theme 6: Traumatic Experiences

This analytical theme emerged from four studies (7,8,9,10) whereby participants recalled distressing and traumatic experiences relating to their CHD condition. Some of these experiences related to comments and reactions from others, whilst others were linked to traumatic memories from hospital stays and medical procedures. Two descriptive themes underpin this: upsetting comments from others and traumatic memories from hospital experiences.

Upsetting Comments from Others

In two studies (8,9), two participants recalled memories of upsetting and humiliating experiences relating to unpleasant and insensitive comments from others about their physical appearance:

“Once a woman who was with a girl, who was about 20 years old, held me from my arm while I was going down from the ladder (to the sea) and she said, Come up look what a violet mouth you have, if you feel bad it will be my problem!....and all the people were looking, for me it was a trauma.” (Callus et al., 2013, p. 235).

Hospital Experiences.

Across two studies (7,10), participants shared traumatic memories relating to previous hospital stays and medical procedures:

“I was terrified, I was practically unconscious, all these voices … I could hear mum and dad crying and the priest was there, it was frightening, extremely frightening ... there still is that fear that it could happen again ... you know the fear is terrible”. (Cornett & Simms, 2014, p. 399).

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

(Keir et al., 2018, p. 744).

Discussion

The aim of this systematic review was to critically appraise, synthesise, and summarise the findings from qualitative research exploring the psychological experiences of adults living with CHD. The thematic synthesis generated six analytical themes which were underpinned by descriptive themes.

A common theme related to the determination of participants not to let the condition control or dominate their life. Participants spoke of choosing to view themselves as healthy, which motivated them to remain active. Two participants alluded to this as being in denial of their symptoms, with one participant describing it as being like “a mask”. This finding links to previous research findings, such as those reported by White et al. (2016) who found that there was an elevated rate of denial in ACHD. The authors also reported that denial was *negatively* associated with depression and anxiety. Similar results have been reported in studies of patients with myocardial infarction (MI) whereby those with higher illness denial are less likely to have difficulties with anxiety and depression (Patierno et al., 2023). This suggests that, in some cases, denial may have a protective influence on mental health. However, White et al. (2016) also reported that denial was predictive of non-adherence to follow-up cardiac care, indicating an adverse effect on physical health.

Living with uncertainty was another significant theme reported across eight studies. Lack of control and the possibility of future health difficulties are significant challenges for ACHD that can cause psychological distress. A recent systematic review reported that higher levels of illness uncertainty were associated with worse psychological and QoL outcomes in people with long-term conditions (LTCs) (Gibson et al., 2023). Intolerance of uncertainty can have a negative impact on an individual’s ability to adjust to living with an LTC, such as CHD. In their systematic review, Skojec et al. (2024) reported that coping strategies have a direct influence on whether individuals experience psychological adjustment or distress in response to illness uncertainty. The authors found that avoidant or passive coping often led to increased psychological distress. However, psychological interventions using Acceptance and Commitment Therapy (ACT) principles have been shown to lower distress associated with illness uncertainty, leading to greater acceptance (Molton et al., 2019). This suggests that an ACT based approach may be beneficial in supporting people with LTCs to cope with uncertainty.

Feeling different was another shared psychological experience. Participants recounted early experiences of being excluded and treated differently, which triggered negative self-beliefs. These findings have been echoed by other studies focusing on the experiences of young people with CHD. For example, a recent qualitative study reported themes of children with CHD experiencing social exclusion, shame and embarrassment (Bennett et al., 2021). A study by Enomoto et al. (2012) reported that, compared to a control group, ACHD scored low on a measure of self-esteem, stating that they lacked confidence and did not have positive feelings towards themselves. These findings may explain why some ACHD experience mental health difficulties relating to low mood and self-esteem due to negative core beliefs.

Participants reported feeling reluctant to tell others about their CHD due to concerns about how they would react. Based on the other themes generated in this review and previous studies, it is possible that these fears are grounded in real experiences of being negatively judged and excluded by others. Previous studies have shown that anxiety and depression can influence relationships in adults with CHD. Concerns regarding sex, body image, lack of understanding, and fears of being stigmatised have been commonly reported (Savas et al., 2024; Stapel et al., 2023).

Participants in two studies in this review recalled traumatic experiences of feeling humiliated by others due to comments made about aspects of their appearance relating to CHD (e.g. cyanosis). This could also explain why some people with CHD may feel compelled to conceal their condition, due to a lack of trust. These findings highlight the importance of raising awareness of the impact of living with CHD to foster understanding in others. It also highlights the stigmatisation that exists when living with CHD (Kovacs et al., 2022) which can exacerbate mental health difficulties.

Other traumatic memories relating to hospitalisation and medical procedures were shared. This links to recent research findings that have shown a high prevalence of trauma within the CHD population. A recent study by Simeone et al. (2022) reported that 1 in 8 adults with CHD had diagnosed post-traumatic stress disorder (PTSD) and the prevalence was 30-50% higher than adults without CHD. Freiberger et al., (2023) also reported elevated levels of PTSD in ACHD. The most frequently reported reasons were medical intervention, cardiac related symptoms, loneliness, social stigma and exclusion. This highlights that individuals with CHD may be at higher risk of developing PTSD due to adverse experiences.

In contrast to the other themes generated in this review which relate to challenging psychological experiences of living with CHD, many participants reported positive experiences of living with this condition. Participants reflected on having a greater sense of maturity, appreciation of life, and feeling motivated to achieve their goals. Some also described CHD as being an important part of their identity. This theme of positive experiences was unexpected. However, it is echoed by previous research which has found similar themes of adults with LTCs reporting strengths and qualities including optimism, resilience, courage, compassion and increased insight (Kristjansdottir et al., 2018). As previously highlighted, individuals with CHD are more likely to experience trauma and adverse experiences. The theme of positivity can therefore also be linked to post-traumatic growth. A systematic review of post-traumatic growth in physical illness reported themes such as reappraisal of life and priorities and self-development/transformation (Hefferon et al., 2009). These findings emphasise the importance of recognising and nurturing individual strengths and positive qualities to support people with LTCs to live a better quality of life.

Implications for Psychological Care

It has already been highlighted that there is a need for psychological interventions to be integrated into CHD care due to the higher prevalence of mental health difficulties in this population (Kovacs et al., 2022; Moons et al., 2023). The psychological experiences of ACHD that have been highlighted in this review emphasise important areas that could be prioritised and targeted for psychological intervention.

Increasing public awareness and understanding of CHD through the dissemination of research, education, and campaigns may be helpful in addressing misconceptions and reducing stigmatisation. Providing guidance on appropriate terminology and avoiding the use of stigmatising medical terms (e.g. “defect”) may also be pertinent. Ensuring that individuals with CHD are educated about lifestyle issues could empower them to live fulfilled lives by enhancing acceptance and adjustment to the condition.

Early intervention regarding psychological support for people with CHD may help with managing challenges and reducing negative feelings, such as self-blame.

Psychological interventions targeted at supporting people with CHD to cope with uncertainty may also be helpful and should be researched further to strengthen the evidence-base. Furthermore, this review has highlighted that people with CHD are vulnerable to traumatic and adverse experiences. Psychologists could, therefore, have a useful role in delivering training to healthcare professionals working in the CHD field about trauma informed practice.

This review has highlighted that, despite the challenges faced by people living with CHD, there are also positive aspects including strengths and the potential for personal growth. This should be acknowledged and utilised to support people who are living with and/or newly diagnosed with a LTC, such as CHD, with acceptance, coping, and adjustment. Opportunities for peer support may help to normalise experiences and instil hope.

Strengths and Limitations

To the author’s knowledge, this is the first qualitative review that has synthesised adults’ psychological experiences of living with CHD. The findings may provide a deeper level of insight into the psychological needs and vulnerabilities of this population. This review was pre-registered with PROSPERO and the author completed the ENTREQ checklist, both of which enhanced transparency. The data extraction and critical appraisal were cross-checked by a second reviewer which enhanced credibility. Furthermore, the author acknowledged the importance of reflexivity.

A limitation of this review is that the search, screening, and selection was only conducted by the author. This limited the scope of the search and means that there is the potential for error and/or bias in the selection process. The search was mainly restricted to electronic databases. A wider, more thorough search of unpublished literature and other sources may have retrieved other eligible articles.

Another limitation is that the thematic synthesis was conducted solely by the author. The author endeavoured to acknowledge reflexivity by noting potential biases and underpinned themes using quotations. However, the lack of cross checking of codes by a 2nd author may have impacted on the credibility of the resulting analytical themes.

Finally, the author recognises that the results of the quality appraisal of the included studies could have been integrated more effectively into the thematic synthesis. For example, higher quality studies could have been coded first, and the resulting themes could have been prioritised in the thematic synthesis. The codes from lower quality studies could have been used to supplement codes and themes from the higher quality studies. This may have strengthened the credibility of the thematic synthesis.

Conclusions

This review has summarised the psychological experiences of adults with CHD. In contrast to existing reviews, this systematic review has highlighted the reasons why individuals with CHD may be more vulnerable to experiencing mental health difficulties. This has implications for clinical practice as it can allow psychologists and other healthcare professionals to identify areas for early intervention and to support young people and adults with CHD to improve their mental health. Furthermore, this review has also emphasised the importance of recognising the strengths and positive aspects of living with a LTC, including the potential for personal growth and resilience. This concept has not been widely reported or researched with people living with long term physical conditions and should be researched further. Future research should also aim to include people with lived experience and strengthen the evidence base for psychological interventions for people with LTCs.

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Chapter 2-Major Research Project

A qualitative exploration of the views and experiences of adults with congenital heart disease about their knowledge of their condition using interpretative phenomenological analysis.

Prepared in accordance with the author requirements for

Qualitative Health Research

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Conflict of Interest: Not Applicable.

Plain Language Summary

Title: A qualitative exploration of the views and experiences of adults with congenital heart disease about their knowledge of their condition using interpretative phenomenological analysis.

Background

Congenital heart disease (CHD) is a term for conditions that affect the heart. “Congenital” means that the person is born with the condition. Previous research studies have reported that some adults living with CHD have gaps in their knowledge and understanding of their condition. This can negatively impact on coping, adjustment, health, and quality of life. Although this issue has been identified by previous studies, it has not been explored in depth from the perspectives of adults living with CHD. People with CHD are at risk of developing mental and physical health difficulties. It is important that more research is conducted to understand how we can better support this population to improve their health and quality of life.

Aims

This study asked adults with CHD to tell us:

1. Their views about their knowledge of their condition and how this has impacted on their mental and physical wellbeing in adulthood.
2. Their experiences of learning about their condition, including what they found helpful and unhelpful and why.
3. Their views on how to support people with CHD to learn about their condition.

Methods

Six adults between the ages of 18-30 years old with a diagnosis of CHD were recruited to take part in this study. The participants were registered as outpatients with the Scottish Adult Congenital Cardiac Service at the Golden Jubilee National University Hospital. Written, informed consent was provided by each of the participants. The participants took part in interviews, which were conducted by video call and telephone. Interpretative phenomenological analysis (IPA) was used to explore the participants’ views and experiences and identify themes.

Results

Four main themes emerged: current knowledge and understanding, pros and cons of knowing, experiences of learning about their condition, and supporting people with CHD to learn about their condition. Each of these themes were supported by smaller ‘sub’ themes and quotations from the participants.

Conclusions

The adult participants in our study recognised that understanding their condition is important and has many benefits for their mental and physical health. They identified that supportive, person-centred discussions and visual resources helped them to learn about their condition. Some barriers to learning were also identified which should be recognised and addressed by healthcare professionals. The participants provided suggestions about how to support other people living with CHD to learn about their condition, which have useful and practical implications for CHD services.

Abstract

Congenital heart disease (CHD) refers to anomalies of the heart that are present from birth. Historically, CHD was a fatal diagnosis. However, due to medical advancements, the survival rate has significantly improved. Previous studies have identified that some adults living with CHD (ACHD) may have knowledge gaps regarding their condition. This is linked to poorer health outcomes and reduced quality of life. To date, no studies have explored this issue in depth. This study aims to explore the views and experiences of ACHD about their knowledge of their condition and the mental and physical health implications of this.

Six adults aged 18-30 were recruited from the Scottish Adult Congenital Cardiac Service in the Golden Jubilee University National Hospital to participate in semi-structured interviews. Interpretative phenomenological analysis was used to analyse the data. Four overarching themes emerged: current knowledge and understanding, pros and cons of knowing, experiences of learning about their condition, and supporting people with CHD to learn about their condition.

The adult participants in our study recognised the importance of understanding their condition and the mental and physical health benefits of this. This study has highlighted their experiences of learning about their condition and perspectives about how to support people with CHD to develop their knowledge. The findings from this study could help address barriers to learning and improve outcomes for this population.

Key words: congenital heart disease; qualitative research.

Background

Congenital heart disease (CHD) is a term that describes problems with the structure and function of the heart that are present from birth (British Heart Foundation (BHF), 2025). Approximately 2.3 million people in the United Kingdom (UK) are living with CHD (BHF, 2025). Due to medical advancements, the survival rate has improved and 97% of children with CHD will reach adulthood (Delborg et al., 2023). The CHD population are at increased risk of physical health complications and many people living with CHD require lifelong medical review and intervention.

Living with a long-term condition (LTC), such as CHD, can also impact on mental health. There is a high prevalence of depression, anxiety, and trauma within the adult CHD (ACHD) population (Kovacs et al., 2024; Simeone et al., 2022). This is linked to adverse experiences, uncertainty, and difficulties with coping and adjustment (Kovacs et al., 2022). Mental health is a strong predictor of quality of life (QoL) in ACHD (Moons et al., 2023).

Adhering to lifestyle advice, medication compliance, and engaging with follow-up care is also crucial to maintaining good health and QoL when living with an LTC, such as CHD (Lee & Jung, 2019). Supported self-management of LTCs involves increasing an individual’s “knowledge, skills, and confidence in managing their own health and care” (NHS England, 2025, para 1.) It also means involving patients in decisions about their healthcare. Research has demonstrated that supporting people with LTCs to effectively self-manage their condition can improve mental health and QoL (Musekamp et al., 2016: Turner et al., 2015).

Effective self-management of a LTC is predicated on the individual possessing sufficient health literacy, which refers to the ability of individuals to access, understand and use information to promote and maintain optimum health (World Health Organisation, 2024). A recent scoping review found that individuals with limited health literacy experience difficulties with aspects of self-management, including medication adherence, attending screening appointments, and communication with healthcare professionals regarding their healthcare (van der Gaag et al., 2022). The authors highlighted medical “jargon” and patients being presented with large volumes of information as being potential barriers to health literacy. Other barriers to learning about health are educational attainment level, learning difficulties, cognitive impairment, and language and cultural differences (Allen-Mears et al., 2020).

Research has highlighted that some ACHD lack knowledge about important aspects of their condition. A recent single-centre, observational, cross-sectional study reported that less than 50% of ACHD were correctly informed about issues such as medication side effects, identifying at least two symptoms of clinical deterioration, and the risks of smoking and alcohol consumption (Barbas de Albuquerque et al., 2025). The authors discussed the influence of education level on knowledge and highlighted the need for person-centred patient education.

People living with CHD are at an increased risk of developing infective endocarditis (IE), which is a life-threatening disease (Havers-Borgersen et al., 2023). It is therefore important that individuals with CHD are aware of the risk factors and symptoms of IE. Haider et al. (2024) sought to evaluate ACHD’s understanding of risks, preventative measures, and symptoms of IE. They reported that 37% of participants could accurately define IE, 47% could identify more than two risk factors, and 22% were able to identify a minimum of three symptoms. 80% of participants had regular dental reviews and half maintained optimal dental hygiene. 39.4% were not aware that IE could be fatal. The authors emphasised the need for comprehensive, individually tailored education for people with CHD.

In a systematic review of outcomes and experiences of transition, Heery et al. (2015) reported that a high proportion of young people with CHD lacked knowledge about their condition and wished to be better informed. Uzark and Wray (2018) reported similar findings in their review of young people with CHD transitioning to adult care. Knowledge gaps relating to symptoms of clinical deterioration, reasons for follow-up care, and lifestyle issues (e.g. pregnancy) were reported. The authors discussed that anxiety and overprotectiveness in parents can limit opportunities for learning in young people with CHD. They also highlighted that people living with CHD are at increased risk for developmental delay and cognitive impairment, which can impact on learning.

Leventhal et al. (1980) proposed the ‘common sense’ model of self-regulation as a conceptual framework to explain how individuals self-manage and respond to health threats and health information. Leventhal et al. (2016) stated that the model can also predict behaviours relating to self-management of health conditions, such as treatment adherence. The model proposes that an individual’s coping response to health stimuli (e.g. health information and symptoms) is influenced by cognitive and emotional representations of the illness. The five cognitive representations are: cause, consequences, identity, personal control, and timeline (Hagger & Orbell, 2022). The cause dimension relates to beliefs about the cause of the illness. Consequences refers to the individual’s beliefs regarding the impact of the illness on functioning and quality of life. Identity reflects the symptoms and labels of the illness and timeline relates to the expected duration of the illness. Personal control is the individual's beliefs about whether the illness can be cured, controlled or influenced by personal behaviours, such as taking medication. Emotional representations are beliefs that the illness is associated with emotions such as anger, anxiety and depression. The coping strategies that individuals employ in response to these representations may be adaptative (e.g. seeking support, taking medication) or maladaptive (e.g. avoidance). The model posits that individuals will appraise the effectiveness of these coping behaviours on illness outcomes (e.g. physical health and functioning) and emotional outcomes (e.g. psychological wellbeing). Consequently, the individual will decide whether to use this same coping behaviour in future or explore alternative ways of responding to the health threat.

The beliefs (illness perceptions) that an individual has about an illness or health condition are formed through the acquisition of knowledge and experiences (Hagger & Orbell, 2022). Marcil et al. (2023) reported that ACHD who perceived their illness as more threatening (i.e. in terms of severity, impact on functioning, and their ability to control the illness) were more likely to employ avoidant coping strategies and scored higher on measures of anxiety. The authors suggested that psychoeducation combined with cognitive behavioural therapy (CBT) could help modify misconceptions and encourage adaptive coping. In a longitudinal study, Schoormans et al. (2014) found that negative beliefs about illness were predictive of poor QoL in ACHD. In concurrence with other studies, the authors suggested that education combined with CBT could address illness misconceptions, which could have a beneficial impact on mental health, coping and QoL.

Healthcare Improvement Scotland (HIS) CHD standards emphasise the importance of person-centred care and shared decision making. The standards state that people living with CHD should be supported to develop knowledge, skills, and confidence to manage their condition (HIS, 2023). It is crucial that ACHD possess adequate knowledge of their condition, as this is associated with improved self-management and health outcomes (Correia et al., 2022).

Although previous studies have highlighted that knowledge gaps exist within the ACHD population, none have attempted to explore this in depth from the perspective of the individuals. There is also a dearth of qualitative research exploring the lived experiences of ACHD (Andonian et al., 2018). Consequently, there is a lack of insight into *why* ACHD may lack knowledge about aspects of their condition and how this could be rectified. The focus of the current study was determined through discussions with clinicians who work in the Scottish Adult Congenital Cardiac Service (SACCS). It was recognised that gathering information from ACHD about their experiences of learning about their condition could help to inform and improve healthcare practice.

The aim of this qualitative study was to explore the views of ACHD about their knowledge of their condition and their experiences of learning about their condition. It is hoped that the findings will provide insight into the experiences and perspectives of ACHD about their knowledge and understanding of their condition and how to support others in learning about this.

Research Objectives

1. To explore the views of ACHD about their knowledge of their health condition and the physical and mental health implications of this.
2. To explore the experiences of ACHD in learning about and developing an understanding of their condition, including what they found helpful and unhelpful and why.
3. To explore ACHD's views about how best to support people living with CHD to understand their condition.

Methods

Ethical Approval

The proportionate review subcommittee of the London - Camden and Kings Cross Research Ethics Committee granted ethical approval on 19th March 2024 (REC Reference: 24/PR/0197) (see Appendix G). NHS Golden Jubilee University National Hospital (GJUNH) health board management approval was granted on 10th May 2024 (Ref: 24/MISC/02) (see Appendix H).

Study Design

This qualitative study adopted an interpretative phenomenological analysis (IPA) approach. IPA has theoretical underpinnings in phenomenology, hermeneutics, and ideography (Creswell & Poth, 2024). This aligns with the research objectives because it facilitates a rich and detailed exploration of lived experiences and the meanings of these. IPA has been widely used within health psychology research because of its ability to explore and capture complex, emotive, and deeply personal experiences and perspectives (Smith & Osborn, 2015). To enhance transparency, the consolidated criteria for reporting qualitative research checklist (COREQ) (Tong et al., 2007) was completed (see Appendix I).

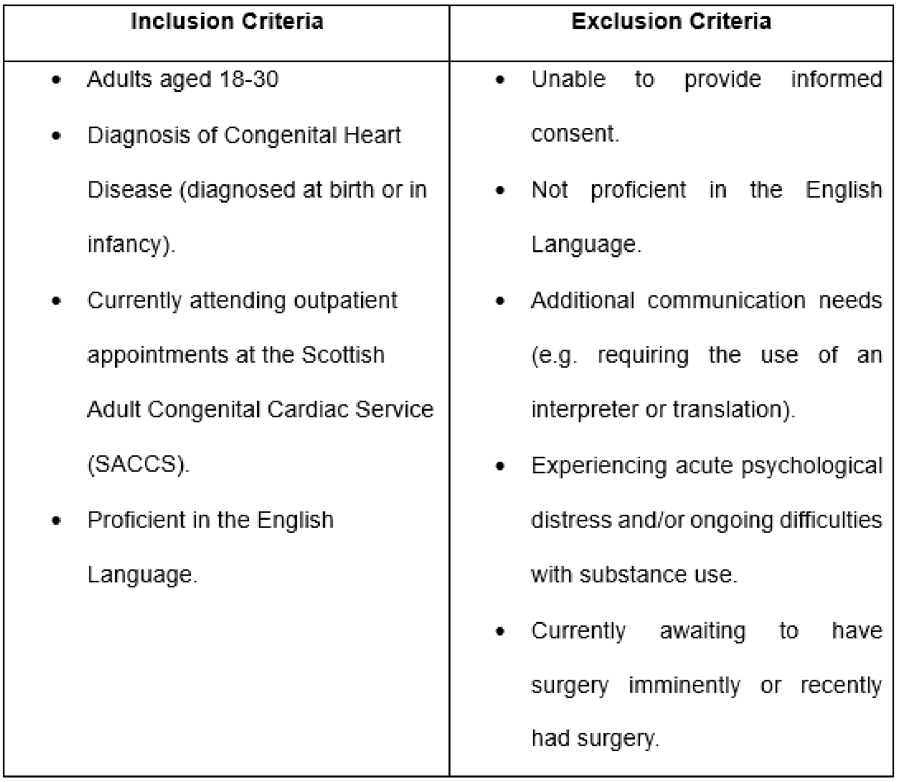
Participants and Recruitment

Eligibility Criteria

The eligibility criteria were formed through discussions with clinical and research staff (see Table 1). The age range was chosen to provide a homogenous sample of participants in terms of their experiences of CHD healthcare services and transition from paediatric to adult services. Regarding language proficiency, it was determined that individuals had to be proficient in reading and speaking English to be eligible for participation in this study. Due to constraints on time and resources, individuals with additional communication needs (e.g. requiring the use of an interpreter or translation) were not eligible to participate in this study.

Table 1

Participant Eligibility Criteria



Inclusion Criteria	Exclusion Criteria
• Adults aged 18-30 • Diagnosis of Congenital Heart Disease (diagnosed at birth or in infancy). • Currently attending outpatient appointments at the Scottish Adult Congenital Cardiac Service (SACCS). • Proficient in the English Language.	• Unable to provide informed consent. • Not proficient in the English Language. • Additional communication needs (e.g. requiring the use of an interpreter or translation). • Experiencing acute psychological distress and/or ongoing difficulties with substance use. • Currently awaiting to have surgery imminently or recently had surgery.

Sample Size

IPA studies typically involve small, homogenous samples to allow for a detailed exploration of experiences (Cresswell & Poth, 2024). Smith et al. (2022) recommend that for professional doctorate courses, a sample size of between 6-10 should be adopted and this was the aim for the current study. It was decided that recruitment would end when data saturation was reached. Additionally, Smith et al. (2022)

caution against gathering too much data in IPA studies, which can impact on the quality and depth of the analysis. A total of six participants were recruited in this study. The researcher determined that data saturation had been reached because no new themes were emerging from the interview transcripts. This was discussed with the researcher’s supervisors. Furthermore, the data that was gathered from the six interviews was deemed to be sufficient to answer the research questions (Saunders et al., 2018).

Interview Guide

The development of the semi-structured interview guide was informed by a literature search and discussion with specialist clinicians (e.g. doctors, nurses, and a clinical psychologist) working in the SACCS service. This identified gaps in the knowledge base that the current study hoped to address. The researcher constructed open-ended questions which were designed to answer the research questions of the study. The questions were designed to be open-ended to elicit thoughts, feelings, and experiences from participants. The researcher also included a list of prompts in the interview guide which could be used to probe further into certain topics discussed in the interviews. The interview guide was reviewed by people with lived experience at a “learning café” group facilitated by a clinical psychologist working in the SACCS service. They were asked to provide feedback on the readability of this, which was incorporated into the final draft. A copy of the semi-structured interview guide can be viewed in appendix J.

Recruitment Procedures

Participants were recruited using purposive sampling. The study was advertised within clinic areas and on GJUNH social media. SACCS clinicians also informed eligible patients about the study during routine clinic appointments. Participants were invited to express interest by emailing the researcher's NHS email address. Individuals who expressed interest were emailed a copy of the Participant Information Sheet (PIS) (see Appendix K). The PIS was also accessible via a QR code on the recruitment flyer. Potential participants were invited to an initial telephone call with the researcher where further information and clarification was provided. It was made clear that participation was voluntary and would not affect their care or treatment. The researcher asked screening questions to check eligibility. Eligible participants were invited to take part in a research interview. Written, informed consent was obtained from participants before any data collection commenced. A copy of the consent form is in Appendix L.

Demographic information regarding age, employment status, relationship status and name of congenital heart condition was gathered from participants prior to the commencement of the research interview. These demographic variables were determined through discussions with the researcher's supervisors and by reviewing demographic data gathered by similar research studies. It was agreed that the researcher should only collect demographic data that was deemed necessary and relevant to the research study. Notably, the researcher did not gather information about level of education, which is acknowledged as a limitation of this study. All participants received a £20 Love2Shop gift voucher as a thank you for their time and contribution to the research study.

Participant Characteristics

Ten individuals expressed interest in the study. Three were ineligible because they were not currently open to SACCS. One eligible individual withdrew prior to data collection (no reason was provided).

Six participants were recruited. Table 2 depicts their demographic characteristics. The mean age was 24 years (range=21-27 years). Three participants were employed full time (50%), one part time (17%), one was a full-time student (17%), and one was a student and employed part time (16%). Four participants were female (67%) and two were male (33%). Four participants were single (67%), one was married (16%), and one was in a relationship (17%). To preserve anonymity, pseudonyms and CHD diagnoses are reported separately.

The participants self-reported their CHD diagnoses: pulmonary atresia with ventricular septal defect, atrioventricular septal defect (AVSD) with pulmonary stenosis and transposition of the great arteries corrected by a Fontan procedure, transposition of the great arteries with complete pulmonary stenosis and atrial septal defect, tetralogy of Fallot, and transposition of the great arteries.

Data Collection

Data was collected independently by the researcher through semi-structured interviews via video call (using NHS Near Me) (n=5) or telephone (n=1). Participants were asked to complete a demographic information form prior to the commencement of the interview (see Appendix M). Audio from the interviews was recorded using a digital voice recorder. Interviews lasted between 30 minutes 3 seconds and 48 minutes 2 seconds.

Analysis

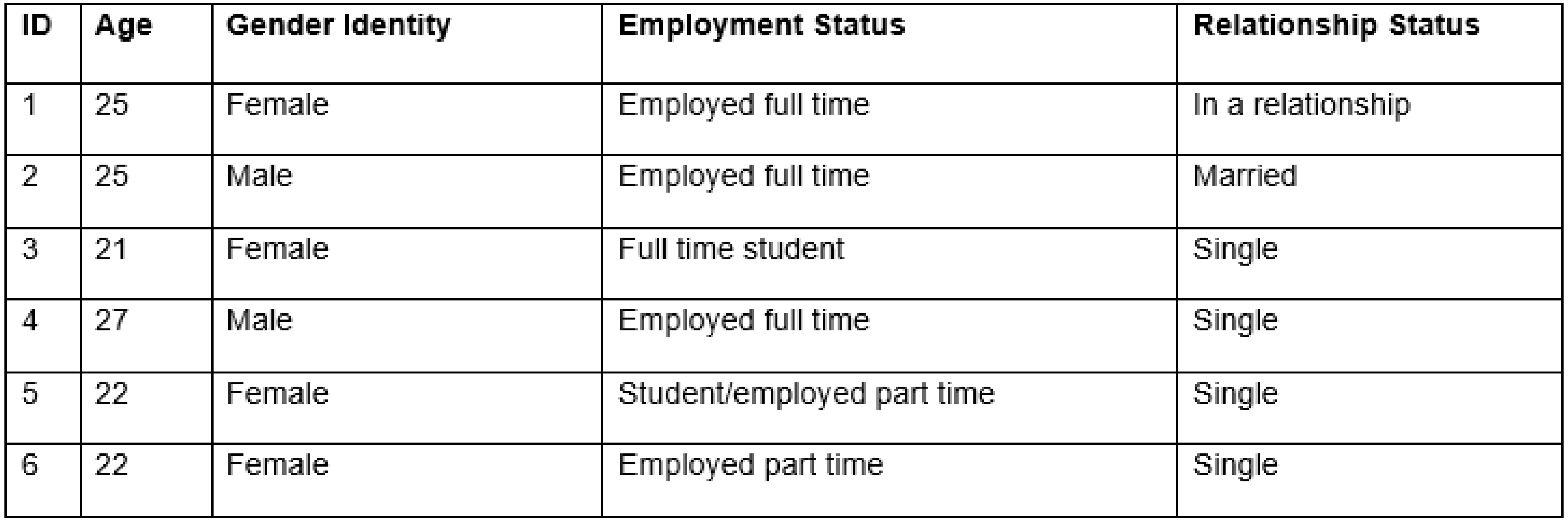
The researcher manually transcribed the interview recordings. Pseudonyms were used to protect confidentiality, and identifiable information was removed from the transcripts. The researcher independently conducted the analysis in accordance with the seven steps outlined by Smith et al. (2022) (see Appendix N). A detailed overview of the data analysis process is in Appendix O. The data availability statement is in Appendix P.

Researcher Reflexivity

The researcher is a female trainee clinical psychologist who has prior experience of working in the field of clinical health psychology. The researcher’s interpretative framework position is that of social constructivism (Cresswell & Poth, 2024). Their ontological beliefs are that multiple realities are constructed via lived experiences and social interactions. Their epistemological beliefs are that reality is constructed jointly between the researcher and participant and is formed through individual experiences. These beliefs align with an inductive method of obtaining information (e.g. interviews) and the analysis of text, which is in keeping with IPA. The researcher practised ‘bracketing’ by recording biases, assumptions, experiences, and beliefs in a reflective journal. Reflections were also discussed in research supervision. The full reflexivity statement is in Appendix Q.

Table 2

Participant Demographic Information



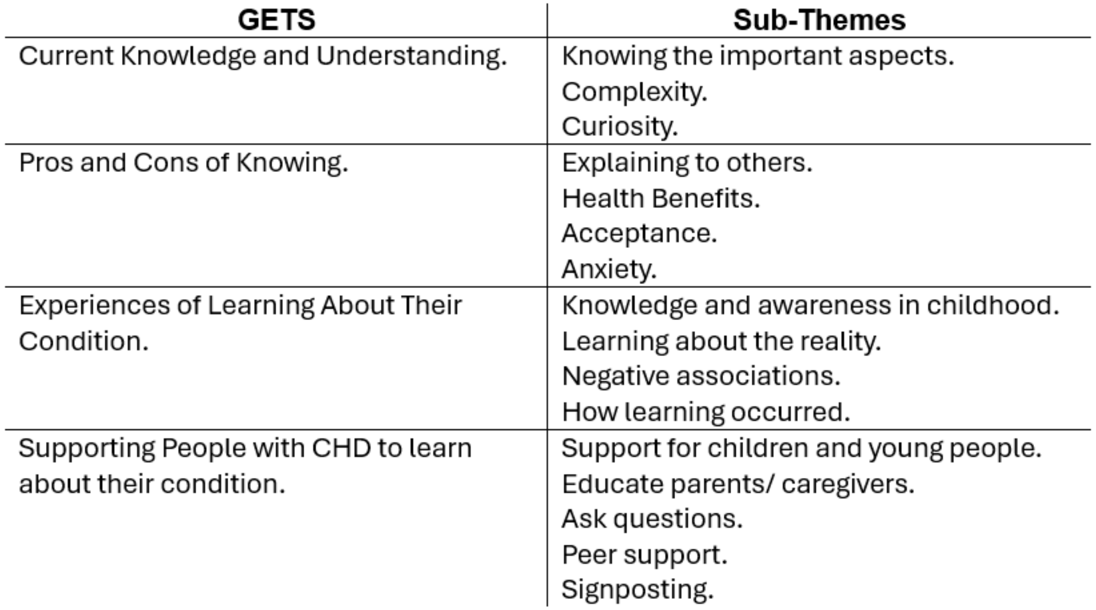
ID	Age	Gender Identity	Employment Status	Relationship Status
1	25	Female	Employed full time	In a relationship
2	25	Male	Employed full time	Married
3	21	Female	Full time student	Single
4	27	Male	Employed full time	Single
5	22	Female	Student/employed part time	Single
6	22	Female	Employed part time	Single

Results

The analysis generated four Group Experiential Themes (GETs) (see Table 3). An interpretative analysis of the themes is presented below. Table 4 contains the full list of themes and supporting quotations (see Appendix O).

Table 3

Group Experiential Themes (GETs) and Sub-Themes



GETS	Sub-Themes
Current Knowledge and Understanding.	Knowing the important aspects. Complexity. Curiosity.
Pros and Cons of Knowing.	Explaining to others. Health Benefits. Acceptance. Anxiety.
Experiences of Learning About Their Condition.	Knowledge and awareness in childhood. Learning about the reality. Negative associations. How learning occurred.
Supporting People with CHD to learn about their condition.	Support for children and young people. Educate parents/ caregivers. Ask questions. Peer support. Signposting.

Current Knowledge and Understanding

Knowing the Important Aspects

Overall, participants felt they had a good understanding of their CHD condition. They reflected that, although they did not fully understand or remember all of the medical terminology, they knew the most important aspects:

> *"…. I don't know if I get all the terminology correct, but I at least know what's going on when I go into the hospital to get procedures done…I feel I've got a good understanding of what's going to happen or what could happen in the future…"* (George, p.2).

> *"…Medically, I don't understand all of the ins and outs of it, but I feel I understand what's important for me to know."* (Tanya, p.2).

George and Tanya conveyed uncertainty regarding the medical terminology associated with their condition. However, despite this, they felt they had sufficient knowledge about what the condition means *for them.* Additionally, Poppy reflected that she had sufficient knowledge about her condition to allow her to explain the important aspects to others:

> *"… if I'm having to explain it to my friends and family…I know the basic things that they need to know if something was to go wrong with me, if I was to take unwell …"* (Poppy, p.2.).

Max explained that it is not necessary for people living with CHD to know all the medical ‘facts’, and rather, they just need to know the key information:

> *“…You need to know you’ve got a condition; you need to know how to name it, you need to know how severe it is and the medication…but the actual mechanics of it… is more needed for the doctor.”* (Max, p.6).

This theme reflects an important aspect of health literacy which is that individuals with LTCs require sufficient knowledge and understanding to be able to effectively self-manage their condition. However, participants have highlighted that in-depth knowledge about the medical “mechanics” of the condition is more of a requirement for health professionals involved in their care. This suggests that it is important to achieve a balance when educating people with LTCs so that they have enough of an understanding to effectively self-manage their condition, without being overwhelmed by information.

Complexity

There was a general recognition amongst participants that the heart and CHD is complex:

> *“…anyone who’s not a cardiologist who looks at the heart, you just think “Oh my goodness” …there’s so much to it, it’s not just the four chambers that you learn about in school…there’s loads to it…*” (Ruth, p.3).

> *“It’s just a lot of big Latin words that don’t…necessarily mean a lot to you...I’ve done Higher Human Biology so I have a basic understanding of how the heart works, but I can imagine if you don’t then…it would all mean nothing to you…”*
>
> (Tanya, p.2).

Ruth and Tanya's phrasing emphasises the overwhelming and complex nature of the heart. Tanya highlights that, despite having some prior education, it is still challenging to comprehend information about the heart. Her use of "big Latin words" conveys the inaccessibility of medical terminology to lay people. Max shared that, due to the complex nature of his condition, *he* often has to explain it to non-specialist health-care professionals:

> *"…whenever I go into a GP or just an average hospital that's not...the Jubilee, I need always to explain my condition to the doctors… you see a Junior Doctor and they go "What the hell is this?" and I have to be the one to tell them about it [laughs softly]…"* (Max, p.2).

Max's description emphasises the perplexity of the doctors who are unfamiliar with his condition. His laughter suggests that he is unphased by this, indicating that it may be a frequent occurrence.

The theme of complexity regarding some aspects of health information conveys a common barrier within health literacy. The participants' reflections illustrate the feelings of anxiety and overwhelm that may be triggered when people are faced with complex information about their health condition and the care and treatment associated with this (e.g. medication, surgery).

Curiosity

Some participants conveyed curiosity and interest in learning about their condition:

> *"As a curious person I really am interested in it, and I like learning about that sort of thing and its implications… It's important to me mostly just because I like to understand what's going on with my body…"* (Tanya, p.7).

> *"…. I'll continue to want to learn about… as treatments go on, make sure I fully understand what's happening and help me better advocate for myself too."*
>
> (Amy, p.11).

Tanya and Amy's phrasing emphasises a strong desire to learn about and understand their condition. Both communicate their personal motivations for this, which are to understand their body and to "better advocate" for themselves.

The theme of curiosity regarding one's condition reflects an eagerness and desire within ACHD to learn more about their health condition. It appears that, for some individuals, this helps them to feel more in control. Subsequently, it could have a protective influence on mental health and coping by empowering individuals to feel more confident in self-managing their condition. Furthermore, curiosity is also prompted by a desire to advocate for one's health and care treatment. This may become more salient to individuals as they get older because of the implication on lifestyle choices (e.g. having children). This theme also demonstrates the individual differences within the ACHD population in terms of their personal values and motivations.

Pros and Cons of Knowing

Explaining to Others

Some participants articulated that knowledge of their condition helps them to explain *why* they may not be able to do certain tasks or may find activities (e.g. exercise) more challenging:

> *"…having a knowledge and understanding enables me to…highlight at a top level the reasons why I may not be so fit and able as others to do certain things in situations…"* (Amy, p.10).
>
> *"… if I was doing some adventurous hike… everyone would always know if I was like "I need a second", they'd be like "Oh, yep, she does need a second to just catch her breath" …. because they know why."* (Ruth, p.8).

Amy and Ruth highlight that explaining to others helps to raise awareness about the physical impact of their condition, thereby fostering a more supportive response. George reflected that having a knowledge of his condition has helped to alleviate misconceptions:

> *"…it was handy to tell my employer so it doesn't seem like I am skiving off work….I have to get my teeth checked every 4 months…my employer was like "why are you always off?"…I explained to him that teeth infection is really bad for me because it will destroy my heart and the scar tissue in my heart… it's handy to know, why, the reason… so now my employer understands…."* (George, p. 3-4).

George's phrasing (e.g. "destroy my heart") conveys that he understands the serious implications of infection. His use of "skiving" suggests a feeling of being judged by his employer. Having the knowledge to explain the rationale for regular dental reviews appears to have helped his employer understand the importance of this.

Explaining to others about their CHD condition appeared to be particularly important in relation to risks and challenges associated with physical activity and physical health. Participants alluded to the outward "invisibility" of CHD, which may contribute to a lack of awareness and understanding in others about the physical impact of living with the condition. Being equipped with the knowledge and understanding of their condition appeared to instil a sense of confidence in the participants about communicating important aspects to others. In turn, this may help to improve self-esteem, relationships, and functioning within work and social life.

Health Benefits

All participants agreed that having a knowledge and understanding of their condition has important implications for their health:

> *"…I've never been involved in drugs because I know that if I ever needed heart surgery, if I take drugs, they're not going to touch me… I've never got tattooed because I know that's a risk to my health…or piercings… I just know, because of the understanding I have been given about my condition….it wasn't a disappointment because from the get-go, I've always been told..."* (George, p.13).

> *"…MRI scans… I…absolutely hate them with a passion…but if they didn't tell me how important it was that I needed to have it, I probably would have just flat out refused because I hate them so much, but…because they would tell me…how much it would help them, then of course help me…it just makes it easier for me to get through…."* (Ruth, p.8).

George reflected that having a knowledge and understanding of the risks associated with his condition has allowed him to make informed lifestyle choices, but he was not disappointed due to being informed from an early stage. Ruth's repeated use of emphatic words (e.g. "hate") conveys her dislike of these procedures. This highlights the impact that knowledge has had on her behaviour, as she explained that understanding the benefits of MRI scans has made it "easier" to get through.

Max reflected that it is important for those around him to have some knowledge and awareness of his condition:

> *"…the only thing with knowledge really is the people you live with around you need to know the tell-tale signs of when you're not well as well. My mum has noticed a few times before I get ill, I go pale white, and I can't see that, but she can…she makes sure I'm feeling alright…" (*Max, p.8).

Amy shared that knowledge of her condition has helped her to advocate for herself:

> *"…I think the more you understand, the more you can question your treatment and... push back or query further, whereas if you don't have the understanding, you maybe can't appreciate…what's being discussed, and it allows you to champion…for yourself and use your voice …."* (Amy, p.10).

Amy's use of "question", "push back", and "champion" suggests a desire to have more input into decisions about her health and treatment. She reflected that not having an understanding may hinder an individual's ability to advocate for themselves, which may be disempowering.

Clearly, there are several health benefits for ACHD who possess a sound knowledge and understanding of their condition. It appears that having this knowledge allows people to make informed decisions relating to their health. The participants' reflections suggest that having this knowledge and understanding from an earlier stage is beneficial as it allows them to form realistic expectations about their future and avoid disappointments. It has also been highlighted that, not only is it important for the individual themselves to have the knowledge of their LTC, but it is also crucial for significant others. This can be helpful in identifying early warning signs/symptoms and improving understanding within relationships (e.g. with partners). Additionally, it appears that knowledge and understanding can foster a more collaborative approach to health and care treatment. Consequently, this may empower individuals living with LTCs, resulting in better engagement, adherence, and improved health outcomes.

Acceptance

A few participants reflected that having a knowledge and understanding of their condition had increased acceptance and confidence:

> *"… I know to not push myself, because it's not just me being tired or lazy, I know that it's because my heart has maybe been overworked or it's maybe feeling it a bit. So, I can just relax and just give myself a day to rest and that's okay."* (Poppy, p.7).

Poppy reflected that understanding her condition has alleviated self-blame. Her use of "that's okay" suggests that it has prompted her to be more compassionate towards herself. Tanya shared that understanding her condition has increased her ability to cope with it:

> *"…if everything has been explained to me, I feel I can deal with that. I'm like "okay, these are my things, I've had them explained to me, I've had some diagrams, I know that it looks a little different to a normal heart, I know what I need to do to keep myself safe and healthy. I can deal with that" ..."* (Tanya, p.9).

Tanya repeated the phrase "I can deal with that" which conveys a sense of self-confidence in managing her condition. She repeatedly stated that having things "explained" to her has helped improve her understanding, and consequently, her acceptance.

Some participants shared that a lack of acceptance or avoidance may be a barrier to learning about or discussing one’s condition:

> *“…it’s quite a hard thing… to see how different you are from other people. I think that can be a barrier…and just…knowing that you’ve got to live with that your whole life…”* (Poppy, p. 2-3).

> *“…I just got fed up of the topic…it’s not nice to think that there was something wrong with you.”* (Ruth, p.5).

Poppy and Ruth’s use of terminology “to see how different you are...” and “something wrong with you” allude to the negative feelings that may be internalised by discussing one’s CHD condition.

The theme of acceptance conveyed a sense of conflict for the participants. From one perspective, it appeared that having a good knowledge and understanding of their condition helped some people to be more compassionate towards themselves and it also increased their confidence in coping with the condition. However, it was also highlighted that some individuals may not wish to learn more about their condition due to the negative thoughts and feelings associated with this. Examples of these feelings include loss, grief, anger, sadness, and/or anxiety. This indicates that difficulties with acceptance and discussing one’s health condition may be a barrier to learning about it. However, the positive gains and outcomes from learning about one’s health condition may be a motivational factor to overcoming these barriers.

Anxiety

Four participants reflected that having a knowledge of their condition reduced their anxiety. George explained that understanding his condition prevented him from worrying unnecessarily:

"…I'd rather know what's going to happen than not know and worry about something that might not even happen…" (George, p.2).

Ruth and Tanya explained that having a better understanding of their condition provided reassurance and helped them to feel more prepared:

".... knowing as much as I needed to know reassured me on a day to basis that I was fine and I was looked after by the best people for the job and if there was something they were worried about, they would do something." (Ruth, p. 8-9).

"…the phrase "knowledge is power" is coming into my head. I would just prefer to know these things…and…eventually, if something does go wrong, that's not a shock to me…." (Tanya, p.8).

The phrase "knowledge is power" emphasises the significance for Tanya of having a knowledge and understanding of her condition. Conversely, there was a recognition that knowledge may increase anxiety:

"…I know the risks and what could go wrong…and then I worry about them… so maybe having a good understanding has not helped…because I knew what could go wrong and how it could go wrong and why it could go wrong… so maybe if I was less educated, it might help me mentally…. "(George, p.14)

George explained that having more knowledge about the risks associated with his condition has increased his worry and rumination. It appears that being less informed may have been more helpful for his mental health in this regard. Poppy shared a similar reflection that knowing about her condition sometimes makes her feel "paranoid" about things going wrong:

> *"…sometimes it can make me a bit paranoid that something is going to go wrong, and I feel like I'm going to have a heart attack..."* (Poppy, p.7).

. Amy reflected that there are more advantages to disadvantages to being informed:

> *"…the more you know, you can maybe worry about it…. but the good…outweighs the bad in that situation."* (Amy, p. 11).

There appeared to be some conflicting views about the impact of knowledge and understanding of one's LTC on anxiety. Participants reflected that it could increase or decrease anxiety, depending on the individual's response and interpretation of the information. For some, greater knowledge and understanding appeared to have a protective influence on mental health. However, other participants shared that it had increased their worry and paranoia. This indicates another potential barrier to learning about one's health condition, which is that some individuals may feel concerned about the impact of health knowledge on their mental health. It also highlights the importance of the availability of psychological support for ACHD who may experience psychological distress in response to increased insight and awareness of their health condition.

Experiences of Learning About Their Condition

Knowledge and Awareness in Childhood

Most participants shared that they did not fully understand their CHD condition in childhood. They referred to having an awareness of being different or unwell, but without understanding the reality and/or severity:

> *"Well, you know you're no well. Back then, I was blue, up until my 7th surgery, I was literally the colour blue. You don't ask too many questions, you're a kid, you don't really understand that you're meant to be healthy, you're meant to be well. You're no meant to be like this."* (Max, p.3).

Max shared that he knew he was not well because of the cyanosis associated with his condition. However, he explained that as a child, it is difficult to understand the implications of this. Max reported that he did not ask "too many" questions, emphasising the innocence and naivety of childhood. Some participants reflected on feeling confused:

> *"…I always had questions about "why I was going to hospital…?" …I was always told I had a leaky valve but never really told how bad it was… …I always thought I had an understanding…"* (George, p.6).

> *"… "why am I in hospital?" …especially having siblings who don't have that... it was…potentially confusing…"* (Amy, p.5).

George explained that he was always told he had a "leaky valve" but was not informed about the severity of his condition, suggesting that he was shielded from this as a child. Amy alludes to comparing herself to her siblings who did not have to attend hospital. Poppy and Tanya shared similar reflections:

> *"… when I was younger, I didn't really know anything about it. I knew that I had a heart condition…. when I was in Primary School…. I would maybe say "Oh, I've got a hole in my heart" …* (Poppy, p.3).

> *"… I would always explain it as "oh, I have a hole in my heart", which I think was a bit of a dramatic way of explaining it…But that's what people told me and that's what I told other kids in the playground…that was still my understanding well into my teens…"* (Tanya, p.4).

Poppy and Tanya recalled explaining their condition to other children using the term "hole in my heart." Poppy reflected that, as a child, she knew she had a heart condition, but did not know the details. Similarly, Tanya shared that her choice of terminology was because of what she had been told by others. She described it as a "dramatic" way of explaining it, which provides an indication of how others may have reacted to hearing this terminology.

Some participants felt that it was not necessary to have known more about their condition during childhood:

> *"…they never really warned me that there could be a possibility that I could need an operation when I was older…I think they must have thought there's no point in telling her and scaring her …I can't say whether they should have told me sooner because… when I was younger, I wouldn't have really understood what they were saying to me anyway."* (Ruth, p.3).

Ruth reflected that it would have been difficult to have understood the information at this age and the health professionals may have withheld some information due to concerns about frightening her. Max expressed a similar view:

> *“...you could shoot all these facts at a kid and they’re not going to remember them, you’re just going to scare them so what’s the point? You need to inform the parents; you don’t need to inform the kids.”* (Max, p. 5).

Max highlighted that children are unlikely to remember all the “facts” and additionally, it may “scare” them. Conversely, some participants would have liked to have known more about their condition in childhood:

> *“…it would have been good to have more of a “would you like to know about this? I can tell you a little bit?” [child friendly voice] …Because I think if they’d asked “would you like to know about this? Can I give you a leaflet? Or would you like to see a picture of what your heart looks like?” I would have jumped at the chance.”* (Tanya, p.6).

> *“…it would have made me feel more comfortable and would have had less of a shock factor when I was 17 and figuring it all out for the first time…”*
>
> (Tanya, p.4).

Tanya’s use of “jumped at the chance” emphasises how eager she would have been to have learned more about her condition in childhood. Furthermore, she explains that it would have mentally prepared her more for learning about the reality of it in adulthood. Amy shared that having more knowledge and understanding in childhood would have helped to normalise her condition and increase awareness and understanding in others:

> *“Even things like, going to school… raising awareness in between about what my limitations are, particularly with [voice breaking] ….PE and things like that… …because at times, otherwise you look quite healthy…it can end up being*

> *misunderstood or kind of patted down a little bit, the severity of that situation [voice breaking]…* " (Amy, p.8).

The breaking of Amy's voice indicates an emotive subject. She appears to be expressing feelings of sadness when recalling her experiences of physical activity at school. Amy reflected that the impact of the condition can be "misunderstood" or minimised (e.g. "patted down") by others due to the outward invisibility.

All participants reflected that they had a limited knowledge and understanding of their condition in childhood. One participant highlighted the importance of protecting children and not scaring or overwhelming them with information that they do not need or may not understand. However, there was a shared sense of several participants wishing that they had known more about their condition during childhood. For some, this may have prepared them better for what to expect in the future and for others, this could have helped them to advocate for themselves.

This theme highlights the importance of considering the terminology used to explain conditions to children, which can be potentially confusing and may perpetuate misconceptions. It also conveys the importance of considering the developmental needs of children and adolescents in relation to learning about their health condition. The conflicting views of the participants reinforces the need for person-centred and individually tailored approaches to communication.

Learning About the Reality

All participants shared that they learned more about the reality of their condition in adulthood:

> *"…It wasn't until I went to the adult hospital, they started explaining everything, it was like…. oh, okay, maybe I was a bit sheltered from what was actually going on, how bad stuff was…"* (George, p.6).

> *"…I was a bit more protected from how serious it was when I was younger compared to when I was an adult…when I went to the adult clinics, they would tell you a lot more in a much more…not brutal way, but to the point, way… "(*Ruth, p.3).

Ruth and George explained that they were both protected from the severity of their condition in childhood and only learned more about this following transition to the adult service. George indicated that this may have come as a shock when he described being "sheltered" as a child about how "bad" the situation was. Ruth explained that the clinicians in the adult services were more direct in their delivery of information.

All participants reflected that it is somewhat anxiety provoking to learn about the severity and/or reality of their condition. Some participants described feeling very anxious and overwhelmed:

> *"…it was such a shock when I turned 18 and went to my first appointment at the adult hospital…and they told me more serious things…I suffered really badly with anxiety because of it because I was like "oh my gosh, they didn't make it seem as bad as they did once I got there". I think maybe they could have verbally prepared me a bit better…"* (Ruth, p.6).

Ruth explained that it was a “shock” to be informed about the seriousness of her CHD condition when she attended the adult hospital. She described wishing that she had been more prepared for this and consequently, she experienced severe anxiety.

Tanya shared a similar experience:

> *“…I had one conversation when I first moved to adult cardiology where it…felt like there was a lot of information coming at me at once…they suddenly started talking about all the implications…. that I’d never heard of before… it made me come away and be like “oh, I’m just scared, this feels like this big, impossible thing that I’ll never understand, and it has all these implications and I’m never going to be able to manage it” …it definitely did make me feel a bit scared… “*
>
> (Tanya, p.3).

Tanya uses rhetorical questions and emphatic words “scared”, “big”, “impossible” to emphasise how anxious she felt upon receiving this information. She explained that it felt as though a large amount of information was “coming at me at once” indicating that it was overwhelming for her. Amy reflected that although it felt ‘daunting’ to learn about the severity of her condition, it was always done in a “respectful way”:

> *“…daunting …it’s only when I’m in those situations that you probably realise the depth of what’s going on…it can be nerve wracking to hear what’s going to happen or why it’s going to happen…. not to the point that I was ever like “oh, I need to go out the door and I’m going to be frightened”, it was always in a…very respectful…way….”* (Amy, p.6).

The theme of learning about the reality of one’s LTC conveyed the transition that occurs when ACHD transfer from paediatric to adult healthcare services. Most participants reflected that they were “sheltered” from the reality of their condition during childhood and they only learned more about this when they transferred to the adult service. It appears that for some, this was an anxiety provoking experience, particularly when information was communicated in a more direct manner by healthcare professionals.

There was a shared sense of feeling shocked and overwhelmed by the volume and gravitas of the information that was being communicated to them. Consequently, this seems to have triggered psychological distress for some individuals who felt unprepared and/or unable to cope with the situation. This suggests that there may be some psychological benefits to educating and preparing people living with CHD from a younger age about their condition, and the possibility of future surgeries and complications. It also highlights the importance of considering the manner in which information is communicated to young adults with CHD about their condition.

Negative Associations

Three participants reflected on negative associations that were formed with discussing their condition because it was only discussed in medical settings or when there was a problem:

> *“…a lot of the time I’ve learned about it is when I’m in hospital and…when I’m ill or requiring treatment, your association with it then becomes…more daunting…”*
>
> (Amy, p.7).

> *"…It wasn't something we really focused on until it came to when I had surgeries coming up…we only really focused on it when it became an issue."* (Poppy, p.4-5).

The same participants expressed a desire to have discussed and learn more about their condition in between appointments and to have created more positive associations with this:

> *"…I don't want to constantly talk about what's wrong with my heart, I'd rather talk about how it's cool or it's interesting and how amazing our bodies and hearts are for what we're going through."* (Ruth, p.11-12).

Ruth shared that she would like to focus more on the "cool", "interesting" and "amazing" aspects of the heart and body, instead of the negatives. She explains that she does not want to "constantly talk about what's wrong with my heart". Her use of the words "constantly" and "wrong" emphasises the negative beliefs that can be internalised by people living with CHD about being different or defective.

This theme indicates that it is important for individuals with CHD to have more opportunities to discuss and learn about their condition out with medicalised settings. The participants reflections suggest that focusing solely on the challenging aspects of the condition (i.e. "what's wrong with my heart...") may perpetuate and reinforce negative beliefs about the condition being a flaw or weakness. However, encouraging more open discussions and highlighting strengths and positive aspects may empower ACHD to feel more confident and hopeful about living with this condition. Furthermore, it may create more positive associations with discussing the condition, thereby reducing stigma and anxiety.

How Learning Occurred

A few participants reflected on the shift in dynamics following the transition from paediatric to adult services:

"…in the child's one, they talked to my mum and dad about it and I kind of sat in the background. Whereas nowadays, they explain it to me then I have to explain it to my parents, so that's been a fun learning curve [sarcasm] where my mum and dad are asking me all these questions and I'm like "well, I didn't know I had to ask that?!" [sounding exasperated] … "(George, p.4).

George explained that he "sat in the background" in the paediatric service, suggesting a passive role. He reflected on the change in role since transitioning to the adult service, whereby he now has the responsibility of remembering and relaying information to his parents. His use of sarcasm and "fun learning curve" suggests that this transition has been challenging for both him, and his parents.

Most participants agreed that discussions with specialists have helped them to learn more about their condition:

"…every time I've went into hospital the nursing team have always asked "do you know what's going to happen?" "Do you know what's wrong with you?" …they have had diagrams of hearts outlining what has happened and have explained it all and…explained it to my wife… so that really has helped." (George, p.3).

"…the SACCS team have been really good. Every time I go in, they're like "We want you to understand it" …they'll explain it every year, they always answer questions. So now every time I go, they're like "You have this" and I'm like "Oh, I remember that! I know that I know what that looks like!" [upbeat tone] …." (Tanya, p.2).

George and Tanya's reflections emphasise that the clinicians wanted them to understand their condition. They both repeat "explain/explained" to emphasise the clarity of the discussions. Tanya advised that she "remembers" the information from previous discussions, indicating that it has been helpful. Clear explanations, repetition, and having information broken down into manageable chunks aided participants' understanding:

> *"…everyone has always explained it to me in a very clear and concise way and if I didn't understand it, they explained it in a different way…"* (George, p.4).

> "…*it's more so repetition for me that's important…"* (Tanya, p.3).

Five participants stated that visual diagrams had been key in supporting their learning. Interestingly several participants identified themselves as being visual learners:

> "…*visual drawings…and explaining the current situation… how it is versus a normal heart… I'm quite a visual person so seeing that written down does...help me understand that better…"* (Amy, p.2).

> *"…the SACCS nurses…sometimes they'll show me diagrams and things, which is good because it's hard to understand what's going on inside of your body..."*
>
> (Poppy, p.2).

One participant highlighted the impact of anxiety on his ability to remember verbal information that has been communicated to him:

> *"…a lot of the time if I get bad news, I kind of just go a bit blurry, and don't really remember stuff… [laughs softly]"* (George, p.5).

George described that when receiving bad news he goes “a bit blurry” and doesn’t remember. This illustrates the impact of anxiety on memory. He goes on to suggest that being provided with a written summary could help with this:

> *“… maybe if we had an email on that day of what was said then you don’t have to remember everything….”* (George, p.8).

Three participants shared that doing their own research helped them to learn more about their condition:

> *“…. the British Heart Foundation website has a lot of information that helped me, especially like running up for surgery and stuff. They have a lot of information on how to manage that…”* (Poppy, p.2).

This theme captures the main ways in which participants learned about their CHD condition. All participants reflected on discussions with healthcare professionals as being key to facilitating their learning. It appears that these discussions are most effective when supplemented with visual diagrams to aid understanding. Having information broken down, repeated, and communicated in a clear and concise manner appears to have been very helpful for most people. This links to an earlier theme about the complexity of health information and the importance of a person-centred approach when communicating with patients. One participant highlighted that it is important to consider the impact of anxiety on an individual’s ability to retain information. This is potentially a key barrier to learning about one’s health condition and therefore it is important to consider ways of mitigating this (i.e. by providing written summaries). Several participants spoke of having done their own research into their condition. This supports an earlier theme of ACHD being curious and keen to learn more about their condition.

Supporting People with CHD to Learn About Their Condition

Support for Children and Young People

Participants shared that age-appropriate conversations with children and young people are helpful in supporting them to learn about their condition. Amy's reflection highlighted that this could help to facilitate understanding within children about why certain events or procedures are happening:

> *"…engaging in that conversation about what your condition is made up of, whether that's through age-appropriate means, visual aids, toys…having that conversation about what's going to happen… explaining what's happening, why it's happening… would be really useful."* (Amy, p.5).

Poppy reflected that, as a child, it was difficult to remember information from hospital appointments. She suggested that a visual resource/information pack for children may be useful to support their knowledge and understanding:

> *"…when I came home…I wouldn't have anything to help me remember everything … When I was moving up into the adult services, they gave me this big pack… it had lots of information and lots of different books and that helped me…a visual…something would help younger kids..." (*Poppy, p.5).

Tanya reflected on a positive experience of attending a transition day for adolescents and suggested this should be made available to younger children:

> *"…when you turn 16 or 17 there's this open day you can go to which is the transition day…And that's awesome, they've got videos…I really liked that, that was really helpful in making me feel more comfortable and less alone… I feel like there could*

> *have been maybe something like that for kids for 11- or 12-year-olds…just as like a "here, have a basic understanding, here are other kids that are like you!"."*
>
> (Tanya, p.4)

Tanya's use of "awesome" and repetition of "really" emphasised how impactful and beneficial she found this transition day. Tanya reflected that it helped her feel "less alone" and "more comfortable", suggesting positive associations.

This theme suggests that it is important to create developmentally appropriate opportunities for children and young people to learn more about their CHD condition. The participants' reflections indicate that this is something they would have liked to have experienced themselves during childhood as it would have created more positive associations, increased their understanding, and helped them to feel more prepared. A variety of suggestions are made about how to facilitate this, including the use of toys, visual aids, information packs and transition days for younger children. It appears that transition days may have a dual impact of educating children and young people and providing peer support, thereby reducing feelings of isolation.

Educate Parents/Caregivers

Two participants reflected that parents/caregivers should be educated to increase their own understanding and awareness and facilitate open discussions:

> *"… learning when…their child isn't feeling well…it is to do with their heart…because a lot of the symptoms do get caught up with… just being tired…I think just making you as a parent more aware of what your child is going to be going through."*
>
> (Poppy, p.5).

> “*...having the information available and understanding it yourself so when your kid does ask, it’s like “oh yeah, cool, I can show you this if you’d like?” you know?”* (Tanya, p 6).

Poppy and Tanya’s reflections indicate that it is important for parents/caregivers to understand their child’s CHD condition to prevent physical symptoms being minimised and to support the child’s own understanding. This theme indicates that educating parents/caregivers can have a profound impact on creating positive associations for children living with CHD, including helping them to feel validated. In turn, this may mitigate the onset of psychological difficulties relating to low self-esteem. Furthermore, it may provide an opportunity for parents/caregivers to model positive and open discussions about the condition. This could increase children and young people’s confidence in discussing their condition openly with others.

Ask Questions

All participants highlighted the importance of asking questions. Max emphasised that the clinicians *want* to be asked:

> *“…Most cardiologists I’ve dealt with want you to know about it so you can see the signs if there’s any problem. “(*Max, p.2).

> “...ask your doctors, especially at the Golden Jubilee…genuinely, they’re nice and will take the time…” (Tanya, p.4).

The theme of asking questions links to a previous theme about the ways in which participants learned about their condition, which was mainly via discussions with healthcare professionals. The participants emphasise that clinicians want to be asked questions and will devote time to answering these, which indicates that they have had positive experiences of these.

Peer Support

Several participants discussed the importance of peer support. Max reflected that, although the cardiologists are experts in the field, they may be unable to relate to the ‘feelings’ of what it is like to live with CHD:

> *“…try to arrange speaking to someone who’s been through it as well because doctors, as much as they know about the condition and the mechanics they don’t actually know about the feelings and going through the surgery.”* (Max, p.6).

Ruth reflected that connecting with others who have CHD reduces isolation:

> *“…it was actually just like really, really nice in a weird way to know that there’s other people going through it… it makes you feel less alone.”*
>
> (Ruth, p.10).

This theme illustrates the importance of peer support in terms of reducing isolation and providing opportunities for learning. The participants’ reflections demonstrate the value of peer support because of the unique insight that people with lived experience of CHD can offer, particularly regarding the emotional impact. This theme suggests that peer support opportunities are important for people living with CHD and could be a valuable tool to facilitate learning about and coping with the condition.

Signposting

Several participants highlighted that people living with CHD should be signposted to reliable information by healthcare professionals where they can learn more if they wish:

> *"…Direct them to points of research they could look up… because non-medical people don't know where to find this stuff. "*(Max, p.6).

> *"...if there is other research out there...that...SACCS or other people have access to and can...signpost that would be... beneficial and interesting to read up about as well."*
>
> (Amy, p. 3).

> *"…if you go to your GP with questions and they don't know, they should definitely sign post you, which they should know how to do…."*
>
> (Tanya, p. 7).

This theme reinforces that some individuals living with CHD have a desire to learn more about their condition. It also highlights the power dynamics that exist within healthcare whereby health professionals have access to knowledge and information that patients may not have access to. It is therefore important that healthcare professionals are mindful of signposting individuals living with CHD to credible sources of information to foster their own learning.

Discussion

This qualitative study aimed to explore the perspectives and experiences of ACHD regarding their knowledge of their condition using IPA. Four GETs emerged: current knowledge and understanding, pros and cons of knowing, experiences of learning about their condition, and supporting people with CHD to learn about their condition. Sub-themes were also reported for each overarching GET.

All participants felt that they had sufficient knowledge about the aspects of their condition which they viewed as being most important for them and others to know. A sense of curiosity was also expressed by participants who wished to learn more about their condition. This was motivated by personal values relating to control and self-advocacy. It appeared to be more salient for individuals in adulthood due to the impact on lifestyle choices and future planning. However, there was some uncertainty expressed by participants relating to understanding and remembering complex medical terminology. This has previously been identified as a common barrier to health literacy and effective self-management of LTCs (Asp et al., 2015; Burns et al., 2022). This finding emphasises the importance of a person-centred approach to education and communication within health care to empower and instil confidence in patients with LTCs (Burton et al., 2017).

All participants agreed that understanding their CHD condition was beneficial for their health. In terms of mental health benefits, participants reported greater acceptance and confidence in coping with their condition and reduced anxiety. This appeared to be linked to having realistic and accurate beliefs and expectations about their CHD condition. This finding suggests that the participants’ knowledge and understanding of their illness (i.e. illness beliefs/representations) has influenced their coping response, which is in keeping with the ‘common sense’ model of self-regulation (Leventhal et al.,1980).

In terms of physical health, understanding their condition helped participants to make informed decisions about their health (e.g. avoiding risks and engaging in important medical procedures). This links to the Health Belief Model, which posits that the likelihood of undertaking a health behaviour is influenced by beliefs regarding illness severity, consequences, and benefits/costs (Rosenstock, 1990). Being equipped with a knowledge and understanding of their condition also appeared to instil confidence within participants when communicating and/or explaining aspects of their condition to others. One participant reflected that it motivated them to advocate for themselves in relation to their health and care treatment.

These findings can be conceptualised within self-determination theory (SDT), which proposes that individuals have three basic psychological needs: autonomy (the need to feel in control of one’s own choices and behaviours), competence (the need to feel capable and effective within one’s own actions), and relatedness (the need to feel connected to and cared for by others) (Ryan & Deci, 2000). According to SDT, greater satisfaction of these needs leads to increased motivation to enact a certain behaviour. The findings from the present study indicate that having a knowledge and understanding of CHD may help to fulfil the competence element of SDT, which in turn may have a positive impact on health behaviour. This links to findings reported in a study by Shackleford et al. (2019) who found that the competence and relatedness aspects of SDT were significantly associated with health-related quality of life (HRQL) in adolescents with CHD.

In terms of disadvantages, it was discussed that some individuals may not wish to learn about their condition due to negative feelings associated with this. The use of avoidant coping (e.g., denial) is common in the CHD population and is concerning because of the negative impact on physical health due to a lack of engagement in follow up care (White et al., 2016). Some participants reflected that increased knowledge worsens their mental health due to increased rumination about potential problems. This theme is echoed in a study by Schiele et al. (2019) in which they reported that CHD patients who had a greater understanding of the risks of future cardiovascular complications reported greater anxiety and poorer emotional HRQoL, particularly when there was uncertainty related to the diagnosis. However, the authors acknowledged that risk related knowledge may be more likely to contribute to emotional distress than general disease related knowledge. Conversely, in their study of adults with Type 1 and Type 2 diabetes, El-Tantawy et al. (2024) found that lower illness knowledge was significantly associated with higher anxiety and depression scores in this population.

The variation in how illness knowledge impacts on mental health in people with LTCs could be explained by individual differences in illness perceptions. This is supported by Marcil et al. (2023) who found that illness perceptions were significantly associated with anxiety in adults with CHD. Furthermore, the authors found that more threatening illness perceptions (in terms of severity and/or impact on functioning) was associated with greater anxiety and more avoidant coping styles. These findings suggest that illness perceptions and mental health difficulties (e.g. depression or anxiety) may be barriers to learning about one’s CHD condition.

The participants shared that they had a limited understanding of their condition during childhood. Some individuals described this as confusing, and they would have liked to have had a better understanding of their condition during childhood and adolescence. However, others reflected that it is important to protect children and avoid overwhelming them with information that they cannot comprehend. There was a theme of participants learning about the reality and severity of their condition when they reached adulthood. Feelings of shock, anxiety, and overwhelm were reported when reflecting on this experience. Some participants shared that they wished they had been more informed and prepared about the reality and severity of their condition from an earlier age.

These findings emphasise the importance of considering the developmental needs of children and young people with CHD within the context of healthcare and education. Moons et al. (2021) recommended that, during the transition and transfer of care in adolescents with CHD, individual needs must be assessed, and counselling and education should be provided. A randomised controlled trial (RCT) demonstrated that the STEPSTONES programme (a structured, person-centred transition programme for adolescents with CHD incorporating education about the condition, health behaviour and dealing with school and friends) was effective in increasing patient empowerment and knowledge of their condition, with moderate to large effect sizes reported (Bratt et al., 2023). These studies demonstrate that there is emphasis within the research field on the importance of educating adolescents with CHD. However, a recent scoping review highlighted that the needs of younger children (aged <13 years old) appear to be overlooked and there is a critical need for tailored educational interventions for children with CHD (Barbazi et al., 2025).

Participants agreed that most of their learning occurred via supportive discussions with nurses and cardiologists. Clear explanations, repetition, opportunities to ask questions/seek clarification, and visual diagrams supported learning and understanding. These findings are supported by existing research. For example, in a longitudinal qualitative study of facilitators and barriers to health literacy, the authors found that positive interactions and clear communication from healthcare professionals facilitated health literacy in adults attending a cardiovascular disease risk reduction programme (McKenna et al., 2020).

One participant shared that anxiety about receiving “bad news” impacted on his ability to remember verbal information about his health and care treatment. This is supported by theoretical knowledge that anxiety can impair working memory performance (Lukasik et al., 2019) and is an important consideration when delivering information to patients. Some participants reflected that they had formed negative associations with learning about their condition because it was only discussed in medical settings or when there was a problem. They expressed a desire to have discussed it more openly and in a more positive light. This links to the psychological difficulties (e.g. low self-esteem) that can develop in people living with LTCs (such as CHD) due to internalised negative beliefs and associations (Kovacs et al., 2022). Providing opportunities to discuss and learn about LTCs in more positive and supportive contexts may help to empower individuals and enhance self-confidence through normalisation and validation.

Clinical Implications

The findings from this study have highlighted that, supportive discussions with healthcare specialists, supplemented by visual diagrams are key to facilitating learning about one’s CHD condition. There is a higher prevalence of cognitive impairment and anxiety in the CHD population (Feldmann et al., 2021), and it is important to be aware of the impact of this on memory. Written summaries, visual resources, repetition, and including significant others in appointments may help with retention of information.

The participants in this study made several practical suggestions about how to support people with CHD across the lifespan to learn about their condition. It was highlighted that parents/caregivers should be educated to increase their own awareness and understanding of CHD and to equip them to have discussions with their child. It was also suggested that facilitating developmentally appropriate conversations with children and young people and providing visual information packs may help to educate them from a younger age about their condition. Some participants reflected that having more frequent and open discussions about CHD may help to normalise and validate individual experiences, increase awareness and understanding in others, and reduce feelings of stigmatisation.

Providing opportunities for peer support and peer learning, particularly for younger children, was highlighted as a way of creating positive learning experiences and reducing feelings of isolation. Additionally, it was suggested that individuals with CHD should be encouraged to ask questions and should be signposted by health care professionals to credible sources of information and research.

Psychologists can help to address some barriers to learning about CHD by providing evidence-based interventions to reduce psychological distress and improve coping skills (Kovacs et al., 2022; Li et al., 2021). Psychologists can also raise awareness and provide guidance to patients, families, and health care professionals about the impact of trauma and cognitive and/or neurodevelopmental difficulties on health education.

Theoretical and Research Implications

The findings from this research study support existing theories and models, such as those proposed by Leventhal et al. (1980) and Ryan and Deci (2000).The participants’ reflections suggest that their illness beliefs, perceptions, and coping styles have been shaped by their knowledge and understanding of their condition. Several participants reflected on how knowledge and understanding of their condition had influenced their feelings of autonomy, control, competence, and expectations, which supports SDT (Ryan & Deci, 2000). Additionally, some participants shared that peer support and connection is an important element of learning about their condition, which links to the relatedness component of SDT.

The findings from the current study support previous research findings about the facilitators and barriers to health literacy and health education. Accessible, person-centred communication appears to be key to enhancing learning in people with LTCs, such as CHD. The findings have also highlighted the relevance of other psychological and neuropsychological models relating to acceptance, self-esteem, information processing and memory, within the context of health education and health literacy.

This study has generated novel findings in that it has provided insight into the experiences and perspectives of adults with CHD in learning about their condition. It has highlighted areas that could be explored in future research, including how to educate and support younger children with LTCs, such as CHD, to develop a knowledge and understanding of their condition. Future research studies should aim to recruit more representative samples of the CHD population by including people with neurodiversity, cognitive impairments, and learning disabilities.

Strengths and Limitations

The findings from this study have provided insight into the experiences of ACHD in developing knowledge and understanding of their condition. Furthermore, it has generated practical suggestions that can be implemented by services. The use of remote interviews improved accessibility to the study.

In terms of limitations, there was a higher proportion of female compared to male participants, which could impact on the generalisability of the results. Individuals with lived experience were asked to review the study documents (e.g. PIS, interview guide) for readability. However, it is acknowledged that it would have been beneficial to have involved people with lived experience more in the design of the study and the interview topic guide. Due to constrictions on time and resources, member checking was not conducted. The analysis was conducted independently by the researcher, which may have increased the risk of bias; however, researcher reflexivity was acknowledged.

Conclusions

This study found that ACHD recognise the importance of having a knowledge and understanding of their condition and the mental and physical health benefits of this. Participants shared that their knowledge and understanding of their condition developed in adulthood via supportive discussions with healthcare professionals and doing their own reading and research. Participants reflected on some of the barriers to learning about their condition, including the complexity of medical terminology, anxiety, difficulties with acceptance, and a lack of opportunity to learn about and discuss this during childhood. Finally, the participants made several practical suggestions about how to support others with CHD to learn about their condition.

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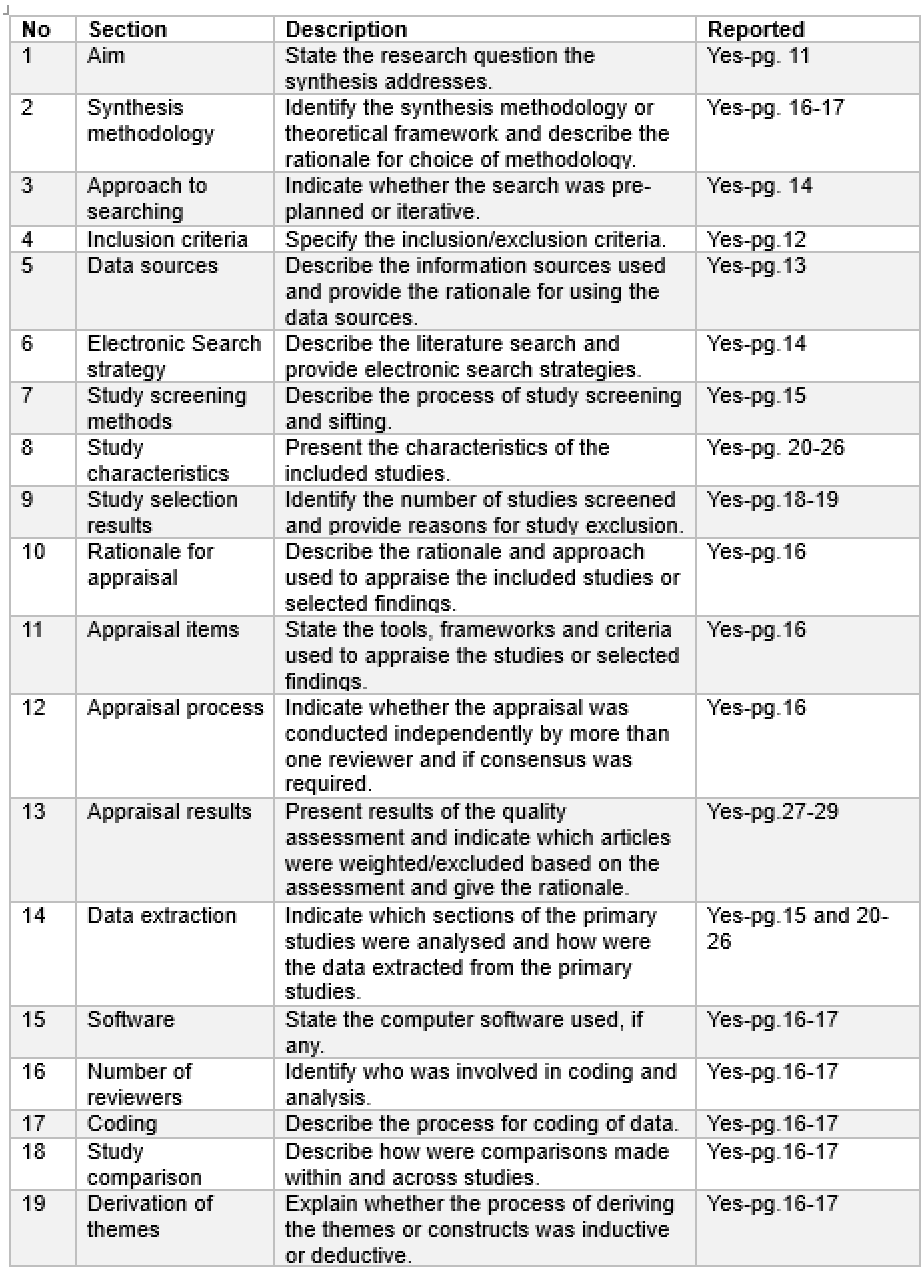
World Health Organisation. (2024). *Health literacy.*

https://www.who.int/news-room/fact-sheets/detail/health-literacy

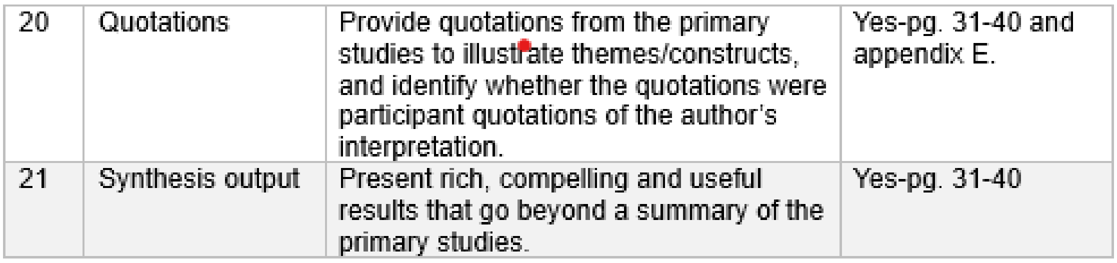
Appendices

Appendix A

Completed ENTREQ Checklist.



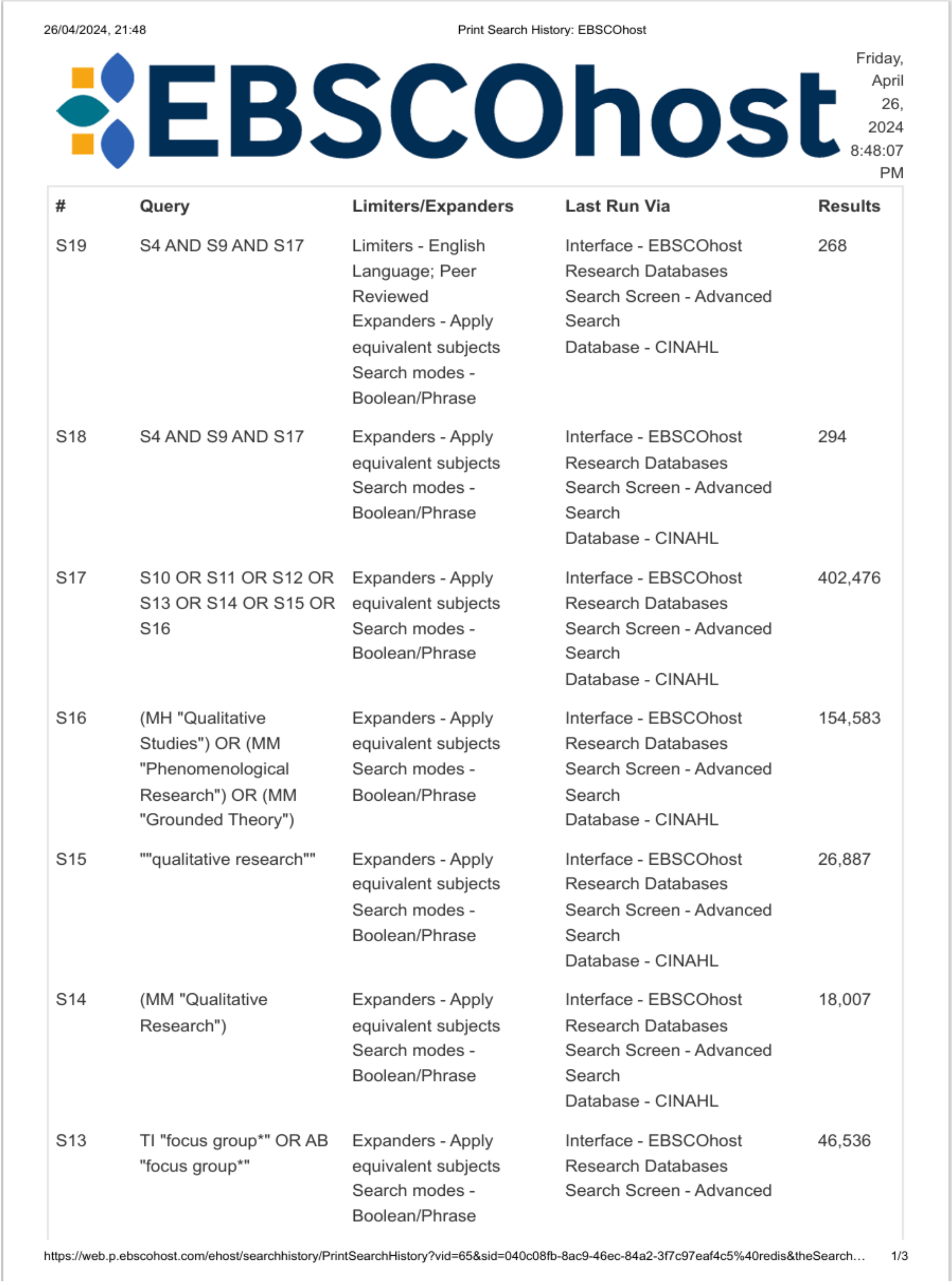
No	Section	Description	Reported
1	Aim	State the research question the synthesis addresses.	Yes-pg. 11
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework and describe the rationale for choice of methodology.	Yes-pg. 16-17
3	Approach to searching	Indicate whether the search was pre-planned or iterative.	Yes-pg. 14
4	Inclusion criteria	Specify the inclusion/exclusion criteria.	Yes-pg.12
5	Data sources	Describe the information sources used and provide the rationale for using the data sources.	Yes-pg.13
6	Electronic Search strategy	Describe the literature search and provide electronic search strategies.	Yes-pg.14
7	Study screening methods	Describe the process of study screening and sifting.	Yes-pg.15
8	Study characteristics	Present the characteristics of the included studies.	Yes-pg. 20-26
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion.	Yes-pg.18-19
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings.	Yes-pg.16
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings.	Yes-pg.16
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	Yes-pg.16
13	Appraisal results	Present results of the quality assessment and indicate which articles were weighted/excluded based on the assessment and give the rationale.	Yes-pg.27-29
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies.	Yes-pg.15 and 20-26
15	Software	State the computer software used, if any.	Yes-pg.16-17
16	Number of reviewers	Identify who was involved in coding and analysis.	Yes-pg.16-17
17	Coding	Describe the process for coding of data.	Yes-pg.16-17
18	Study comparison	Describe how were comparisons made within and across studies.	Yes-pg.16-17
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Yes-pg.16-17



20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	Yes-pg. 31-40 and appendix E.
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies.	Yes-pg. 31-40

Appendix B

Example of a Database Search.



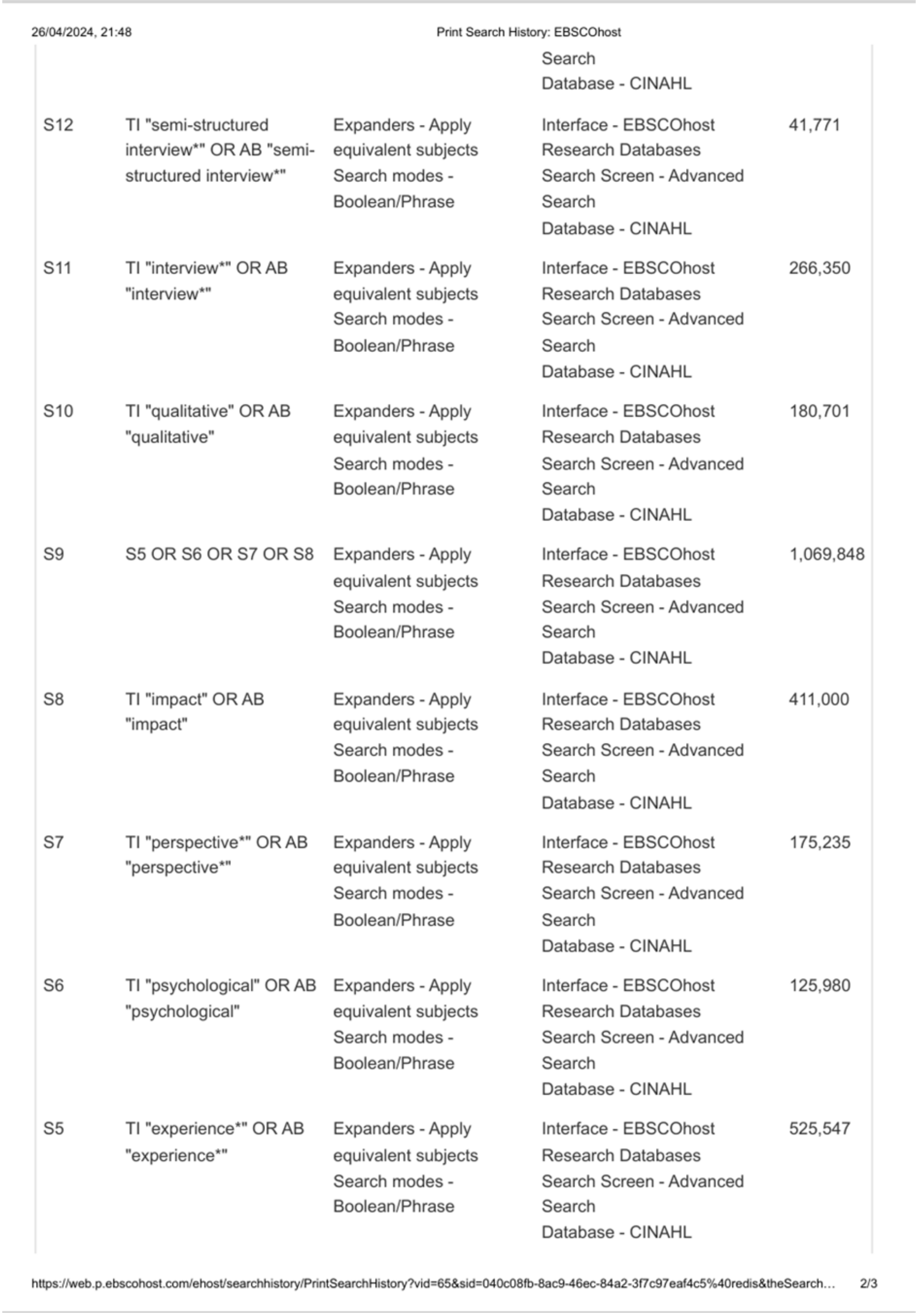
26/04/2024, 21:48 Print Search History: EBSCOhost

EBSCOhost

Friday, April 26, 2024 8:48:07 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S19	S4 AND S9 AND S17	Limiters - English Language; Peer Reviewed Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	268
S18	S4 AND S9 AND S17	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	294
S17	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	402,476
S16	(MH "Qualitative Studies") OR (MM "Phenomenological Research") OR (MM "Grounded Theory")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	154,583
S15	""qualitative research""	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	26,887
S14	(MM "Qualitative Research")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	18,007
S13	TI "focus group*" OR AB "focus group*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	46,536

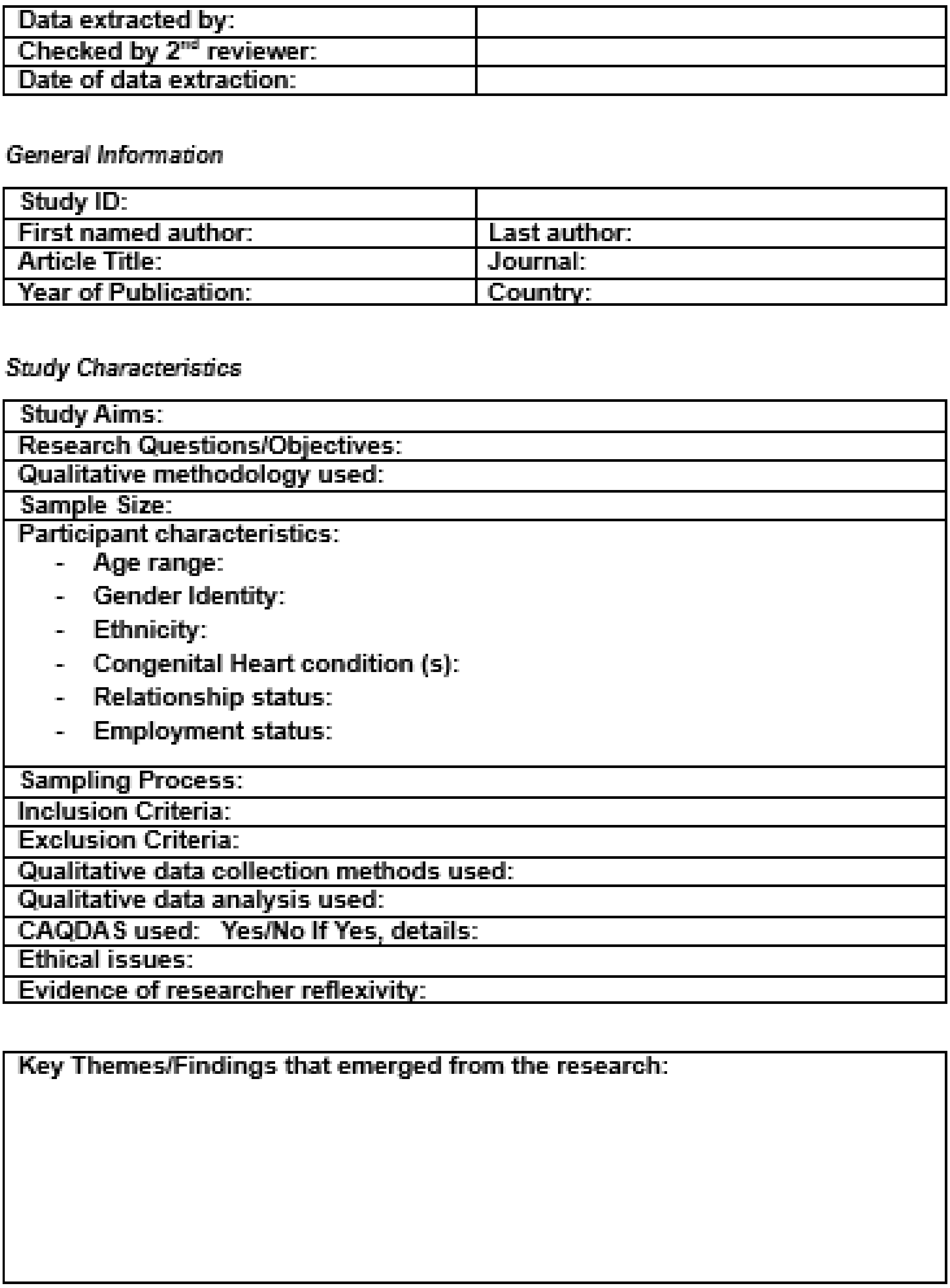
https://web.p.ebscohost.com/ehost/searchhistory/PrintSearchHistory?vid=65&sid=040c08fb-8ac9-46ec-84a2-3f7c97eaf4c5%40redis&theSearch… 1/3



			Search Database - CINAHL	
S12	TI "semi-structured interview*" OR AB "semi-structured interview*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	41,771
S11	TI "interview*" OR AB "interview*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	266,350
S10	TI "qualitative" OR AB "qualitative"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	180,701
S9	S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,069,848
S8	TI "impact" OR AB "impact"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	411,000
S7	TI "perspective*" OR AB "perspective*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	175,235
S6	TI "psychological" OR AB "psychological"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	125,980
S5	TI "experience*" OR AB "experience*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	525,547

Appendix C

Data Extraction Form.



Data extracted by:	
Checked by 2nd reviewer:	
Date of data extraction:	

General Information

Study ID:	
First named author:	Last author:
Article Title:	Journal:
Year of Publication:	Country:

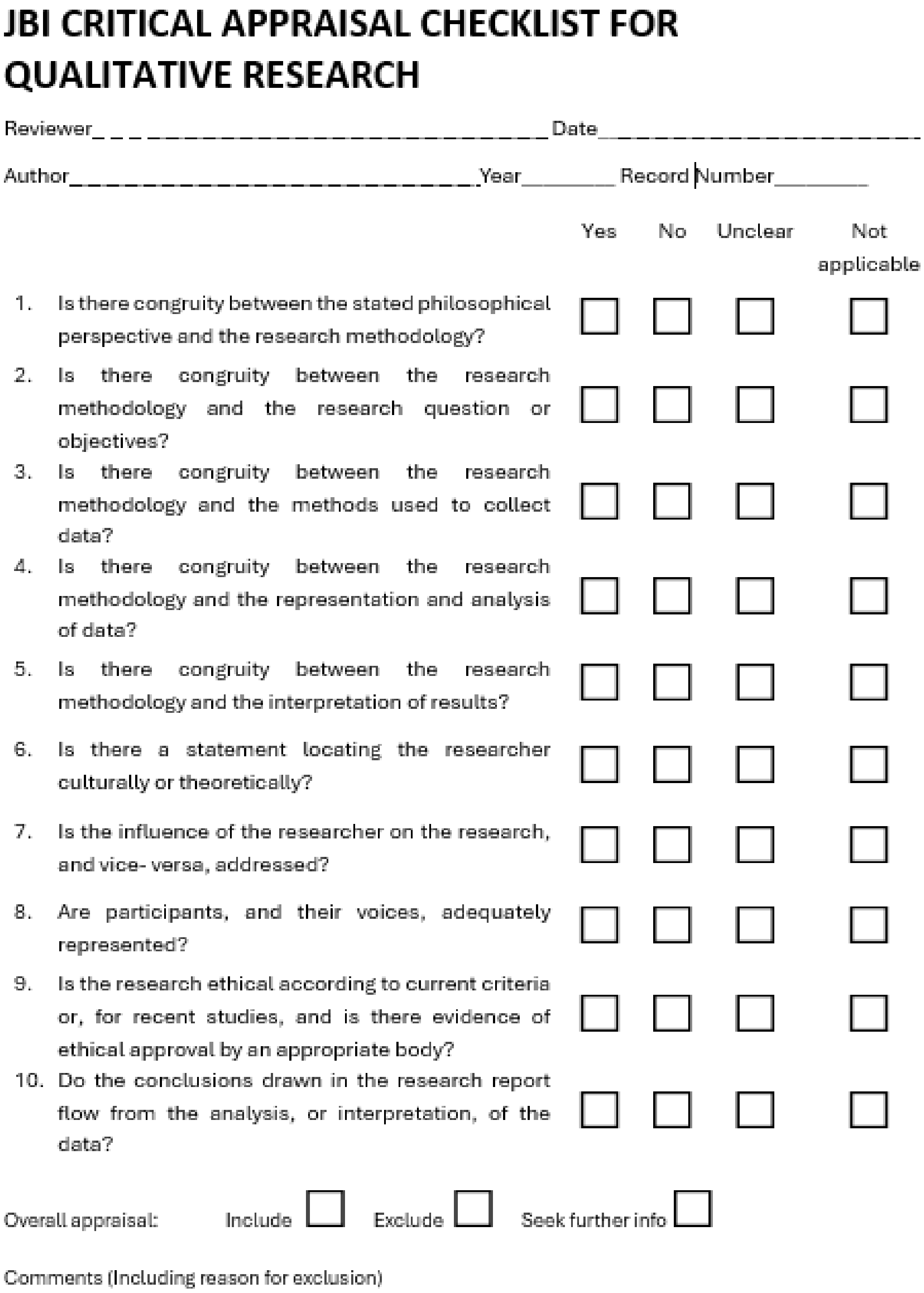
Study Characteristics

Study Aims:
Research Questions/Objectives:
Qualitative methodology used:
Sample Size:
Participant characteristics: - Age range: - Gender Identity: - Ethnicity: - Congenital Heart condition (s): - Relationship status: - Employment status:
Sampling Process:
Inclusion Criteria:
Exclusion Criteria:
Qualitative data collection methods used:
Qualitative data analysis used:
CAQDAS used: Yes/No If Yes, details:
Ethical issues:
Evidence of researcher reflexivity:

Key Themes/Findings that emerged from the research:

Appendix D

Copy of JBI Critical Appraisal Checklist for Qualitative Research.



JBI CRITICAL APPRAISAL CHECKLIST FOR QUALITATIVE RESEARCH

Reviewer______________________________Date____________________

Author____________________________Year________ Record Number________

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix E

Table 3. Full List of Analytical and Descriptive Themes with Supporting Quotations.

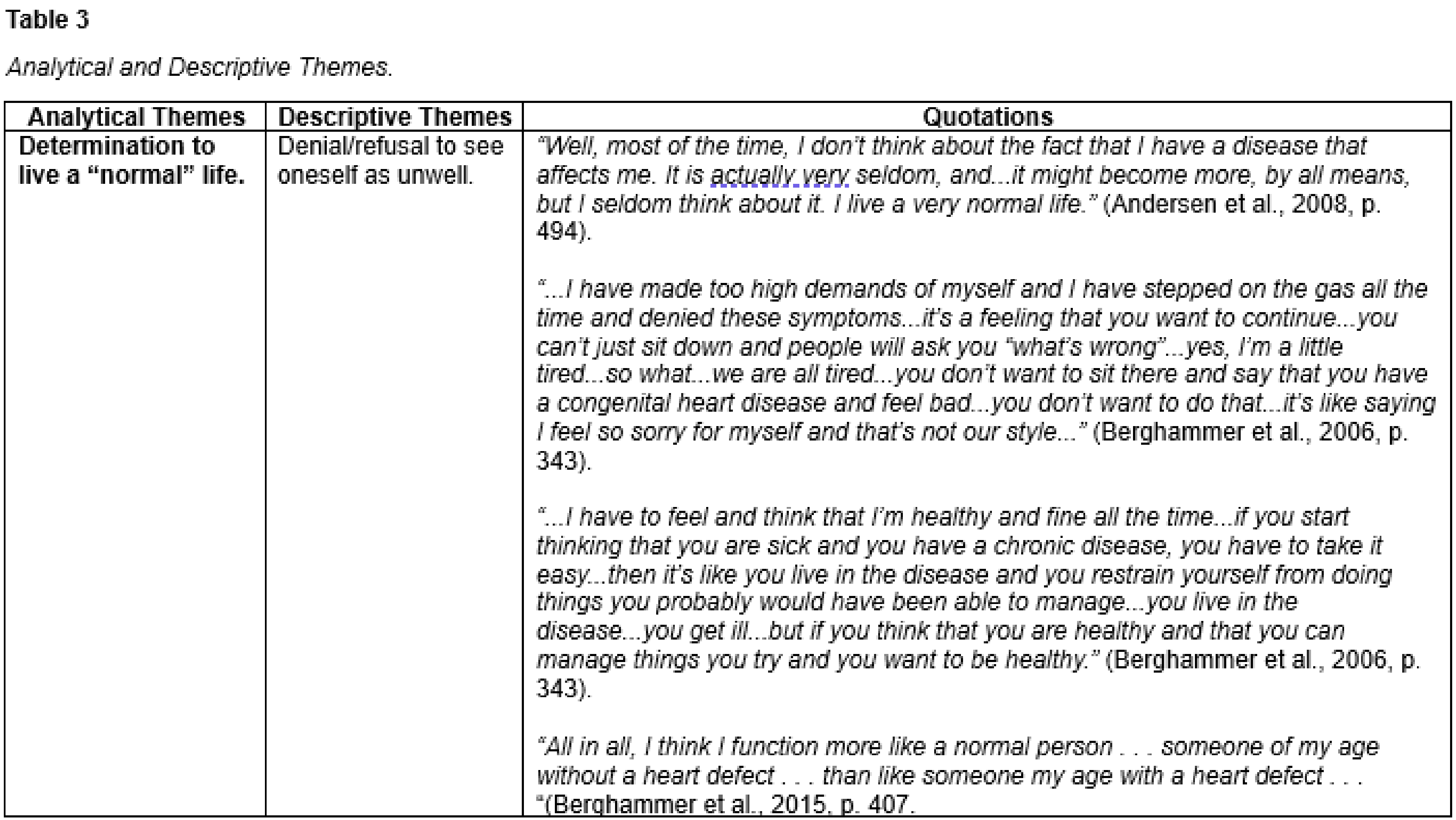


Table 3

Analytical and Descriptive Themes.

Analytical Themes	Descriptive Themes	Quotations
Determination to live a “normal” life.	Denial/refusal to see oneself as unwell.	*“Well, most of the time, I don’t think about the fact that I have a disease that affects me. It is actually very seldom, and...it might become more, by all means, but I seldom think about it. I live a very normal life.”* (Andersen et al., 2008, p. 494). *“...I have made too high demands of myself and I have stepped on the gas all the time and denied these symptoms...it’s a feeling that you want to continue...you can’t just sit down and people will ask you “what’s wrong”...yes, I’m a little tired...so what...we are all tired...you don’t want to sit there and say that you have a congenital heart disease and feel bad...you don’t want to do that...it’s like saying I feel so sorry for myself and that’s not our style...”* (Berghammer et al., 2006, p. 343). *“...I have to feel and think that I’m healthy and fine all the time...if you start thinking that you are sick and you have a chronic disease, you have to take it easy...then it’s like you live in the disease and you restrain yourself from doing things you probably would have been able to manage...you live in the disease...you get ill...but if you think that you are healthy and that you can manage things you try and you want to be healthy.”* (Berghammer et al., 2006, p. 343). *“All in all, I think I function more like a normal person . . . someone of my age without a heart defect . . . than like someone my age with a heart defect . . .* “(Berghammer et al., 2015, p. 407.

		"I will do everything that everyone else does and I am not ill, but I think I have become more determined . . . Yes, that I am healthy and that's the way it should be…" (Berghammer et al., 2015, p. 408). *"I consider myself healthy, but, yes even though I have a heart defect but I . . . but anyway I see myself as healthy . . ."* (Berghammer et al., 2015, p. 407). *"Oh, especially compared with friends, but I see no difference, I'm normal. We are the same . . ."* (Berghammer et al., 2015, p. 407). *"Because if you dig yourself into a hole by always thinking, oh I can't handle it because I'm ill and yes, I'm ill, I'm ill, I'm ill, you can't do that. Because then you can't live your life . . .* (Berghammer et al., 2015, p. 407). *"It's a mask, it's your alter ego ... I'm normal just like everyone else, you know the denial part, you are completely sick ... you're in complete denial and try to be something that you're not"*. (Cornett & Simms, 2014, p. 401).
	Not letting it control me	*"I'm not sick. I have a heart defect, and I have symptoms every day, but I don't feel sick. This is how I choose to view things and cope with having a chronic heart defect. I think my heart defect is important, but it shouldn't dominate my life."* (Overgaard et al., 2013, p. 192).

		“Yes . . . so I’d like to have more challenges, just to see that I can do it, and I know I’m sure and strong in myself and that I can handle things. Nothing is impossible, nothing can stop me . . .” (Berghammer et al., 2015, p. 407-8.) *“I try to look upon my illness or heart defect as something I have control over, it must not be allowed to control me, and I have made a decision that it never will. The heart defect will never stop me from doing anything . . .”* (Berghammer et al., 2015, p. 408).
Feeling different.	Experiences of being bullied and excluded.	*“You are always different; you’re never going to do the same as everyone else ... you were bullied in school for being different”.* (Cornett & Simms, 2014, p. 400). *“I can’t really do anything physical. When I was 10 years old, I had to quit football and couldn’t really do any sports. So, I was naturally excluded because I couldn’t keep up with the others. I felt different.’* (Overgaard et al., 2013, p. 192). *“The friends that I had left me behind, because they knew that I wasn’t able to follow them ... that was a period that I didn’t want to live anymore. It was hard for me to accept that my friends put me aside ... most of my friends went to play football, which is a very intensive sport, so ... they thought, “he isn’t able to do that” ... and that was very difficult for me.”* (Claessens et al., 2005, p. 6). *“My peer relationships have been impaired because I was unable to join them at any activity. I could not spend time with, nor I could do any extra activity, enjoyment, outing with them. When my friends asked me to join them, I rejected their offer because I did not have any courage to go out, due to muscles pain. So, they gradually stopped asking me and the relationships became distracted”* (Yasseen et al., 2023, p. 1599).

		"[I was] excited to be able to go to high school and join the team. And then as my friend group was going to do that, I was clearly not allowed to do it, so it was a little traumatic" (Steiner et al., 2021, p. 2).
	Internalisation of negative feelings about oneself.	*"I was the first born. I had two brothers … and my middle brother quickly became the leader of the family because while I had ideas, I couldn't actually execute any of them. And I definitely felt like my brothers wanted very little to do with me, especially in later childhood, and I think it's because I was weird. Different."* (Keir et al., 2018. p. 742). *"You sort of internalize those things, as like, 'Oh, well, am I a bad person?'… because you do feel like you did something wrong or bad, just because of who you are"* (Steiner et al., 2021, p. 2). "*Whereas before I wasn't that bothered that I had heart problems, this thing over here differentiated me completely from others and I started to feel a bit sad, and so I thought "what shall I do now? Am I going to remain like this all my life?".* (Callus et al., 2013, p. 233. *"I've always felt I'm faulty, I don't fit in, you're an outcast ... I've always felt like a reject." (*Cornett & Simms, 2014, p. 400).

Positive outlooks.	Inner strength and maturity.	*"I have been able to experience things that not so many people around me have experienced . . . I feel more mature and experienced than others because of my heart defect and my other illnesses, and I see that as a positive thing . . . I feel proud of both myself, and my heart defect" (*Berghammer et al., 2015, p. 406). *"But I want to be who I am (giggles). And I've also been able to experience a lot, thanks to my heart defect. I've been through a lot. Like this health care and, yes, I've been able to do many things . . ."* (Berghammer et al., 2015, p. 406). *"Well . . . but the truth is, those who haven't . . . been through the same thing, they sort of. . . I can't speak for everyone else . . . but . . . I feel that I have a little more . . . think a step further than my classmates"* (Berghammer et al., 2015, p. 406). "*My heart defect has at the same time given me a lot, I have become humble and have a great acceptance of people and that they are all different . . . and that people know and can manage different things . . ."* (Berghammer et al., 2015, p. 406). "*It kind of adds something positive, rings positive, so to speak, you get a pat on the back, that you can do this . . . you are strong enough to handle it…"* (Berghammer et al., 2015, p. 407). "*My heart defect has brought with it lots of other things. But I can handle it and I also think I have only got the heart defect because I can handle it…"* (Berghammer et al., 2015, p. 408). *"That is in order to deal with these things you have to strengthen yourself, think positively and on the one hand a bit more of maturation, maybe more quickly than others and trusting others, doctors, parents, so for sure the positive things were also more present*" (Callus et al., 2013, p. 235).

	Part of me	*“I am tougher than others. When you have gone through the things that I have, you see life in a completely different way. For me, problems have to be very big before they get to me.”* (Overgaard et al., 2013, p. 192). *“Yes, but I suppose it’s me, it’s a part of me. It isn’t something that is wrong with me but it’s . . . yes but it’s just the way I am . . . Well, I’ve never seen it as being ill . . .”* (Berghammer et al., 2015, p. 406). *“I’m not ashamed of it, nor of my scars, it has kind of become a part of me, or part of my personality, and it would feel very empty without it. My chest would have been very bare without the scar . . . I don’t really know who I would have been in that case. I can’t imagine my chest with no scars, it would have looked dull and ordinary . . .”* (Berghammer et al., 2015, p. 406). *“I see myself as healthy, but with a special heart, half a heart, a different heart.* (Berghammer et al., 2015, p. 407). *“It feels like just part of my story and part of who I am*" (Steiner et al., 2021, p. 2).
	Greater appreciation of life.	*“Your life is precious and until something like that happens to you, you just take it for granted ... It has made everything make sense, it makes me feel I can do anything”* (Cornett & Simms, 2014, p. 399). “*It’s made me a better person in terms of the quality of life I try and live. It means so much to me to make the most of my life”* (Cornett & Simms, 2014, p. 399). *“…because I am alive I sort of feel I have to do something with it”* (Cornett & Simms, 2014, p.399). “*You appreciate life much more when you’ve fought for it. People forget that it’s a gift. Tomorrow, you may be gone.”* (Overgaard et al., 2013, p. 192).

	Motivation to achieve goals.	“*If I had the choice of having congenital heart disease or not, obviously I would prefer to have a normal heart. But I don’t have that choice, so I have become really aware of and thankful for everything that is good*” (Overgaard et al., 2013, p. 192-3). *“Well, I have a very different view on life than many others. I have a different perspective. And it is especially regarding values in life, what is valuable and what I might call trifles, right?”* (Andersen et al., 2008, p. 493). *“Yeah, you make the most of life. Have fun as long as possible. That’s the main thing.”* (Berghammer et al., 2015, p. 409). “*Sometimes I get sad, but sometimes it will also motivate me to do this, do that, check things off the bucket list … I regularly do re-evaluations of my life and myself of, ‘this is what I want to be doing with what's left on the clock’”* (Steiner et al., 2021, p. 2). *“I was also angry that I was supposed to have these limitations that I didn’t have. At 10 I was able to beat all the teams that were 16 and 18, things like that. And I got invited to [elite training], which was pretty cool, and then they denied me because of my heart—they said “you can’t go” … there was no option. I was really angry about it … it was pretty hard…. So, I quit skiing, and I started snowboarding. That was right at the beginning of snowboarding, there weren’t any rules. I learned and could compete and do whatever I wanted. I was able to get sponsors and travel around”* (Keir et al., 2018, p. 743). *“I haven’t achieved all of my dreams yet and that is very important to me, as I constantly feel that the clock is ticking there is still a lot to do”* (Overgaard et al., 2013, pg. 193).

	Optimism	*"I was not worried about the disease; I was hopeful for the recovery. I even did not think about the physical limitations that will be stopping me in daily routine functioning. And I even do not care about the comorbidity that the heart disease can affect the kidney, lungs or others*" (Yasseen et al., 2023, p. 1599). *"My emotional reaction towards the disease was positive. Because I have seen many people surviving a healthy life after the treatment of the disease. The plus point of mine being optimistic is, I was sure that the disease is curable. I was not fearful about the disease and also, I did not feel death anxiety. While I was suffering from the disease at the initial level my parents encouraged me to cope with the disease, no need of worrying because the disease is curable, you will be alright with the passage of the. So, I also motivated myself and even do not think of death. Due to SVD I will die"*. (Yasseen et al., 2023, p. 1599). *"Every time I've survived a surgery; it's been a victory. My biggest strength is my will to survive."* (Overgaard et al., 2013, p. 193).
Living with uncertainty.	Pregnancy and having children.	*"It is rather, what if I were to start a new generation and all of them should have it and it spreads out. Yes, that's more what I'm concerned about. It is more that, than the fact that I have it."* (Andersen et al., 2008, p. 493). "*And I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt and all those things (...) you know you have a life today and you can in a way survive. (...) When you think about having a child, it is very frustrating not to get a clear answer as to whether you might die or not (...). If I choose to take the risk, because it is a hard burden on the heart, it is entirely up to me. No one can say whether it will work out well or not."* (Andersen et al., 2008, p 494). *"I've decided that I want a child; whether it costs me my life or not, I will take that risk."* (Overgaard et al., 2013, p. 193).

	Future and life expectancy.	*“.. I think it’s more like when you think about the future and that you have had a transplant...that you might not be able to think about the future like everybody else...you know that a transplant is not a solution for life...I mean...I will live with it as long as I live but it’s probably not something that will make me have a normal long life...but on the other hand no one can say for sure... I mean...I’m one of those it’s gone very well for... “(*Berghammer et al., 2006, p. 344). *“I don’t know much about the future; I don’t really think that I’ll live until I’m very old . . . I don’t think about it that often but when someone with a heart defect dies (someone I know) then I am kind of reminded about death, that it might be my turn next . . . We’re sitting in the same boat, so to speak. It worries me or I feel a little afraid of it, afraid that I probably also need another operation…”* (Berghammer et al., 2015, p. 408). “*And maybe in the back of my head there’s a little concern about how long it will hold out, whether it will last a lifetime. But that’s how it is…”* (Berghammer et al., 2015, p. 408). “*You may not make it into adulthood or far into adulthood ... Every time they operated was to prolong life, but you were never guaranteed, just kind of depended what science brought”* (Cornett & Simms, 2014, p. 398). “*Now that I have kids, I think about ‘will I be able to see them grow up, will I be able to see them get married?’ I've tried to make better choices”* (Steiner et al., 2021, p. 3). “I do make plans and that sort of thing, but I don’t dare to carry them out. Now I understand that ... I must start something independently ... but I’m scared, because ... you start to think how it is going to be 10 years from now if I make that

		decision now .... I want to make lots of plans but making an important decision ... I do not dare make." (Claessens et al., 2005, pg. 7).
	Prognosis and future health problems.	*"I was angry at not being warned, it was the fear of it happening again, and I know it could happen again ... It's the not knowing I can't deal with."* (Cornett & Simms, 2014, p. 398). *"There is a sense of being out of control ... I can control everything else, well as far as possible ... there is something in that ... it's out of my control when it's going to go downhill and I hate that, I hate that". (*Cornett & Simms, 2014, p. 398). "*My emotional reactions towards the CHD were negative while I was diagnosed as right ventricular hypertrophy. And negative thoughts hits in my mind whether it will be treated or not. I went through depression because of this disease that what I am going to do with my life*" (Yasseen et al., 2023, p. 1598). "*I was worried about the disease; I was fearful for the recovery and the level of death anxiety enhanced. I was totally concerned about the physical limitations that will be stopping me in daily routine functioning. And I was afraid of the comorbidity of other physical or psychological disease/disorder*" (Yasseen et al., 2023, p.1599).
Fear of being negatively judged by others.	Worry about the reactions of others.	*"...You said that you don't want to tell people about the heart disease when you first meet them ...why is that? I think it's better if people form their own opinion about me first, instead of telling the person about it before... otherwise they form another opinion...If you had told them, do you think they would have treated you differently? Yes, definitely...Are you afraid of getting treated differently? Yes, I am... you want to be treated like everybody else and not be seen as different."* (Berghammer et al., 2006, p. 342-3).

	Reluctance to tell.	*"...you are forced to explain sometimes...yes...and…. even my friends who know about my congenital heart disease...forget...they think it's strange when I can't manage different things just because...I don't know... it can't be seen on the outside..."* (Berghammer et al., 2006, p. 343). *"You don't know how people will react to you ... I'm pretty sort of cagey ... I don't have the confidence to build relationships"* (Cornett & Simms, 2014, p. 401). *"I felt like, I tell you, you won't want to hang out with me anymore"* (Cornett & Simms, 2014, p. 401). *"I wouldn't share it willy-nilly because people can be very judgmental"* (Cornett & Simms, 2014, p. 400). "*I used to tell different people different things about the scar all the time—but never the truth…. I don't know, I guess you don't want people to know there's something wrong."* (Keir et al., 2018, p. 743). "*that scar was there every single day, and I saw it every single day, and I tried to hide it every single day"* (Steiner et al., 2021, p. 2). *"I noticed that when meeting new people, suddenly my problem came into my mind, that is that with the valve, when one is particularly excited the person close to you can perceive it, so my problem was that capacity the other had to understand…when I used to like someone it used to stop me, that is I had some hesitation and I used to tell myself, how do I deal with this thing?"* (Callus et al., 2013, p. 235).

Traumatic experiences.	Upsetting comments from others.	“*Once a woman who was with a girl, who was about 20 years old, held me from my arm while I was going down from the ladder (to the sea) and she said, Come up look what a violet mouth you have, if you feel bad it will be my problem!....and all the people were looking, for me it was a trauma.*” (Callus et al., 2013, p. 235). “*Once, when I was working in the ICU, I got a very rude comment from one of the nurses there. He said the following: there is blue, bluer, and bluest ... and then you have [name of the girl interviewed]. That was really horrible.”* (Claessens et al., 2005, p. 8).
	Hospital experiences.	*“I was terrified, I was practically unconscious, all these voices … I could hear mum and dad crying and the priest was there, it was frightening, extremely frightening ... there still is that fear that it could happen again ... you know the fear is terrible”.* (Cornett & Simms, 2014, p. 399). “*It was classed as Post Traumatic Stress ... It’s the trauma you go through”* (Cornett & Simms, 2014, p. 399). *“She passed away, pretty much as I was talking to her … I remember everyone running in and my bed kind of got pushed to the side and I got taken out of the room. I was 7. So that was a pretty awful memory.” (*Keir et al., 2018, p. 744). *“It was not a pleasant time. I felt lonely. I felt abused, because all of the needles, all of the tests. And I just wanted to get out of there.*” (Keir et al., 2018, p. 744). *“I felt like I had no voice … No, nobody discussed it with me. So, I was four, woke up on the table from my first cath, and that’s when I … like, my last cath was at thirteen and from then to when I was legally allowed to take over my own health care, at sixteen, when you can tell your parents not to come in for appointments.*

		That's when I said, "No more caths" because at four, that was very traumatic." (Keir et al., 2018, p. 744). *"I came home, and I couldn't walk, and I had the Betadine all on my legs. I remember my mom putting me in the tub. Now I hate tub baths because of the, in my head, the vision of the orange coming off. I can't do tub baths."* (Keir et al., 2018, p .744).

Appendix F

Table 4. Prevalence of Analytical and Descriptive Themes Across Studies.

Study ID	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
First Author and Year	**Yaseen et al. (2023)**	**Steiner et al. (2021)**	**Anderson et al. (2008)**	**Berghammer et al. (2006)**	**Berghammer et al. (2015)**	**Overgaard et al. (2013)**	**Keir et al. (2018)**	**Callus et al. (2013)**	**Claessens et al. (2005)**	**Cornett et al. (2014)**
Analytical Theme 1										
Determination to live a “normal” life.			x	x	x	x				x
Descriptive Themes										
Denial/refusal to see oneself as unwell.			x	x	x					x
Not letting it control me.					x	x				
Analytical Theme 2										
Feeling Different.	x	x				x	x	x	x	x
Descriptive Themes										
Experiences of being bullied and excluded.	x	x				x	x		x	x
Internalisation of negative feelings about oneself.		x					x	x		x
Analytical Theme 3										
Positive Outlooks	x	x	x		x	x	x	x		x
Descriptive Themes										
Inner strength and maturity.					x	x		x		
Part of Me.		x			x					
Greater appreciation of life.			x		x	x				x
Motivation to achieve goals.		x				x	x			
Optimism.	x					x				
Analytical Theme 4										
Living with uncertainty.	x	x	x	x	x	x			x	x
Descriptive Themes										
Pregnancy and having children.			x			x				

Study ID	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
First Author and Year	**Yaseen et al. (2023)**	**Steiner et al. (2021)**	**Anderson et al. (2008)**	**Berghammer et al. (2006)**	**Berghammer et al. (2015)**	**Overgaard et al. (2013)**	**Keir et al. (2018)**	**Callus et al. (2013)**	**Claessens et al. (2005)**	**Cornett et al. (2014)**
Future and life expectancy.		x		x	x	x			x	
Prognosis and future health problems.	x									x
Analytical Theme 5										
Fear of being negatively judged by others.		x		x			x	x		x
Descriptive Themes										
Worry about the reactions of others.				x						x
Reluctance to tell.		x					x	x		x
Analytical Theme 6										
Traumatic memories.							x	x	x	x
Descriptive Themes										
Upsetting comments from others.								x	x	
Hospital experiences.							x			x

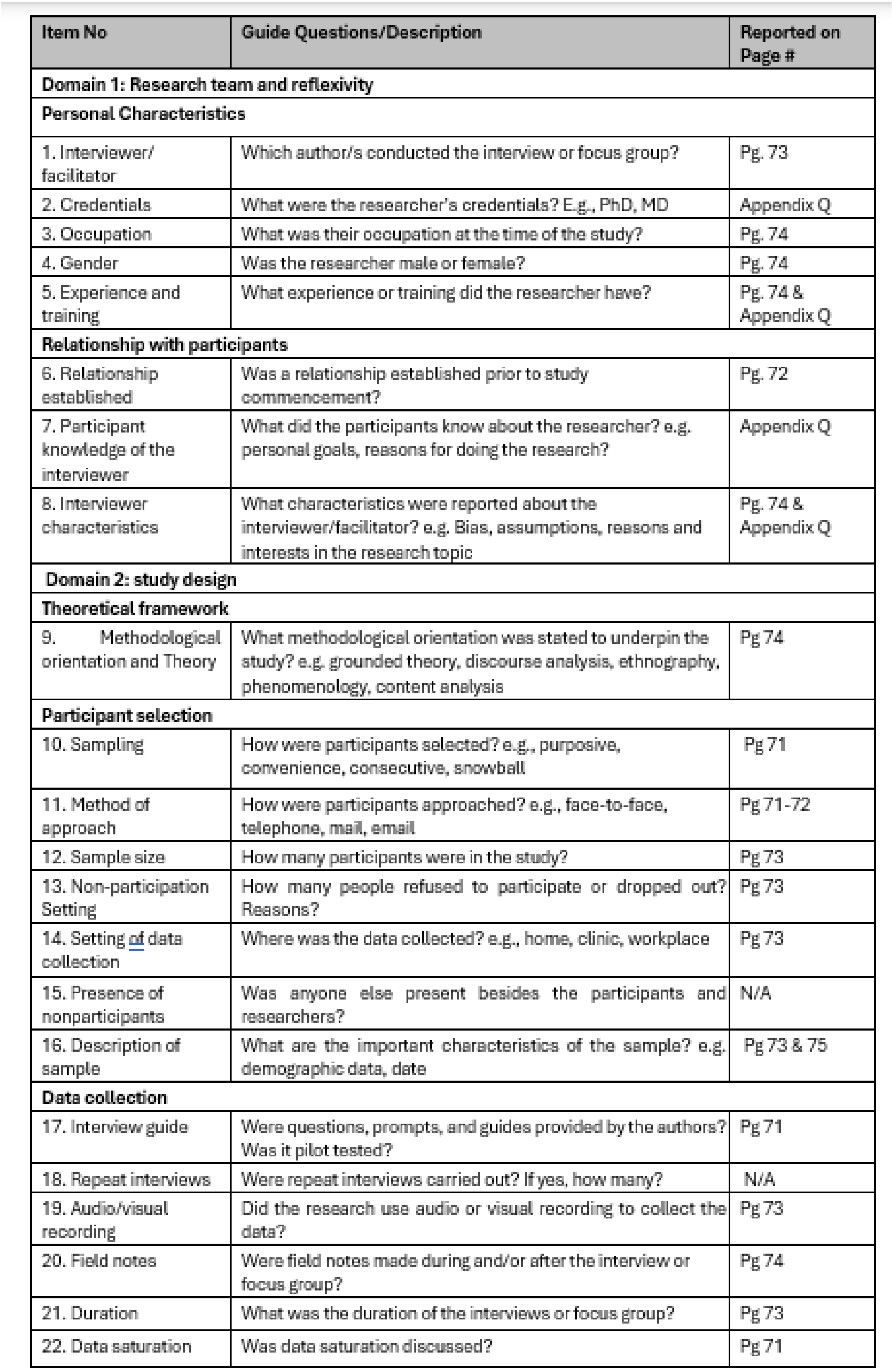
Appendix G
Ethical Approval Letter

Ethical Approval Letter removed due to confidentiality issues.

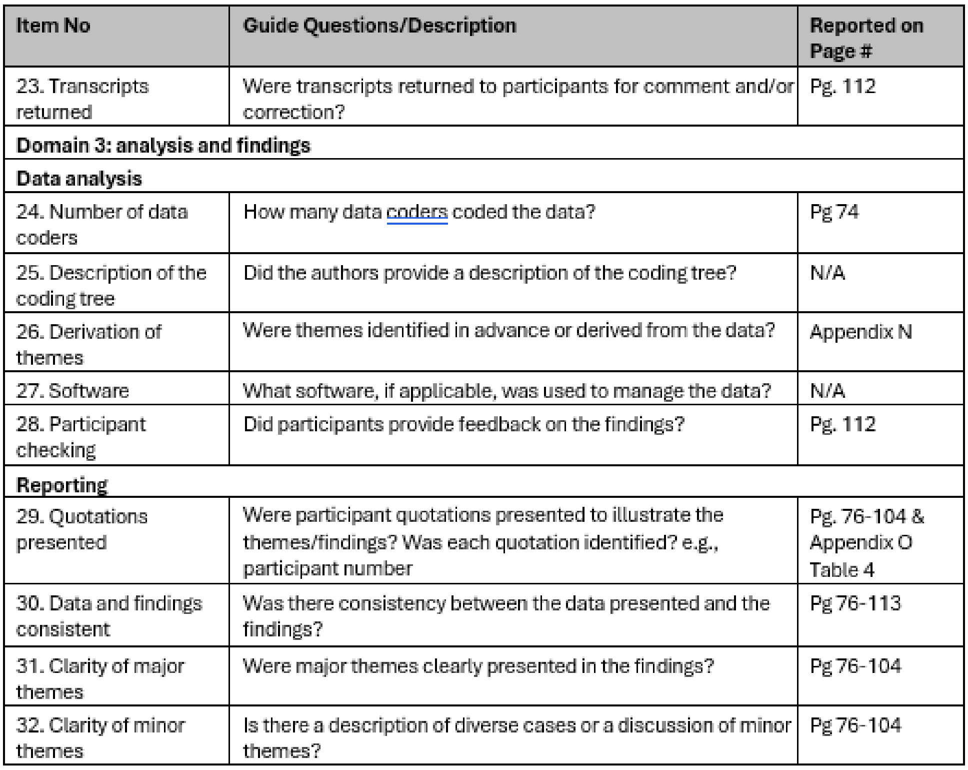
Appendix H
NHS Golden Jubilee Health Board Management Approval Letter

NHS Golden Jubilee Health Board Management Approval Letter removed due to confidentiality issues.

Appendix I
Completed Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32-item checklist.



Item No	Guide Questions/Description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Pg. 73
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	Appendix Q
3. Occupation	What was their occupation at the time of the study?	Pg. 74
4. Gender	Was the researcher male or female?	Pg. 74
5. Experience and training	What experience or training did the researcher have?	Pg. 74 & Appendix Q
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Pg. 72
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?	Appendix Q
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg. 74 & Appendix Q
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 74
Participant selection		
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	Pg 71
11. Method of approach	How were participants approached? e.g., face-to-face, telephone, mail, email	Pg 71-72
12. Sample size	How many participants were in the study?	Pg 73
13. Non-participation Setting	How many people refused to participate or dropped out? Reasons?	Pg 73
14. Setting of data collection	Where was the data collected? e.g., home, clinic, workplace	Pg 73
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Pg 73 & 75
Data collection		
17. Interview guide	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	Pg 71
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Pg 73
20. Field notes	Were field notes made during and/or after the interview or focus group?	Pg 74
21. Duration	What was the duration of the interviews or focus group?	Pg 73
22. Data saturation	Was data saturation discussed?	Pg 71



Item No	**Guide Questions/Description**	**Reported on Page #**
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Pg. 112
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Pg 74
25. Description of the coding tree	Did the authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Appendix N
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	Pg. 112
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	Pg. 76-104 & Appendix O Table 4
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pg 76-113
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pg 76-104
32. Clarity of minor themes	Is there a description of diverse cases or a discussion of minor themes?	Pg 76-104

Appendix J

Interview Topic Guide

Weblink: https://osf.io/p5xm6

Appendix K

Participant Information Sheet

Weblink: https://osf.io/64x8b

Appendix L

Participant Consent Form

Weblink: https://osf.io/m3zpu

Appendix M

Participant Demographic Information Form

Weblink: https://osf.io/w3m7e

Appendix N

IPA Data Analysis Plan

Weblink: https://osf.io/mcuk6

Appendix O

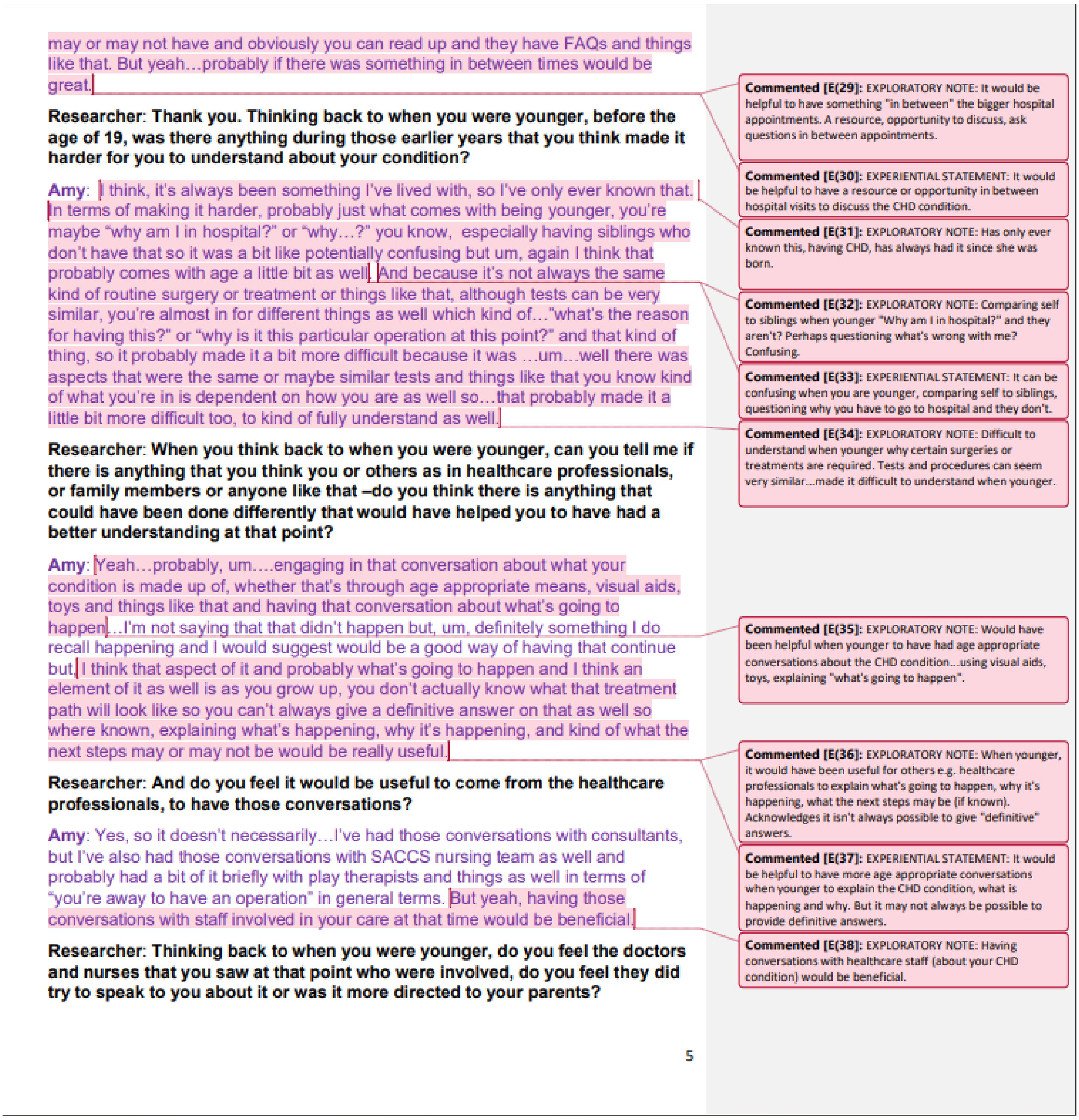
Detailed IPA Data Analysis Process

Examples of:

Step 1: Reading and re-reading transcript.

Step 2: Exploratory noting (Amy).

Step 3: Constructing experiential statements (Amy).



may or may not have and obviously you can read up and they have FAQs and things like that. But yeah…probably if there was something in between times would be great.

Researcher: Thank you. Thinking back to when you were younger, before the age of 19, was there anything during those earlier years that you think made it harder for you to understand about your condition?

Amy: I think, it's always been something I've lived with, so I've only ever known that. In terms of making it harder, probably just what comes with being younger, you're maybe "why am I in hospital?" or "why…?" you know, especially having siblings who don't have that so it was a bit like potentially confusing but um, again I think that probably comes with age a little bit as well. And because it's not always the same kind of routine surgery or treatment or things like that, although tests can be very similar, you're almost in for different things as well which kind of…"what's the reason for having this?" or "why is it this particular operation at this point?" and that kind of thing, so it probably made it a bit more difficult because it was …um…well there was aspects that were the same or maybe similar tests and things like that you know kind of what you're in is dependent on how you are as well so…that probably made it a little bit more difficult too, to kind of fully understand as well.

Researcher: When you think back to when you were younger, can you tell me if there is anything that you think you or others as in healthcare professionals, or family members or anyone like that –do you think there is anything that could have been done differently that would have helped you to have had a better understanding at that point?

Amy: Yeah…probably, um….engaging in that conversation about what your condition is made up of, whether that's through age appropriate means, visual aids, toys and things like that and having that conversation about what's going to happen…I'm not saying that that didn't happen but, um, definitely something I do recall happening and I would suggest would be a good way of having that continue but. I think that aspect of it and probably what's going to happen and I think an element of it as well is as you grow up, you don't actually know what that treatment path will look like so you can't always give a definitive answer on that as well so where known, explaining what's happening, why it's happening, and kind of what the next steps may or may not be would be really useful.

Researcher: And do you feel it would be useful to come from the healthcare professionals, to have those conversations?

Amy: Yes, so it doesn't necessarily…I've had those conversations with consultants, but I've also had those conversations with SACCS nursing team as well and probably had a bit of it briefly with play therapists and things as well in terms of "you're away to have an operation" in general terms. But yeah, having those conversations with staff involved in your care at that time would be beneficial.

Researcher: Thinking back to when you were younger, do you feel the doctors and nurses that you saw at that point who were involved, do you feel they did try to speak to you about it or was it more directed to your parents?

5

Commented [E(29]: EXPLORATORY NOTE: It would be helpful to have something "in between" the bigger hospital appointments. A resource, opportunity to discuss, ask questions in between appointments.

Commented [E(30]: EXPERIENTIAL STATEMENT: It would be helpful to have a resource or opportunity in between hospital visits to discuss the CHD condition.

Commented [E(31]: EXPLORATORY NOTE: Has only ever known this, having CHD, has always had it since she was born.

Commented [E(32]: EXPLORATORY NOTE: Comparing self to siblings when younger "Why am I in hospital?" and they aren't? Perhaps questioning what's wrong with me? Confusing.

Commented [E(33]: EXPERIENTIAL STATEMENT: It can be confusing when you are younger, comparing self to siblings, questioning why you have to go to hospital and they don't.

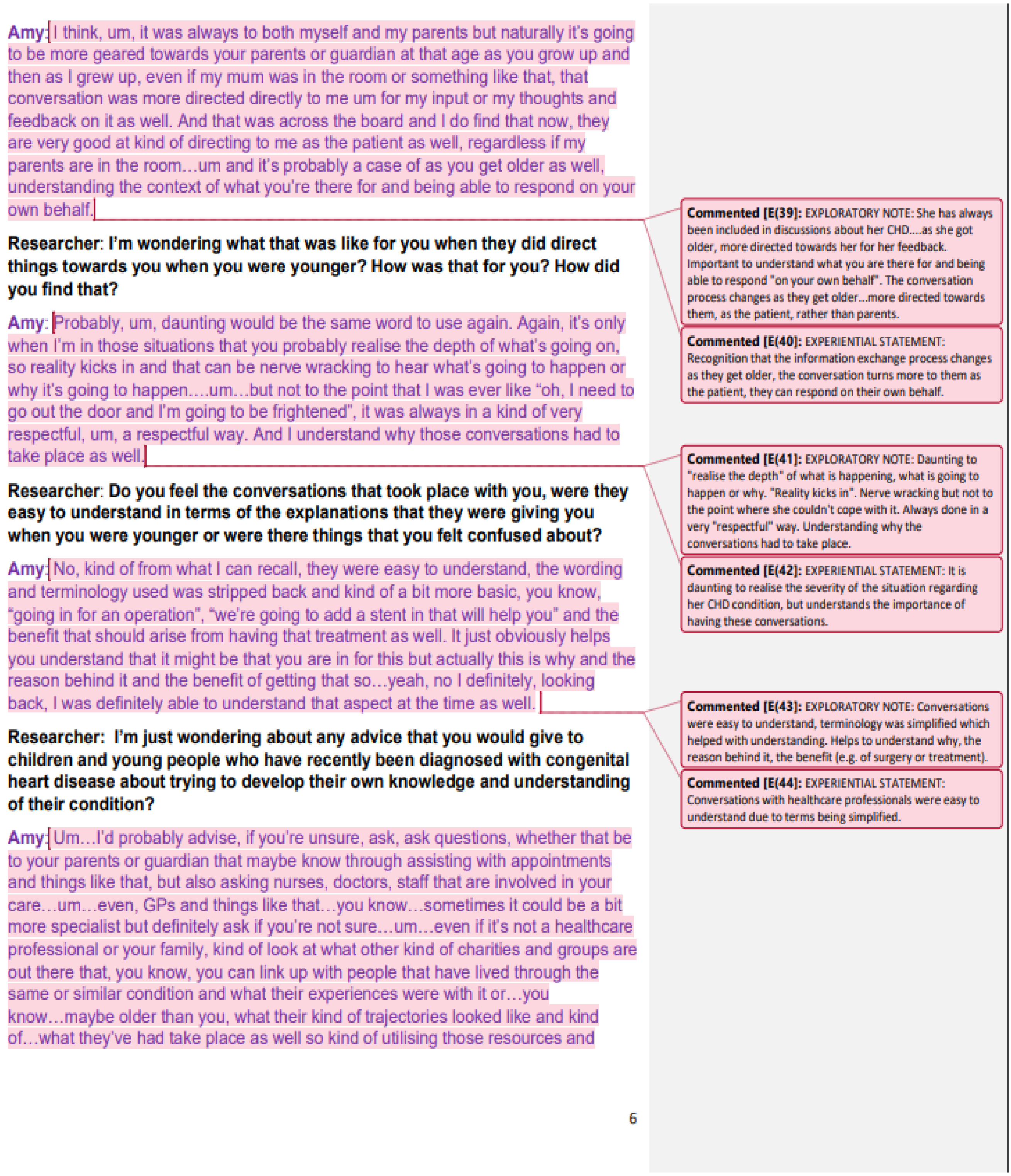
Commented [E(34]: EXPLORATORY NOTE: Difficult to understand when younger why certain surgeries or treatments are required. Tests and procedures can seem very similar…made it difficult to understand when younger.

Commented [E(35]: EXPLORATORY NOTE: Would have been helpful when younger to have had age appropriate conversations about the CHD condition…using visual aids, toys, explaining "what's going to happen".

Commented [E(36]: EXPLORATORY NOTE: When younger, it would have been useful for others e.g. healthcare professionals to explain what's going to happen, why it's happening, what the next steps may be (if known). Acknowledges it isn't always possible to give "definitive" answers.

Commented [E(37]: EXPERIENTIAL STATEMENT: It would be helpful to have more age appropriate conversations when younger to explain the CHD condition, what is happening and why. But it may not always be possible to provide definitive answers.

Commented [E(38]: EXPLORATORY NOTE: Having conversations with healthcare staff (about your CHD condition) would be beneficial.



Amy: I think, um, it was always to both myself and my parents but naturally it's going to be more geared towards your parents or guardian at that age as you grow up and then as I grew up, even if my mum was in the room or something like that, that conversation was more directed directly to me um for my input or my thoughts and feedback on it as well. And that was across the board and I do find that now, they are very good at kind of directing to me as the patient as well, regardless if my parents are in the room…um and it's probably a case of as you get older as well, understanding the context of what you're there for and being able to respond on your own behalf.

Commented [E(39]: EXPLORATORY NOTE: She has always been included in discussions about her CHD….as she got older, more directed towards her for her feedback. Important to understand what you are there for and being able to respond "on your own behalf". The conversation process changes as they get older…more directed towards them, as the patient, rather than parents.

Commented [E(40]: EXPERIENTIAL STATEMENT: Recognition that the information exchange process changes as they get older, the conversation turns more to them as the patient, they can respond on their own behalf.

Researcher: I'm wondering what that was like for you when they did direct things towards you when you were younger? How was that for you? How did you find that?

Amy: Probably, um, daunting would be the same word to use again. Again, it's only when I'm in those situations that you probably realise the depth of what's going on, so reality kicks in and that can be nerve wracking to hear what's going to happen or why it's going to happen….um…but not to the point that I was ever like "oh, I need to go out the door and I'm going to be frightened", it was always in a kind of very respectful, um, a respectful way. And I understand why those conversations had to take place as well.

Commented [E(41]: EXPLORATORY NOTE: Daunting to "realise the depth" of what is happening, what is going to happen or why. "Reality kicks in". Nerve wracking but not to the point where she couldn't cope with it. Always done in a very "respectful" way. Understanding why the conversations had to take place.

Commented [E(42]: EXPERIENTIAL STATEMENT: It is daunting to realise the severity of the situation regarding her CHD condition, but understands the importance of having these conversations.

Researcher: Do you feel the conversations that took place with you, were they easy to understand in terms of the explanations that they were giving you when you were younger or were there things that you felt confused about?

Amy: No, kind of from what I can recall, they were easy to understand, the wording and terminology used was stripped back and kind of a bit more basic, you know, "going in for an operation", "we're going to add a stent in that will help you" and the benefit that should arise from having that treatment as well. It just obviously helps you understand that it might be that you are in for this but actually this is why and the reason behind it and the benefit of getting that so…yeah, no I definitely, looking back, I was definitely able to understand that aspect at the time as well.

Commented [E(43]: EXPLORATORY NOTE: Conversations were easy to understand, terminology was simplified which helped with understanding. Helps to understand why, the reason behind it, the benefit (e.g. of surgery or treatment).

Commented [E(44]: EXPERIENTIAL STATEMENT: Conversations with healthcare professionals were easy to understand due to terms being simplified.

Researcher: I'm just wondering about any advice that you would give to children and young people who have recently been diagnosed with congenital heart disease about trying to develop their own knowledge and understanding of their condition?

Amy: Um…I'd probably advise, if you're unsure, ask, ask questions, whether that be to your parents or guardian that maybe know through assisting with appointments and things like that, but also asking nurses, doctors, staff that are involved in your care…um…even, GPs and things like that…you know…sometimes it could be a bit more specialist but definitely ask if you're not sure…um…even if it's not a healthcare professional or your family, kind of look at what other kind of charities and groups are out there that, you know, you can link up with people that have lived through the same or similar condition and what their experiences were with it or…you know…maybe older than you, what their kind of trajectories looked like and kind of…what they've had take place as well so kind of utilising those resources and

Example of Step 4: Searching for connections across experiential statements (Amy).

Weblink: https://osf.io/ct4rq

Example of Step 5: Naming the Personal Experiential Themes (PETS) and Consolidating and Organising them (Amy).

Weblink: https://osf.io/ptx3w

Example of Step 7: Working with PETS to Develop Group Experiential Themes (GETS) Across Cases

Weblink: https://osf.io/cfgy7   (& see Table 4 below)

Table 4

Group Experiential Themes (GETs), Sub-themes, and Supporting quotations.

Group Experiential Themes (GETs)	Subthemes	Quotations
Current Knowledge and Understanding.	Knowing the important aspects.	*“I feel quite comfortable that I understand it”* (*Amy, p. 2).* *“…. I don’t know if I get all the terminology correct, but I at least know what’s going on when I go into the hospital to get procedures done…so, I feel I’ve got a good understanding of what’s going to happen or what could happen in the future…um… so, yeah, that’s pretty much it. I believe I have a good understanding of what I have” (George, p. 2).* *“…it’s quite high…. I’ve been living with it literally my whole life. When you have something like this, you learn up about it a lot because it has a big part of your life, so you need to know about it. “(Max, p 2).* *“…I’d say I’ve got a pretty good knowledge of it and understanding.” (Ruth, p. 2).* *“I have an understanding of what like…what it means for me. Medically, I don’t understand all of the ins and outs of it, but I feel I understand what’s important for me to know.” (Tanya, p. 2).* *“Yeah, I’d say like in terms of if I’m having to explain it to my friends and family, um…I know the basic things that they need to know if something was to go wrong with me, if I was to take unwell….I’d say it’s just the basics that I know so it’s quite hard like…to show awareness if that makes sense…” (Poppy, p. 2).* *“…there’s a point where you don’t actually need to know as much as the doctor. You need to know you’ve got a condition; you need to know how to name it, you need to know how severe it is and the medication and stuff but the actual mechanics of it… is more needed for the doctor.” (Max, p. 6).*

		"…So, it's helpful to have a basic understanding. But I don't think they would ask you to explain the ins and outs of it. I hope they wouldn't because I wouldn't do very well with that [laughs softly] But I suppose they could." (Tanya, p. 7).
	Complexity.	*"…whenever I go into a GP or just an average hospital that's not like the Jubilee, I need always to explain my condition to the doctors. Especially the fact that you normally go in and you see a Junior Doctor and they go "What the hell is this?" and I have to be the one to tell them about it [laughs softly] … (Max, p. 2).* *"…because anyone who's not a cardiologist who looks at the heart, you just think "Oh my goodness", you know, there's so much to it, it's not just the four chambers that you learn about in school…there's loads to it… (Ruth, p.3).* *"It's just a lot of big Latin words that don't…necessarily mean a lot to you. And I've done higher human biology so I have a basic understanding of how the heart works, but I can imagine if you don't then that would…it would all mean nothing to you…" (Tanya, p.2).*
	Curiosity.	*"…I've always been curious, I always ask questions any way, I like to know how things work."* (Max, p.2). *"As a curious person, I would love to know, so every time I get told the information I'm like "oh, this is so interesting!" I really am interested in it, and I like learning about that sort of thing and its implications and…the research, I like it. It's important to me mostly just because I like to understand what's going on with my body…" (Tanya, p. 7).* *"Just that having an understanding is definitely something I'm glad I have an understanding of now and I'll continue to want to learn about as well*

		and…yeah, as treatments go on, make sure I fully understand what's happening and help me better advocate for myself too." (Amy, p. 11).
Pros and Cons of Knowing.	Explaining to others.	"*Explaining it to other people out with the hospital setting so having a knowledge and understanding enables me to kind of highlight at a top level the reasons why I may not be so fit and able as others to do certain things in situations…"* (Amy, p.10). "*It's good to know….because I can explain to people what's wrong and not look silly in a sense…it's really good to know and I know why I can't do that thing in my life, like I know why I can't lift more than my body weight because it puts strain on my heart muscle and my blood pressure rises… it's one of those things where it's kind of handy to have because you can just tell them exactly what you have …so if anything did happen, they can relay that to paramedics or if I am unconscious, they can relay that to other people. So, it's handy to know what I have so I can tell other people, for that reason."* (George, p. 3). *"…it was handy to tell my employer so it doesn't seem like I am skiving off work in a sense….for instance I have to get my teeth checked every 4 months instead of every year, so my employer was like "why are you always off?" and I explained to him that teeth infection is really bad for me because it will destroy my heart and the scar tissue in my heart…. so, in cases like that, it's handy to know, why, the reason of it is, so now my employer understands…."* (George, p. 3-4). "*Yeah, I would've told the people that obviously I had a good relationship with because otherwise I would have been quite private but yeah, it just meant…it might sound really stupid but if I was doing some adventurous hike or something and everyone would always know if I was like "I need a second", they'd be like "Oh, yep, she does need a second to just catch her breath"….because they know why." (Ruth, p. 8).*

		"It is important for instances if I was to take unwell. If I was maybe out with my friends and they didn't know anything about my heart condition maybe that could cause something to go wrong. But if I was unwell and I'm able to tell my friends what's wrong with me, then they can help in instances if I do take unwell." (Poppy, p. 7). *"… I went travelling this summer. I took with me my documents that said everything. So, the doctors, I was like "I'm sorry, they're all in English" and they're like "it's Latin words anyway, we can understand that". But I did things like having to say, "I'm at higher risk of endocarditis; I would need antibiotics pre this operation". So yeah, it was a whole thing. But it's like being able to say to doctors and being able to explain "my ECG looks a little different" … Or "I have low blood pressure, this is normal". I think it's good to have a basic understanding so you can tell your doctors…" (Tanya, p. 7).*
	Health Benefits.	*"…I think the more you understand, the more you can question your treatment and maybe push back or query further, whereas if you don't have the understanding, you maybe can't appreciate…what's being discussed, and it allows you to champion probably for yourself and use your voice as well if you can have at least a decent or basic understanding of your condition and understand maybe the gaps in it or…maybe what you might want to find more information on that might impact you without realising, I think that's really important. The key thing probably is so you can stand up for yourself if needed and you know, question…use your voice to kind of question things you are unsure of …now that you have an understanding of it whether that be ongoing care or operations and things like that as well." (Amy, p. 10).* *"…I've never been involved in drugs because I know that if I ever needed heart surgery, if I take drugs, they're not going to touch me sort of thing…or I've never got tattooed because I know that's a risk to my health or my heart*

		or piercings or anything like that, I just know, because of the understanding I have been given about my condition, I've not done any of those things because it might… hinder my condition even more having that done or doing those things …it wasn't a disappointment because from the get go I've always been told that I can't or maybe if it was a case of I was never told, it would be more of a shock and disappointment, maybe? So having an understanding of it has helped with that sort of thing because I know I can't get that stuff done because it would just be stupid." (George, p. 13). *"…Oh yeah, 100%, for instance, I don't smoke because I know that would be bad, I wouldn't want to anyway but it's a good reminder. I've never taken drugs or anything like that, so it's probably made me change how I've lived or make better decisions in life because I have that excuse. Well…it's not really an excuse it's always in the back of my mind that I have a heart condition, so I better look after yourself. …I don't watch my weight, but I make sure I don't put weight on because I might need to recover from the heart surgery…So I always need to stay fit and healthy, so I am ready for that. Because if I go into heart surgery really overweight and unfit, I know that will really affect my recovery. So, it's always in the back of your mind, you're getting fit and healthy so you're ready for that, but you don't know when it's going to happen and you're all ready for it. If that makes sense." (George, p. 13).* *"…I know what I probably shouldn't do…the good thing about it is because of my heart condition, it's probably made me, hopefully, look after myself a bit more physically because my body needs that little extra help than the average person because it's a little more on the delicate side because of my heart, you know." (Ruth, p. 9).* *"You know the tell-tale signs of when something is up, you know when you're not feeling right…." (Max, p. 7).*

		“…before I went into ventricular tachycardia, I was having palpations for over an hour. If you have it over 5 minutes, you know something is up. Stuff like that is really good. You can phone doctors and say “Look, this is a sign, should I be coming in?” and pretty much giving them better information.” (Max, p. 7). *“…the only thing with knowledge really is the people you live with around you need to know the tell-tale signs of when you’re not well as well. My mum has noticed a few times before I get ill, I go pale white, and I can’t see that, but she can. So, she says that, and she makes sure I’m feeling alright. So, it’s kind of important for people around you to know as well.” (Max, p. 8).* *“…I guess it’s been… good to know because I don’t know, I mean could you imagine someone telling you something’s wrong with you, but then just not telling you what, you’d be like…. that would just be really confusing for you. So, I think, just having like a proper understanding of the seriousness and what it was and how it could affect you in the future if they didn’t do what they were doing, that was a big thing actually. So, I would have MRI scans and things like that and I absolutely, like to this day, absolutely hate them with a passion. Um, but if they didn’t tell me how important it was that I needed to have it, I probably would have just flat out refused because I hate them so much, but I think because they would tell me how like how much it would help them, then of course help me, you know, it just makes it easier for me to get through because I’m like right, this is just an hour of my life, something that could help me for years.” (Ruth, p. 8).*
	Acceptance	*“Yeah, because when I was younger, I knew I would get tired and things. But the older that I’ve gotten, the more I know shortness of breath and chest pains and extreme tiredness and having to take naps and things, I know that’s part of having my heart condition. But when I was younger, I wouldn’t have known that. I just knew that I would maybe get tired running and things like that. But just day to day life. Like walking up the stairs can sometimes*

		knock me back. When I was younger, I just thought "I'm unfit" [laughs softly]. "(Poppy, p. 6). *"I think just I know from my own body if something's wrong, I'll know if it is something to do with my heart. I know to not push myself, because it's not just me being tired or lazy, I know that it's because my heart has maybe been overworked or it's maybe feeling it a bit. So, I can just relax and just give myself a day to rest and that's okay." (Poppy, p. 7).* *"I feel now that, if everything has been explained to me, I feel I can deal with that. I'm like "okay, these are my things, I've had them explained to me, I've had some diagrams, I know that it looks a little different to a normal heart, I know what I need to do to keep myself safe and healthy. I can deal with that". I think the unknown is often also scary. I'm sure once you get over the initial shock of it, I think you're better off knowing, because you can learn to be fine with that." (Tanya, p. 9).* *"…I think just having it my whole life, I've not really given much thought to learning more. Yeah…I think…it's quite a hard thing to look into to see how different you are from other people. I think that can be a barrier. Um…and just kind of knowing that you've got to live with that your whole life. I'd say that's mainly the hardest thing…" (Poppy, p. 2-3).* *"…I just got fed up of the topic and I think as well, it's not nice to think that there was something wrong with you." (Ruth, p. 5).*
	Anxiety	*"…to this day, like a little bit anxious…not just with things to do with my heart, just like physical health, I would always get anxious about because I had a lot going on with my physical health, my whole life. But just being able to know exactly what is wrong and what could affect my health negatively and I would then know if I avoid those things, I don't need to worry and I guess it just….knowing as much as I needed to know reassured me on a day to basis*

		that I was fine and I was looked after by the best people for the job and if there was something they were worried about, they would do something." (Ruth, p. 8-9). *"…I'd rather know what's going to happen than not know and worry about something that might not even happen…" (George, p 2).* *"…I'd say it's better to know than to not. Because if I didn't know and then I suddenly had these horrible chest pains then that would be a lot worse. But I think me knowing that that's just part of having my heart condition. It means I'm not phoning an ambulance all the time and things like that." (Poppy, p. 7).* *"…the phrase "knowledge is power" is coming into my head. I would just prefer to know these things…and that way, you know, eventually, if something does go wrong, that's not a shock to me, because I know which part of my heart has the issue and I know why it's gone wrong. And I'm sure they'll explain it to me again and what they'll do. But it won't be a shock. It's good to know the information before you need to know the information. Because when you need to know the information, you're already dealing with other things. I think it's just, the more you know, the better." (Tanya, p. 8).* *"…the more you know, you can maybe worry about it in a way that if you're pushed to the side…not enough to the point that I wouldn't want to know because of that but yeah certainly that's probably a downside, depending on your situation that can then mean difficult conversations or more treatment and things like that which you could maybe feel a bit anxious about too…. but the good kind of outweighs the bad in that situation." (Amy, p. 11).* *"…Maybe, understanding it, I know the risks and what could go wrong, so maybe that, and then I worry about them sort of thing, so maybe having a good understanding has not helped, like been quite bad because I knew what could go wrong and how it could go wrong and why it could go wrong…*

		so maybe if I was less educated, it might help me mentally…maybe having the understanding makes me worry more because I know what's going to happen. Um…maybe if I didn't know it would be better in a sense because what you don't know doesn't hurt you sort of thing. So, it's between a rock and a hard place where I really want to know what's going on but on the other hand it's like "oh, I've just realised that all this could go wrong" [sarcastic] um…and the side effects of it all. If this does go wrong, it could be quite bad [laughs softly]." (George, p. 14) *"…Some people might scare themselves more, but I think once they've been through the surgeries…they've already got a sense that they are ill [inaudible]I don't know if there is much disadvantage. "(Max, p. 8).* *"I think sometimes it can make me a bit paranoid that something is going to go wrong, and I feel like I'm going to have a heart attack and things like that. It does make me worry sometimes. If I get a chest pain that's slightly different to what I'm used to having, then I get worried. Yeah, that's mainly it." (Poppy, p. 7).* *"I guess if you're the type of person…which I definitely was when I was 17, or if you've been newly diagnosed. If you get a lot of information thrown at you, that's really overwhelming. And also, it opens your mind to "oh my god, this specific part of my heart isn't working properly, that's horrible!!!" I guess, over thinking about it is always a possibility…" (Tanya, p. 8).*
Experiences of Learning About Their Condition.	Knowledge and Awareness in Childhood.	*"…In terms of making it harder, probably just what comes with being younger, you're maybe "why am I in hospital?" or "why…?" you know, especially having siblings who don't have that so it was a bit like potentially confusing but um, again I think that probably comes with age a little bit as well…" (Amy, p. 5).*

		“”what’s the reason for having this?” or “why is it this particular operation at this point?” and that kind of thing, so it probably made it a bit more difficult because it was …um…well there was aspects that were the same or maybe similar tests and things like that you know kind of what you’re in is dependent on how you are as well so…that probably made it a little bit more difficult too, to kind of fully understand as well. “(Amy, p. 5) *“…I always had questions about “why I was going to hospital sort of thing?” so they would always explain “oh, you’re away to get your heart checked.” …because you have a leaky valve. I was always told I had a leaky valve but never really told how bad it was…I was just always told it was leaky, and it could become more leaky…I always thought I had an understanding… (George, p. 6).* *“Well, you know you’re no well. Back then, I was blue, up until my 7th surgery I was literally the colour blue. You don’t ask too many questions, you’re a kid, you don’t really understand that you’re meant to be healthy, you’re meant to be well. You’re no meant to be like this.” (Max, p. 3).* *“Yeah, so when I was younger, I didn’t really know anything about it. I knew that I had a heart condition. And I remember lots of people would ask me “What heart condition do you have?” and I just looked to my mum and dad and be like “they know, they can tell you” …I would say only in recent years I actually remember what it’s called because it’s quite a complicated name. Even when I was in Primary School, I would just say “Oh, I’ve got a heart condition” but I wouldn’t go into detail. I would maybe say “Oh, I’ve got a hole in my heart” and things like that, but that’s really it…I wouldn’t have known much.” (Poppy, p. 3).* *“So, when I was explaining it, I would always explain it as “oh, I have a hole in my heart”, which I think was a bit of a dramatic way of explaining it actually. But that’s what people told me and that’s what I told other kids in the*

		playground, if they asked. Which was probably fine…but…that was still my understanding well into my teens I think…" (Tanya, p. 4). *"…if I ever had any questions, it always got explained to me…um…and…. maybe at a younger age I didn't know what to ask? Um….so, what I didn't know didn't hurt me sort of thing. Just later on in life, I always had questions and as I grew up and went to the adult side, everything was always explained. So, everything has been pretty spot on to be fair. (George, P. 6).* *"…I was just a wean, I was just being a wean. When I went in for surgeries and stuff like that, I didn't fully know what was going on, I just went." (Max, pg. 3).* *"…I think any kid is not going to think about it. They don't know about life and stuff like that yet, they just go on with it. I don't think any kid's going to think about it or worry about it." (Max, p. 4).* *"…But also, until they're a bit older, you really don't need to bombard them with these facts, they don't need it." (Max, p. 4).* *"…when they're young, don't wrap them in cotton wool, let them go and live, don't tell them about the scary facts, wait until they're a bit older. Again, as long as the parents learn the information, the kids don't need to until they are a bit older. Once they start moving to the adult hospital, that's when they need to know. "(Max, p. 5).* *"...you could shoot all these facts at a kid and they're not going to remember them, you're just going to scare them so what's the point? You need to inform the parents; you don't need to inform the kids." (Max, p. 5).* *"…when they're young, don't wrap them in cotton wool, let them go and live…" (Max, p. 5).*

		"…I think they just told me what I needed to know. But they never really warned me that there could be a possibility that I could need an operation when I was older, which I think they probably would have known because there were signs, but I think they must have thought there's no point in telling her and scaring her…they'd rather just tackle that when I actually needed it. So…I don't know, I can't say whether they should have told me sooner because I guess… when I was younger, I wouldn't have really understood what they were saying to me anyway." (Ruth, p 3). *"Yeah definitely, it would have been helpful to have probably more of that knowledge earlier on as well, as I say it was probably only in the last 5-6 years and even then, 19 is more than old enough for me to have probably understood that it could have taken place earlier as well." (Amy, p. 11).* *"…And I kind of feel like…maybe it would have been better if the explaining of it had started younger with my child doctor to me." (Tanya, p. 4).* *"….in terms of the conversations with my specialist every year growing up, it would have been good to have more of a "would you like to know about this? I can tell you a little bit?" [child friendly voice], that sort of thing. Because I think if they'd asked "would you like to know about this? Can I give you a leaflet? Or would you like to see a picture of what your heart looks like?" I would have jumped at the chance." (Tanya, p. 6).* *"Even things like, going to school, and sharing that, obviously the school would be aware of that condition, um or that I have that condition, but kind of raising awareness in between about what my limitations are, particularly with [voice breaking]…..things around…..kind of….PE and things like that… …because at times, otherwise you look quite healthy and things like that, it can end up being misunderstood or kind of patted down a little bit, the severity of that situation [voice breaking]… (Amy, p. 8).*

		"I just think it would have made me feel more comfortable and would have had less of a shock factor when I was 17 and figuring it all out for the first time…" (Tanya, p. 4). *"…I just think for preventing it from not being a positive experience when you get to be an adult and you have to understand it, it's better to start earlier." (Tanya, p. 5).* *"…Mainly just for those around me, it would have been good for me to have been able to tell my friends and things what's wrong with me when I was younger, but then again when you're younger you don't really need to know those things…" (Poppy, p. 3).* *"…Maybe my friends didn't really think about things. Like, if I was tired and things they would just think "Oh, she's just lazy or she's just unfit and things. So, if I maybe had enough knowledge, I could say, actually, there's something wrong with me here…" (Poppy, p.3).* *"Yeah, I think it is important when you're younger to know what's wrong with you, but also you can help raise awareness from a younger age. Maybe if I had known more, maybe my friends or family round about me would have been able to support me more. But also, there's more children that don't know what's wrong with them if they have a heart condition. So, if they had known more about that then they can tell other people, and more people can know about it. I think it is such a thing that is swept under the rug, heart conditions, because so many people have them. So I think more knowledge, more support would have been good. "(Poppy, p. 3-4).* *"I think just understanding. Because it's hard if I am not feeling well. Like even in school, if I wasn't feeling well, my mum and dad would be like "oh, just stay in school" and things like that. So, I think as well, my wider family, they don't really understand what is actually wrong with me. So, if they had*

		more knowledge as well that I was able to give them, maybe they'd be more supportive and be more aware of when I'm not feeling up for things or if I'm feeling tired or down, that's part of having my heart condition." (Poppy, p. 4).
	Learning about the reality.	*"I think over time, my level of knowledge has got better probably just as I've gotten older and things like that, um…growing up, I probably knew, well I knew I had a heart condition that was from birth…um… I knew that it was to do with my pulmonary valve but probably didn't understand quite the extent or… severity of it until I kind of got older and was involved more in those conversations…" (Amy, p. 2).* *"…It wasn't until I went to the adult hospital, they started explaining everything, it was like…. oh, okay, maybe I was a bit sheltered from what was actually going on, how bad stuff was…" (George, p. 6).* *"Yeah, because at that point, you're actually going to remember it. I don't remember my surgery when I was 7 or any before that. You're going to remember that you need to know more about it. I'd just moved from xxxxxx to Jubilee. It was an adult hospital. Jubilee is very different because there's no visiting times, but depending on the hospital, you might be there yourself" (Max, p.4).* *"…so obviously when I would go with my parents, my mum and dad would often ask questions as well and they'd never ask me to leave or say they didn't want to talk about it because it would upset me…I would say I was a bit more protected from how serious it was when I was younger compared to when I was an adult. Because when I went to the adult clinics, they would tell you a lot more in a much more…what's the word…. not brutal way, but to the point, way. "(Ruth, p. 3).* *"I think sometimes, seeing it in black and white, again, depending on the situation, understanding the severity of it, perhaps, that can be a*

		bit…daunting, but equally, I would rather know than be in the dark about it, um… so I found it interesting, I find it kind of…what I was saying earlier, I like the idea of knowing what my particular situation looks like and set up is like and so, yeah, probably a bit daunting at first, but not in the way it was approached, probably the realisation of the severity and the set up that I have, as well" (Amy, p.4). *"Probably, um, daunting would be the same word to use again. Again, it's only when I'm in those situations that you probably realise the depth of what's going on, so reality kicks in and that can be nerve wracking to hear what's going to happen or why it's going to happen….um…but not to the point that I was ever like "oh, I need to go out the door and I'm going to be frightened", it was always in a kind of very respectful, um, a respectful way. And I understand why those conversations had to take place as well."* *(Amy, p. 6).* *"… it's not until you learn the actual facts…that you realise how…one, lucky you were to be one of the few who actually survived but you actually realise how bad your condition is. It is quite a bit "oh, wow", but you just realise there's nothing to worry about now, because I've had 15 years and yeah there's been hard bits, but you live normal." (Max, p. 5).* *"…there were a few things that they probably most definitely knew would happen when I was older but they just didn't ever really say it and then that's why it was such a shock when I turned 18 and went to my first appointment at the hospital with my heart and they told me more serious things and it really, really…I suffered really badly with anxiety because of it because I was like "oh my gosh, they didn't make it seem as bad as they did once I got there". I think maybe they could have verbally prepared me a bit better by telling me "You are fine, but there are things wrong with your heart" if that makes sense." (Ruth, p. 6).*

		"I truly, fully believed I had this heart condition, I need to be more careful, but never in a million years did I think I'd have to have an operation again, so when they told me when I was 18/19, I just thought…. like…yeah…it just wasn't a very nice moment, at all." (Ruth, p.6). *"…I had one conversation when I first moved to adult cardiology where it sort of felt like there was a lot of information coming at me at once. It was an intake appointment, and they were like "we're going to talk to you about all these things now that you're an adult" …but it was sort of…they suddenly started talking about all the implications and things like that that I'd never heard of before. And what that did was it made me come away and be like "oh, I'm just scared, this feels like this big, impossible thing that I'll never understand, and it has all these implications and I'm never going to be able to manage it and blah de blah de blah". But…. it's sort of calmed down and then year after year there's been no more conversations like that, and it's more just been like "let's just break it down" and that has helped. But it definitely did make me feel a bit scared and like "oh, I'm never going to be able to understand this". "(Tanya, p.3).*
	Negative associations.	*"…my interactions with the hospital are kind of ad hoc, they're kind of routine appointments but you've then got maybe 2 years, maybe even 3 years between appointments…where you're kind of in that environment of discussing and considering your situation. So that kind of gap in between those periods where you're at home, you're not in that hospital environment or in active treatment or having an operation or something like that, probably hinders a wee bit of that and then before you know it, you've had another 3 years where it might be at the point where there is intervention required or something maybe not going so well and then you're suddenly talking about it, um…that then kind of makes it a bigger conversation and maybe actually if it was throughout or additional resources in between would maybe help kind of*

		stage that a bit better as you grow up and things like that as well." (Amy, p. 4). *"I probably learned most about it when I was in hospital and in that kind of environment…but potentially because a lot of the time I've learned about it is when I'm in hospital and potentially when I'm ill or requiring treatment, your association with it then becomes, um…more daunting than actually if you'd kind of had it intervened in your own environment in home or at school and things like that…" (Amy, p.7).* *"I think maybe speaking more about it. I think when I was younger, I'd have my regular hospital appointments…It wasn't something we really focused on until it came to when I had surgeries coming up and things like that. So, I think maybe looking at things more closely and taking it into consideration more. We only really focused on it when it became an issue." (Poppy, p. 4-5).* *"…I think to be honest, once I left, every time I'd go to an appointment, once I'd leave, I would be like "right I don't want to talk about it anymore". I was quite bad for just trying to forget that I had it, which might sound contradictory to what I said before that I thought it made me cool, but I would often not want to talk about it if it was brought up and everyone respected that so…yeah…" (Ruth, p. 5).* *"…we would have been able to compare experiences but in a nice, social way. It would just have allowed me to talk about it positively, rather than only talk about the problems with it, I would have been able to have been like "oh look these people had this experience and that's interesting because I experienced like this" so I just think it would have created more positive connotations around it, rather than negative. Because the only time you ever talk about it is when there's an issue. It would have been nice to have talked about it in a light-hearted way, if that makes sense." (Ruth, p. 11).*

		"…you've only ever been told the things that need changing or the things that need to be better, which I get and understand, but I don't want to constantly talk about what's wrong with my heart, I'd rather talk about how it's cool or it's interesting and how amazing our bodies and hearts are for what we're going through." (Ruth, p 11-12).
	How Learning Occurred.	*"…it's suddenly daunting going into adults perhaps, but I'm quite lucky as well at the Golden jubilee, if you want to have your parent and things as well, too which definitely helps that transition, especially because it is quite a unique set up…um….in terms of…you're kind of with those people throughout your life and things like that as well…" (Amy, p. 10).* *"…it was strange in a sense because it's kind of like, for everyone else going to the dentist with your parents and then the first time you go by yourself, and you have to listen. It was kind of like that, but a bit more serious in a sense because…" (George, p. 5).* *"Everything was pretty good to be fair. Because they still involved my parents in that transition as well. So, my mum still kept coming with me and they'd just ask her, "do you have any questions?" and then if they had any questions, they'd explain it to them as well. Um, so that was kind of good. Um, so everyone was always kept involved" (George, p. 10.)* *"It was good because then I didn't get 101 questions when I came out and phoned them about how it went and if they had questions, they got it explained to them as well in as much detail as they explained to me. Um, so it was good because then I didn't have to relay to them what's going on and timescales and that sort of thing…" (George, p. 10).* *"…it was always to both myself and my parents but naturally it's going to be more geared towards your parents or guardian at that age as you grow up and then as I grew up, even if my mum was in the room or something like that, that conversation was more directed directly to me um for my input or*

		my thoughts and feedback on it as well. And that was across the board and I do find that now, they are very good at kind of directing to me as the patient as well, regardless if my parents are in the room…um and it's probably a case of as you get older as well, understanding the context of what you're there for and being able to respond on your own behalf. " *(Amy, p. 6)* *"…a big one, when I moved from the child surgery to the adults, in the child's one, they talked to my mum and dad about it and I kind of sat in the background. Whereas nowadays, they explain it to me then I have to explain it to my parents, so that's been a fun learning curve [sarcasm] where my mum and dad are asking me all these questions and I'm like "well, I didn't know I had to ask that?!" [sounding exasperated] … (George, p.4).* *"My mum and dad have had it all my life since I was born and understood it all, where I'm kind of just learning all that now. The questions to ask the doctor, what they want to know…" (George, p. 4).* *"…I don't think my doctor when I was a kid, up until the age of 16 was still sort of…she started speaking to me when I was maybe 16, but she was mostly talking to my parents…it kind of just "woosh" went over my head, so I just sat there and let the adults talk about it…" (Tanya, p. 4).* *"…when I was in the child hospital they talked to my parents, now they talk to me so I'm like "Oh, right, I need to kind of listen now" and take on what they're saying and ask them questions to…. look interested [uncertain tone]." I never know what to say as well because they ask you "how are you feeling?" like, well kind of bricking it because I don't know what you're going to say…um…whereas before I could just kind of sit back and my parents would take it all in and then explain to me. Where now I have to explain to them because they're not there…" (George, p. 8-9).*

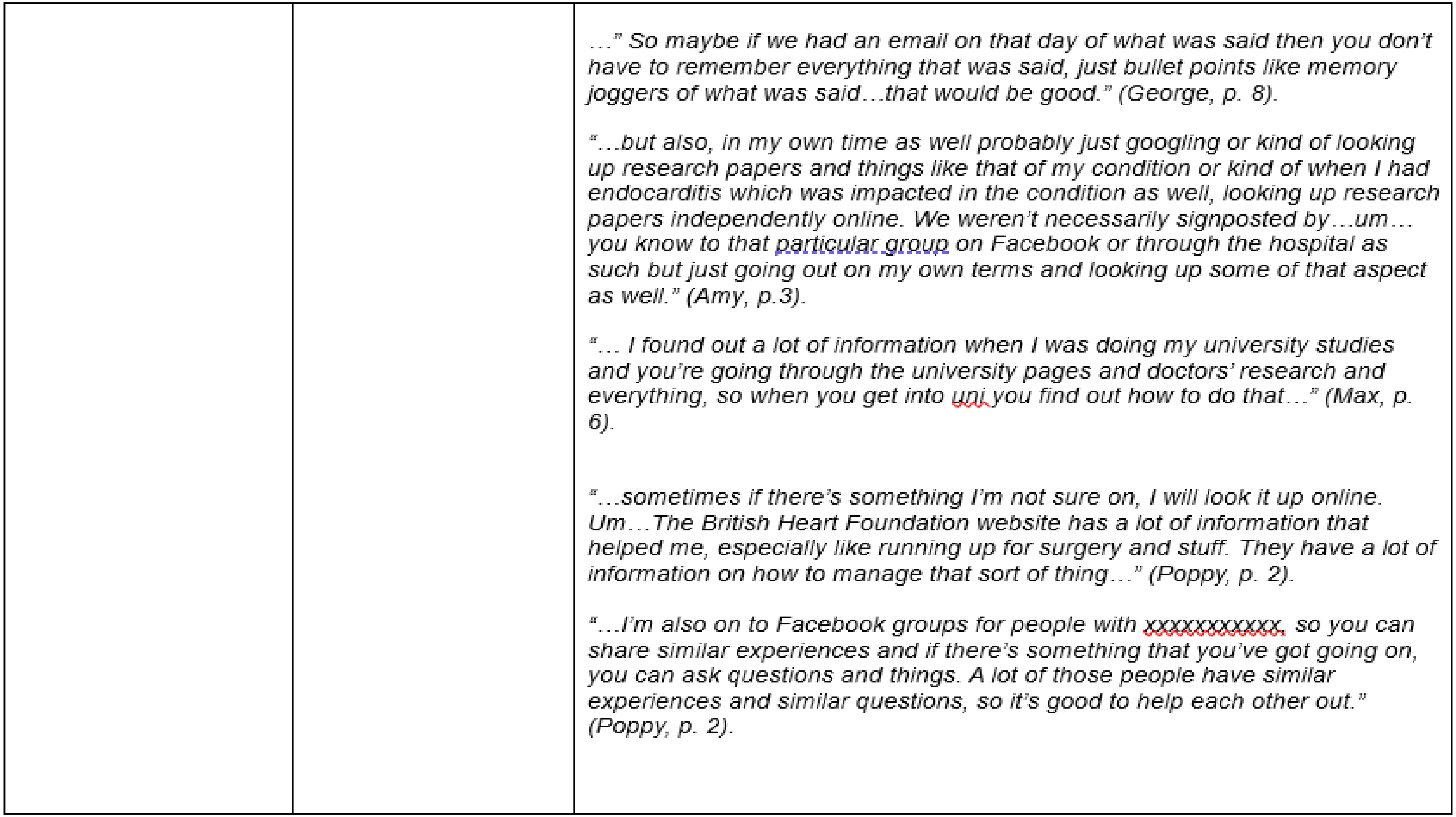
		"…very fortunate that um, you know if we've ever had questions, um we being myself or my parents, kind of growing up that we feel we can ask those questions, you know whether that be the xxxxx team or the SACCS team in particular, you know, always very good at being able to pick up the phone and get in touch with somebody who can then advise or um, yeah, answer any of those queries and things like that…. (Amy, p. 3). *"…so, every time I've went into hospital the nursing team have always asked "do you know what's going to happen?" "do you know what's wrong with you?" So, they have explained in the past and had diagrams of hearts outlining what has happened and have explained it all and also explained it to my wife as well so she understands… what's happening, why it's happening, why I take my medication at night and why I can't lift stuff, so that really has helped. And I could message the team as well and they would explain it all as well." (George, p. 3).* *"…before my heart surgery, one of the nursing team took me aside and kind of had a diagram of a heart and went "can you explain to me what's wrong with your heart?" So I explained to them, pretty much bang on, because I explained everything, where everything was and what went wrong just from having the condition for my whole life, um…but then they also, they like asked "xxxxx, did you understand that?" and they explained everything to my wife, as well, so it was kind of good that she has a full understanding of it as well, so that was kind of a really good interaction where they sat me down and explained everything and they kind of filled in bits of my knowledge of what they were going to do as well. So this is what happened in the past, and this is what is going to happen tomorrow, it was going to happen the next day, the heart surgery, so they explained everything and they explained all the recovery after, so it was really good that time because I could ask all the questions I had, um, I think that was part of the Glasgow nursing team that did that, so that was really good." (George, p. 9).*

		"Talking to cardiologists is the main one by a lot because a lot of stuff you read online you don't actually know if it's true or not because it's some random person who might not have the background knowledge. "(Max, p. 2). *"…having open heart surgery taught me a lot because when you go into hospital, they explain everything that is going to be happening, and they also explain what is wrong and what they are correcting and things…" (Poppy, p. 2).* *"…even when I was a child, they were really good at going through every little detail with me, so I understood." (Ruth, p. 3).* *"…so, every year I had the same two ladies, the cardiologist and her assistant, not too sure what her title was, but I had the exact same ladies for as long as I remember, so that was really good because it meant that I got very comfortable with them. So yeah, I would happily be in a room on my own with them and talk about it, and it wouldn't make me feel scared or nervous, and yeah, I guess, they would really take the time to listen to me, given that I was a little child…. which was really nice." (p. 7).* *"…the SACCS team have been really good. Every time I go in, they're like "We want you to understand it" so they try and explain it, they'll explain it every year, they always answer questions. So now every time I go, they're like "You have this" and I'm like "Oh, I remember that! I know that, I know what that looks like!" [upbeat tone]. They've drawn me a diagram and things like that…." (Tanya, p. 2).* *"…And nurses, I don't know, in terms of the SACCS nurses, I genuinely don't think I could fault them. They've got lots of information, they often go about with it in a really good way, explaining it, and they'll explain it over and over again…" (Tanya, p. 7).*

		"…from what I can recall, they were easy to understand, the wording and terminology used was stripped back and kind of a bit more basic, you know, "going in for an operation", "we're going to add a stent in that will help you" and the benefit that should arise from having that treatment as well. It just obviously helps you understand that it might be that you are in for this but actually this is why and the reason behind it and the benefit of getting that so…yeah, no I definitely, looking back, I was definitely able to understand that aspect at the time as well." (Amy, p. 6). *"…everyone has always explained it to me in a very clear and concise way and if I didn't understand it, they explained it in a different way…. Everything has been well documented, and I've always been kept in the loop, even as a young child…my parents have also kept me in the loop as well…" (George, p. 4).* *"Lots of conversations with the SACCS nurses. I mean there's only been a few because I'm 21 so I think I've been seeing them for a few years. It's the SACCS nurses and I spend half of my year in xxxxxx so I see them as well, but it's just conversations with doctors over and over helps develop it because every time they tell you something a bit new…it just starts to click after a while. The first time it is very overwhelming when they try and explain it to you and its implications and what not…but like…it starts to click a few years in when you're hearing the same things over and over." (Tanya, p. 3).* *"…it's more so repetition for me that's important. I guess anyone who's taken the time to draw diagrams and…. that sort of thing. There wasn't really a click point sort of thing…it was just more, it's more repetition, I think." (Tanya, p. 3).* *"…it's more just been like "let's just break it down" and that has helped…" (Tanya, p. 3).*

		"…through things like visual drawings and kind of sitting down and explaining the current situation is we… how it is versus a normal heart, that kind of thing. I'm quite a visual person so seeing that written down does kind of help me understand that better…" (Amy, p. 2). *"… one of the things we have just touched on there is that kind of visual, um, when I've actually been in hospital so, kind of this is the surgery, just a basic, this is what normal looks like, this is your set up of your heart and things like that um and likewise the stenting or what's going to happen in the operation, kind of just a diagram of, this is kind of roughly what's going to take place.." (Amy, p. 3).* *"I think probably again because it was a larger operation, that one 6 years ago, having that visual, just a rough sketch, you know, this is your heart, this is your valve, this is the collateral arteries coming off of it, this is where you'd have stenting and things like that, so that definitely sticks out in my mind, but that is also probably because that was quite a big surgery and it has only been since I've been older that I've been able to appreciate that a bit more. But definitely not even much, just a quick…while they were explaining what the terms were and things like that, that actually having it visually on a piece of paper as well, um, was really, really useful. "(Amy, p. 4).* *"100%, yeah because you got a representation of where stuff was and what it does in a sense ….is it an echocardiogram? The heart scan of your heart. I…end up talking to them and asking, "what part is what" and they end up explaining it to me quite well. I don't need them to tell me what's wrong with my heart, they can explain that, but "what's that big white thing?" and they'll be like "oh, that's your new heart valve" or "this is this valve and that's that" so I kind of understand it from that point of view…." (George, p. 10).* *"…Like the SACCS nurses, if I visit them, sometimes they'll show me diagrams and things, which is good because it's hard to understand what's*

		going on inside of your body. So, they've been really helpful with that." (Poppy, p. 2). *"…all my cardiologists that I've had have always been really good, they've used pictures and drawn things to help me understand…" (Ruth, p. 2).* *"…because anyone who's not a cardiologist who looks at the heart, you just think "Oh my goodness", you know, there's so much to it, it's not just the four chambers that you learn about in school…there's loads to it. Yeah, they'd usually help me visually because when someone is just telling you, you're a bit like "mmm, I don't get it", but yeah, it really helped me being able to look at pictures in hospital of the heart or pictures they would draw." (Ruth, p. 3).* *"…so having a diagram is really useful and also it's just…I'm just quite visual in that way so it helps." (Tanya, p. 2).* *"…a lot of the time if I get bad news, I kind of just go a bit blurry, and don't really remember stuff, so I can always just email back and go, "what did they say again?" [laughs softly]" (George, p. 5).* *"…Because there's nothing worse when the hospital phone me at work, so I've got all the stuff at work to deal with and then I've got to remember everything they said to then relay to my parents or my wife what they told me…" (George, p. 10).* *"...maybe…every time they speak to you on the phone, you get a wee email of a summary of what was discussed sort of thing….um because a lot of the time it can just take you by surprise that you have a phone call from them. And you have to like come out of the world you're in and focus on what they're saying and then try to take in all of the information they've just said to you…" (George, p. 8).*



		…" So maybe if we had an email on that day of what was said then you don't have to remember everything that was said, just bullet points like memory joggers of what was said…that would be good." (George, p. 8). *"…but also, in my own time as well probably just googling or kind of looking up research papers and things like that of my condition or kind of when I had endocarditis which was impacted in the condition as well, looking up research papers independently online. We weren't necessarily signposted by…um… you know to that particular group on Facebook or through the hospital as such but just going out on my own terms and looking up some of that aspect as well." (Amy, p.3).* *"… I found out a lot of information when I was doing my university studies and you're going through the university pages and doctors' research and everything, so when you get into uni you find out how to do that…" (Max, p. 6).* *"…sometimes if there's something I'm not sure on, I will look it up online. Um…The British Heart Foundation website has a lot of information that helped me, especially like running up for surgery and stuff. They have a lot of information on how to manage that sort of thing…" (Poppy, p. 2).* *"…I'm also on to Facebook groups for people with xxxxxxxxxxx, so you can share similar experiences and if there's something that you've got going on, you can ask questions and things. A lot of those people have similar experiences and similar questions, so it's good to help each other out." (Poppy, p. 2).*

Supporting People with CHD to learn about their condition.	Support for Children and Young People	*"…engaging in that conversation about what your condition is made up of, whether that's through age appropriate means, visual aids, toys and things like that and having that conversation about what's going to happen…I'm not saying that that didn't happen but, um, definitely something I do recall happening and I would suggest would be a good way of having that continue but, I think that aspect of it and probably what's going to happen and I think an element of it as well is as you grow up, you don't actually know what that treatment path will look like so you can't always give a definitive answer on that as well so where known, explaining what's happening, why it's happening, and kind of what the next steps may or may not be would be really useful. ". (Amy, p. 5).* *"…But also, when I was younger, I feel as if they didn't really… they were always speaking to my parents and telling my parents all the information. So having something to maybe help explain things to a child would have been easier. "(Poppy, p. 6).* *"…I think having stuff to take away with you rather than just… like when I would go into hospital, they would show me the diagrams and show me everything. But then when I came home, I wouldn't have any of that, I wouldn't have anything to help me remember everything. So yeah, having maybe something to take home with you from the hospital…Something to help you day to day remember what's going on for you. When I was moving up into the adult services they gave me this big pack, this big folder and it had lots of information and lots of different books and that helped me. But I didn't get that until I was 16. So, I think when you're younger, maybe having something, like a visual…something would help younger kids know." (Poppy, p. 5).* *"…resources for younger people to take home with them would be good, like a fun kind of thing…" (Poppy, p. 6).*

		"…when you turn 16 or 17 there's this open day you can go to which is the transition day they call it. And that's awesome, they've got videos, and…I really liked that, that was really helpful in making me feel more comfortable and less alone and what not. And I feel like there could have been maybe something like that for kids for 11- or 12-year-olds or something just as like a "here, have a basic understanding, here are other kids that are like you!" that sort of thing." (Tanya, p. 4).
	Educate parents/caregivers.	*"Find the research, I guess. There's a lot of helpful leaflets you can have of various different… I think I have one on pulmonary stenosis and one on AVSD and things and you sort of put them together and that shows you what your heart looks like. So, you can get those, I'm sure you can get them from the hospital or something if you don't have the knowledge yourself which, most people wouldn't [laughs softly]. It's just, maybe having the information available and understanding it yourself so when your kid does ask, it's like "oh yeah, cool, I can show you this if you'd like?" you know?" (Tanya, p 6).* *"…maybe just teach them. Find out more information for yourself and make yourself aware. But also, the things it can impact in your life. It will make you tired, it will cause you to not be able to do everything that everyone else can. I think just teaching your children that from a young age. Learning when to pick up when their child isn't feeling well, and it is to do with their heart and not just because they're tired and a child. Because a lot of the symptoms do get caught up with, you know, just being tired. So, I think just making you as a parent more aware of what your child is going to be going through." (Poppy, p.5).*
	Ask Questions	*"…I'd probably advise, if you're unsure, ask, ask questions, whether that be to your parents or guardian that maybe know through assisting with appointments and things like that, but also asking nurses, doctors, staff that are involved in your care…um…even, GPs and things like that…look at what other kind of charities and groups are out there that, you know, you can link*

		up with people that have lived through the same or similar condition and what their experiences were with it…maybe older than you, what their kind of trajectories looked like and kind of…what they've had take place as well so kind of utilising those resources…, definitely…even if you're not sure about questions, I've found it really helpful to just even read and hear about other people's experiences as well." (Amy, p. 7). *"…I would say if you have questions, ask, don't be shy. But that's me personally. People might not want to know about what's going on and be shielded by it. But I would just ask heaps of questions, that's what I normally do in life [laughs softly], just ask heaps of questions and find out as much things as you can. Because if you know, you know what's going to happen, if you know the worst thing that can happen, there's no point in worrying about something that might never happen because it's physically impossible, but if you don't know, you don't know, sort of thing. That's what I tend to do, just ask lots of questions and figure out what's going to happen." (George, p. 8).* *"I've literally had to grow up with cardiologists…. they want you to know about your condition as well, so you know when there's something up and when there's something wrong. I've always been curious, I always ask questions any way, I like to know how things work. Most cardiologists I've dealt with want you to know about it so you can see the signs if there's any problem. "(Max, p. 2).* *"They want to get asked as much questions as possible and again, I'm curious." (Max, p. 8).* *"I guess just ask the questions if you think about it, don't be scared to ask, just do it. The cardiologists have trained very long for a reason so they can have this knowledge and understanding about such a complex part of your body and so…just ask the questions that you want to know and the ones that will reassure you, I guess…" (Ruth, p. 4-5).*

		“...ask your doctors, especially at the Golden Jubilee, they’re all really nice, genuinely, they’re nice and will take the time…” (Tanya, p. 4).
	Peer support	*“…an opportunity to meet up with other people similar age and stage that might be moving into that service as well that you can kind of meet up and have an opportunity to ask questions in that kind of environment so you can understand it better as well. “(Amy, p. 10).* *“…try to arrange speaking to someone who’s been through it as well because doctors, as much as they know about the condition and the mechanics they don’t actually know about the feelings and going through the surgery.” (Max, p. 6).* *“…I think one thing is important for people who do have congenital heart conditions is to talk about it because… I’ve only ever met one other person in my entire life who has a congenital heart problem, and it was actually just like really, really nice in a weird way to know that there’s other people going through it, so I think it would just be nice for people. And I understand it’s a personal thing, but it’s just nice when people are open about it because then it makes you feel less alone.” (Ruth, p. 10).* *“…in a not very nice way it’s nice to know other people are going through it, even though you don’t want anyone to go through it, it’s just nice knowing you’re not the only one and I guess you don’t feel as alone.” (Ruth, p. 11).* *“…I think, as much as the cardiologists are absolutely incredible and they know so much about the heart, more than anyone else, because it’s their job, but as much as they know about it, and how hard it can be, they’re not actually going through it. So, if you meet other people who are the ones actually going through it, I just think that would really positively impact others who have congenital heart conditions, because you’re told its very rare, but if you met other people with it, I just think it would be nice.” (Ruth, p. 11).*

	Signposting.	*"…having more, if there is other research out there, that you know, SACCS or other people have access to and can maybe signpost that would be something that, um…would be kind of beneficial and interesting to read up about as well. (Amy, p. 3).* *"I think, kind of opening that conversation of questions, you know, some people find it easy to ask questions and others maybe not so much… so providing that time for that, so you might have your appointment and it might be a part of the end of the conversation or throughout your treatment kind of making sure there is a bit of time to open up that conversation about questions and that understanding and…also, signposting to resources and support groups, perhaps to do with the hospital or the local area or through charities and things like that…as an option to go and explore in your own time…would be something I would probably advise. "(Amy, p. 9).* *"…Direct them to points of research they could look up, if doctors read medical reports somewhere, you can direct someone else to that because non-medical people don't know where to find this stuff. "(Max, p. 6).* *"…GPs…often they'll have a basic understanding. When I go in for my appointments, every time I see a new GP they're like "hmm, I need to read your notes" and then sometimes they're like "I'm just going to google that", which is absolutely fine, I understand that [smiling]. But I feel that if they have an understanding, that's easier. But if they don't, they can obviously say "ask your cardiology team"- that's fine. But it's like, if you go to your GP with questions and they don't know, they should definitely sign post you, which they should know how to do…." (Tanya, p. 7).*

Appendix P

Data Availability Statement

The participants in this study have consented to their anonymised transcripts being uploaded to Enlighten, the University of Glasgow’s data repository.

Appendix Q

Reflexivity Statement

Weblink: https://osf.io/thr5v

Appendix R

MRP Proposal

Weblink: https://osf.io/9xjw4