Navigating Menopause: A Qualitative Exploration of the Mental Health Implications for Women with Congenital Heart Disease.

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1. **Statement of Publications**

   The systematic review which forms part of this thesis has been peer reviewed and published in the British Medical Journal.

   Amato, M., Adeoye, M., Schofield, R., & Di Cesare, M. (2026). Reproductive journey in women with congenital heart disease: a systematic review of mental health implications. *BMJ open*, *16*(3), e112904.

2. **Statement Regarding Use of Artificial Intelligence**

   No artificial intelligence tools were used in this thesis.

3. **Statement of Training**

   In addition to training associated with the Doctorate in Clinical Psychology, I attended a formal Reflexive Thematic Analysis Training.

Abstract

Background: As survival from congenital heart disease (CHD) improves, there is a rapidly growing population of adults with congenital heart disease. Women with CHD experience unique reproductive health challenges throughout their lifespan and these challenges are characterised by complex medical risks alongside significant psychological burden. Reproductive health amongst women living with CHD has mostly focused on menstrual irregularities and pregnancy. There are currently no studies which explore menopause and its impact on mental health.

Aims: The aim of this study was to explore the mental health impact of menopause on women living with CHD by:1) identifying the facilitators and barriers to accessing support; 2) to explore the psychological and social resources available for them.

Methodology: A qualitative design was used. Semi-structured interviews were conducted with 15 women living with CHD who were transitioning or had transitioned through the menopause. Participants were recruited via the National Health Service (NHS) in a hospital which has a specialist adult CHD department. Reflexive thematic analysis (RTA) was used to analyse the data.

Results: Six themes were identified 'The Cumulative Impact of Health Factors', 'Physical Change as an Emotional Reminder', 'Gaps in Knowledge and Holistic Understanding', 'Seeking Safe Choices', 'Personal Coping Resources' and 'Social Connectedness as Support'.

Conclusion: Women living with CHD and transitioning through the menopause are navigating several new and existing mental and physical health symptoms, often overlapping with their CHD condition. However, this transition is not just about managing symptoms but the uncertainty within healthcare systems not yet set to address their needs.

Implications: This study offered new insights into the experiences of transitioning through menopause for women living with CHD. Increasing knowledge among both CHD teams and patients is crucial, to develop CHD-specific materials, strengthen collaboration with GPs in order to improve the care of women living with CHD as they enter a new life stage.

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Abbreviations

Abbreviations	Meanings
ACT	Acceptance and Commitment Therapy
BA	Behavioural Activation
BMJ	British Medical Journal
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CHD	Congenital Heart Disease
CVD	Cardiovascular Disease
GBD	Global Burden of Disease

GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HRA	Health Research Authority
HRT	Hormone Replacement Therapy
ICU	Intensive Care Unit
IPA	Interpretative Phenomenological Analysis
IRAS	Integrated Research Application System
LGBTQ+	Lesbian, gay, bisexual, transgender, queer
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analyses
QR	Quick Response
RTA	Reflexive Thematic Analysis
SDI	Socio Demographic Index
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Chapter One: Introduction

Chapter Overview

This chapter firstly outlines a statement on terminology used throughout this research study. The background literature and theories relating to the present research study is considered. The historical and socio-economic context of individuals living with congenital heart disease (CHD) outlines the advancements in medicine for this group of individuals. Prevalence, incidence and mortality data is presented to describe trends over time and across countries. The chapter then considers the mental health experiences for adults living with CHD as well as background information about reproductive health and the menopause in the context of CHD. Women living with CHD experience a different reproductive life course from women with acquired or non-congenital cardiovascular disease because their cardiac condition is present from birth and influences reproductive decision making throughout their lifespan. The intersections of cardiovascular health, mental health and menopause are then detailed. The role of clinical psychologists within cardiovascular care and CHD more generally is provided based on an appraisal of the literature and guidelines. Psychological approaches specifically related to cardiovascular health and CHD are outlined which include positive psychology, behavioural psychology, humanistic psychology, attachment theory and systemic family therapy. The current guidelines for menopause guidance for adults are later detailed.

Statement on Terminology

Throughout this research study, the author uses the term “women” and “woman” to reflect the terms used in similar research samples. This is not intended to deny the fact that people born biologically female may not identify as a woman. The research study is therefore referring to cis women. This research study does not include the unique experiences faced by

non-binary or intersex people or transgender men, a separate study could be designed to incorporate the experiences of these individuals.

Mental health is defined by the World Health Organisation (2004) "*a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn and work well, and contribute to their community. It has intrinsic and instrumental value and is a basic human right. Mental health exists on a complex continuum, which is experienced differently from one person to the next. At any one time, a diverse set of individual, family, community and structural factors may combine to protect or undermine mental health*". The term mental health is used throughout this research study to capture both diagnosable conditions (if applicable) and psychological distress. Mental health is a broad concept that goes beyond diagnosable mental health disorders (Moons et al.,2022). The term "mental health" aligns with language used in some of the existing literature and healthcare policies. However, the studies included in the systematic review which forms part of this research, uses the term "psychological wellbeing" to describe the impact of reproductive health in the context of women living with CHD. Additionally, in the methods section, the recruitment site for this research study is specifically known as a "psychological service" rather than a "mental health service" and therefore, the language used in the methods section reflects this. In summary, the terminologies used in this research study are reflective of the existing literature, the preferences of the service and in line with the research aims. At times therefore, the terms "mental health", "psychological wellbeing" or "psychological impact" may be used interchangeably.

Background

Congenital heart disease is a term used to describe a fault or problem with the heart that is present at birth (Centres for Disease Control and Prevention, 2023). In 2023, CHD was the leading cause of death for non-communicable diseases in the first year of life globally

(Institute for Health Metrics and Evaluation, 2024). Developments in medical and surgical techniques have improved the survival of individuals living with CHD, with affected people living well into their adult life (Gurvitz et a., 2016). Much of the existing literature focuses on children living with CHD to examine its impact on cognitive and physical development (Mari et al., 2016).

CHD is considered a physical disease and differs in severity and complexity. Some people living with CHD have a structural difference in the heart and will not need surgery in infancy, whereas other individuals will need multiple surgeries at a young age (Peterson et al., 2003). There is a two-way relationship between mental health and menopause in women living with CHD. Transitioning through the menopause leads to changes in hormones which impacts on heart health. However, there is limited research on the unique impact of menopause on mental health. The association between cardiovascular diseases and mental health has been widely explored (Bueno et al., 2025; De Hert et al., 2010) with clear evidence that individuals living with physical diseases and illnesses have an increased risk of developing mental health disorders (Dare et al., 2019) and vice versa, for example, people living with mental health conditions are more likely to develop a deterioration in their heart health (Frasure-Smith & Lespérance, 2005).

The Historical and Socio-Economic Context of Individuals with Congenital Heart Disease

Hajar (2002) suggests that one of the first representations of CHD was in the form of a drawing by Leonardo da Vinci in the 15th century. There was little progress in the understanding or treatment of CHD until 1938 when a surgeon in Boston completed the first successful operation on an infant which to date remains a milestone in the world of CHD (Goss & Hubbard, 1984). This was later followed in 1944 with two successful operations in Sweden and in Baltimore (Crafoord & Nylin,1945). In the 1950's, the understanding and

research on the topic heavily focused on surgical techniques; at this stage only around 15% of children born with CHD survived (Brida & Gatzoulis, 2020). A major step forward was the development of 'The Ross procedure' by a surgeon from London which is still successfully used to date (Ross, 1962). Improvements have also been achieved in intensive care skills and diagnostic measures (Bonnet,2021). The advances in medical surgeries and care have enabled children with CHD to survive into their adult life and have resulted in improved quality of life (Raissadati et al., 2015).

Progress in diagnosis, treatment and management of CHD has shifted the prevalence of individuals living with CHD from infancy to adulthood. In 2008, the number of adults in the European Union living with CHD was greater than the number of children living with CHD for the first time (Baumgartner, 2014), with a growing number of middle-aged individuals and those over 60 living with CHD (Brida & Gatzoulis, 2020). However, despite these advancements, the risk of adverse health outcomes for these individuals remains high (Tran et al., 2023) with differences observed by socioeconomic and sociodemographic factors (Tran et al., 2023). Whilst the evidence available shows progression with medical advancements for people living with CHD, there are observed differences when comparing high-vs low-income countries (Vervoot et al., 2021). Associations have also been found between low socio-economic status and higher rates of mortality for infants with CHD (Best et al.,2019). Explanations include the limited access to advanced medical care or poor post discharge aftercare (Xiang et al., 2019). Additionally, because CHD can be diagnosed at a 20-week scan during pregnancy, this can lead to pregnancy counselling and termination, this may explain part of the differences in the mortality rates and health outcomes due to decisions regarding the continuation of pregnancy (Jicinska et al., 2017).

Disparities within countries also exist. A study conducted in the United States of America (USA) showed how Hispanic and Black infants had an increased risk of mortality

following surgery (e.g. corrective surgery) compared to non-Hispanic White infants (Collins et al., 2017). Possible explanations of ethnic disparities include delayed access to infant surgeries in African American children compared to White children (Milazzo et al., 2002) as well as potential biological, genetic, cultural and societal factors (Oster et al., 2011). Access to resources such as private medical insurance in the USA has been found to be a factor in successful outcomes. A meta-analysis found an increase in hospital mortality for those with public healthcare versus private medical insurance (Best et al.,2019). This may be due to resources available within public healthcare (Erickson et al., 2000). Higher parental education was also found to be associated with a decreased risk of CHD associated infant mortality but not with long term mortality (Best et al.,2019). Between and within countries inequalities highlight the need for equity with resources so that an infant born anywhere in the world with a CHD has the opportunity to reach their full life potential (Gatzoulis, 2006).

In the United Kingdom (UK), CHD came under scrutiny due to a public inquiry at the Bristol Royal Infirmary from 1984 to 1995 due to high mortality rates post-surgery (NHS England, 2015). Since then, recommendations into improving CHD services have been considered (Huxter & Holden, 2015) to improve early diagnosis, service standards and information sharing to overall improve patient experience. This included recommendations for access to practitioner psychologists working within CHD teams (NHS England, 2015).

Global Incidence and Prevalence of Congenital Heart Disease

Here the most recent estimates of CHD associated incidence, prevalence, and mortality from the Global Burden of Disease (GBD) in 2023 (Institute for Health Metrics and Evaluation, 2024) of CHD are presented.

Globally, an estimated 2.3-2.5 million newborns each year are affected by CHD, representing approximately 2% of all live births. The progress in early diagnosis and timely and more efficient treatments (e.g. surgery) has led to an improvement in survival rates and a

consequent increase in the number of people living with CHD worldwide. Now this number is estimated to have reached 16.0 million, from 11.8 million in 1990. As expected, the age-standardised prevalence rate (per 100,000 people) shows higher prevalence in Europe and Central Asia compared to other areas of the world (Figure 1).

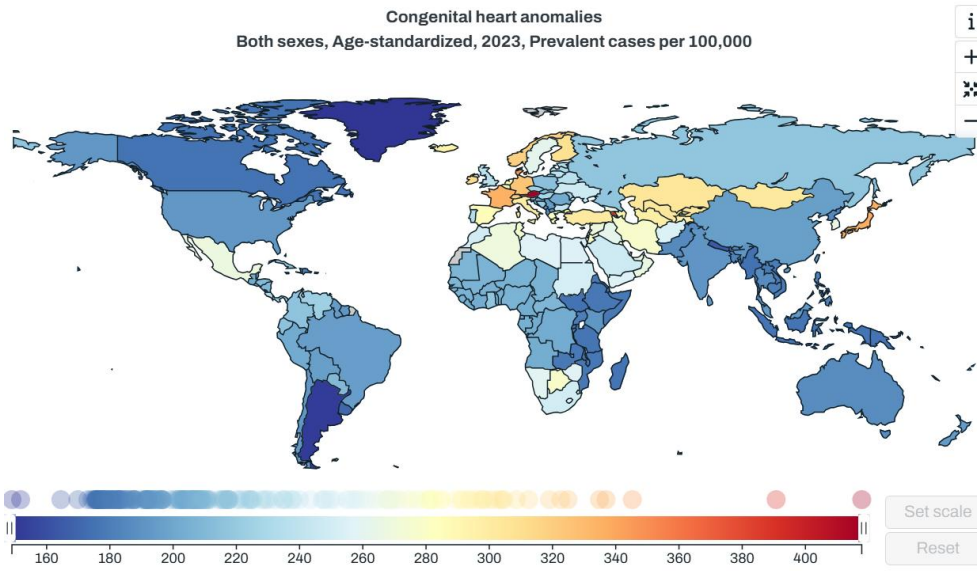

Figure 1. *Global Age-standardised Prevalence Rate (per 100,000 people) of Congenital Heart Disease, 2023 Both Sexes.*

Note: Figure downloaded from: https://vizhub.healthdata.org/gbd-compare/

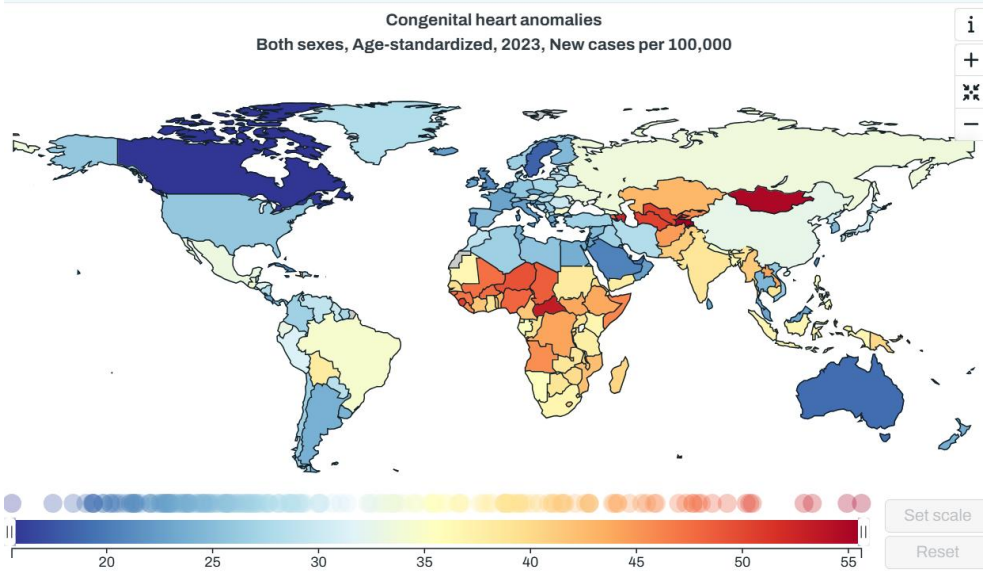

Figure 2. *Global Age-Standardised Incidence rate (per 100,000 live births) of Congenital Heart Disease 2023, both sexes*

Note: Figure downloaded from: https://vizhub.healthdata.org/gbd-compare/

The incidence rate of CHD (cases per 100,000 live births) is higher in Central and West Africa and lower rates observed in North America, Europe, Australia and parts of South America and Asia (Figure 2). The across countries heterogeneity is partly explained by the use of different practices, screening availability, pregnancy termination laws (Tomek et al., 2023) and parental decision-making (Nakao et al., 2024).

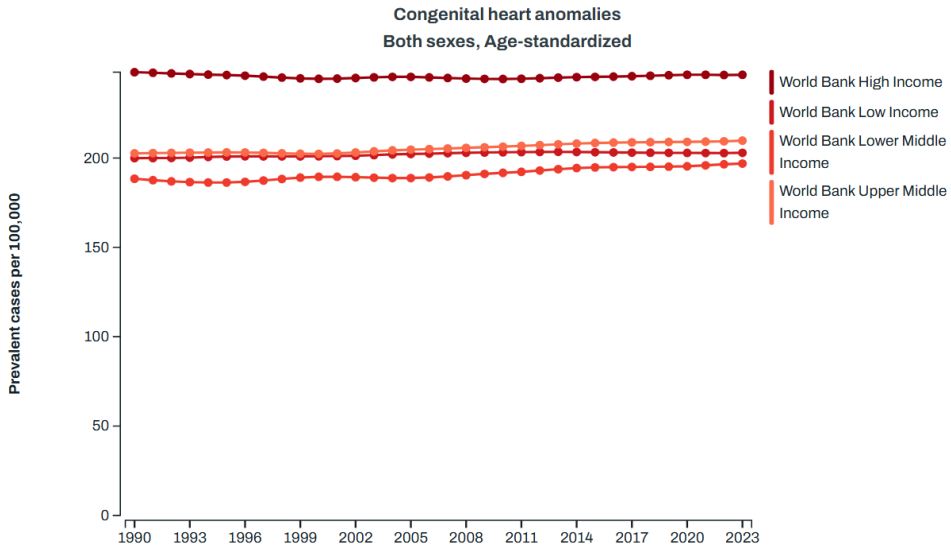

Figure 3. *Age-standardised Prevalence rate (per 100,000 people) of Congenital Heart Disease by World Bank Income Regions, 1990-2023*

Note: Figure downloaded from: https://vizhub.healthdata.org/gbd-compare/

Trends in prevalence of congenital birth defects by income region (based on the World Bank classification) show no change or slight increase over time with the high-income region recording the higher levels in the age-adjusted prevalence (Figure 3).

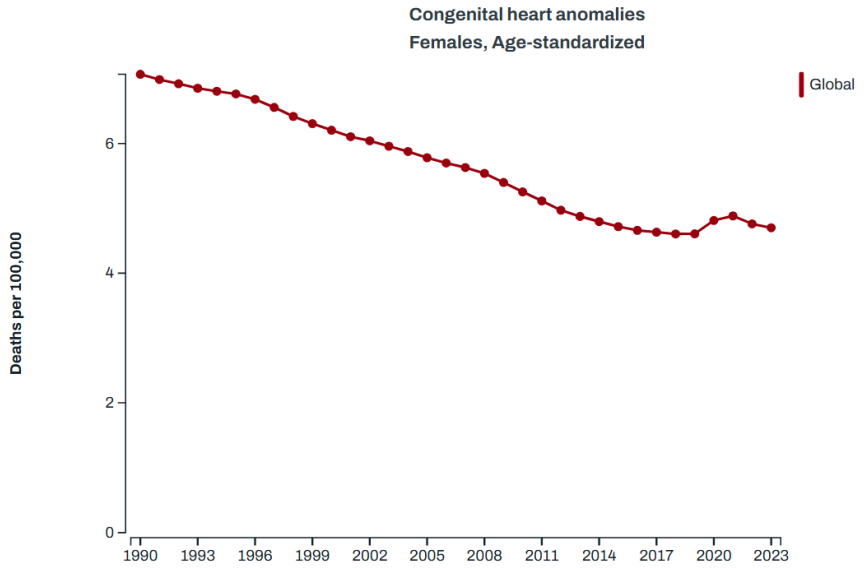

Figure 4. *Global age-standardised CHD mortality rate (by 100,000 people), 1990-2023, female*

Note: Figure downloaded from: https://vizhub.healthdata.org/gbd-compare/

Worldwide, in 2023, approximately 8.2 million females lived with CHD. Of these 3.2 million were of reproductive age (15-49 years old), a 1 million more than in 1990. This is the results of a consistent decline in the level of mortality (Figure 4).

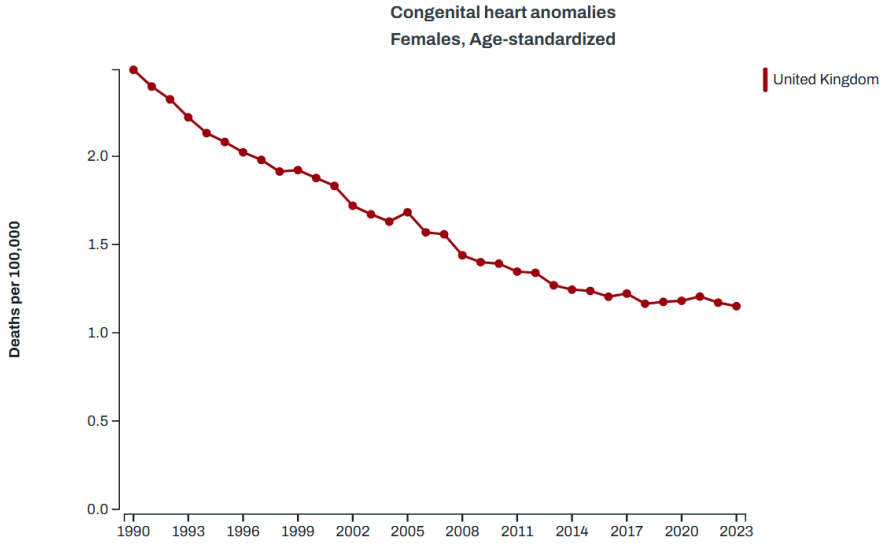

Figure 5. *UK Age-standardised CHD mortality rate (by 100,000 people), 1990-2023, female*

Note: Figure downloaded from: https://vizhub.healthdata.org/gbd-compare/

In the UK every year approximately 7 thousand children are born with CHD, with 145 thousand people living with CHD in 2023 (76 thousand females, and 68 thousand males). As observed globally trends in mortality have declined over time consistently (Figure 5). In 2023 approximately 32 thousand women living with CHD were of reproductive age, 4 thousand more than in 1990.

Mortality

Although life expectancy for some individuals living with CHD is increasing, the lifespan trajectory requires long term research (Verheugt et al., 2010). There has been some research which has found that there is a lower life expectancy for adults living with CHD compared to their healthy counterparts (Nieminen et al., 2010). However, until recently little was known about the cause of death (Morris et al., 1991). One study investigated this issue and found excess mortality in a sample of 6933 patients with CHD with a median age of 48.8 (Verheugt et al.,2010). The causes of mortality were mostly cardiovascular including chronic heart failure or sudden death. This has later been supported by recent research which suggests later in life, concerns move away from the CHD such as surgical repair, and more towards acquired cardiovascular complications, such as hypertension, coronary heart disease, atrial fibrillation and heart failure (Liu et al., 2023), which contribute to premature cardiovascular mortality as well as increased complications in the management of CHD (Bonanni et al., 2025).

Mental Health in Adults with Congenital Heart Disease

The increasing number of adults living with CHD has highlighted the importance of understanding the broader health implications associated with lifelong disease management, including mental health outcomes. There is a large body of literature looking at common mental illnesses, such as anxiety and depression, and their associations with cardiovascular health (Chaddha et al., 2016). Research has been conducted specifically looking at the mental

health impact on those living with CHD. A study found that adults living with CHD had higher self-reported depression symptoms on an outcome measure, Hospital Anxiety and Depression Scale (HADS) in comparison to the general population (Moons et al., 2022). Similarly, the mean scores for self-reported anxiety symptoms were higher in CHD individuals compared to the general population (Moons et al., 2022). This is supported by a recent study which found that one third of participants (adults living with CHD), self-reported symptoms of anxiety and/or depression, which were associated with poorer health status and quality of life (Kovacs et al., 2024). However, it has been shown that it is not the complexity of CHD that predicts mental health difficulties, but the subjective experience (Apers et al., 2016). The subjective experience is shaped by patients' lifelong hospital visits, possible surgeries, the way they deal with uncertainty and individual coping behaviours (Kovacs et al., 2022). A study found that older adults (aged 60 or older) living with CHD, reported to experience better mental health when compared to younger patients (aged 18-59) living with CHD (Moons et al., 2023), suggesting that individuals may become more adjusted to their condition over time. Qualitative studies have explored the psychological impact of adults living with CHD. Yaseen et al. (2023) found that participants shared concerns about experiencing stress and anxiety around their future and mortality with some participants adopting maladaptive coping strategies such as avoidance to cope. However, some participants felt able to seek support and use religion as a source of strength. Similarly, Callus et al. (2013) found participants experienced intense suffering from hospitalisations, experiencing isolation and as a result adopted avoidant coping strategies such as minimising and denying downplaying their experience of living with CHD. Feelings of denial have been reported to be elevated in adults living with CHD (White et al., 2016) which led to fewer feelings of anxiety and depression. This may be explained by the suppression of feelings, providing a somewhat protective element on mental health in the short term. However, denial

and avoidance have found to be a predictor of disengagement with cardiac care and follow up (White et al., 2016). Skojec et al. (2025) conducted a review to understand how uncertainty for those living with chronic illnesses relates to psychological adjustment. The authors found that maladaptive coping strategies led to an increase in psychological distress, compared to adaptive coping strategies such as information seeking and problem focused coping. Therefore, although maladaptive coping may provide short term relief to individuals, in the long term, this may exacerbate their psychological suffering and lead to avoidance of health-related care. Supporting this, a qualitative study conducted in adults living with CHD reported that participants described feeling strong and healthy as they focused on making the most out of life (Berghammer et al., 2015). Additionally, participants in this study also described being able to deal with the physical restrictions of CHD by focusing on what is possible for example by developing strategies to manage everyday living and accepting the lifelong nature of CHD (Berghammer et al., 2015).

Reproductive Health in CHD

As increasing numbers of individuals living with CHD survive into adulthood, reproductive health also represents an important consideration. Reproductive health amongst women living with CHD has mostly been examined during adolescence to consider menstrual irregularities as well as the risk pregnancy can pose on women living with this condition (Van der Zande et al., 2023). The physiological changes happening during pregnancy pose additional risks to women living with CHD with increased risk of fatal complications for both the mother and the baby (Haberer & Silversides, 2019). This is due to the increased risk of heart failure, a potential deterioration of their CHD and risk of arrhythmias which may complicate the pregnancy (Hagen & Ross-Hesselink, 2020). Reproductive health aside from pregnancy for women living with CHD can include a delayed menstrual period, irregular or heavy menstrual periods, infertility and uterine bleeding (Phillips & Pirics, 2017). For these

reasons, the existing research recognises the importance of adolescence as a developmental reproductive milestone in women living with CHD (Lopez et al., 2015). As a result, for women living with CHD, there may also be increased fear and anxiety around available contraception, pregnancy and childbirth (Nakamura et al., 2018). Given the heterogeneity in the physiological profiles of CHD, reproductive health advice can differ greatly, and mental health support may be recommended to explore the associated concerns, which may relate to family planning (Canobbio et al., 2017). The importance therefore of healthcare providers being able to discuss women's reproductive health and the associated risks and complexities is something that should be considered in a sensitive manner during medical appointments (Lindley et al., 2015).

In the presence of CHD, further research regarding the impact of menopause is needed. Menopause is defined as the absence of menses for 12 consecutive months as a consequence of the loss of the ovarian follicular function, after a reduction in blood oestrogen levels (World Health Organisation, 2022). The menopause typically takes place in women aged between 45 and 55 years but can happen earlier (known as perimenopause) or later. During the different stages of menopause (pre- peri- and menopause) women experience major changes in their hormonal level (oestrogens and progesterone) (British Menopause Society, 2022).

During the menopause, the cardioprotective effects of oestrogen diminish, increasing cardiovascular risk (El Khoudary et al., 2020; Mass et al., 2021). When there is a reduction in oestrogen, fat can build up in the arteries increasing the risk of developing coronary heart disease, a heart attack or stroke (British Heart Foundation, 2023). For women living with CHD, this transition can precipitate a worsening their existing condition, heightening the risk of thromboembolism (blood clots), weight gain, elevated cholesterol, diabetes, and atherosclerosis (inflammation of the arteries) (American Heart Association, 2015; Canobbio

et al., 2005; El Khoudary et al., 2020; Mass et al., 2021). Despite growing awareness of cardiovascular risks for women transitioning through the menopause, gaps remain in the literature regarding understanding how this transition is managed and experienced by women.

Hormone replacement therapy (HRT) is a medical intervention to improve the transition through the menopause. It combines oestrogen and progesterone or oestrogen only hormones and can be taken in the form of medication, patches, gel or spray. However, HRT presents a complex therapeutic dilemma, as it may contribute to further cardiac complications in those with complex CHD (Cho et al., 2023;Wander et al., 2023). Primary care services such as General Practitioners (GPs) are often the first line of support for women experiencing menopausal symptoms. However, menopause training is not compulsory for GPs (Dintakurti et al., 2022) and this knowledge gap may affect clinical decision making and result in patients not receiving appropriate medical guidance (Harper et al., 2022). A systematic review which looked at the lived experiences of the menopause transition amongst women in the UK, found that women experiencing health conditions such as cancer or polycystic ovary syndrome as well as the menopause, experienced difficulties with symptom differentiation (Anto et al., 2025). The findings from the review also highlighted that there was limited guidance from GPs as often their queries were not answered about the menopause and their health comorbidities (Anto et al., 2025). This highlights key gaps in knowledge amongst healthcare professionals for those with additional health conditions, which may lead to barriers to accessing support during the menopause.

In the UK the discussion around menopause is growing and increased attention is being directed towards improving awareness with conversations being had in parliament (Laker & Rowson, 2024) and celebrities and campaigners for women's health trying to promote recognition for healthcare systems and workplaces. Davina McCall, a British television presenter and menopause awareness campaigner, has been advocating for more

discussions around mental health and the menopause (Jermyn, 2025). A study by Rowson et al. (2023) examined the changes in the British media surrounding menopause from 2001 to 2021. They found that coverage of the menopause has increased over the decade however, stories largely continue to focus on negative portrayals around dysfunction and decline.

However, the needs of women living with chronic conditions, such as CHD, are unique. The lack of research into women living with CHD and their experience of the menopause represents a major obstacle to ensuring that they can equally benefit from the increasing discussions. Additionally, women's cardiovascular health also remains misunderstood and undertreated contributing to the disparities within outcomes and care (Tayal et al., 2024).

Cardiovascular Health, Mental Health and Menopause

While cardiovascular and mental health are recognised as important determinants of wellbeing among adults living with CHD, these outcomes do not occur in isolation. The associations between cardiovascular and mental health have been found to be bidirectional (Figure 6). Individuals with cardiovascular diseases are more likely to have an increased risk of mental illness (Amarasekera & Jha, 2022) with depression being the most common form, particularly after a heart attack (Hare et al., 2024). Explanations may be due to the impact of a significant event such as a heart attack, for example, the associated stress and anxiety (Kubzansky & Kawachi, 2000), the physical changes that take place in the body (Riba et al.,2012), change in lifestyle behaviours as a consequence of the event (Rippe, 2019), fears and worries around the reoccurrence (Lebel et al., 2020) as well as a series of biological factors, for example, altered autonomic nervous system and neurotransmitter functioning (Carney & Freedland, 2017). Likewise, individuals with a history of depression are more likely to experience poor cardiac health (Celano et al., 2016). Reasons for this association include the physiological responses to anxiety and depression such as an increase in the

hormone cortisol, as well as fear and pain which can also impact cardiac reactivity (elevated levels of blood pressure, increased heart rate) (Bremmer et al., 2018).

The co-existence of depression and a cardiovascular disease impact the outcomes for both conditions with poorer self-management, treatment compliance and higher mortality for both depression and cardiovascular diseases (NICE, 2015). Epidemiologic evidence suggests that depression is a risk factor for cardiac problems (Frasure-Smith & Lespérance 2005) and can be attributed because of poor cardiovascular health (Möller-Leimkühler, 2007). Both conditions are associated with impairments in everyday life and increased mortality (Zhang et al., 2018). A research study found that depression is more strongly associated with an increase in cardiovascular diseases in women and women who experience cardiovascular diseases experience higher levels of depression compared to men (Möller-Leimkühler, 2007).

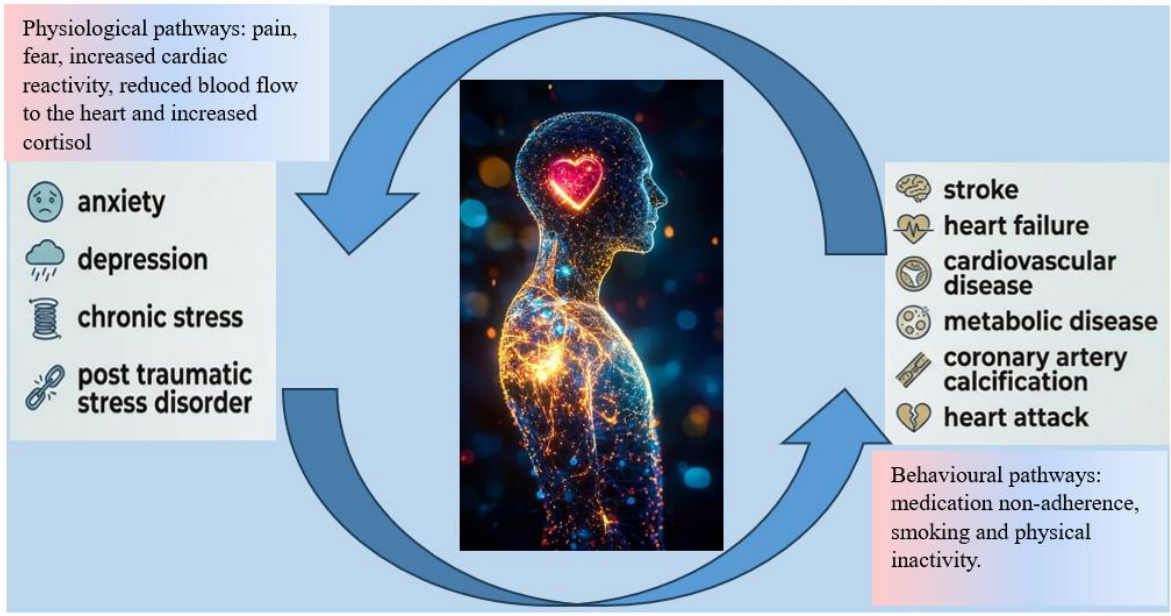

Figure 6. *Associations Between Mental Health and Cardiovascular Health*

Notes: redesigned based on: National Centre for Chronic Disease Prevention and Health Promotion.

Research has shown an increased risk of developing either, mental health difficulties or cardiovascular conditions, because of menopause (Dalal & Agarwal., 2015). Women

living with CHD transitioning through the menopause, may be more at risk of cardiovascular deterioration as well as poor mental health. In particular, a series of physiological changes during menopause may overlap with both symptoms of cardiovascular conditions and mental health, such as heart palpitations, aches and pains in the chest area, difficulties with concentration or brain fog (British Heart Foundation, 2023). While CHD is present at birth this group of patients is affected by other well-known cardiovascular disease (CVD) risk factors such as obesity, increased cholesterol, hypertension, diabetes, smoking, and physical inactivity (Adihikary et al., 2022). Certain behaviours can also contribute to worsening of cardiac health in this groups, for example, lifestyle choices such as poor diet (high levels of salt, sugar and saturated fats intake), and how well someone responds and is concurrent with managing their heart medication (Abed et al., 2014). A cross-sectional study found that fewer than 50% of adults living with CHD were correctly given information about medication interactions and side effects, risks of smoking and alcohol consumption, risks related to pregnancy and awareness of signs and symptoms CHD deterioration (De Albuquerque et al., 2025).

In menopause consideration is given to HRT to alleviate some of the mental health symptoms (such as low mood and anxiety) that may arise because of the menopause (NICE, 2015). However, when medication for managing symptoms of the menopause is not an option, as for some of the case of women living with CHD, it is crucial to understand the impact this transition may have on mental health. Generally, a combination of psychological support and pharmacological medication is recommended as safe and effective management of mental health disorders, this is unrelated to the treatment of menopause (NICE,2019).

The Role of Clinical Psychologists within Cardiovascular Care and Congenital Heart Disease

While advances in CHD care have traditionally focused on improving cardiovascular outcomes, there is increasing recognition of the psychological factors that influence health outcomes across the lifespan. Cardiovascular and mental health remain top priorities in healthcare (Smolderen et al., 2024). Both behavioural and psychological mechanisms are closely related to cardiovascular care (Dornelas et al., 2018). These interact bidirectionally in cardiovascular care: psychological factors (e.g. stress, anxiety, depression) influence health behaviours and health behaviours (e.g. diet, smoking, lack of physical activity) impact on cardiovascular care outcomes. Some of the key elements of managing cardiovascular and mental health focus on behavioural and psychosocial factors. This is due to the somatic feature of cardiovascular health (Dornelas et al., 2018). The role of clinical psychologists in cardiovascular care goes beyond changing behaviour alone. Psychologists often support with therapeutic assessments, therapy, research, multidisciplinary psychoeducation, quality improvement and leadership (Smolderen, 2024).

Adults living with CHD may not only experience the above challenges with managing cardiovascular health and risk factors during their reproductive years and the menopause, but there can also be additional mental health related concerns due to the impact of hospital admissions and surgeries from a young age. A study in North America found that 88% of adults living with CHD experienced a reduction in reported psychological distress following psychotherapy input (Ferguson & Kovacs, 2016). However, a study found that in clinical practice, access to psychological or mental health support for adults living with CHD does not frequently happen (Bromberg et al.,2023). Research from Kovacs et al. (2006) in Canada identified the factors which determined psychological care within CHD teams, depended on the size of the adult CHD department, the availability of psychologists with cardiac

experience and the commitment shown from the organisation to address psychosocial concerns.

There are currently no specific guidelines in understanding the management of mental health difficulties for individuals living with CHD. However, Molinari et al. (2006) suggested that approaches typical of clinical psychology may be a good framework to begin with.

Psychological Approaches for Cardiovascular Health and Congenital Heart Disease

Despite the limited research on psychological approaches for women living with CHD transitioning through the menopause, theoretical perspectives on the associations between psychological wellbeing and cardiovascular health more widely have been explored (Boehm & Kubzansky, 2012). Behavioural and biological mechanisms are common features of both the understanding and management of cardiovascular and mental health (Diener & Chan, 2011). Psychological interventions may also form part of the cardiac rehabilitation programmes which focus on stress reduction (Rees et al., 2004). This recognises not only the impact of cardiovascular health on the body but also its effect on mental wellbeing such as quality of life and lifestyle choices (Pedersen et al., 2017). The function of this is to promote positive mental health, which can support cardiovascular functioning and reduce the biological effects on the nervous system, to reduce the reactivity to stressful experience (Levine et al., 2021). There are also systemic factors which contribute to psychological wellbeing and healthy lifestyle behaviours including affordable food and housing, improving access to healthcare and eliminating discrimination and poverty (Smolderen et al., 2024). Therefore, a holistic understanding and access to health and social care in society is crucial.

Positive Psychology

One theoretical framework for understanding the interactions between cardiovascular and mental health is based on positive psychology which is underpinned by philosophical approaches (Boehm & Kubzansky,2012). A meta-analysis found that having a sense of

control over one's environment was associated with a reduced risk of cardiovascular disease (Surtees et al., 2010). Similarly, Surtees et al. (2006), in a study of 20,000 participants aged 40 to 80 years, reported that feeling a sense of mastery and control in life was associated with a reduced risk of mortality from all causes, including cardiovascular disease, even when demographic factors, smoking and health conditions were accounted for. A group based psychosocial intervention which focused on coping skills and relaxation found lower mortality for the intervention group specifically for acute coronary events (Celano et al., 2018). However, it is important to recognise that CHD may be understood differently compared to cardiovascular diseases as CHD is not lifestyle related, but could worsen by cardiovascular risk factors (Lui et al., 2014). A qualitative study conducted on adults living with CHD found that their primary focus remains on their CHD and lifestyle diseases such as high cholesterol and being overweight, (typical cardiovascular risk factors) felt secondary (Hoyos et al., 2024).

Behavioural Approaches

Psychological therapies such as Cognitive Behavioural Therapy (CBT) are evidence-based interventions widely used within the National Health Service (NHS). CBT focuses on how an individual's thoughts and behaviours ultimately impact and have an influence on emotions (Beck, 1995). CBT has been the intervention commonly used for people with heart diseases, with the majority of studies focusing on the management of depression (Celano et al., 2016). Within this framework, behavioural activation (BA) is an evidence-based intervention for depression which stems from cognitive and behavioural theories (Hollon & Garber, 1990). The aim of this type of psychotherapy is to help individuals try out new and helpful coping responses based on their values and goals (Martell, 2010). The purpose of this is to attempt to tackle some of the features of depression: withdrawal and avoidance (Lewinsonhn, 1984). Withdrawal and avoidance are often maintained by negative

reinforcement (Skinner, 1938). This is when an individual may stop doing an activity they used to like because they might not have the motivation to get going (avoidance) and by not engaging with the activity or event, as a consequence the struggle to get going is removed, making more likely for an individual to choose this option again (reinforcement) (Skinner, 1938). However, by not going to the activity an individual may unintentionally lose the opportunity for fun, pleasure, social interaction and praise and this therefore translates in fewer opportunities for positive reinforcement (Jacobson et al., 2001). The goal of the therapy is to increase activity in an individual's life which is in line with their goals and values but also brings them a sense of achievement, closeness and enjoyment and therefore, focuses more on what works and not just doing pleasant things (Jacobson et al., 2001). A study found that BA and physical activity support the reduction and severity of depressive symptoms in the long term (two months after follow-up) (Soucy et al., 2017). Reed et al. (2021) highlighted that physical activity delivered safely for individuals with coronary heart disease was beneficial at improving both physical and mental health functioning. Similarly, a nine-week online CBT programme for patients with cardiovascular diseases was found to correlate with the reduction in reported depressive symptoms compared to a general online discussion on depressive symptoms (Johansson et al., 2021). However, some opposing literature suggests BA is not recommended for the treatment of depression in people with non-communicable diseases e.g. cancer, cardiovascular diseases, diabetes and chronic respiratory conditions (Uphoff et al., 2020). The recommendations emerging from this research suggested the importance of assessing BA for individuals without formal diagnoses of depression or subthreshold depression to consider if it is an effective intervention for mild to moderate symptoms of depression in individuals with non-communicable diseases (Upholff et al., 2020). Individuals with both depression and cardiovascular diseases are even more at risk of not engaging in activities, particularly physical activities (Rogerson et al.,

2012). A systematic review looking at the efficacy of psychosocial interventions (non-pharmaceutical) found that most studies did not report long-term effects with most psychosocial interventions demonstrating only short-term effects for individuals with cardiovascular diseases (Klainin-Yobas et al., 2016). Similarly, one study reported no differences in outcomes or re-admission rates for coping skills versus cardiovascular health education alone (Blumenthal et al., 2016). A systematic review specifically aimed at exploring the effectiveness of several psychological interventions for reducing depression symptoms for adolescents and adults living with CHD. The therapies included counselling, psychotherapy and CBT. However, their review found that no studies met their inclusion criteria and they were unable to analyse the data (Leo et al., 1996). The authors later re-visited their review and found that based on three studies, psychological interventions may reduce depression in CHD patients, but the evidence remained low and there was insufficient evidence the draw definite conclusions about the impact of psychological input on quality of life (Leo et al., 2023). The evidence base for psychological interventions for individuals living with CHD, remains an under researched topic.

Exercise and physical activity generally have been shown to reduce depression due the increase in neurotransmitters in the body for example, serotonin, dopamine and endorphins (Basso & Suzuki, 2016). These neurotransmitters are linked with an increase in mood (Craft & Perna, 2004). Physical activity also influences cognitive functioning such as attention and memory which can support with skills such as problem solving and coping strategies which in turn can reduce depressive symptoms (Mandolesi et al., 2018). Individuals who engage with regular physical activity may feel a sense of achievement in line with their desired goals, improving their self-efficacy (Murphey et al., 2022). A qualitative study conducted on adults living with CHD found that participants overtime often learnt to understand their physical limitations, for example, when they have felt overexerted or have

struggled with weight management (Hoyos et al., 2024). There may therefore be some limitations or barriers to people living with CHD engaging with physical activity. However, participants also wanted to strive towards looking after their physical health and not to let their CHD define them (Hoyos et al., 2024).

Acceptance and Commitment Therapy (ACT) is a third wave CBT intervention and has been shown as an effective therapeutic intervention for the management of long-term health conditions (Graham et al., 2015). Third wave interventions focus on a newer generation of CBT which goes beyond traditional CBT by focusing on concepts such as mindfulness, acceptance and values (Hayes, 2017). ACT intends to increase one's ability to engage in meaningful activity despite living through distress. Often, in long term health conditions, the distress and negative beliefs may be realistic and therefore, instead of attempting to alter them, a practise of acceptance may prove more effective (Low et al., 2012).

Further research is needed to understand the specific aspects of mental health that are most relevant for women living with CHD who are transitioning through menopause. There is also limited research and information about the facilitators and barriers of the impact of menopause on women living with CHD, as a result it cannot be assumed that traditional evidence-based interventions are effective among individuals living with CHD and their experiences of mental health symptoms.

Humanistic Approaches

A humanist perspective considers the client at the centre of any kind of therapeutic work also known as "patient focused therapy" (Raskin & Rogers, 2005). According to this view, effective therapy requires the therapist to offer three conditions: unconditional positive regard, empathy and congruence (McMillan, 2004). There is an emphasis that all individuals have their own resources to help themselves and therefore a therapist should remain non-

directive (Waterman, 2013). Adults living with CHD face many ongoing health and personal challenges throughout their lives (Kools et al., 2002). As they age, there is also a potential for heath deterioration, which can further impact their quality of life (Horner et al., 2000). Given the heightened awareness of mortality often experienced with this population, gaining a psychological understanding of their experiences is essential (Kovacs et al., 2006).

Attachment Theory

Attachment theory is a psychological framework that explains how early life experiences with caregivers in infancy, shapes relationships throughout life (Bowlby, 1988). For newborn babies, attachment is essential for physical survival (Holmes, 2015). Parental response and sensitivity to an infant's distress is a factor in creating a secure attachment. This involves caregivers responding to an infant in a timely and appropriate way as well as managing their own emotional discomfort. An insecure (avoidant) attachment may form when infants experience parents who find it hard to tolerate their distress, for example, their crying or expression of need. Overtime an infant learns to self-soothe or rely on themselves (Ainsworth & Bowlby, 1991). This may be because expressing a need, is a threat to their survival. Additionally, an insecure attachment (ambivalent) may form when infants experience inconsistent responses to their needs and as a result may seek closeness and fear rejection (Ainsworth & Bowlby, 1991). Although these early attachment patterns are not permanent, they shape how adults navigate relationships, friendships and help-seeking. CHD creates an ongoing vulnerability, and the caregiver-infant dyad may be impacted in many ways early in life. From infancy, CHD babies may experience difficulties with their regulatory capacities such as sleeping, settling, feeding and soothing due to early exposure to stressors and cardiac surgery (Massaro et al., 2011). Additionally, being in intensive care with loud noises, unusual smells, painful procedures and bright lights (Carbajal et al., 2008) may also influence their developmental trajectory. High emotional distress in caregivers,

along with limited opportunities for bonding may also affect the attachment. Marcil et al. (2023) reported that adults living with CHD 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. These coping strategies may be formed because of a combination of early attachment experiences, attempts to seek help, perceptions around navigating healthcare, family patterns, culture and religious beliefs. Therefore, exploring the lived experiences of the mental health impact of CHD is critical.

Systemic Family Therapy

Systemic family therapy aims to understand the interpersonal relationships and patterns that exist within family structures (Dallos & Draper,2015). It is thought that significant life events can destabilise the homeostasis of a family which can result in a breakdown in the family system. In the context of this client group, a diagnosis of a CHD or other health condition may contribute the challenges within a family system. The innate nature of parents wanting to protect their child is common (Hahn-Holbrook et al., 2011). It can be typical for parents to be overprotective (Brandhagen et al., 1991). As a result, individuals living with CHD may experience a heavy reliance on parental care throughout their life (Kokkonen & Paavilainen, 1992). Qualitative studies which have considered the experiences of parents of children living with CHD found that parents experienced difficulties with medical decision making, experienced uncertainty, self-blame and constant changing of emotions (Harvey et al., 2013; Wei et al., 2016). Therefore, the mental health impact on the family system, is an important consideration.

Guidelines for Clinical Practice

Whilst there is awareness of the cardiovascular risks around the menopause due to the depletion of oestrogen, there may also be risks for women living with CHD in taking

medication. Current guidelines from the National Institute for Health and Care Excellence (NICE 2019) provide evidence-based recommendations for a number of health conditions. Specifically, the NICE guidelines on cardiovascular disease and menopause indicate that HRT does not increase cardiovascular risk when it is initiated in women under the age of 60, with risk primarily linked to existing cardiovascular risk factors. However, these general recommendations may not apply to women who experience early menopause (before the age of 45) as they face a higher risk of developing coronary heart disease due to the drop in levels of oestrogen in the body from an earlier age (British Heart Foundation, 2023). Mental health medications including antidepressants and antipsychotic drugs can also produce side effects which may contribute to cardiovascular complications, for example, cardiac arrhythmias which may contribute to mortality (Pacher & Kecskemeti, 2004). The recommendations for the medication management for adults living with CHD is complex and some medications may not be recommended due to the demonstrated effects on the cardiovascular system (Diller et al., 2016). It is important to consider the potential interactions between HRT, mental health medications and the risk of cardiac side effects (Manrano et al., 2011). CBT has been recommended as a psychological intervention for mental health symptoms associated with the menopause such as depression and anxiety (NICE, 2015). However, research remains limited regarding the impact of CBT for women managing both menopausal symptoms and living with CHD.

This chapter has brought together the background literature in relation to CHD, reproductive health and mental health showing the complexity and their interactions. This thesis is structured as follow:

- Chapter Two provides an overview of the relevant literature and identifies the gap in the research topic and the rationale for this study.

- Chapter Three details the methodology used in this study including the ontology and epistemology, recruitment and ethical considerations.
- Chapter Four contains the thematic analysis results from this study which included anonymised participant quotes.
- Chapter Five integrates the results of this study in relation to existing literature, theory and practice.

Chapter Two: Systematic Literature Review

Chapter Overview

In this chapter, an in-depth overview is presented which examines the existing research on the experiences of reproductive health for women living with CHD. The aim of this review was to understand the lived experiences of reproductive health for women living with CHD. The culmination of the existing research highlights the gaps that exist and offer a purpose for this current research study. At the time of submitting this thesis this systematic review has been submitted and published in *British Medical Journal Open* (See Appendix A).

Introduction

Systematic literature reviews are essential in academic research as they facilitate knowledge advancement by building on existing studies (Clarke, 2011). Therefore, reviewing literature helps to capture the scope of existing research and identify gaps requiring further exploration (Xiao & Watson, 2019). This can then offer recommendations for future research studies and apply recommendations to clinical practice (Fink, 2019).

In this chapter, the author will present a systematic literature review of the studies that considers the following research question: "What are the lived experiences of the reproductive journey for women living with congenital heart disease?"

Reproductive health and becoming a parent are an important life event for a lot of women (Ngu et al., 2014). For women living with CHD, there are additional complexities due to the cardiovascular risks (Schlinchting et al., 2019). A study conducted by Sabanayagam et al. (2017) found that from a survey, pregnant women living with CHD were not aware of the cardiovascular risks related to their pregnancy and that improvements in knowledge and understanding for women living with CHD were needed. Women face a higher cumulative effect from CHD (Pugnaloni et al., 2023), in part due to the distinct set of reproductive challenges faced throughout their lifespan. From adolescence, those with

complex cardiac lesions or on anticoagulation therapy, report menstrual irregularities (Leroy-Melamed et al., 2020). Yet, clinical discussions surrounding sexual health, contraception, and family planning are frequently insufficient or entirely absent in routine practise, potentially leading to unplanned pregnancies (Abarbanell et al., 2019; Haberer & Silversides, 2019). Pregnancy causes substantial physiological stress on the cardiovascular system, marked by increased blood volume and cardiac output, which can significantly exacerbate pre-existing CHD (Sanghavi & Rutherford, 2014).

Beyond medical complexities, women living with CHD encounter unique psychosocial challenges throughout their reproductive years (Kovacs et al., 2022). The transition from paediatric to adult healthcare systems frequently occurs during adolescence and early adulthood, coinciding with critical periods of reproductive development and decision-making. Many women report there is inadequate discussions regarding reproductive health, because their healthcare has primarily focused on cardiac management rather than comprehensive reproductive planning (John et al., 2022; Moons et al., 2021). Family planning decisions for women living with CHD involve multifaceted considerations extending beyond conventional reproductive counselling. These women must balance personal desires for motherhood against potential health risks, consider genetic implications of their condition for future offspring (if applicable), and navigate complex contraceptive decisions accounting for cardiac medications and hemodynamic (blood flow and blood pressure) considerations (Vallido et al., 2010). The intersection of chronic illness identity and reproductive desires creates complex emotional terrain that women must navigate, often with limited specialised support.

Existing research in this field has focused on clinical outcomes and risk stratification, especially quantitative measures of maternal and foetal morbidity and mortality. Although this clinical perspective is essential for medical management, it provides limited insight into the

lived experiences of women living with CHD as they navigate their reproductive journeys. The voices and perspectives of these women have been largely absent from research literature, creating a significant gap in understanding their needs, challenges, and experiences beyond clinical risk assessment. Qualitative research approaches offer valuable insights into subjective experiences of illness and healthcare that quantitative measures cannot capture, thereby providing deeper understanding of how individuals make sense of their health conditions within their daily lives.

Given the physiological and mental health challenges in managing CHD throughout the reproductive lifespan, coupled with current gaps in research and clinical practice, there is an urgent need to understand the lived experiences of women living with CHD during their reproductive years. Here, we review the qualitative literature on reproductive health in women living with CHD to identify key experiential elements and critical gaps across puberty, menstruation, contraception, pregnancy, childbirth, and the menopause. Our objective is to inform clinical practice and support more integrated, patient-centred care.

This review draws on the experiences of reproductive health that women living with CHD experience. The synthesis of the existing literature captures existing knowledge about this topic, assesses the quality of the research, and addresses gaps in the literature that warrant research attention.

To capture a broad experience of women's reproductive journey, this review did not exclude based on the type of reproductive experience. Studies included in this review share the experiences of women going through puberty, pregnancy, childbirth, and the menopause. This is so that women who are unable to have children or chose not to have children are not excluded based on one element of reproductive health.

Method

Design

Due to the research aim, a qualitative meta-synthesis approach was chosen to combine and synthesise study findings to capture themes across multiple studies (Gough et al., 2018). This approach was appropriate compared to a meta-ethnography because although similarities are shared, a meta-ethnography may be more helpful to reconstruct and reinterpret findings to identify new frameworks (Noblit & Hare, 1988). A thematic synthesis was followed using the steps outlined by Thomas and Harden (2008) for systematic reviews. A research question was initially defined, and search terms were generated to select relevant studies in this topic area. Inclusion and exclusion criteria were applied to narrow down the search and studies which met the criteria were included for the synthesis. The review was in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

Inclusion and Exclusion Criteria

To determine the inclusion criteria, the Sample, Phenomenon of Interest, Design, Evaluation, Research (SPIDER;Cook et al., 2012) was used to determine inclusion and exclusion criteria, see Table 1 below.

Table 1.

SPIDER Framework

Spider	**Justification**
Sample	Women with congenital heart disease
Phenomenon of Interest	Reproductive health
Design	Qualitative methods
Evaluation	Experiences
Research Type	Qualitative studies

Studies were included if they (a) included the lived experience of women with CHD (b) focused on any element of reproductive health for these women, (c) qualitative studies, (d) published in English, (e) published in any time period (f) published in any geographical location. Papers were excluded if they (a) focused on the experiences of family members or healthcare professionals or men (b) focused on reproductive health in relation to other non-communicable diseases such as cancer and diabetes (c) did not focus on the lived experience of women with CHD going through reproductive journey (d) single case studies (e) focused on acquired cardiac diseases during pregnancy (f) quantitative studies. The synthesis focused on studies which met the inclusion criteria.

Search Strategy

To determine if a systematic review had already been conducted in this topic, a search on Cochrane Library was completed. Initially, menopause was specifically explored in conjunction with other search terms however, no papers were identified.

An electronic search (APA Psyc Articles, Medline Ultimate, APA Psyc Info, APA Psyc Tests, CINAHL Ultimate) was conducted on 10th March 2025 using the following search terms:

1. "reproductive health OR pregnancy OR sexual health OR family planning or contraception"
2. "congenital heart disease OR congenital heart defect"
3. "qualitative research OR qualitative study OR qualitative methods OR interview"
4. #1 AND #2 AND #3

See appendix B for more details.

Quality Assessment

To assess the methodological quality of the studies included in this review, the Critical Appraisal Skills Programme (CASP, 2018) checklist was used. As this review

focused on qualitative studies, the qualitative checklist was used to assess the relevance, credibility, and rigour of each study (CASP, 2018). The checklist has ten broad questions which aim to systematically assess the relevance and trustworthiness of each study. The guidance on whether to accept or reject a study for synthesis based on their quality has been debated (Atkins et al., 2008; Fosse et al., 2014). Given that the guidance remains unclear and there are few studies in this area of research, the current review, included all eleven studies for synthesis regardless of their methodological rigour to prioritise gaining a comprehensive understanding of the topic (See appendix C for CASP checklist).

Screening and Data Extraction

Title and abstract were independently reviewed by two reviewers. Inconsistencies and conflicts in assessment were resolved by discussion and if needed resolved by a third reviewer. Full-text screening was performed by two independent reviewers (MA & MAd). Data extracted included author(s), aims, location, design, method, analysis, results and clinical implications.

Results

The database search yielded a total of 222 articles with APA Psyc Articles generating 21 articles, Medline Ultimate generating 142 articles and, CINAHL Ultimate generating 59 articles. Additional relevant studies were searched through hand searching reference lists of included articles. See Figure 7 for PRISMA flowchart.

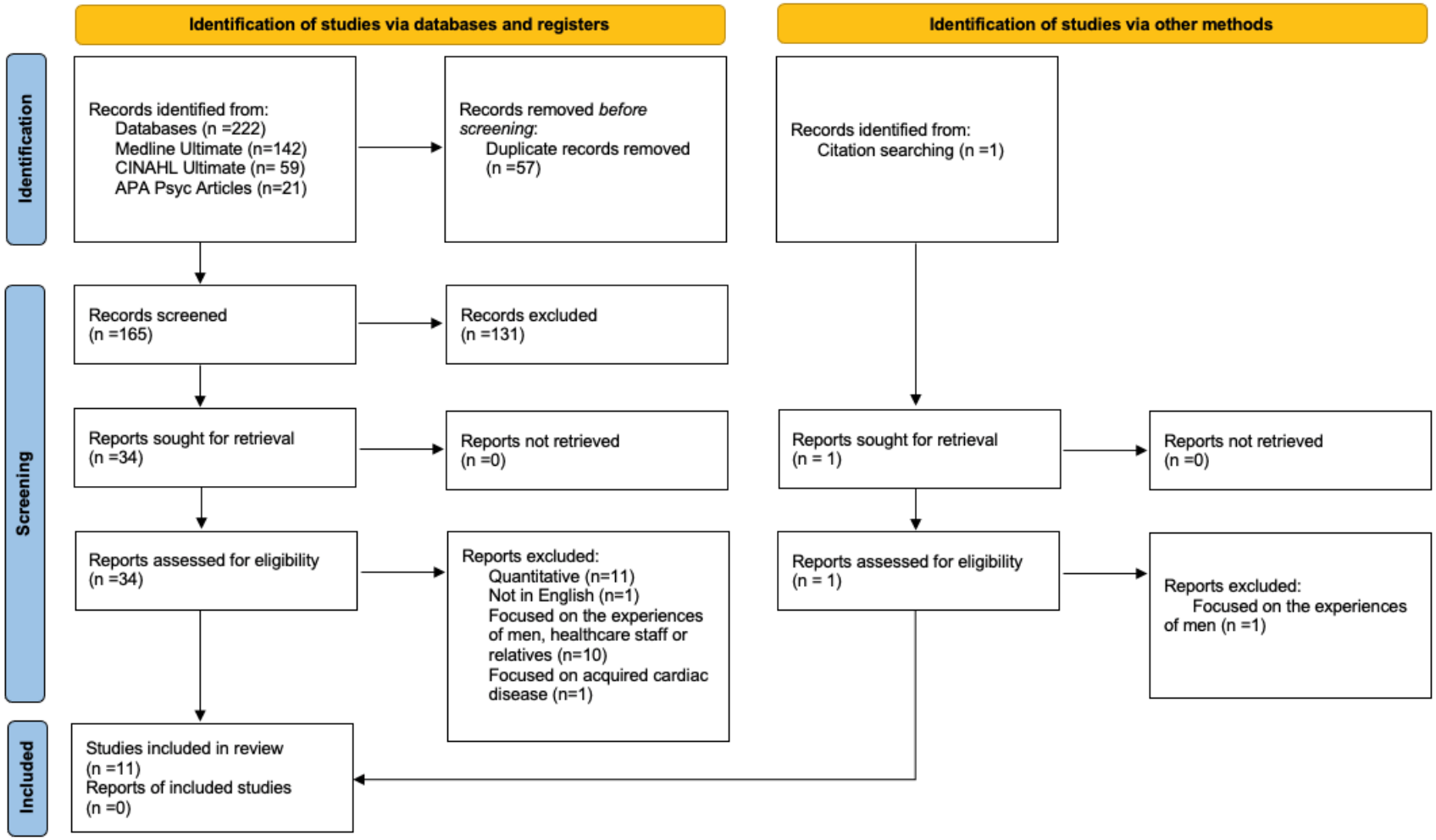

Figure 7. *PRISMA Flowchart*

Study Characteristics

A total of 223 papers were identified, 222 in APA Psyc Articles, Medline Ultimate, CINAHL Ultimate and 1 was manually identified. After removing duplicates, title and abstract,165 papers were assessed of which 35 were included for full-text assessment, with final 11 studies meeting the inclusion criteria and included in the systematic review (Table 2). The studies were based in the USA (*n=4*), Italy (*n=2*), UK (*n=1*), Australia (*n=1*) Taiwan (*n=1*), Japan (*n=1*), Jordan (*n=1*). A total number of 152 women were interviewed across the studies. The sample sizes of the studies ranged from 7 to 25. Four studies used telephone or an online platform to conduct the interviews; the rest were conducted face to face. One study (Ngu et al., 2014) conducted the interviews in person where possible but offered telephone if face to face was not viable. All studies carried out one to one interviewing except one which conducted focus groups.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
Flocco et al. (2020)	To explore the lived experiences of women with CHD during pregnancy and early motherhood.	Italy	Qualitative	Face to face 12 semi-structured interviews recruited using purposeful and consecutive sampling	Interpretative Phenomenological Analysis (IPA)	Three key themes were identified: (1)'being a woman with CHD';(2) 'being a mother with CHD'; and (3) 'don't be alone'.	Individual support is needed for women with CHD. Specialist prenatal and postnatal care which covers both physical and mental health support should be offered for CHD women. Family members should be involved in care, if appropriate.
Gant (1992)	To explore what young women with	United States of America	Qualitative	Face to face 13 unstructured	Grounded Theory	Three categories were identified: (1) 'growing up heartsick' (2)	HCPs should be trained to understand these women's reproductive needs. HCPs to

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
	CHD perceive as the impact of their disease on their sexuality, body images, sexual decision making, and potential pregnancies.			interviews using theoretical sampling		‘growing up female’ and (3) ‘living against the body’.	help CHD women with knowledge about contraception, pregnancy and childbearing to make their own decisions.
Ghizzardi et al. (2023)	To explore the barriers and	Italy	Qualitative	Secondary data analysis	Interpretative Phenomenolo	The barriers were: (1) ‘need for careful manage of clinical risk during pregnancy’ (2) ‘fear that	Psychological support is needed as women expressed worries around passing their

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
	facilitators impacting CHD mothers' experiences in pregnancy and early motherhood.			of Flocco (2020) study	gical Analysis (IPA)	children may have CHD' (3) 'need to physical and psychological support in childcare' (4) 'carrying the burden of their parents' concern' (5) 'uncertainty about future prospects'. The facilitators were: (1) 'positive mental attitude' (2) comparison with non heart disease mothers' (3) 'search for inner strength and hope in facing difficulties' (4) 'involvement in children in dealing with the disease' (5) 'acceptance of support from the partner and	condition on. Trusting relationships with clinicians and nurses is important.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
						family of origin' (6) 'trusting relationship with healthcare providers'.	
Harb et al. (2024)	To explore the healthcare needs and experiences of Jordanian women with CHD during pregnancy.	Jordan	Qualitative	Face to Face 15 semi-structured interviews recruited using purposive sampling	Colaizzi Data Analysis	Three themes were identified: Three themes were identified: (1) 'a broad spectrum of health needs during pregnancy' (2) 'not being cared for' (3) 'the healthcare journey'	A holistic approach in healthcare is needed. Knowledge about CHD should be incorporated in the HCPs training curriculum. HCPs should be skilled to work with CHD during pregnancy.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
Liu et al. (2022)	To explore the lived experience of first time mothers with CHD.	Taiwan	Qualitative	Face to Face 11 semi-structured interviews recruited using purposive sampling	Giorgi's Phenomenological Analysis	Six themes were identified: (1) 'recognising pregnancy risks', (2) 'performing self- care for health', (3) 'building self-worth from my baby', (4) 'adapting to postpartum life and adjusting priorities', (5) 'enjoying being a first-time mother', and (6) 'the factors contributing to success in high-risk childbirth'.	Appropriate social support and psychological interventions are important. The findings highlight the emotional burden experienced by women with CHD during their pregnancy.
Nakamura et al. (2018)	To examine the perceptions of pregnancy and	Japan	Qualitative	Face to Face 12 semi-structured interviews recruited	Grounded Theory	Three categories were identified: (1) 'the realisation that I live with CHD' (2) 'I want to be someone who has sufficient knowledge of CHD' (3) 'the awareness of	HCPs should assess adolescent girls' awareness of their disease before discussing pregnancy and childbirth risks. HCPs to provide support

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
	childbirth among adolescent girls with CHD.			using purposive sampling		getting pregnant and birthing a child while having CHD'.	specific to the timing, stage and degree of pregnancy and childbirth. HCPs should continuously assess concerns around pregnancy and psychological issues
Ngu et al. (2014)	To explore the motivations of women with CHD to conceive.	Australia	Qualitative	Face to Face or telephone 20 semi-structured interviews using purposive sampling	Thematic Analysis	Four themes were identified: (1) 'influence of existing relationships' (2) 'personal influences' (3) 'biological influences' (4) 'cultural and social influences'	Discussions with HCPs should begin in adolescence to support women with decisions about contraception and pregnancy.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
Osteen et al. (2024)	To understand the childbearing decision-making and adaptation experiences of women with CHD.	United States of America	Qualitative	Telephone 17 semi-structured interviews using convenience and snowball sampling	Narrative Thematic Analysis	Five stages of childbearing decisions (1) 'stimulus to consider childbearing'(2) 'exploring childbearing options' (3) 'considering childbearing options' (4) 'choosing to bear or not to bear a child' (5) 'adapting to the childbearing decision'.	There is a need for HCPs to validate and support women's concerns, fears and grief around childbearing decisions.
Steiner et al. (2022)	To understand adults with CHD expectations	United States of America	Qualitative	25 semi-structured telephone interviews recruited	Thematic Analysis	Four themes were identified: (1) 'expectations about pregnancy' (2) 'testing, education, and planning '(3) 'balancing recommendations with logistical	The confidence of the clinician caring for pregnancy in adults with CHD is important. Strong communication skills, multidisciplinary collaboration

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
	for and experiences with pregnancy, including factors that influenced patients' perceived quality of care.			using purposive sampling		reality' (4) 'importance of clinician confidence and communication'	and counselling should be provided to all patients with CHD.
Stokes et al. (2023)	To explore women's perceptions of pregnancy	United States of America	Qualitative	20 semi-structured telephone interviews	Thematic Analysis	Five key themes were identified: (1) 'CHD impacted their reproductive health goals and decisions' (2) 'women with CHD	Women with CHD may have limited information in relation to their reproductive health. Cardiologists should play a role

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
	and family planning care as related to CHD.			recruited using purposive sampling		perceived a lack of safe contraceptive methods for their condition' (3) 'women desired tailored, disease-specific sexual and reproductive health (SRH) information' (4) 'women viewed their cardiologist as the primary source for SRH information and prefer provider-initiated discussions starting in adolescence' (5) 'women desire coordinated pre-pregnancy and intrapartum care between their cardiologists and women's health providers'.	in counselling, pre- pregnancy counselling and peripartum management. This should begin in early teenage years and continue through and after transition to adulthood. Interdisciplinary communication is important for successful patient experiences.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
Tylek et al. (2024)	To explore, examine and identify the experience that women with CHD face as they transition through adolescence to into womanhood.	United Kingdom	Qualitative	Three focus groups on Microsoft Teams with 7 participants recruited using snowball sampling.	Thematic Analysis	Three themes were identified: (1) 'the impact of womanhood and the potential influence of motherhood on the young women themselves transitioning through adolescence with CHD, within medical and sociocultural contexts' (2) 'the challenges of being a woman and undergoing heart surgery during adolescence on the young women's health before, during and after surgery' (3) 'the effect of existing online/offline healthcare and social structures on women's	HPCs should provide CHD patients with practical, psychological and social support. Care plans should address women- specific issues and offer psychological support. Psychological support may be beneficial for young women transitioning through adolescence and should be embedded throughout the lifespan.

Table 2.

Summary Characteristics of Included Studies

Author(s)	Aim	Location	Design	Method	Analysis	Results	Clinical Implications
						health during transitioning through adolescence'.	

Note: CHD: Congenital Heart Disease; F2F: Face to face; HPCs: Healthcare professionals

Quality Appraisal

The quality assessment highlighted that all studies had good methodological quality which addressed clear aims and research questions as well as appropriate research design and methodology. There were clear findings and implications for practice outlined in all studies. The CASP tool did, however, identify that seven studies (Gant, 1992; Ghizzardi et al.,2021; Harb et al.,2024; Ngu et al., 2014; Liu et al., 2022 Steiner et al., 2022; Nakamura et al., 2018) did not examine the relationship between participant and the researcher. Stokes et al. (2023) described their professional roles as researchers and were able to acknowledge that they had no prior interactions or professional relationships with the participants. Given that all studies were qualitative, the beliefs and positions of the researchers may have influenced the data collection, interpretation, and analysis. Flocco et al. (2020), Osteen et al. (2024) and Tylek et al. (2024) demonstrated overall strong methodological rigour when assessed using the CASP checklist. These studies demonstrated the measures they took to acknowledge the researcher and patient relationship. The studies employed a researcher reflection strategy which involved writing and noting their preconceptions of the research area, highlighting how their own beliefs can affect data analysis. Flocco et al. (2020) used a bracketing approach. Researcher reflexivity was practised by Tylek et al. (2024) using their supervisor and research team. Osteen et al. (2024) shared similar lived experiences with the study participants and engaged in reflexivity throughout the research process by employing bracketing techniques and maintaining a reflexive journal. All studies outlined a rigourous analysis which led to clear findings and conclusions.

Ethical approval was granted for all studies except for Gant (1992) where it was unclear if ethical consideration was granted. Steiner et al. (2022) and Stokes et al. (2023) provided a statement that ethical approval was granted but did not provide any reference to

specific ethical considerations that were made. An ethical strength highlighted from Tylek et al. (2024) was the use of patient involvement at every stage of the research.

The studies represent participant populations from Australia, Italy, UK, USA, Japan and Jordan which enabled reflections and experiences from different cultures and healthcare providers.

Synthesis

The synthesis followed the Thomas and Harden (2008) approach which involved line by line coding of the full results sections of the selected studies. To avoid re-analysing the raw data from the authors, participant quotes were not used in this write up, as this risks conducting a secondary analysis of the primary data (Sandelowski & Barroso, 2006). Codes were organised to develop descriptive themes. The descriptive themes did not go beyond what the studies report but rather summarised the findings from the primary studies. This enabled a summary of what different studies have found in relation to this topic area. Analytical themes were then generated to provide a deeper insight into the findings. These were generated by interpreting the descriptive themes to answer the review question.

The thematic synthesis of the included studies led to the development of four analytical themes detailed below.

The Need for Psychological Support in High-Stakes Decision Making

Across all studies, multiple women highlighted the emotional implications of having to make high stake decisions about their reproductive health. Within this theme, women alluded to having to make life and death decisions about their health and their baby's health due to their CHD (Flocco et al., 2020; Liu et al., 2022; Nakamura et al., 2018; Ngu et al., 2014; Osteen et al., 2024; Steiner et al., 2021; Tylek et al., 2024). The lifelong implications of choosing whether to have or not to have a child appeared to be held within cardiology care, where there was an emphasis on medicalising decisions with little offering of

psychological support in that process. The lack of psychological support in recognising the emotional burden of having to make such big decisions was detailed in multiple studies (Flocco et al., 2020; Ghizzardi et al., 2023; Harb et al., 2024; Nakamura et al., 2018; Osteen et al., 2024; Tylek et al., 2024). Two studies suggested that women often used their own inner strength or support systems to seek emotional support during this time (Flocco et al., 2020 & Ghizzardi et al., 2023) and this was their primary source of psychological support.

Subtheme: The Emotional and Psychological Burden of Parenthood

This theme expands further on the need for psychological support in high-stakes decision making highlighting how not only did participants describe having to make life changing decisions but also their concerns about potentially passing on their CHD to future offspring (Flocco et al., 2020; Ghizzardi et al., 2023; Liu et al.,2022; Ngu et al., 2014; Osteen et al., 2024; Stokes et al., 2023). There were also fears of being in situations where their own or their baby's survival was at risk and having to make life or death decisions if complications arose (Steiner et al., 2021). This was later echoed in studies where fears and worries were translated into women not being alive long enough to see their child grow up and the burden of their own health needs exceeding their child's needs (Ghizzardi et al., 2023 & Flocco et al., 2020;). The opportunities for parent-child interactions was another dimension which was perceived as important in relation to the potential physical limitation of their CHD to keeping up with the physical demands of playing with their children (Stokes et al., 2023). The emotional impact of having to face these dilemmas appeared to exacerbate the usual anxieties that come with parenthood.

The Challenge of Receiving Conflicting Medical Guidance

Several studies described conflicting medical advice among the healthcare teams (Flocco et al., 2020; Ghizzardi et al., 2023; Harb et al., 2024; Nakamura et al., 2018; Osteen et al., 2024; Steiner et al., 2021; Tylek et al., 2024). Some women recalled being told that

having children would never be possible due to their CHD, yet later went on to have children after being informed that it was, in fact, possible (Gant, 1992; Ghizzardi et al., 2023; Stokes et al., 2023; Tylek et al., 2024). Others reported having no conversations or discussions about contraception or pregnancy in relation to their CHD which led to unplanned pregnancies, which put their heart health at greater risk (Lui et al., 2022; Stokes et al., 2023). There was an emphasis in the studies that women felt that they needed professional expertise in understanding their CHD and how it impacts their body, and this was not always available or the advice was conflicting (Flocco et al., 2020; Ghizzardi et al., 2023; Harb et al., 2024; Nakamura et al., 2018; Osteen et al., 2024; Steiner et al., 2021; Tylek et al., 2024). There appeared to be a strong focus on the support from cardiologists who were often described as a person the women trusted for their understanding of their CHD (Flocco et al., 2020; Ghizzardi et al., 2023; Ngu et al., 2014; Osteen et al., 2024; Stokes et al., 2023). However, the understanding of their health needs and risks across different departments such as gynaecology and obstetrics was less understood and often participants reported a feeling of insecurity (Harb et al., 2024; Steiner et al., 2021; Stokes et al., 2023; Tylek et al., 2024). Women felt that the complex nature of their CHD became even more confusing when other healthcare professionals did not have a good understanding of their needs. Studies which focused on contraception or puberty similarly highlighted the limited information around contraception from their GP and shared examples of being put on contraceptive pills that were associated with cardiac risks (Liu et al., 2022; Nakamura et al., 2018; Tylek et al., 2024 & Stokes et al., 2023). The consideration of the intersections of participants health needs (physical, mental and reproductive health, medical care and personal circumstance) should be important factors in understanding the reproductive journey of women living with CHD.

Balancing Reproductive Autonomy and Health Risks with Congenital Heart Disease

Concerns around having little or no control over participants decision to have children or not was often removed from their agency due to their CHD (Gant, 1992; Ghizzardi et al., 2021; Liu et al., 2022; Nakamura et al., 2018; Stokes et al., 2022). Women felt that the decision to have children or not was very personal and wanted to have autonomy over their body and decisions they made for their family which wasn't always possible (Harb et al., 2024; Tylek et al., 2024). There were also concerns on the overall medicalisation of their pregnancy and there was an overreliance on medical interventions compared to their own concerns or experiences (Liu et al., 2022; Steiner et al., 2021). This was particularly relevant when women's birth plans had not been followed or their hopes were not considered (Steiner et al., 2021). It was broadly suggested that women wanted healthcare professionals to hold optimistic and hopeful views so that they could feel empowered in their own ability to make the right decision (Harb et al., 2024 & Steiner et al., 2021). However, participants emphasised the importance of acknowledging their own limitations specifically on what would be safe for them (Flocco et al., 2020 Nakamura et al., 2018; Stokes et al., 2022).Therefore, placing greater emphasis on person-centred care could help women better manage the challenges of tolerating uncertainty, particularly if they are supported in making their own informed decisions.

Subtheme: Social Norms and Comparisons of Pregnancy Experiences

Many women reported on the social comparisons between them and their peers who did not have a CHD (Gant, 1992; Ghizzardi et al., 2023; Harb et al., 2024; Nakamura et al., 2018; Ngu et al., 2014; Osteen et al., 2024; Steiner et al., 2021; Tylek et al., 2024). Aligning with this, the concept of womanhood and societal expectations of being able to carry and birth a child were major concerns. This was apparent in two non-western studies (Liu et al., 2022 & Nakamura et al., 2018) where there was a desire to become a mother, which could

reflect cultural gender norms where women provide for children and household duties whereas men provide financial stability. This suggested an 'othering' that women living with CHD may feel in relation to their identity and cultural norms. Despite the concerns with pregnancy, the desire to become a mother appeared to outweigh the potential fears of parenthood and the possible health implications (Ghizzardi et al., 2021).

Impact on Geographical Location on Access to Support

Several studies highlighted the importance of location in relation to having access to resources, with differences in support available depending on location. Women who lived in rural areas described having to travel far to be able to access specialist hospitals to manage the safety of their pregnancy and childbirth (Harb et al., 2024 & Steiner et al., 2021). Three studies (Harb et al., 2024; Liu et al., 2022 & Tylek et al., 2024) highlighted the importance of a social network for these women which included family members, friends and peer support. The idea of having to move away for childbirth appeared to contribute to feelings of fear and isolation from their support network (Harb et al., 2024; Liu et al., 2022; Steiner et al., 2021). This then contributed to some concerns of finances and employment which was detailed in two studies (Harb et al., 2024 & Steiner et al., 2021).

Discussion

The aim of this systematic review was to understand the lived experiences of the reproductive journey for women living with CHD using thematic synthesis of the qualitative literature. This thematic synthesis highlighted the complex nature of health needs for women living with CHD particularly around their reproductive health. There are clear health risks for this group of women (Opotowsky et al., 2012). Women's own desires and wishes may not always be accommodated, particularly around pregnancy. There is ultimately an ethical dilemma which healthcare providers face which needs to balance patient safety and responding to reproductive choices due to the cardiovascular risks (Schlitchting et al., 2019).

However, there did appear to be little consideration or support for the emotional and psychological impact of having to make critical decisions about their reproductive health. Themes relating to 'the need for psychological support in high-stakes decision making' and 'the challenge of receiving conflicting medical guidance' appear to overlap because receiving conflicting medical guidance is likely going to exacerbate the emotional impact of the decision-making process. This leads to doubt and uncertainty, ultimately diminishing confidence in the decision. A collaborative approach has been previously suggested which was to include women and their partners in conversations with cardiology about safe pregnancy (Kovacs et al., 2008). Additionally, healthcare providers may be able to mitigate some of that stress by increasing their confidence and knowledge around reproductive health for women living with CHD. With these findings in mind, psychological based support should be routinely offered which can assist women living with CHD with their reproductive health.

A common concern throughout the reproductive cycle included the decisions around contraception. The studies also highlighted the frequent reports of contradictory advice around hormonal contraception and examples were shared of women being put on contraceptive pills by healthcare providers that had risks for their CHD. Previous studies have highlighted the need for early discussions with healthcare providers for family planning decisions (Canobbio, 2004).

Women often reported that they relied on their own inner strength or support network. The emotional toll of having to make life changing decisions appeared to be reinforced by the healthcare systems because of the limited emotional support available to these women. Whilst in some studies, women described their inner strength as a protective factor in their reproductive journey, other studies focused on the strength provided by other people, for example, family, friends or other women with similar experiences. Previous studies which

have focused on other chronic conditions share similar findings in that sharing experiences with others with lived experiences has been seen as a supportive factor (Sparud-Lundin & Berg, 2011). However, due to the unique and complex nature of CHD, professional guidance should not be negated.

Despite studies recognising the importance of cardiology care for CHD, the same understanding within other disciplines was not always visible. Previous studies have found that family planning decisions are not consistently addressed for this population (Sable et al., 2011).

The inequalities experienced by these women was highlighted by the theme of 'social norms and comparisons of pregnancy experiences' and 'impact on geographical location on access to support'. Previous studies have found that individuals with chronic or long-term conditions strive to move away from feeling 'different' and aim to achieve a sense of normality (Dellafiore et al., 2022). The ability to have children may contribute to having a sense of normality (Tyler-Viola & Lopez, 2014) which reinforces the societal expectation that motherhood is a key aspect of womanhood. However, the access to specialist support varies based on geographical location. Women who have limited access to healthcare may face greater challenges in attempting to achieve normalcy.

Limitations

Although the synthesis aimed to bring together the experiences of women throughout their reproductive health journey, the majority of studies focused on pregnancy and motherhood with only four referring to contraception or puberty (Liu et al.,2022 ; Nakamura et al., 2018; Tylek et al., 2024 & Stokes et al., 2023). The decision to focus on the entirety of reproductive health was to capture all possible qualitative studies that focused on reproductive health for women living with CHD. This was to generate a comprehensive

overview of the reproductive health experience for women living with CHD to offer a holistic view of the reproductive journey.

While the diversity of geographical locations and variations of cultural and socioeconomic experiences and norms of the studies included can be considered a strength of this review, differences within healthcare systems across countries and regions as well as cultural norms and access to resources may result in the themes or subthemes relevant in other contexts.

Although there was input from a second reviewer (MAd) to screen studies, there was no additional input for the interpretations of the findings. This may have led to methodological bias. This was due to the nature of this research being conducted independently due to time restrictions under the conditions for which the review was being conducted.

Conclusions

This systematic review highlighted the significant role that healthcare providers play in women's childbearing decisions and reproductive health amongst CHD patients. It highlighted that despite the clear medical implications for these women; medical advances are not the only significant factor in decision making for reproductive health concerns. This review highlighted the gap within healthcare for the psychological support available for women making life changing decisions, not only for their health but for their family. The review revealed the importance of cardiologist care but also the need for a multidisciplinary understanding of reproductive health for women living with CHD.

Rationale for the Primary Study

The systematic review highlighted the unique strengths and challenges that this group of women face. Given this group of women have complex health needs, their reproductive journey warranted research attention to understand their experiences. As discussed in the

background literature, it is only now with the advancements of surgeries and medical care that we are seeing people living with CHD living to menopausal and older adult age. The menopause is yet again an additional consideration which warrants research attention due to its own unique physical and mental health challenges. Menopause and mental health may be widely explored within 'sub-clinical' populations or within other non-communicable diseases such as cancer and diabetes, but there are no studies which explore the mental health experiences of women living with CHD transitioning through the menopause.

Aims

The overall aim of this research was: To explore the mental health impact of menopause in women living with CHD. The research study had three specific aims:

Aim 1: To explore the lived experiences of women living with CHD during their transition through menopause.

Aim 2: To identify the facilitators and barriers to accessing support for CHD women transitioning through menopause.

Aim 3: To explore psychological and social resources for women living with CHD transitioning through the menopause.

Chapter Three: Methods

Chapter Overview

This chapter presents the method used to collect and analyse the data to explore the mental health impact of transitioning through the menopause for women living with CHD. It considers the primary researcher's positionality in relation to this topic as well as the ontological and epistemological positioning of the research. The research design, procedure, participant sample, recruitment, data collection and analysis are detailed. This chapter addresses ethical considerations taken for this research study as well as quality criteria considerations. The chapter concludes with a dissemination plan.

Reflexivity

My interest in this topic, started vague, in being interested in non-communicable diseases and the impact on mental health. This initially stemmed from having several family members diagnosed with such diseases including cardiovascular diseases and cancers. I also had a strong interest in women's health from my own experiences of being a woman and at times feeling like women's health needs are under researched or minimised.

As I started to research this topic, I thought about how mental health, menopause and congenital heart disease are conditions which in their own right present with broad symptoms. This led me to wonder about the way that services are structured, and how this aligns (or not) with the complexity of the health and wellbeing for this group of women. As I started to examine the intersections of these health conditions, I was curious about the existing care and support offered for these women. I hypothesised if care is isolated to cardiovascular, gynaecology and mental health, then the challenges faced by these women to get integrated support are likely to be high.

I also felt this was an opportunity to broaden the research within this area. The focus of reproductive health research among women living with CHD has been limited to puberty

and pregnancy with little to no research on the menopause, as only recently have women with more complex CHD have increasingly survived to the age of menopause. I became curious about the quality of life of these women and if the combination of these three factors resulted in a different experience. I was also interested in exploring the experiences of those who were accessing healthcare through the NHS to understand their experiences with navigating mental health support and the menopause within adult CHD teams. I am aware that my background in psychology may predispose me to focus more on mental health and overlook the impact of menopause and CHD. For this research study, it is important to examine my own biases and assumptions by self-monitoring.

In my view, it is therefore, of considerable importance to understand the lived experience of these women to help shape services so that holistic approaches can be offered. I am mindful that this research study was based in a high-income country where access to surgeries and healthcare may be more readily available than for women in low-income countries.

I do not have experience of transitioning through the menopause or have CHD; however, I do have experience of having close family members with non-communicable diseases. This may have influenced how I interacted, engaged with and analysed the data for this research study. I therefore maintained a reflective approach throughout the different stages of the research. Rather than seeking an absolute truth, my goal was to offer more deeper and subjective understanding.

Ontology and Epistemology

In research, it is essential to provide a philosophical standpoint to understand how we interpret the world and the impact it has on the research process (Syanley & Wise 1983). Epistemology refers to the theory of knowledge and is a critical aspect of research which includes how researchers understand the world and what they consider valid knowledge

(Raddon, 2010). There are several epistemological positions including positivism, interpretivism, contextualism and constructionism. Epistemology exists on a spectrum from positivism to constructionism (Alvesson & Skoldberg, 2009). A researcher focused on objective and scientifically measurable phenomena may identify with a positivism epistemological stance (Maksimovic & Evtimov, 2023). Conversely, constructionists suggest that knowledge is constructed through interactions and social processes and individuals give subjective meanings to their experiences (Ormston et al., 2014).

Ontology similarly is a division of philosophy that considers the study of what exists and the nature of reality (Crotty, 1998). Ontological positions exist on a spectrum from realism, critical realism to relativism. A realist position proposes that a single, objective reality exists which is independent of our perceptions (Harper, 2011). Critical realism sits in the middle and argues that a reality exists, but it is mediated by social experiences and conditions (Bhaskar,2020). A relativist ontology propose that knowledge and reality are co-constructed through individual experience and different perspectives (Cupchik, 2001).

Several different epistemology and ontological perspectives can be used in research and is often dependent on the design of the study, how it is conducted and how findings are analysed. This research study contained in this thesis has followed a critical realist ontology and a constructionist epistemology as it does not deny the existence of a reality, but it focuses on understanding a reality which is influenced by social experiences. It aims to explore and understand individuals lived experiences, whilst acknowledging there is a real world that can be understood (Scotland, 2012).

The acknowledgment of the reality of living with CHD and transitioning through the menopause is crucial to this research, as well as understanding how their social contexts differ and influence their knowledge and perceptions of their experiences. Although this group of women have shared characteristics, their experiences are likely to differ based on

wider social factors. While this may apply to other group of patients (e.g. women living with other chronic conditions) women living with CHD are uniquely characterised by a lifelong condition which in most of the cases is diagnosed at birth and accompany women through their life, impacting on their life experience. The use of a reflective journal throughout this research ensured that my reactions, thoughts, feelings and judgements were considered throughout this research. This is fundamental to acknowledge my position as an active participant in the research process. An inductive approach was used to enable analysis to take place based on the data context rather than an existing theory.

Study Design

A qualitative research design was conducted and 15 participants were recruited. The justification to include 15 participants was based on the evidence (Hennick & Kaiser, 2022) that qualitative studies with relatively homogenous samples can reach saturation at relatively small sample sizes (9–17 interviews or 4–8 focus group discussions). The upper limit was chosen so that the sample size was large enough to capture some diversity and variations but small enough to allow for rich data analysis.

Participants

Participants were selected among women living with CHD aged between 40 and 60 who were transitioning or had transitioned through the menopause. There was no age limit as to when women were diagnosed with their CHD. No specific timeframe was set for how long into the menopause journey the women were, as it was felt that the women could decide how ready they felt to discuss and reflect on their experiences. It was important to capture the voices of women facing a range of experiences across the menopause transition. Participants were not excluded if they had co-morbidities. Transgender men were excluded due to potential of confounding the study results (their experiences could justify a separate study based on their experiences and inequalities to accessing mental and physical health support).

Consultation Process and Patient and Public Involvement

From March to April 2024, a total of five meetings with professionals working with people living with CHD were arranged. This included two professors, a cardiologist, a clinical psychologist and those working in the third sector. These were people from different regions of the world including Sweden, USA, South Africa and the UK. These consultations took place to explore the potential of this research study and possible avenues for it. The final meeting was with a clinical psychologist who was working within the NHS in an adult CHD team at a hospital in the Southeast of England. This meeting highlighted that their team had conducted a focus group on a smaller scale a year prior as there was limited understanding about the menopause transition for women living with CHD. Their reflections placed an emphasis on the need for this research. As such, the clinical psychologist offered their availability to become a second supervisor in this research and offered to support with recruitment (subject to ethical approvals).

During the ethical approval process which proceeded in 2024, we discussed the importance of the inclusion of participatory action within research (Baum et al., 2006). The involvement of people with lived experience was important to shape the research from the start. The foundations of this research wanted to truly capture the participants and their voices. Email exchanges with a third sector charity took place to explore the possibility of co-producing this research and interview schedule with someone with lived experience, however this was beyond the scope of their remit, and their policy and practise required ethical approval to first be sought. Following this, it was explored through the NHS within the adult CHD team. An email was sent to the NHS trust research department to enquire if ethical approval was needed to involve patients in the co-production of the research questions. Confirmation was sought and approval was not required for this to take place. As a result, patients who had previously attended the hospital-based focus group and expressed an

interest in being involved in future research were contacted. Three individuals expressed an interest and a meeting on Microsoft Teams was arranged with them individually to co-produce the interview schedule. There was no mutually convenient time for all to meet as a group, and a decision was made to meet individually. Two out of the three co-production meetings took place on Microsoft Teams and the third was cancelled by the primary researcher due to personal circumstance. The meetings each lasted approximately one hour and was facilitated by just the primary researcher. Potential interview questions and prompts were discussed, and efforts were made to keep the interviews semi-structured so that participants were able to discuss and share what is important to them. The aim was to ensure the interview questions felt meaningful and relevant to women living with CHD. Prompts were thought to be helpful along with the interview questions to invite participants to discuss their experiences in more depth if they would like to. A £20 Amazon voucher each was granted by the primary researcher's supervisor for their time and expertise in co-producing the interview schedule. See appendix D for final copy of the co-designed interview schedule.

Recruitment

Recruitment of women living with CHD took place through an NHS hospital, in the Southeast of England as this was a specialist adult CHD service. The decision to recruit via the NHS was made as these women remain under the care of NHS cardiology services throughout their life. Participants were recruited via purposive sampling through the support of the psychological service in the hospital. Purposive sampling involves recruiting participants based on shared characteristics of experiences (Creswell & Poth, 2016). Purposive sampling was an important consideration as the research study focused on the experiences of being a woman living with CHD who was transitioning or had transitioned through the menopause. A poster (Appendix E) was displayed on the wall within the hospital to advertise the research, this contained a quick response (QR) code which participants could

scan, directing them to the email address of the primary researcher, therefore, self-selection sampling was additionally used. All clinical staff were emailed about the research study, and it was discussed in a service level meeting. The poster was disseminated to the teams and clinics relevant to the CHD team at the hospital. Access to in house translators was available which included Bengali/Sylheti, Arabic, Turkish, Spanish/Portuguese, Somali, Romanian, Russian, Latvian, Polish, Cantonese/Mandarin, Punjabi/ Hindi/Urdu and for other languages access to language line was available.

The clinical psychologist in the adult CHD team contacted potential participants via telephone, email or in person and shared the information sheet (Appendix F) and consent form (Appendix G) if they expressed an interest. The participants were asked to give consent to be contacted by the primary researcher who then arranged the interviews. The primary researcher emailed each prospective participant on their University of Essex email address and participants were given the opportunity to ask questions. Reflecting in action on this process, enabled some changes to the recruitment strategy. The co-ordination of interviews became difficult as although participants expressed an interest, contact was then stalled. Therefore, the strategy changed and if participants expressed an interest in participating, the co-ordination and timetabling of the interviews was completed by the clinical psychologist who had access to the primary researcher's availability. Participants were asked to make a final decision if they would like to participate in the research study and return their signed consent forms via email to the primary researcher prior to the interview taking place. The participants that expressed an interest using the QR code from the posters displayed in the clinic rooms were co-ordinated directly by the primary researcher. Participants were all given some flexibility and choice on the dates and times of the interview. Participants received a Microsoft Teams link for the interviews to take place online which was sent from the primary researcher's University of Essex email address. The use of remote interviews enabled

participants to access the research study from wide geographical regions and allowed participants to take the interview within the comfort of their environment and participate at a convenient time for them without needing to travel (Dodds & Hess, 2020). To address the issue of technological literacy which may cause potential difficulties with conducting the interviews remotely (Dodds & Hess, 2020) participants had the option to take the interview in person at the hospital. All participants opted for the Microsoft Teams interview except for one who requested for a telephone interview (they gave consent for the telephone number to be shared with the primary researcher for the interview to take place). Their telephone number was called from a withheld number at the agreed time of the interview. One of the individuals with lived experience who co-designed the interview schedule, later went on to sign up and participate in the research study.

Ethical Approval

Ethical approval was obtained through NHS ethics and the University of Essex before recruitment started. On 13th December 2024, a favourable opinion was granted from Health Research Authority (HRA), IRAS project reference 343439 (Appendix H). Following this, on 19th December 2024 the University of Essex granted ethical approval for this research study, project reference: ETH2425-0600 (Appendix I). Site approval was then sought via NHS trust ethics for capacity and capability approval, and this was granted on 2nd July 2025 (Appendix J). Stringent ethical guidelines were followed to ensure the safety and wellbeing of all participants.

Interviews

All interviews were conducted by the primary researcher and participants were unknown to them personally or professionally. At the start of each interview, introductions were made and participants were given an outline on what to expect with the interview. It was explained that the interview would last approximately one hour, and participants could

answer questions in as much or as little detail as they felt comfortable with. Participants were also reminded that they could have a break or withdraw from the interview at any time before it ended and were not required to use the hour. It was explained that demographic questions would be asked before the interview questions which were relevant to the research study. An additional aim of this was to build rapport prior to the interview questions, as these questions are usually familiar to participants and allow them to ease into the interview before considering the reflective or sensitive questions. Participants were reminded that as per the information sheet and consent form, the interview would be audio recorded and transcribed.

Confidentiality was explained and the debrief sheet (Appendix K) and letter template to their GP (Appendix L) was discussed at the start of the interview with each participant. The purpose of the letter template to the GP was a recommendation from the ethics committee who suggested that participants' GP may welcome them knowing they are taking part in a research study which was health related. The letter was optional for participants to share with their GP, if they chose to. Participants were reminded that the primary researcher would not notify their GP about their participation in a research study, but a letter was available to them to send to their GP, if they wanted to notify them. These documents were both emailed across by the researcher prior to the interview starting. A decision was made to send these at the start of every interview as a precaution in case the connection was lost, or the participant had to leave the interview and was unable to re-join.

Participants were reminded that they did not have to keep their camera on throughout as audio recording was only required. Before the record button was pressed on Microsoft Teams, participants were asked if they had any questions prior to starting. Interviews lasted between 40-80 minutes. At the end, participants were given the opportunity to debrief and ask any final questions before the interview was ended. Participants were reminded that they were each entitled to a £20 Amazon voucher for their participation for which consent was

requested to share their email address to the finance officer at the University of Essex to process their voucher. At the end of the interview participants were asked if they would like to receive a copy of the full research study once completed.

Microsoft Teams provided an automatic transcription of the interviews; these were downloaded onto the primary researcher's personal computer and saved as an encrypted files on Box. Box was selected to host the data as access requires 2-step verification for users. This increased security and prevented data breaches. Recordings were therefore stored securely following Data Protection Act (2018) and recordings were deleted after transcription to protect participant's privacy. The transcripts were checked manually against the recordings for accuracy. The telephone interview was also recorded via Microsoft Teams, which provided the automatic transcript, this was later organised and checked for accuracy by the primary researcher.

Pseudonyms were assigned to each participant and used in the write up in order to protect their anonymity. The procedure followed ethical procedures according to NHS and University of Essex ethics.

Recruitment closed on 11th November 2025 once 15 interviews were complete.

Ethical Considerations

Participants had the right to withdraw from the study at any point during the interview without the need for justification. However, once the interviews ended, it was not possible to remove. The protection of participant's identity was maintained by anonymity and confidentiality. Personal identities were anonymised following the transcription of interviews to protect privacy and ensure that individual responses could not be traced back to the participants. Consideration was given to the sensitive nature of the research topic to ensure discomfort or harm was minimised during the interview. The primary researcher was able to monitor for signs of distress and respond appropriately to ensure that the wellbeing of

participants was paramount. Following the interviews, participants were provided with time for a debrief.

In line with the National Institute for Health and Care Research (2024) (NIHR) guidelines for payment of member of the public involved in research, a £20 Amazon voucher was provided to each participant to thank them for their time and participation in the interview. Funding to support the payment was obtained the facilitating research fund from the University of Ethics

Informed Consent

To ensure participants understood the nature of the research study, an information sheet detailing the purpose of the study, the process, potential risks, and benefits was provided to all individuals who expressed interest in participating. All participants were asked to confirm that they had read this prior to completing the consent form. The information sheet enabled participants to make an informed decision about their involvement. Prior to participation in the research study, written informed consent was obtained, and electronic signatures were accepted.

Confidentiality

Given that participants were recruited from a hospital site in which they were receiving care, it was crucial that participants were aware that their involvement in the research study did not impact the care that they received. The personal data and demographic data collected during the interviews remained anonymous and participants were given pseudonyms. Participants' demographic data was input into a collective table which was stored separately on a word document from their interview transcript.

Right to Withdraw

Participants were notified that their participation in the research study was voluntary and that they had the right to withdraw from the study during the interview without giving

any reason. However, once the interview was finalised, their data would become anonymous and therefore, it wouldn't be possible to identify and remove their data.

Risk of Harm

The nature of discussing mental health difficulties along with the experiences of living with a non-communicable disease and transitioning through the menopause, could bring up feelings of discomfort or distress for participants. Participants were reminded at the start of the interview to share as much or as little detail as they feel comfortable about their experiences. Participants were reminded that they can take a break throughout. The debrief sheet was discussed prior to commencing the interview to manage any difficulties with internet connection. Due to the nature of the primary researcher working as a trainee clinical psychologist, they were familiar with working in emotive circumstances, therefore, to provide comfort throughout the interviews, the researcher offered non-verbal cues such as nodding, smiling and giving eye contact to support. The aim was to create a space that was curious and non-judgemental whilst remaining in the role as a researcher. The use of the interview schedule helped to contain the questions and direction of the interview. Time was given to allow participants time to process each question. A reflective journal was completed following each interview to attend to thoughts and feelings for the researcher. Meetings with the primary supervisor took place every three weeks throughout the research, including during the recruitment process. Clinical supervision was also offered by the clinical psychologist working at the hospital to explore the primary researchers' feelings in relation to what had been heard in the context of challenging health circumstances. However, due to the researcher's own time constraints, this wasn't taken up.

Analysis

Reflexive thematic analysis (RTA) is widely used in psychological research because of its flexibility in theory and methodology (Braun & Clarke, 2006;2022). RTA involves

identifying patterns and systematically analysing the data by creating codes which are significant to the research question (Braun & Clarke, 2006;2022). The coding process is flexible, and new codes often emerge through analysis. The codes can be grouped into themes and sub-themes which capture the richer description of the topic. This can help to reveal commonalities and differences in how individuals experience and cope with these overlapping conditions. The analysis process was followed using Braun and Clarke (2006;2022) six stage approach following the data collection which involves, familiarisation of the data, generating codes, identifying themes, reviewing themes, defining and naming the themes and producing the report (Table 3). To ensure rigour of the analysis the 15-point checklist suggested by Braun and Clarke (2006;2022) was also followed to ensure high quality RTA (Appendix M). The software NVivo version 15 was used to code the transcripts.

Table 3.

Six Stages of Reflexive Thematic Analysis (Braun & Clarke, 2006;2022)

Thematic Analysis Six Stages	Analysis
1. Familiarisation with the data	The data was auto transcribed by Microsoft Teams, and it was checked by the primary researcher for inaccuracies. The audio recording was listened to, transcribed and each transcript was read and re-read multiple times to become familiar with the dataset (see appendix N for anonymised example of a transcript). The familiarisation stage also involved writing initial codes and a journal was kept by the primary researcher after each interview to write personal reflections on analytical ideas that were coming through.

2. Generate initial codes	Each dataset was coded twice using NVivo software and this was in line with text that was relevant to the three research questions. The transcript was read line by line, highlighted and labelled using the software. The codes were descriptive in the form of a word or a few words. Codes were both semantic i.e. it was based on the words the participant used which helped remain grounded in what the participant said. Latent codes were also used which considered what the researcher may have assumed the participant meant, not in the words they used, but what may be under the surface in what they were implying. The Flick (2009) open coding prompts to support with assigning data with codes was used. As the software NVivo was used, the highlighted text and the code associated with the text was available to later extract into excel. This enabled quotes to be later easily accessed during the write up.
3. Search for themes	The codes were then grouped by what they had in common, and this was completed in a map (Appendix O) and then later in a table. This was initially completed using pen and paper to group them based on similarity, and on the topic or problem they faced. The generation of themes was then completed by

	capturing the codes that overlapped and these were grouped together with each other to help represent more interpretative codes and then into a broader theme. At this stage, some codes were felt not to be important and discarded. The themes were not just based on frequency but were also based on salient points to help tell the story which felt to be important based on the research questions.
4. Review the themes	The coded extracts and the data set was reviewed to check if it reflected what was said in the raw data. The themes were reviewed to ensure that they collectively formed a coherent story that remained true to the data.
5. Define and name the themes	The themes were defined and meaningful names were given to capture what they represented (see appendix P for the final codebook).
6. Produce the report	The final report is produced in the results section which outlines the primary researcher's interpretations of the participant's experiences to answer the research questions. The results use anonymous quotes to detail the experiences shared by participants.

This approach was chosen as it is well suited for complex topics where there can be multiple factors and experiences interacting. RTA allows for depth in participants' experiences and perceptions to capture the mental health impact of the menopause and CHD for this group of women. This approach emphasised participants' voices, as personal experiences and insights are central to this topic area and are necessary for generating rich data to enhance understanding. The approach is flexible and can be adapted to different theoretical frameworks which is important when dealing with the individualised nature of health experiences.

RTA also allows for reflexivity, as mentioned above, it is crucial that my own experiences shape my understanding and approach to the research. My own biases, assumptions and cultural understandings of health and healthcare were also thought about. Reflexivity is essential for ensuring that this research was conducted ethically and rigorously so that the findings accurately represent the participant's experiences.

Rigour and Trustworthiness

Qualitative methods consider rigour and trustworthiness as central to the methodology, which is different to quantitative research whereby reliability and validity are crucial (Lietz et al., 2006). Trustworthiness is established when findings accurately represent the meanings conveyed by the participants (Guba & Lincoln, 1994). Therefore, to consider biases that may have arisen between the primary researcher and participants, the following strategies were employed.

Audit Trail

Sandelowski (1986) highlighted that findings are auditable when an independent researcher can trace the decision-making process undertaken by the researcher. In addition, when given the researcher's data, context and perspective, another researcher should be able to arrive at comparable, though not contradictory conclusions. Throughout this research, the

primary researcher kept written notes of meetings and decisions made including during the data collection and analysis (Creswell & Millar, 2000). This aimed to improve the rigour of the research study.

Triangulation

To mitigate the potential of findings being interpreted based on the researchers own assumptions towards health, the interviews were audio recorded and transcribed. Although the analysis was not completed by two independent researchers, the themes were reviewed by two supervisors to minimise biases. The aim was not to arrive at a complete consensus, but to give attention to the different ways to the data could be interpreted (Patton, 2002) to enable the research to be transparent. This was to ensure it is visible and understandable throughout this research about how conclusions and interpretations were made (Sandelowski, 1993).

Participants' Quotes

Direct but anonymised quotes from participants were used in the results section to support findings and trustworthiness of the data (Smith & Noble, 2014). This also helped to offer depth and richness to the research by including the lived experiences and feelings shared by participants.

Reflective Journal

The primary researcher used a reflective journal following each interview, this helped to note down their feelings, thoughts and assumptions about what was being heard to ensure biases were attended to when analysing the data. The idea of completely separating the beliefs of the researcher throughout the research may not be possible (Ahern, 1999). However, being honest and attending to the pre-existing beliefs, help to support with attending to the experiences of others with an open mind. To do this, the primary researcher, remained open and showed sensitivity to the experiences shared by the participants by

adopting a stance of “not knowing” and “wanting to understand” (Dahlberg & Dahlberg, 2003).

Quality Criteria and Considerations

It is important to acknowledge the motivations and reflections of the primary researcher in this research study, due to the sensitive aims and objectives in exploring the mental health impact of the menopause on women living with CHD. The social context of the primary researcher as a non-menopausal woman who does not have CHD was reflected upon and acknowledged. The primary researcher was transparent in the fact that she had no research or clinical experience of working with this client group, but the inspiration had come from wanting to understand the mental health impacts of those living with non-communicable diseases. The researcher felt that this research study was important in shaping the experiences of women living with CHD and their access to healthcare.

It is possible that the primary researcher’s personal experiences may influence interpretations of interviews and women’s accounts, particularly in relation to mental health. It may be difficult to remove all assumptions, as emotional responses are likely to be elicited.

Alternative Methodologies

Further clarification is provided regarding the decision to choose RTA over other qualitative analysis.

Grounded Theory, developed by Glaser and Strauss (1967), seeks to generate new theories. This method was not chosen for this research as the aim of this research study is to look at women’s experiences of the mental health impact on CHD, whilst transitioning through the menopause, rather than developing a new theoretical framework.

Interpretative Phenomenological Analysis (IPA) developed by Smith (1996) aims to explore individual’s personal and social experiences and how these are made sense of. It focuses on examining in detail individual experiences and how the person makes sense of

what is happening to them. Given that the experience of women in this research is likely driven by complex biological, medical, social and psychological constructs, IPA may not be suitable as it requires deep reflection on personal experiences. Although IPA offers a deeper insight into individual experiences, it may not address the broader patterns across participants in relation to accessing support or systemic factors.

Dissemination

The study findings are presented here in a doctoral thesis format. However, this research will be submitted in peer-reviewed journals in the field of cardiology (e.g. the International Journal of Cardiology Congenital Heart Disease or the British Medical Journal), women's reproductive health (e.g. the Lancet, Obstetrics, Gynaecology & Women's Health Journal), or clinical psychology practice (e.g. Journal of Clinical Psychology). In addition to the academic outputs, an infographic poster will be created and shared at the recruitment site and other hospitals and services that support women living with CHD who are transitioning through the menopause. The findings of the research may support or inform policies within NHS and charitable services, particularly focusing on the mental health offer available to women living with CHD. A copy of the research will be produced and shared with participants via the researcher's primary email address.

The potential impact of researching the lived experiences of women with a CHD is significant. The research aimed to understand the mental health impact of women transitioning through the menopause and how their unique health challenges are navigated. It aimed to understand the complexity of both mental health and physiological changes, with the view to give holistic insight. The voice of women at the heart of this research can identify areas of support for this population. The results will contribute to providing a more inclusive and holistic practice so that medical care and mental health support can co-exist. This

research study may prompt future research about how the menopause can impact the mental health of those living with other non-communicable diseases.

Chapter Four: Results

Chapter Overview

This chapter presents the findings of this research study. Participant demographics are presented. The themes developed from the reflexive thematic analysis are provided and quotes from the interview transcripts are shared to illustrate the themes. Participants' anonymity has been protected, and no identifiable data has been published. Pseudonyms have been used throughout.

Participant Demographics

Seventeen participants expressed an interest and signed up to participate in the research study. However, two were no longer able to participate due to personal circumstances (one person did not respond to contact made and one declined and were no longer interested). As a result, fifteen participants were recruited for the study and completed the interviews. Table 4 outlines participant demographics.

Table 4.

Participant Demographics

Demographic		Frequency
Age	40-45	1
	46-50	8
	51-55	5
	56-60	1
Age diagnosed with CHD	Birth	7
	20 months old	1
	4 years old	1
	28 years old	1
	31 years old	1
	37 years old	1
	42 years old	1

	40 years old	1
	52 years old	1
Name of CHD	Pulmonary Valve Stenosis	3
	Transportation of the Great Arteries	2
	Atrial Septal Defect	1
	Congenital Connective Tissue Disorder, Marfan Syndrome	1
	Pulmonary Atresia	1
	Tricuspid Atresia	1
	Unsure	1
	Patent Foramen Ovale	1
	Transportation of the Great Arteries, large VSD, Pulmonary Stenosis	1
	Cor Triatriatum	1
	Bicuspid Aortic Valve and Coarctation	1
	FLNA Deficiency	1
Menopause stage	Perimenopause	4
	Menopause	6
	Postmenopausal	2
	Unsure	3
Ethnic Group	White	13
	Mixed	1
	Bangladeshi	1
Nationality	American	1
	British	13
	Welsh	1
Sexual Orientation	Heterosexual	14
	Lesbian	1

Religion/Spirituality	None	8
	Christian	5
	Muslim	1
	Prefer not to say	1

Summary of Themes

The themes and subthemes were developed using reflexive thematic analysis (Braun & Clarke, 2006;2022) and details about how the researcher arrived at these themes has been outlined in the methods chapter. Overall, six themes and eleven subthemes were identified (Table 5, Appendix Q).

Table 5.

Themes and Subthemes

Main Themes	Subthemes
The Cumulative Impact of Health Factors	Overlapping Symptoms
	Anxiety and Bodily Vigilance
Physical Change as an Emotional Reminder	
Gaps in Knowledge and Holistic Understanding	Caught Between Conflicting Advice
	Siloed Services
	Insufficient Access to Comprehensive Menopause Services
Seeking Safe Choices	Specialist Psychological Support

	Living Safely with System Delays
Personal Coping Resources	The Strain and Strength of Self-Advocacy
	Menopause in the Context of Serious Health Conditions
Social Connectedness as Support	Community Support
	Intergenerational Support, Family and Partner Relationships

Theme One: The Cumulative Impact of Health Factors

The first theme highlights the breadth of health factors that women living with CHD face and have largely experienced from a young age. Personal experiences provided a deeper understanding of the different challenges experienced at various stages during the life course. However, it emerged how the transition through the menopause has added an additional layer of complexity.

Rosalie shared the ongoing trauma of living with CHD from a young age and feeling like she has had to disentangle her symptoms. The additional burden of being left to figure out her health needs may perpetuate the feelings of confusion and isolation.

> *"I never had a mental health problem, but the history of a congenital heart condition from a young age is traumatic. So even if I'm the most stoic person on the planet, I am traumatised by my experiences. So previous trauma comes into it and my experience is that each thing has been treated separately. So heart, menopause, and mental health have been treated separately; it should be like a Venn diagram, it's not being looked at biopsychosocially. So, my experience is fragmented, confusing and lonely because I've had to work it out myself."*

In comparison, Saffron spoke about how multiple health related factors interacted and intensified over time, particularly during the menopause. Saffron highlighted that these changes didn't appear to occur in isolation.

"...But I think sometimes what can happen is that you're aware of the physical symptoms, my periods have stopped, but maybe the other symptoms, I'm like, is it because I'm tired? Particularly when I was first diagnosed with menopause and then I discovered that my blood pressure had gone up, possibly as a result of menopause. I was quite anxious about that. But I do think that from a cardiology point of view, it's weird that I was completely stable for 20 years and then it started changing. I was stable for so long and they don't know if it's changed because of menopause or not. I don't know if I should be upping my hormones or not. That seems like a really interesting bit of information. They should know my hormones are only going to go down, so if it was hormones that caused it, it's only going to get worse. So that's the bit I kind of find perturbing. There was definitely more uncertainty because I'm going through the menopause."

Eve shared not only the physical impact of living with CHD, but how the psychological impact associated with aging reduced her confidence.

"Yeah, everything affects my heart and sometimes the food I eat impacts it. So I have to watch what I'm eating as well. I'm always thinking about it, you know. It's hard for me to exercise because of my mobility is poor. So, I haven't got the confidence to walk on my own so much like I used to. I see it's getting there; it's getting there now."

Skye shared various health concerns, and the combined effect of these needs made the menopause particularly difficult to navigate.

"What I found difficult is what to understand, what is the repercussion of surgery? What's my age, what's general pains from my arthritis? I think I'm more prone to

putting weight on which I think is an age thing. I'm quite tired, but again busy. Recently I've been to the GP because I've had a load of joint pain in other joints which I know can be a menopausal symptom and my GP wanted to try HRT, but she won't do it without [the hospital's] permission. So, she's written to them [the hospital]. I think she's waiting to hear back from them [the hospital]. So yeah, it's really hard to understand what's what if you know what I mean. There's too many other things going on."

Not all participants shared that living with CHD has been traumatic, Josephine and Mary described that they coped generally well living with CHD, despite being treated differently, but as they progressed with aging, the impact on their body was noticed. Josephine said:

"Growing up, it was OK. It was always in the back of my mind, always treated slightly differently with a congenital heart condition, but as I've got older, it's a lot more difficult to cope with...Well, having a congenital heart disease impacts everything."

Similarly, Mary said:

"Well, because I was born with it. It's just me. It's just how I am. So I don't know any different. I used to go to a lot of hospital visits. It's [CHD] is just part of me in my life. I probably noticed it more as I've got older."

Estelle shared that living with CHD has been very difficult and limiting and how the condition itself had led to other associated health challenges.

"Very limiting, life limiting. Very just, I would, say it can be tedious at times, just, you know, it [CHD] causes a lot of anxiety and depression and just constant hospitals and things like that. So yes, it's just very life limiting I would say. Well, I'm noticing now that it's bringing on other conditions, because of the heart condition. So even though the heart is stable, other things in in the body are starting to go wrong because of the

heart, so I suppose as time goes on it, I would say my health has declined because of that."

Managing multiple-conditions was also highlighted by Beatrice who described feeling relieved that she did not require medication for menopausal symptoms, given the number of other health conditions she was managing using medication.

"Now I'm quite happy because I have to take tablets for everything else, to be honest. So another tablet would just have irritated me. To be honest, I have to take something for the hip, I have to take aspirin for my blood, for the heart. I have a thyroid issue so I have to take medication for that."

Subtheme: Overlapping Symptoms

Participants often described how confusing it can be to try to disentangle their bodily symptoms from one another. There were similarities in the ways in which participants described the impossible task of knowing what symptom is related to what problem. The psychological impact of this appeared to have felt isolating and confusing. This may be common amongst complex health conditions. However, in the context of CHD and menopause, symptoms such as hot flushes may be accompanied by increased heart palpitations, making it unclear whether these experiences reflect the menopause of a deterioration in CHD. This perhaps communicates the importance of support being available to disentangle their experiences.

Victoria shared the psychological struggle of attempting to decipher between the overlapping symptoms.

"Some things seem to overlap quite a lot, and I have to try and reassure myself that you know that it's not necessarily heart related. When my anxiety's been acute, I thought there's something wrong with my heart. At one point I did ring them [the hospital] several times. You know that your heart is racing, for example, then you

should go to A&E, and to be fair, when you're a bit anxious, A&E is probably the worst place you could possibly go to and it's not necessary, you know."

Saffron and Skye alluded to the lack of knowledge or understanding that exists as to what symptoms are contributing to their difficulties which creates uncertainty in them. Saffron said:

"It's just solving of the problem: is the menopause causing this problem? This isn't something that anybody seems to know."

Skye said:

"Like that's the problem in some ways with the heart is that it's connected to so many different things and it can react to so many different things. Obviously with anxiety as well, it can be a mixture of all of them and you just don't know what is what...I don't want to be running to A&E every time I have a hot flush just in case there's something wrong with my heart and then probably the one time I go, oh, it's only a hot flush. I won't bother calling the ambulance will be the time that I need to go the hospital. How? How do you know."

Rosalie shared that the overlapping symptoms of her traumatic experience in intensive care unit (ICU), as well as the lack of oestrogen from the menopause has impacted her feelings. It magnifies the importance of mental health professionals and physical health professionals having a dual understanding of the needs of women with living CHD.

"It was triggering because I've been in ICU. It was that which brought me [to psychology], but my emotional vulnerability was the menopause. It wasn't the topic of discussion, the treatment I needed was oestrogen and as lovely as the person was who I saw, who I still see occasionally, who has done a good repair, has read loads about the menopause and has done all the right things, but they missed it. I forgive them but

they also missed it, I missed it. I need oestrogen and a good discussion about childhood trauma, but I needed oestrogen."

Estelle shared that the shift in her hormones whilst transitioning through the menopause contributed to her anxiety symptoms and the worry about this further impacting her CHD.

"I think the hormones are playing havoc in my body and I think that it creates the anxiety which then obviously creates the pounding in the chest. Which then you think to yourself, is it the heart? Is it the anxiety?... In the back of your mind, it is your heart. You know, if I get very hot, I sweat a lot and I'm thinking to myself, oh gosh, I've got to try and stay hydrated because the heart will suffer and I've noticed I've got swelling in my legs, I don't know if that's menopause, pre-menopausal but I'm like well, is that the first sign of the heart struggling? I always think what is it going to do to the heart, is it going to damage it further? I just feel like at the moment my whole mind, body and everything is just the one big jumble, so yeah, I mean it's crazy what's going on."

Margaret recalled the experiences of having a stroke, but the initial symptoms were thought to be menopausal. Margaret also referenced her lifestyle and work pressures which also seem to feature a complicating factor to understanding what symptom was related to what.

"So yeah, before I had my stroke, I'd started to get quite high heart rates through my Fitbit. My heart rate was going up quite a bit, I was getting quite fast heart rates. So I did go to my doctors and say, you know, what's this? And I also had some really quite dodgy tummy issues. I was like having alternative between constipation and diarrhoea and to be fair they did do like a test on me and I haven't got any issues with my bowels. They sort of lump all that together with a bit in menopause and said, this

is all to do with the menopause. So keep a track of your symptoms and that but that was kind of that…I didn't really have brain fog and I was working so hard…They sort of, they didn't fob me off, but they kind of did, they kind of wanted to keep an eye on it and then of course, next thing I knew was that I had my stroke."

Subtheme: Anxiety and Bodily Vigilance

Many participants shared that they felt worried and anxious in relation to their bodily symptoms due to living with CHD. This subtheme captures reports of the menopause and/or mental illness compounding existing feelings of bodily awareness. Victoria shared that her existing anxiety has been exacerbated through the menopause period.

"I've lived with anxiety on and off throughout my life anyway. So it [the menopause] did sort of slightly compound things to be fair."

Similarly, Saffron indicted that parts of her temperament and personality make her aware of bodily sensations.

"…I'm a bit of a worrier, so it's very difficult to know whether it's anxiety or whether because I know I have a heart defect, whether that then made me feel anxious."

Cassie described that her symptoms of CHD had been dismissed which led her to question her experience. The feelings of being silenced or embarrassed by professionals came at a cost to her health.

"I was very anxious at that point, I mean you're sent home there's nothing wrong with you and I could feel it. Yeah and then to be told it's in your head you're like, well, is it in my head? Because then you start going away thinking, oh, maybe I am imagining it and he [the doctor] would say things like if you listen out for it, you're bound to hear it. It's like again, it was really unhelpful. You know, it was a very significant issue, my heart was two and a half times as big as it should have been, so it could have been really difficult if it had not been picked up, you know, really bad."

Theme Two: Physical Change as an Emotional Reminder

Some participants clearly expressed how the physical symptoms of the menopause may have resurfaced earlier losses or identity challenges around womanhood for women living with CHD. It may have been a reminder of the ending of their reproductive potential in their lifecycle.

Josephine felt that the physical symptoms of the menopause was a reminder that she was not able to have children due to her CHD. It felt unfair that she had to bear the symptoms of menopause and not have children.

> *"I feel it's quite difficult to say because the menopause is something for women who have had their children and effectively done with their body, what they were born to do. Well, I couldn't have children, so I have to go through something that was completely pointless in my whole life anyway. So going through the menopause is quite frustrating because there was no joy of having a child through going through all of this."*

Josephine later went on to share that for her; the menopause not only highlighted the physical changes in her body but the psychological impact as someone who wasn't able to have children due to her condition.

> *"See, all of that is within the mental health sort of issue, like it was the mental health of not having children because of the heart condition and now add the menopause to it as well. Yeah, it's even more difficult because your hormones are all over the place, but you're still having to deal with not having a child and having a congenital heart condition."*

The mental health implications of not being able to become a mother was also shared by Alina. Alina described her experience of the unfair decisions being made around her body

and reproductive health as a result of CHD. Perhaps the menopause was an emotional reminder of this.

> *"It made me make decisions that a lot of women didn't have to make, so I chose not to have children, so I was sterilised at 20 because I wasn't going to get pregnant and taking the risk away was the best option at the time. You know, I've got a husband, you know, I was lucky enough to find a man who was willing to take me on with how I am and not have children."*

Contrastingly, Margaret shared that the transition through the menopause did not feel like this physical change was an emotional reminder of past reproductive choices because she had chosen to not have children earlier. However, she recognised that loss that others may feel.

> *"So another thing you may need to know is that I consciously never wanted children, ever, so there wasn't the potential loss of fertility issues, so I had endometriosis diagnosed when I was 24 and I had because of my job, private medical and I had a womb ablation thing, not a hysterectomy, a womb ablation because I was having such bad endometriosis. At 37 when they decided I was old enough, I had kind of the lining removed of the bit where you would carry a baby in, it helped my endometriosis immediately, but I always knew I didn't want children, so maybe my maybe my thoughts were different because I didn't ever have that worry about, not that worry, but that sort of mourning period about not being able to be fertile anymore."*

Theme Three: Gaps in Knowledge and Holistic Understanding

Most participants spoke about the lack of knowledge and understanding about menopause in the context of living with CHD. The lack of understanding from professionals left some women not seeking help. This may reinforce existing narratives of women's health being a 'taboo', perpetuating the stigma and lack of support. Women also described that they

wanted to be seen and treated as a whole person for some this had serious consequences when this did not happen.

Ava described the sheer lack of information on what someone living with CHD can and can't take was frustrating, when trying to get support for her menopause symptoms.

> *"The stuff that I'm more frustrated about is the lack of information about whether I should be doing this or not. So I take Berocca OK, but I don't actually take anything, vitamin pills and stuff I don't take them cause I'm like, I genuinely don't know. Is it going to be hardening or not hardening the walls of my arteries and veins in a way that I don't want to happen. I'd rather just continue to eat the same diet and hope but I also don't know if that's the right approach, like there is just not enough information."*

Eve described that there was no guidance or support given after she was told she was going through the menopause.

> *"... I spoke to a doctor about certain things, like they haven't said, oh, that I couldn't go on HRT or I could or whatever or anything else out there for me. I just said that I think I'm going through menopause and explained all the symptoms I was getting. She said yes I am but she wasn't sort of like helpful and saying oh, well, you can do this to help you. You can do that to help you, she just left it there. She just basically just said yes, you are going through the menopause and that was it."*

Eve later went on to describe her experience of not knowing what she could or couldn't access to support with managing the menopause symptoms.

> *"I think it's very, very poor, to be honest. Yeah, like I say, I'm not a normal woman, I'm a complicated woman, and I just feel like they could be a bit more helpful, sort of say to me, oh, you know, you can't go on HRT, but you could go on this or that would*

be ok for your heart and like, put me at ease and stuff, but they haven't done any of that."

Skye shared accessing some information leaflet for women living with CHD that are transitioning through the menopause, however, it did not meet her expectations of providing new knowledge or understanding.

"There's probably not enough. I did read the one [leaflet] that I downloaded, the one from the [CHD charity], which is actually written by my consultant at [the hospital] and I meant to read it again before our interview, and I've totally forgot…. It doesn't really say a lot like, it's quite basic information about the menopause and HRT and all of that kind of stuff."

Margaret shared her own understanding of transitioning through the menopause and the complexities of navigating HRT whilst living with a CHD, but she felt that this should have been done by professionals.

"It was interesting how nobody talked to me about the menopause. I was reading The Lancet, is it HRT that gives you heart protection or something?...Which I thought was really interesting because you know I didn't think [the hospital] should have done that. But I wonder whether my doctor should have done that, you know, because they know I've got a heart disease, but they never linked the two or discussed anything about it. I thought that years ago and because nobody ever mentioned it, I just ignored it. If you know what I mean. I know it's [HRT] got its own breast cancer issues. Am I right that when you have the menopause, it does cause issues for the heart, doesn't it? You lose is it oestrogen?"

Estelle felt the knowledge around menopause generally was substantial, however, relating it to her experiences living with CHD, the knowledge remained unclear, perhaps

because access to medical interventions or menopause support was not something that she had been able to access. Estelle spoke about how everything relates back to her heart health.

> *" I think there is quite a lot of knowledge with the menopause. I mean I, I don't know if it's different going through the menopause with the heart condition. I mean I don't know if HRT would be available to me. I mean that's not something I've really looked into and it's not something that I've needed to look into until I am more menopausal. But for me at the moment I would say the support for menopause is good, but then again, I'm not sure if I would access it as I think I would just try and just do it alone and just do it with the older females my family, with their support. So yes, you know, and, I mean again, like I've just mentioned women now would be like, oh, I can just access HRT, I'm much better on HRT because you hear people say since I started taking HRT. Already in my mind, I'm thinking would I be able to access that if I need to, or is that going to affect the heart or is it going to affect the other tablets I'm on? "*

Saffron described the struggles of reaching out for support and being knocked back by the lack of understanding or availability of support for menopause. The constant knock back from professionals or systems which are not equipped to provide the support, may lead to wider silence on the topic of menopause.

> *"I don't remember there being a leaflet or information. I mean, statistics are always dangerous and it is very difficult to a layperson what the risks are, but there didn't seem to be that. You can go on in the internet I suppose now and seek help, but I think what a lot of women find is if I'd had an NHS booklet talking about the menopause, although I'm sure there is that information to access, then that might have made life a bit easier, and I think also contacting a GP and them initially saying no and then contacting someone else and them saying no and then saying to them I'm really*

saying now, I really am losing my, like I'm not in a desperate state, but I feel like my quality of life could be improved."

Subtheme: Caught Between Conflicting Advice

Whilst women shared that generally, there is a lack of information available for CHD and the menopause, some also shared their experiences of being given conflicting advice specifically around menopause which may have led to distrust in healthcare professionals.

One aspect that clearly emerged was the conflicting information around the use of HRT. Alina shared that she was initially told that she would not be able to receive HRT but later was able to.

"Well, I was always told no, no, you can't have it [HRT]. You can't have it because of your heart condition and then a few years ago, I spoke with my consultant and my GP and well, they said, well, you're on blood thinners and the patches are transdermal so it shouldn't affect your bloods or, you know, clotting and all that. So they agreed that I could go on the patches and then I had the progesterone tablet which they were fine with. Yeah, but it was. It was like a bit of toeing and froing."

Similarly Ava described this conflicting advice.

"So, three years ago, I said to the clinic. Should I go on to HRT or not go on to HRT, I want to remain stable. How do I do this? And they said go on to HRT if you want to and I thought well, I'm not really suffering from anything. My body wants to get older, not sure that I really want to fill it with hormones if I don't need to, so I didn't. Then last summer I spoke to her [cardiologist] about HRT and just said would this have been prevented. Would the changes that have happened still happened? Would they have been prevented if my body wasn't changing? And is this something that I should go onto HRT to stop changes getting worse and she said you should never go onto HRT. She said if your hormones get really low we might put you on a very small

amount, but you should never go onto HRT and I was like well that's not what I heard. I was told three years ago I could. They just didn't know, so they didn't know enough. So, the people said I could go on it and I chose not to. And then 2 1/2 years later, the advice is you mustn't go on it."

Josephine's experiences highlight the impact of being unable to get certainty for advice on her menopause.

"The thing when taking any medication is you need to speak to your cardiologist. Nobody makes the definitive answer on anything, so that's probably from my point of view, the difficult thing and that's just not with the menopause. When I became menopausal, I didn't know what I would and wouldn't be able to take because I'm so restricted with medications…. You know everybody says take this tablet take that. I can't just randomly take things. They're both women [doctors] as well, but I just think the support in general from any GP isn't there for most women, and I think for me it just becomes more difficult because I just maybe don't think they're as aware as they could be about medications available that I could have. So, I'm just a little bit more complex where they are just more cautious to give advice."

Subtheme: Siloed Services

Participants reported on the experiences about how healthcare services often operate in isolation from one another. Some participants had spoken about the exclusion of some services because of their CHD.

Rosalie felt that the support that she had received focused on speciality areas and there appears to be no insight into her overall care.

"The other experience that I feel is relevant is that it's not just about the heart, it's about me holistically. So that means it affects other systems of the body and I've never been looked at as a whole person. I've had my stomach looked at over here and my

eyes over there and my heart over here, and no one's put me together, which has meant things have been missed and I've nearly died several times."

Mary also shared the challenges of not being seen as a whole individual but had experienced difficulties trusting that she had received the correct advice.

"I just think there needs to be a more togetherness, so I think it'd be useful to have more of a link up. I mean, firstly we need more doctors who know about the menopause and specialise in it and can support patients. Then you need a good link up if there are other, like medical things going on because like I know [the hospital], my doctor are good at that, you know. So, I think there just needs to be a better link up and probably like you're doing just like more research and understanding."

Alina felt that in the context of her health needs, her GP was unable to provide guidance on aspects of primary care which they should be able to access. This highlighted the anxiety within the system that may exist amongst professionals when working with patients with complex health needs.

"I won't get it [support] because my GP is petrified of me. If I go to the GP, she doesn't know what to do with me. That's why she sends me off to the menopause clinic because she can't deal with it and then you got the heart, you know, obviously the heart consultants they don't know what to do with us, either, because we weren't living this long years ago."

Subtheme: Insufficient Access to Comprehensive Menopause Services

Women experienced limited, inconsistent or non-existent menopause care addressing their condition. Some participants described that menopause services in general seem to be fragmented.

Josephine felt that the lack of support for the menopause is faced by women universally and is not solely related to women with specific conditions and co-morbidities. It

emerged how natural bodily transition such as the menopause which is experienced universally by women is dismissed in society.

> *"No, I don't think it was because of my congenital heart, I just think it's the lack of support offered to people going through the menopause and the heart really doesn't have anything to do with it…If I'm perfectly honest, I think the same amount of support is needed for any woman going through it [the menopause]. I mean, I just, I'd probably get more support because I have additional doctors looking out for me and cardiologists and electrophysiologists that might spot something. Never, never heard of anything until this. Never even knew it was any form of focus. I just feel completely in the same boat as every woman but struggling slightly more because of the difficulties in getting help."*

Cassie shared similar views as she felt unsure if she needed more or less support with the menopause because of her CHD. Menopause awareness and support seemed to be minimal for women generally.

> *"So, you know, that's another thing with the awareness that my heart is probably working a little bit differently. Possibly, I don't know. We're not talking much about this are we? I don't know if I need any more or less than anyone else. You know, that this is what I don't know, and I don't know, right. I know my heart is fixed to a point. This is what's difficult to know, right? How much more help does someone like me need? I don't know. Do we need any more help? Are we allowed hormones? It's not something I've ever thought about or had any conversations about. So it's very difficult to understand what help is needed really, you know. Like I wouldn't necessarily Google it via my heart. I mean, I would probably look at symptoms of menopause I wouldn't necessarily tie it in with my heart or what effect that would have."*

Mary also shared that there is a need for menopause support more generally and identified lack of menopause trained healthcare professionals as well as the stigma that exists when women attempt to reach out for help.

> *"...So, I feel like the help is just generally not that great, considering how much you go through. I don't think it's because of my heart problem, I just don't think there are enough doctors or people available to help. If there was a specific like, you know, trained menopause people then they could work well with like the doctors that I have, it would come together better. I think just generally getting that access is just difficult for women, heart problem or no heart problem…You know, it's not like we're just suddenly going through this, this has been going on forever since women, you know, came to creation, you know, and I just think it's almost sad like in 2025 that we're just not on it at all. There's been lots of documentaries about it, I mean, women have killed themselves because they've been, you know, it's desperate, it's really desperate and just it's really sad, it's really sad."*

Jade shared that she initially received support from a menopause clinic but only received one appointment with no follow up. Jade reflected on the number of health symptoms that she has experienced has meant that accessing services is difficult.

> *"I didn't get a follow up appointment [with a menopause clinic] or maybe she did book, but there wasn't anything to remind me and I am forgetting things more and more now. So even when I asked to see the psychology, she used to give me a text message early to remind me we're meeting up. So, I don't remember lots, and I can't see properly due to cataracts. That's also triggering because of my medical condition, everything for them is that your medical condition is triggering this."*

Saffron recognised that accessing support is available if you pay privately, but that is not possible for most people and the other option is to try to continuously get support from the NHS.

"You know, and there are some people that can afford private care, but there are a lot of people that can't. They can't afford the private care, and they can't afford the time to be going to the doctor every 5 minutes. They're busy, you know, so."

Mary similarly was able to access support via a specialist menopause clinic but had to pay for this privately.

"It's when I couldn't really access the GP, so I kind of went private, I just paid for it through a menopause clinic. So, I just booked a kind of nurse specialist. Yes, it was private, but then I got it transferred to the GP. So yeah, so I take progesterone and then oestrogen. Like the gel I take, but no one ever like, monitors like your levels. You just kind of left to work out on your own."

Rosalie shared her experience of accessing specialist menopause support, which was well received, however, to access the care took a lot of coordination.

"It took far longer than it should. Yeah. GP wasn't going to prescribe HRT. They weren't prescribing much at all, actually and it waiting lists were a big barrier. But when I got to the right people, I got amazing care. The specialist menopause clinic at [hospital] and [hospital] cardiology are amazing, it just takes ages and they don't coordinate. They're too busy, so letters, exchanging and appointments it took an extraordinary long time."

Theme Four: Seeking Safe Choices

Participants described the difficulties with not knowing what medication or supplements are available for both menopause and mental health support as well as the emotional difficulty of managing this uncertainty.

Amara describes how the lack of knowledge around what she can and cannot take and having somebody who understands her health needs is crucial in seeking safe advice.

> *"I don't realise what I can and can't take [medications] but I wouldn't know what it is, what it is that I need without someone being there that I can relate to and would understand my condition."*

Mary highlighted how it feels unfair to be unable to access guidance on which supplements would be beneficial to her health. Mary described having to do her own research but being left worried if it is the right thing to do.

> *"....I'm like, should I be taking testosterone because that's like good for you. You're meant to be taking that for, like, brain stuff and then should I be taking magnesium because that's good for sleep and like, I don't know, it's just like, I feel like you just must work it out on your own. And it's just not fair. Yeah, it's really rubbish. I mean, when you think about it, it makes me and my friends really angry."*

The fears about medical interventions during her menopause transition also had an emotional impact on Jade. She shared concerns about her existing worries about doing damage to her heart.

> *"Yeah, I can't get anything [medication], it could affect my heart and I mean, I'm at risk of having a heart failure anytime so you know, so I can't really take the risk and take something that could actually, you know, have a huge impact."*

Subtheme: Living Safely with System Delays

Participants alluded to the idea that seeking safe choices is not always shaped by personal or professional opinions but by the limitations from the system. The continuous communication (or lack of) with professionals often fed into feelings of frustration and uncertainty.

Josephine offered examples of when professionals do communicate with professionals to seek guidance on medications, but it takes a long time to then get answers.

> *"Getting everybody to communicate and doctors saying they can't speak to me and then other doctors say they've emailed doctors but nothing is happening and so it is a lot of red tape."*

Cassie said:

> *"Well, the GP didn't do anything without speaking to [the hospital] so it's just how long that will take, she'll write to them, but it's how long it takes to respond, I guess. I don't know how long it's going to take. Is it going to take three weeks or is it going to take six months? I just don't know."*

Alina alluded to the fact that CHD and menopause has not been thought about much up until now, with people now living to the menopause age. Therefore, she felt that the existing systems are still catching up and learning.

> *"They're just coming to terms with it themselves, so there's nothing, there's nothing for women in with menopause with CHD you know so, and I think they're trying, you know they are trying, but it's just I think this it's a bit late for me, but I think this should be offered and should be at a much younger age."*

Subtheme: Specialist Psychological Support

The experiences of women who have received psychological support, particularly within a cardiac service is detailed within this subtheme. It represents a resource for supporting women with the uncertainty of seeking safe choices. Many participants shared that their experience of seeing a psychologist within the CHD team, was beneficial. It was felt that they were often seen as a whole person by a psychological professional who understood their physical health needs as well as the mental health implications of them. Participants

conveyed a sense of being heard and understood, creating a sense of compassion towards their feelings.

Skye described her experience of feeling validated, perhaps in a system where she had not felt that previously. Skye recognised a shift from being isolated with her experiences and not being heard, to being empowered to help get her voice heard.

> *"For me to see someone at [the hospital] and they then could work together with the cardiac team was really helpful because they knew what I was talking about…The psychology sessions in 2023 really helped and I was able to see the psychologist while I was there, which was great. But I have to say overall it was a really good experience and it was like a lot of healing for me. Like, I felt like I was listened to, I felt like I had a voice. I felt like an adult."*

Victoria described the benefits of having access to different disciplines within her CHD team, even when medical support may not be offered or required regularly. Victoria shared that despite not specifically requesting for mental health support, this was available for her.

> *"I didn't really ask for mental health support from the GP, but actually [the hospital] was able to offer that. More recently as I said, it was [the hospital] that just volunteered it. I think that they have a specific heart service… it has been invaluable to me."*

Amara shared a positive impact on her wellbeing was seeing a psychologist from the CHD team.

> *"Yes, I've had psychologist from there [the hospital] who's absolutely amazing, absolutely amazing. I wouldn't be where I am now without her. I was advised to have that support and that was more so from the trauma and yeah, throughout my life I've had a lot of counselling, but that's mainly for mental health and it was absolutely*

brilliant. It was kind of like cognitive behavioural therapy, but it was on zoom. So, I was speaking to somebody on a weekly basis and I reached out, I reached out for that help because I felt that no one understood what I'd gone through and the fear of how I was going to be after the after the recovery. But yeah, absolutely amazing. The support and the service there was incredible….Brilliant, absolutely brilliant."

Ava spoke about the need for specialist mental health support within cardiac teams, she described that a lack of understanding of her condition from a generic mental health support would drive her away from seeking that support.

"So actually [the hospital] has been brilliant because I've had two sets of help from their cardiac psychology team. I'd never talk about it because there's no point talking to a normal counsellor about it, because they'd ask stupid questions and I'd lose trust in them. You know, I want to know that I'm talking to someone who can say, you're overthinking that, that bit is a dangerous thing, stop thinking about that bit, that bit you're completely fine to mull on for a bit. Should we mull on that bit? I think the service they provide is fantastic because they work with people who, you know, if you're lucky enough to live this long, you've probably been through some quite traumatic things."

Rosalie felt that the lack of understanding of CHD amongst psychological professionals is a barrier to accessing appropriate mental health support. Rosalie felt that having a good understanding of her CHD and experiences associated with that would be needed.

"The lack of understanding of my congenital heart condition was a barrier, and I think the support for long-term health conditions in primary care is wrong. I'm not a clinical psychologist, but I think there should be more of a mental health presence within physical healthcare settings, not it being separated because the clinical

psychologist or therapist need to understand the physical health conditions, on a specialist level to help me. I needed a clinical psychologist or therapist who worked within a heart team, not primary care, not saying I'm special, but I feel that about diabetes, I feel that about epilepsy. I don't think it should be seen separate to the people's specialist clinics. You need knowledge. The clinical psychology training, and the CBT long term health conditions training is not enough."

Josephine shared the positive experiences of having specialist mental health support within CHD services. Josephine described not recognising herself the need for support but the way professionals recognised the importance of mental health care when preparing for major surgery.

"I have just finished therapy at [the hospital] for having a congenital heart condition. I think that's why I was one of the people who was asked. So yeah, I just finished the therapy and I did sort of six months of it to prepare me for my next surgery. I just sort of think I didn't really feel like I needed it. I'm all for therapy, but I didn't feel like I needed it. But my God, it opened up something and really brought out the best in me. Cognitive therapy was brilliant. Yeah, it was beyond what I actually thought I needed because I didn't really feel like I needed anything. Everybody needs somebody to talk to and I just I found a support that I didn't know I needed and really flourished from it."

Theme Five: Personal Coping Resources

Participants have sought ways of coping with CHD. This theme explores the inner strength of the women as well as faith and self-awareness. Jade shared that her faith has been a supportive factor in her coping resources throughout her life and now in the context managing mental health and the menopause.

"I don't know where I get this, maybe my faith, maybe, it gives me the power if you know what I mean, to get on. But I know a lot of people in my situation probably wouldn't manage the way I'm managing. Maybe it's also the fact I have a young child. I remind myself all the time. Like, you know, I need to be OK for her, you know she needs me and she needs to be in a good way, you know".

Josephine shared that her CHD journey is ongoing, as described by many, adding that the menopause symptoms gave rise to new challenges and how remaining positive is not easy but her coping resources have allowed her to navigate her CHD.

"For me, my journey isn't over. I need open heart surgery again. So, it's still a long process and it's about trying to remain positive. You know what you go through and I think the menopause is a difficult part of your mental health, trying to stay positive during that time. I think with any congenital heart disease, especially if you start becoming poorly again like I have, you have to go through it. So, you may as well go through with it with a positive mind and look at everything positively but it is difficult. I could be right now in the middle of my menopause, I don't know. I'm just muddling through now until it gets to the point where I can't cope with it, but I have found quite a good natural balance on my own."

The self-determination to keep going was also described by Amara. However, she described the struggle of the emerging menopause symptoms.

"I feel so determined to keep pushing through it and that's just the way I am, I think because of the battle and that I've come this far, that's the heart side of it and then there's the body's symptoms from the menopause because of my age, I'm like, why is this happening to me? So yeah, it's a struggle."

Margaret shared her personal coping resources for managing her whole health, which has indirectly supported her with the menopause symptoms.

"I made a real big conscious decision to like to maintain my weight and my exercise and start to get muscle. So bizarrely I feel that although I've been given a bad health diagnosis, I really felt a lot fitter than I maybe had for a couple of years… I used to say to my friends, rather horribly, don't use menopause as an excuse because look, I've lost a stone and I'm eating healthy and I'm feeling better and so I think I, kind of would say it helped me think that the menopause isn't necessarily like the end of it, you know, or the start of going downhill. You can actually make the right changes, you don't have to go down that route of getting bloated or this that and the other etcetera."

Subtheme: The Strain and Strength of Self-Advocacy

Participants described the experience of not being heard as very frustrating. The strength and determination needed to continuously advocate for their needs often is not a one off. It may also feel debilitating if individuals who do feel resilient, are faced with healthcare systems which lack resources, awareness or understanding of their needs. This could be detrimental to help seeking and particularly relevant for those living with complex health needs. The perpetual silence may continue to occur if individuals feel unheard.

Rosalie shared the tiresome nature of having to connect her health conditions. Rosalie also shared the implications of seeking help, leading to difficulties accessing care. However, there may also be a sense of autonomy and empowerment when she has been able to advocate in front of a professional.

"So, it's me who's had to join the dots, and I find that extremely tiring and boring and it pissed me off that I have to do that. It makes me worry about other women who aren't as assertive as me and I think when I look back now, understanding that I've got ADHD and autism, I know what I've got. I've researched this, I've looked at all my symptoms, I fit with this diagnosis and so I got pushed down the hypochondriac root

because I was telling them what it was…The decline in my mental health and inability to manage ADHD was oestrogen related, but then I really started advocating for myself physically for menopause in about 2020 and it took a while, I still have to advocate, so I say things like can you put that in a letter to my GP and then I'll you know, advocate. I need a gynaecology follow up, it's not coming. I'm going to have to advocate. So it's good when I see the professional in front of me, but the navigation of it is extremely difficult, but that's an NHS wide problem at the moment."

Alina shared a poor experience of care after trying to self-advocate and the implications it had for her health and CHD. This was shared in the context of menopause.

"…I ended up going to A&E and having 6 units of red blood cells, but no one listened, but no one listened to me. You know the GP wasn't listening to me and I kept saying that this ain't right. You know, I can't be like this, and it weren't stopping. They just sent you to the hospital for a scan…It's also the physical change, all the bleeding and losing you know all that blood, it's not just the mental side, you've got all the physical things, which is haemorrhaging and that's not good for your condition. Like when I went to the hospital, it was like oh, it's normal when you're in the menopause and no woman really should go through it. Even if there is nothing wrong with them, they shouldn't have to go through things like that."

Margaret alluded to the narratives and stigma around mental health and menopause.

"I think the trouble with the menopause is a lot of people do lose confidence and get told everything's just the menopause and everything's mental health because you feel like you're a bit weird. Sometimes people think they've gone mental."

Subtheme: Menopause in the Context of Serious Health Conditions

Participants shared their experiences of menopausal changes within the context of broader health challenges, which require time and coping resources. It highlights what some

women have to prioritise in the context of living with CHD. Participants seemed to allude to an underlying dilemma, regarding allocating their energy when managing health conditions experienced as more debilitating than menopausal symptoms making the menopause somehow relatively manageable compared to the underlying conditions.

Margaret shared that because of the other health factors and life events, she experienced the menopause symptoms as trivial.

> *"Also, I wonder if there's something to do with the fact that I had a bigger health issue, I didn't focus on the menopause and just bear with me on this, because I'm not one of those people, I am not a mental health denier, I am not a menopause denier…I'm not a denier about that, but I do wonder if sometimes you can focus on the menopause because you're expecting the symptoms and you can play them out more. But because I had something else to focus on, I kind of didn't notice. Do you know what I mean? I don't want to sound like I'm denying people's menopause experiences, but all I would say is my menopause was so trivial to me because I had a bigger issue."*

Similarly Beatrice and Ava reported limited impact of the menopause. Beatrice said:

> *"Can I be honest? I don't really know anything much about that. I haven't really found any difference whatsoever. The only thing, as I said to [the psychologist] the other day is I get the hot flushes, they're horrible. But apart from that, I don't have anything. I think because everything else was happening with the rest of my body. I don't think I really was aware of it [menopause]… I think I've got so much else going on."*

Ava also expressed gratitude for reaching this life stage.

"Generally speaking, I'm quite robust and I don't consider myself to be suffering from the menopause at all. My wife, who's the other way, considers it a really big thing, and I'm like for God's sake, it's fine. I'm very lucky to be menopausal."

Theme Six: Social Connectedness as Support

Many participants spoke about the need for connection with others who have similar health needs to provide a validating and encouraging space to share their experiences. It highlighted the benefits of learning from others who have lived through similar experiences who may have also faced surgeries from a young age, reproductive difficulties and mental health challenges.

Beatrice reflected on the fact that there has been very little support for women living with CHD and the menopause.

"If you go to [my hospital], there's a cancer care support centre, which is fabulous…Why in all these years, there's never been anything for somebody that has heart issues. That could be that could be a study, I suppose, of women that have congenital heart disease that go into the menopause."

Josephine shared that the only support that she has received was from family or friends, however, living with CHD meant that her experiences has been very different to those around her.

"No, only support from my husband. He's actually been really good. But other than that, and friends who are going through similar things, but it's very difficult when you have a congenital heart disease as well."

Subtheme: Community Support

This subtheme captures the experiences (or lack of) from community groups and social media groups, related to CHD. For some participants, connecting with those with lived experience through the menopause transition was perceived as valuable and encouraging.

However, for other participants there appeared to be limited opportunity to connect with other people living with CHD or that the discussion of menopause seemed to be absent within CHD communities.

Jade suggested the idea of peer support to share lived experiences and she spoke about previously attending a research group on a similar topic and reflected on the benefits of hearing and sharing her story.

> *"Yeah. I mean, maybe having an identifying group, creating something there for you know, people to go there and let it all out or just sharing ideas and hear other people's thoughts. It can give you some kind of motivation or just encouragement. When I attended this research event, I think because it was kind, it was nice and it opened my eyes a lot because there's so many people going through this, but in a different way and hearing how it's been affecting them. I came out that day and I was quite emotional."*

Ava also spoke about attending a group for women with similar health needs which she described as liberating. However, she also acknowledged the potential difficulties of accessing a group with people with similar health needs, who may not have positive experiences or who are at a different stage with their heart health. Ava felt this would need to be carefully thought about by those setting up such events.

> *"We did the tree of life thing, and I've never been in a room with a load of people who've got congenital heart defects before, unless it was a waiting room and everyone sitting there shitting themselves. So that was actually kind of liberating…I kind of walked into them and went fuck me. I've only known one other person with a congenital heart defect…It was a cool tree of life workshop, and it was just basically about identity…That was really interesting we all did have a lot in common. So, there is a CHD charity and I used to help the trustees on that, I think it's a really good*

charity. But I've always been worried about going to their events because I didn't want to see people who were in the late stages of heart failure or, you know, I actually don't want to see where I might end up. I mean, it's a cohort they managed and I'm sure they did other cohorts, it was sort of curated and I think that it was a more positive experience than it might have been."

Skye shared that she had conversations about the menopause with her sister which helped her to identify with her symptoms as being menopause related.

"So yeah, groups specifically and maybe they are out there, and I haven't found them yet. Us that are going through the menopause with congenital heart disease can share experiences because if my sister (who doesn't have a congenital heart condition) hadn't said it to me 'that sounds like a hot flush you know', I may not be talking to you."

Cassie and Amara described accessing and experiencing social support through online platforms such as social media. They reflected on how this enabled them to connect with others who had shared similar experiences, however, they also highlighted that the topics were more related to CHD surgeries rather than the menopause.

Cassie said:

"There is an online community that was really useful on Facebook. That was really helpful and it's also really helpful with practical stuff beforehand. Like, what do I need to take to hospital and to do and what can I expect? That was really good."

Amara said:

"I'm on a group on Facebook, which is just like basically it's like open heart surgery…a lot of people speak on there openly about their feelings and their experiences and symptoms but you never get anything come up about the menopause.

But yeah, there are a lot of women in my age, so it would be nice to have that connection."

Subtheme: Intergenerational Support, Family and Partner Relationships

This subtheme captures the relationships people have with their family, and their experiences of growing up living with CHD. The learning or lack of learning about the menopause and how to cope, was often shaped through family stories. It demonstrates the nuanced experiences of the menopause as well as generational changes over time.

Saffron shared the intergenerational roles of being cared for and caring for others. This may represent the lifelong nature of CHD. Saffron highlighted that her understanding and experience of the menopause has not only come from medical guidance, but from past experiences of being cared for and caring for others. Saffron also described feelings of isolation from her community growing up.

"My parents were anxious, my mother would worry a bit...I wanted to reassure my parents that I was OK and that kind of had to compensate for them as my brother had bad asthma. So, he was in that hospital a lot, my parents had a lot to deal with and they were recent immigrants to the country. So, although my mother's Irish, her family are far away. They were quite isolated, it was just the four of us. That's quite an intense experience. So that, if anything, I would say that shaped me as much as my contact with doctors...My mother had an awful menopause, and she didn't really have any other women around her to talk to. So of course she talked to me about it. So, I knew about it because she'd gone through an awful menopause and I don't think mine has been as bad as hers. I mean the HRT for my mum turned her life around within a very short space of time. It was miraculous for her and that, you know, if she'd been born generation earlier, she wouldn't have had access to it."

The expectations on how to ‘cope’ and ‘manage’ life with CHD, was embedded from a young age for Skye. The protective instincts of her family may have reinforced the idea of having to ‘cope’ with difficult circumstances. This may reflect a desire to stay emotionally and physically safe during the menopause transition. However, this was balanced with not having her mother around to support with this transition now.

> *“Going through my operations, she [mother] didn't want me to make a fuss she just, you know, if I wasn't happy with something, I couldn't say anything and obviously now she's not here to talk to about that. So that's really hard. Although in a way I'm glad because I think I'd probably really upset her because she was doing best at the time, you know.”*

Skye also described the difficulties she witnessed as her mother transitioned through the menopause. Skye described a different context and time in which accessing HRT medication was a challenge.

> *“So, I'm 46. I know my mum had a really hard time with the menopause, and now she's not here. I can't ask her. I'm not really sure what she really struggled with. It was at the time when there was that big HRT scare as well, so I think she'd been put on HRT. It had really helped her, but then I think she was taken off it because of the big scare. I don't know whether she was taken off it or whether she decided to stop it herself, and I think she did go back on it eventually, and it was fine.”*

Amara shared that family support around the menopause wasn’t something she remembered. This may imply, based on her experience, that there is a greater need for medical or clinical judgement to seek advice around menopause.

> *“My mother, she only ever had one experience of a fainting episode, and I don't recall her even ever having hot flushes, so I don't know really who I could turn to.”*

Estelle explained that due to her experiences of not being understood by professionals, she navigated the uncertainty by discussing it with her mother.

> *"I mean, they're [professionals] denying that it's happening so I wouldn't bother attempting to get support. I mean, you just get support from my mum. If I find something unusual going on in my body, I'm like mum, do you think this is the menopause and she's like, 'oh yes, that's perfectly normal' and so yeah, I suppose support from other females around me, especially older females is important….I say to mum sometimes, were you like this when you were menopausal or pre-menopausal? She was like, 'well, no, I didn't suffer that'. So, I'm like, do you think it's the heart that's doing it or the menopause so yeah we don't know really what is causing what and then that can create anxiety on its own."*

Contrastingly, Jade described that the problem of not being heard or understood is not limited to health professionals, but similar concerns were felt with those closest to her. It was shared that she has had to keep going throughout difficult periods because her needs were not well considered, which may not always be the lack of support from professionals.

> *"...I feel like I can't say anything, no one understands you know, it's like you're holding it to yourself. No one understands, my partner wouldn't understand. No one. Because they see you as OK, you're getting on with life. You're not moaning. You're not in bed continuously. If I don't know much about these things, how can somebody who doesn't have any knowledge understand what you're going through? I feel like yeah, I just kind of like I don't even explain to anyone, what the point is. There's nothing I can explain, no one would understand me, and that's depressing. That makes you feel frustrated, angry, some points low. Yeah, I feel like you're in this journey on your own, you know."*

Summary

The analysis highlighted six themes using RTA. Participants described the psychological and physiological nature of both CHD and the menopause, which for some intensified their mental health needs. The transition through the menopause for women living with CHD, seemed to represent more than just a life stage. A key finding was the presence of the overlapping symptoms between CHD, menopause and mental health symptoms, such as heart palpitations, hot flushes, cognitive changes and fatigue. The complexity of the three conditions sharing similar symptoms, appeared to heighten the emotional strain, with fears of their CHD worsening. For some participants, the menopause carried meaning around motherhood and fertility. Some participants described the menopause as a reminder of earlier medical advice that had prevented them from having children. It also marked as the endpoint for them being able to birth a child. The toll of having to experience unpleasant menopause symptoms and experience no joy of having a child as a result, resurfaced feelings of loss and grief.

Many participants shared substantial gaps in knowledge amongst healthcare providers for both their heart condition and for the menopause. Some participants felt that women's health generally is neglected in society, irrespective of a CHD diagnosis or not. Others felt that information around the menopause is sufficient, but when you connect CHD and menopause, there is a complete lack of information. Participants described being caught between conflicting advice from primary care services such as GP and cardiology services and this uncertainty placed further emotional burden onto them as individuals. Their accounts shared that specialist psychological support has been largely valued by those who have received it. Participants felt understood by psychological practitioners working within their CHD department and felt that psychological practitioners outside of the CHD field may not truly understand their experiences. The impact of the menopause, however, was not

addressed and some felt this was missing from the support that they received. Participants also relied heavily on their own personal coping resources or from those around them. This was often viewed as a protective factor for them, particularly, if they felt misunderstood in clinical settings. However, access to social support such as family, friends, and older relatives who had transitioned through the menopause was not available to all.

Reflective Summary

The range of feelings experienced during and after the interviews was important for me to reflect on during the analyses.

I felt honoured to hear the lived experiences of participants and I gained a real felt sense of the need for this research. I did however feel that this research wouldn't change the experiences that some had faced, and I felt frustrated in hearing some of the life changing challenges they had to face.

As someone without lived experience of CHD or the menopause, I wanted to create a space during the interviews where individuals could feel they could share their stories openly. I hoped that I set up the interviews in a way that felt containing and comfortable to begin sharing their experiences. I felt that having no lived experience of this topic, helped me remain curious and open to participants. I genuinely wanted to learn and understand as my prior knowledge was limited. From the start of the research, I wanted to ensure that the study objectives and interview questions were not vague and meeting frequently with my supervisors both from an academic and clinical context helped me refine the process. I was supported to reach out to people with lived experience to help frame the interview questions, to ensure the study design and interview questions were suitable. The same process could have been thought about with the analysis. However, a pragmatic decision was made due to limited time available for the research study following recruitment.

The use of online interviews enabled me to reach participants that were located nationally. Although participants were all under the same NHS hospital for their CHD, their geographical location varied. It also allowed for participants to remain in the comfort of their own home during the interview, meaning less pressure on them to travel. This was particularly helpful for those who had experienced additional health complications which limited their mobility. The use of the online platform helped to build rapport, and I felt that the use of telephone interviews would have made it difficult to pick up on non-verbal cues of discomfort or distress. On one occasion I completed one interview on the telephone due to difficulties accessing technology. I found myself being more attuned to what they were saying and I listened carefully. I wanted to be aware of their tone, emotional state and if there were hesitations. I tried my best to show acknowledgment to them, but I found this harder compared to a video interview where I would nod and give non-verbal facial cues from my camera. However, they felt grateful for being able to attend the interview and considerations were made for their needs. They expressed an openness to sharing their story and perhaps, my hesitations were more a reflection of my own worries.

I was also mindful that all participants had experienced CHD and menopause symptoms to some capacity, albeit at very different stages. However, the variations in access to mental health support was different depending on several other life circumstances they experienced. It was also noted that some had no direct involvement in mental health support, which was equally a valid experience. I was struck by the reflections shared throughout the interview and particularly at the end, where participants shared the positive impact of participating in this research, and offering a space to reflect and consider their experience. Some participants acknowledged that as they were transitioning out of the menopause now, the direct benefits of the research may be beneficial for the generations to come which I found heart-warming to hear.

I thought about my dual role as a clinician and a researcher, hearing participant's stories reminded me of the clinical work I engage with, but I had to remember the importance of academic rigour and integrity of the research. The reflective journaling after each interview helped me to manage this, it also helped me to digest emotions related to each interview so that I was present for the next participant. I was aware that although I may hear similar stories, each participant brought their own unique experience and values which helped me gain a sense of their reality, rather than there being an absolute observable truth.

Chapter Five: Discussion

Chapter Overview

This chapter will review the research aims and provide a discussion of the main findings. The findings will be discussed in the context of available literature and theory. The strengths and limitations of the present research study will be explored as well as the implications of the study. Clinical recommendations and dissemination strategy will be shared. The chapter will end with directions for further research, final reflections and conclusions for the research study.

Revisiting Research Aims

The overall aim of this research study was to explore the mental health impact on women living with CHD who were transitioning through the menopause. This research study had three specific aims:

Aim 1: To explore the lived experiences of women living with CHD during their transition through menopause.

Aim 2: To identify the facilitators and barriers to accessing support for CHD women transitioning through menopause.

Aim 3: To explore psychological and social resources for women living with CHD transitioning through the menopause.

Discussion of Main Findings

To the best of our knowledge this is the first research study to focus on the mental health of women living with CHD who are transitioning through the menopause. The overall findings highlight the importance of women being listened to, believed and involved in decision making where possible and supported to help understand their body and symptoms. As highlighted in the systematic review, there is no research in this field. Available literature

has largely been based on studies which have focused on reproductive health and CHD, chronic health conditions or the menopause more generally.

What are the lived experience of women living with CHD during their transition through menopause?

The theme *'The Cumulative Impact of Health Factors'* illustrates the complex nature of the intersecting identities and health challenges for these participants. This theme is relevant to understand how women living with CHD experience the transition through the menopause. Whilst there have been no similar studies researching this topic, the findings have echoed previous qualitative research on women with chronic health conditions, where they described a "balancing act" of having multiple health concerns (Tyer-Viola, & Lopez, 2014). The menopause itself can be a risk factor for cardiac vulnerability due to the reduction in oestrogen, which has a protective effect on the heart, for example by helping to control cholesterol levels (Skafar et al., 1997). Typically, CHD is diagnosed either during pregnancy or at birth. Depending on severity and complexity heart surgery or catheter-based interventions are needed as early as at birth (Gatzoulis, 2010). Yet not all participants in the present study were diagnosed from birth or as a child. The challenge with being misdiagnosed or diagnosed late in life brought its own challenges for participants in this research study. However, the general nature of a lifelong health diagnosis, means that there are several life stages and adjustments that need to be navigated. Given these findings, the additional transition through menopause, should warrant careful consideration because it represents the experience of new symptoms which interact with pre-existing conditions.

The subtheme *'Overlapping Symptoms'* highlights the confusion arising when CHD, menopause and mental health symptoms interact. Participants shared the complicated nature of their CHD and how their symptoms are almost always thought about through a cardiac lens. The longstanding history of cardiac monitoring may have shaped their interpretations of

bodily changes. A qualitative systematic review on children's experiences of CHD found that patients from a young age monitor their bodily symptoms closely for example, chest tightness, to closely monitor signs of their disease progressing (Chong et al., 2018). The participants heightened attentiveness to bodily changes is understandable given a lifetime of symptom monitoring required by CHD, which may increase sensitivity to physiological transitions such as the menopause.

Previous studies have shown that the menopause symptoms can overlap with mental health presentations (Maki et al., 2018). This emerged clearly in the second subtheme of *'Anxiety and Bodily Vigilance'.* Interoception is a term used to describe what is happening inside someone's own body, it is how the brain receives signals from internal organs and bodily systems (Vaitl, 1996). Interoception supports with understanding hunger, thirst, pain, emotional needs, physical health. Studies have found that patients with heart disease often pay close attention to their bodily signals such as breathing, heart rate and fatigue (Clark & Goode, 2013). The heightened sensitivity to the interoceptive cues may contribute to the likelihood of symptoms being confused with one another and potentially perceived as more threatening (Schulz & Vogele, 2015). This understandably, may lead to a cycle of bodily hypervigilance and emotional stress (Rosman & Cohn, 2015). A qualitative study exploring adults living with CHD found that anxiety was an overarching concern, particularly for day-to-day activities (Steiner et al., 2021). The authors found that those living with CHD often shared worries around the worsening of their CHD. A study conducted by Dorfman (2023) found that people living with CHD experience psychological distress associated with the traumatic medical procedures and surgeries, often from a young age. Both the European Society of Cardiology (Arbelo et al., 2023) and the American Heart Association (2022) acknowledge the vulnerability of CHD patients, recommending psychological assessment and interventions. However, a study conducted in the USA found a significant number of

individuals living with CHD sadly do not receive adequate psychological support (Coleman et al., 2020).

The second theme '*Physical Changes as an Emotional Reminder'* highlighted the persistent bodily functions that serve as an emotional reminder for the potential loss for some participants. The meaning associated with the menopause, for some is understood to be the end of their fertile life. Previous qualitative studies have shown that some women living with CHD have expressed strong desires to become mothers, and motherhood has been previously described as a "victory" for women living with CHD, because of the challenges with pregnancy that they can experience (Ngu et al., 2014). Women living with CHD in their earlier life, are often not only limited to their choice to become mothers but also in their contraceptive options (Leroy et al., 2020). The strong desire to become a mother for some women living with CHD has been shared in previous studies looking at reproductive health (Liu et al.,2022). Often there is a need to be seen and treated the same as women without CHD. These experiences may be shaped by narratives about ageing and gendered expectations because of societal expectations about femininity and ageing (Rochon et al., 2021). However, Glyde (2023) proposed that the loss of fertility is often the viewpoint from a heteronormative, white, western lens and may not represent all women's desires and experiences. For example, some individuals from the lesbian, gay, bisexual, transgender, queer (LGBTQ+) community may not view fertility as a life goal and may not experience a sense of loss (Wingo et al., 2018). Additionally, in some African cultures, the menopause transition may be celebrated into a transition of social authority, power in the family and community (Raswswe & Mulaudzi, 2022). Additionally, in parts of Nigeria, the menopause is viewed as a relief from menstrual periods and eliminating pregnancy risk (Bello & Daramola, 2016). Therefore, the menopause transition may evoke a wide spectrum of

women's values and identities. However, in the context of CHD, for some women, the choice over their reproductive health may have been removed due to their condition.

What are the facilitators and barriers to accessing support for CHD women transitioning through menopause?

Theme three '*Gaps in Knowledge and Holistic Understanding'* captured experiences of navigating healthcare systems and professionals to attempt to get support for their menopause symptoms. The gaps in knowledge and understanding felt to be a barrier to accessing support.

Previous studies have highlighted the importance of adults living with CHD having knowledge about their condition, as this has been associated with better self-management and outcomes (Correia et al., 2022). Participants in this research study acknowledged the need for professionals to also understand their specific needs and condition. The importance of this knowledge being shared in a way that feels accessible with no medical jargon felt to be important to participants. A previous study found that medical jargon and large amounts of health information may be a barrier to individuals feeling able to cope, self-manage and communicate effectively with healthcare professionals (Van Der Gaag et al., 2022).

The subtheme '*Caught between Conflicting Advice'* highlighted that even when participants did receive support or advice on the menopause, they often received conflicting advice from different professionals. This seems to align with previous research discussed in the systematic review, which highlighted the contradictory advice often received when discussing contraception and reproductive health (Liu et al., 2022; Nakamura et al., 2018; Stokes et al., 2023; Tylek et al., 2024). Additionally, several qualitative studies within the systematic review reported that participants were told by healthcare professionals that their CHD meant they would not be able to have children but later were then told they could have children (Gant, 1992; Ghizzardi et al., 2023; Stokes et al., 2023; Tylek et al., 2024). The

conflicting advice highlights the importance of training and evidence-informed practise amongst healthcare professionals to understand the health needs and risks for women living with CHD.

The menopause has been described as an intersectional experience (Riach & Jack, 2021) which is not completely universal or biological but that each person's experience will be shaped by their health, age, class, race, religion, cultural norms and employment etc. Therefore, there may not be a 'one size fits all' approach to this and may contribute to the conflicting advice received. However, growing research may widen the existing discussion around women's health for CHD patients. For those participants who have experienced a lack of information on women's health in general, there is a need to consider how societal structures support or fail to support open discussion and education around hormone health. Calow et al. (2023) considered guidance on menopause training for healthcare staff and recommended that both the physiology of the menopause should be spoken about as well as the shame and taboo associated with women's health. This may support with shifting the responsibility solely to the individual to seek knowledge.

The subtheme *'Siloed Services'* captured the frustrations that participants felt when there was no joined up care. Participants' accounts indicated that there appeared to be a lack of shared responsibility for their health needs. Services operating in isolation may reflect structural and financial constraints, including commissioning processes, alongside professional uncertainty with CHD, which participants may experience indirectly through their care. This experience is not isolated to just patients but has been highlighted by healthcare professionals who have reported feeling ill-equipped to provide support for the menopause (Kling et al., 2019). The experience of primary care providers (typically GPs) offering support to patients with complex health needs was researched by Loeb et al. (2016) who found that building trust with patients and preventing hospitalisations were key

priorities. However, the primary care providers in this study described being faced with poor communication with specialist services, insufficient clinical support and needing to prioritise health issues. The World Health Organisation (2016) promotes the integration of services through joined up and integrated care to improve decision making and coordination of health needs. The literature for children and young people has highlighted and emphasised the importance of interprofessional working, service integration and effective sharing of information and co-ordination of care (Young et al., 2004). This integration may not always consistently extend into adult care.

The participants in this present study shared that having segregated or '*siloed services*' meant that their symptoms were being missed, leading to consequences for their overall health. Participants also described professionals being fearful of their heart condition, which contributed to a lack of support. This may perpetuate the need for patients to self-monitor and self-educate, out of fear and uncertainty. A study conducted on older patients with heart failure found that lower support was associated with higher fear of disease progression, suggesting that when patients feel unsupported, they are more likely to experience worries about their health deteriorating (Tian et al., 2025).

The subtheme *'Insufficient Access to Comprehensive Menopause Services'* captured barriers such as, limited access to specialist menopause clinics, long wait times or being discharged without support. Participants spoke about accessing support privately. Whilst previous research has highlighted the hormonal, physical, social, psychological and relational changes that occurs during the menopause (Kingsberg et al., 2019), women continue to report not being well supported around their health and have limited access to women's health services (Hamoda & Moger, 2022). Persistent gender inequalities worldwide remain a major barrier to achieving equitable health outcomes (Kmietowicz, 2019). Reasons for this include cultural norms and stigma that can make women more hesitant to seek medical help

(Benyamini et al., 2008), healthcare barriers (poor knowledge, skills and attitudes) (Jeffrey, 2025) and individual's own psychological factors such as low self-esteem (Brody et al., 2018). The barriers are exacerbated for those in underrepresented groups and areas (Simmons et al., 2024). The experiences shared by participants within this research study highlighted that women continue to feel that women's health generally is under-prioritised and for those with complex health conditions, it can be even harder to discuss with healthcare providers. Access to CHD teams is available within the NHS, however, access to specialist menopause services appear to be privately paid for, demonstrating a lack of provision available for women's health.

Theme four '*Seeking Safe Choices'* highlights the internal conflict that many participants described in wanting to access support to relieve their menopause symptoms, but also not wanting to experience a deterioration in their CHD. Many participants described not accessing any type of support or supplements for the menopause because the medical research or guidance just is not available or known yet. Chiang et al. (2015) conducted a study on adolescents living with CHD and found that to alleviate feelings of anxiety and worry, adolescents should learn about their CHD, treatment options so they can be more involved in decision making. However, Savas et al. (2024) conducted a study with CHD patients and highlighted that there needs to be information available in the first place to enable the joint decision making. These findings support the present research study, as the lack of information available to participants has been described as a barrier to receiving support or treatment in the first place for their menopause symptoms. Participants described that they wanted to have access to information to help with seeking safe choices and not just feel like they are hearing different personal opinions from medical professionals.

The subtheme *'Living Safely with System Delays'* focused on women who accessed support for their menopause but had to manage ways of living safely within those system

delays. The subtheme captured the idea that coping through their menopause transition, physically and mentally, is not just about the symptoms, but managing uncertainty within healthcare systems.

Literature on non-communicable diseases generally has found that waiting times impact patient satisfaction and risks health deterioration (World Health Organisation, 2023). Menopause research and management often centre around symptom management (Crandall et al., 2023); the findings from this research study suggest that there are broader systemic factors that also elicit emotional uncertainty and self-coping. The delays within healthcare may also exist due to the unknown nature of the menopause transition for women living with CHD. Whilst this gap exists, responsibility for managing may feel like a shift from a system problem to patient, leading to an increased reliance on their own support.

The subtheme '*Specialist Psychological Support'* captured the experiences shared by those who received specialist psychological care within their adult CHD team. The trusting relationship participants described having with their psychological practitioner suggests that the existence of barriers were not experienced as a complete restraint on being helped and understood. This is encouraging, considering the research aims, as it highlights the benefits of the integration of psychology within adult CHD teams. It was felt that psychological practitioners within the team had a basic understanding of CHD which enabled participants to feel heard and understood. Participants valued the support of being helped to disentangle their experiences and symptoms, some which may be anxiety driven or some which may warrant further attention.

Conversations around menopause and hormones still lacked for some participants during psychological support. Participants in the present research study described that discussing the impact of their oestrogen depleting as well as their CHD trauma would have been helpful to address. The qualitative nature of this research has highlighted the spectrum

of experiences, triggers and presentations experienced amongst women living with CHD who are transitioning through the menopause. This research emphasised the importance of using a formulation driven lens when working with women living with CHD. Research on those living with non-communicable diseases has found that support and care is more effective when it goes beyond individual behaviours and symptoms and addresses wider societal and social concerns through coordination with systems (Babaita et al., 2024). A symptom-based model of care may focus on the discrete categories of each symptom, which may be helpful to consider for short term support. However, this research has highlighted the complex and lifelong nature of CHD which requires understanding of the interacting factors of CHD, menopause and mental health. In psychological therapy, a formulation can help to understand someone's difficulties and the experiences that have shaped them (Johnstone, 2018). This is used to help consider appropriate interventions and not necessarily locate the problem within the individual. This requires a biopsychosocial understanding of patients living with CHD as well as their contextual factors such as age and their life stage. The biopsychosocial model considers a holistic approach based on the interaction between biological, psychological and socio-environmental factors (Engel, 1977).

What psychological and social resources are available for women living with CHD transitioning through the menopause?

Theme five '*Personal Coping Resources'* captured how participants have coped with their CHD and the transition through the menopause. Often, inner strength was described which may be explained by the lack of available structured support currently for women living with CHD transitioning through the menopause, or the lifelong experiences that many participants have had to face. Participants often described looking after their health through diet and exercise as a way of becoming healthier. The personal coping resources seemed to support participants through their transition, particularly when medication has not been

available to them. Their personal coping resources may have also come from a lifelong experience of living with CHD. A previous study conducted by Chiang et al. (2015) found that inner strength often starts at young age. Their study found that participants living with CHD between the ages of 15-24 reported that they wanted to establish their own positive ways of coping (Chiang et al., 2015). In the context of the findings from the present research study, personal coping resources may be supportive during the menopause transition and may also represent lifelong coping strategies that have been adopted by women who have had to navigate healthcare experiences throughout their life.

Ghizzardi et al. (2023) found that women living with CHD embarking on pregnancy and motherhood often spoke about their positive coping resources and own inner strength to face difficulties. Zahmacioglu et al. (2011) found that adolescents and young adults living with CHD perceived themselves as psychologically strong. However, whilst personal coping is a strength, relying too heavily on this may discourage help seeking or place blame on individuals at times when they cannot cope. No amount of inner strength can fully overcome the lack of support or resources available. Additionally, for those from a poorer socioeconomic background, placing emphasis on personal coping, may create further barriers to accessing support, by limiting access to healthcare. It is important therefore, not to make generalisations about individual or social circumstances. Research has also shown that despite psychological strength, individuals living with CHD generally, are likely to benefit from structured psychosocial support (Birkeland et al., 2005).

The subtheme *'The Strain and Strength of Self-Advocacy'* attempts to capture the empowerment felt by being heard and voicing concerns, but also the tiring nature of having to continuously self-advocate. The power imbalance that exists between patients and professionals is significant and can impact treatment options and trust. The imbalance can be

exacerbated in the context of menopause, particularly from the patient perspective, due to the subjectivity of symptoms, the stigma and the medical uncertainty (Tolman et al., 2015).

Research has been conducted into the role of 'collective action' which combines self-advocacy, collective advocacy and systems advocacy (Van Reusen, 1998). Self-advocacy focuses on an individual being able to identify and communicate their own needs to speak up for themselves. Collective advocacy focuses more on being part of a group with common experiences and a shared voice advocates for their needs. System advocacy involves movement towards changing laws and policies. For individuals living with CHD, a movement towards more 'collective action' may improve the quality of care and social support for their overall health (Ross & Verstappen, 2023). Self-advocacy without the support of collective or system advocacy may become tiresome and disheartening, like some of the experiences shared by participants in this research study.

The subtheme *'Menopause in the Context of Serious Health Conditions'* highlighted the impact of living with CHD and possibly other health conditions. This subtheme demonstrated how it may not just be about managing different health conditions, but how the menopause symptoms are interpreted, prioritised and managed when coping resources and health status must be engaged elsewhere. The menopause transition is closely linked with physical changes in the body, mental health changes and it can impact social functioning (Smail et al., 2020). However, in contrast to this, some participants in this research study situated their menopause experience within their already complex health conditions, which perhaps for them, the menopause felt less like a 'midlife rupture' due to other illnesses that they were coping with. A qualitative meta synthesis found that attitudes on menopause are often determined by women's wider health and lifestyle contexts (Tidblom et al., 2025). Kerr (2025) conducted a qualitative study exploring the lived experiences of adults living with CHD. The study highlighted that women living with CHD often bring established coping

frameworks due to the lifelong nature of CHD and therefore, findings from this present research study may highlight that for some women the menopause transition may not be experienced or seen as a new threat due to their health context.

Theme six '*Social Connectedness as Support'* highlighted the networks and groups around the participants which has supported them. Some participants spoke about their involvement in groups for women living with CHD, either as part of the hospital that they receive care from or from online social media groups. Interestingly, participants accessing these groups shared that the menopause didn't seem to feature as topics of conversations. Possible explanations may be due to shame and stigma associated with women's health or the lack of trusted information (Constatine et al., 2016). There may also be cultural differences in the understanding of menopause, and some cultures may view the menopause as an ending of their femininity, which may impact who and how people share their experiences (Opayemi, 2025). For example, the Vhembe District in Limpopo Province, in South Africa, the menopause is attributed with getting old, losing beauty and becoming less attractive (Ramakuela et al., 2014). Opening discussions about the menopause requires more than just medical interventions but also societal expectations and knowledge that contribute to the availability of support (Virdi, 2024).

The subtheme 'Community Support' captured the value of peer support for some participants. The sense of belonging and connecting to those with similar lived experiences offered opportunities of emotional and practical support. However, access to community support appeared to be limited to isolated to social media. Even then, the discussion of the menopause still appeared to be absent from discussions. Peer support generally has been researched extensively and should be used as a supplement rather than replacement for traditional support (Gidugu et al., 2015). There were mixed opinions amongst participants of this research study about the value of peer support, and some felt it would need to be

carefully curated so that groups were matched based on some shared characteristics, such as life stage. This has been supported in previous research surrounding the menopause discussions generally, whereby women gave preferences to sharing their experiences with those of the same gender, lived experience and ethnicity (Jurgenson et al., 2014).

Resources and services for those living with non-communicable diseases in low-and middle-income countries is limited (Chow et al., 2013). However, with the growing use of the internet and social media, access to health information and support may become more accessible for those with internet access (Bujnowska-Fedak, 2019). The participatory and interactive nature of social media may allow for engagement with health campaigns (Pimmer & Tulenko, 2016). The use of the internet and social media may support with shifting the stigma and taboo of women's health. Careful consideration should be given to all aspects of peer support when navigating health needs to ensure that patients are matched based on life stage and conditions, so that it is felt to be a safe and supportive environment.

The subtheme *'Intergenerational Support, Family and Partner Relationships'* touches on the support that is closer to home for some participants. Participants who learned from experiences of others who had gone through menopause, reported feeling supported by them. Despite not sharing the lived experience of having CHD, the shared knowledge of the menopause symptoms from those around them was felt to be useful. The theme captured participants feeling reassured by navigating their feelings and symptoms with someone who could relate to their experience. However, a qualitative study by Cronin et al. (2023) looking specifically at the menopause, found that the complex nature of family dynamics means that some women may feel silenced by family members or by older generations. The present research study shared some of the supportive experiences that the participants had; yet not all participants had available family members or friends to talk to.

Attachment theorists also propose that help seeking may be shaped by early life experiences (Bartholomew & Horowitz, 1991). Early life experiences may shape how individuals navigate help seeking during difficult times and can influence who they perceive as medically or emotionally reliable (Bowlby, 1988). For example, a study found that individuals who were classified as having higher levels of avoidance in their attachment style, were less likely to seek support and are more likely to play down their distress or suffering in comparison to those with more anxious attachment style who were more likely to amplify their expressions of distress to elicit responsiveness from others (Vogel & Wei, 2005). However, both attachment styles are considered insecure as they can be viewed as interpersonal defences, which once served a purpose to remain safe and receive care from their caregivers (Holmes, 2015). Therefore, early infant experiences as well as unconscious patterns of help seeking may also be a factor into navigating CHD and transitions such as the menopause. Research on adults living with CHD also highlighted how illness uncertainty can contribute to avoidant coping behaviours (White et al., 2016). The additional layer of health status, societal, cultural and individual factors may also shape how help is received and who is considered reliable to provide that help.

The impact of social isolation has been researched in the context of CHD in younger patients. The experiences shared by participants focused on being treated differently due to their CHD, which led to experiencing barriers to forming social connections (Chong et al., 2018). The impact of poor peer relations may have led to difficulties with adapting to CHD and increasing psychological difficulties (Tye et al., 2021). It is possible that throughout life, social connections may become more familiar and secure, however, those support systems will not exist for everyone.

Strengths and Limitations

This is the first known study researching the mental health impact of women living with CHD who are transitioning through the menopause. It extends beyond previous research surrounding reproductive health for women living with CHD. The application of this research extends beyond clinical psychology and offers detailed considerations for adult CHD teams more holistically.

The research study had an adequate sample size of fifteen participants, which is considered a strength given the unique and novel topic. The qualitative methodology meant that patient voice was at the centre of this research (Malterud et al., 2016) and allowed for experiences on this topic to be shared for the first time. The richness of the data enabled discussions around wider social factors influencing their experiences, such as support networks. This led to insights into support which extends beyond clinical practice.

The researcher acknowledged their limited experience on CHD and the menopause and took steps to ensure that the interview questions felt appropriate and suitable for potential participants. The interview schedule was co-designed by those with lived experience of both CHD and the menopause and therefore, steps were taken to ensure that patient voice was at the centre of the research. Participatory involvement is an increasingly crucial part of patient care within healthcare (Smith et al., 2022).

The variations in age of CHD diagnosis, menopausal stage and disease severity may have shaped participants experiences. Some participants may have had lifelong experiences of being aware of their CHD diagnosis and have lived through earlier reproductive limitations, and others may have faced a shock diagnosis and have experienced multiple health challenges at once, for example, CHD and the menopause. The heterogeneity of the sample may have offered rich perspectives, and the qualitative sample was not intended to be statistically representative as participants all contributed to the understanding the topic

(Gobo, 2004). In line with Gobo (2004), the patterns identified during the analysis support analytical generalisation, rather than statistical generalisation. This helps to explain the similarities and differences experienced by women living with CHD during the menopause transition.

As only one recruitment site was used, the themes may have been led by practices within one service, however, selecting participants attending the same service allowed to control for it and avoid heterogeneity due to different models of care received. In addition, participants were located from different parts of the country and would have had very different experiences from their primary care providers.

The use of online and telephone interviews enabled participants to be located nationally and in the comfort and privacy of their own home. There were hesitations from the researcher regarding rapport building and responding to non-verbal cues during the telephone interview. However, previous literature has suggested that telephone interviews can still offer rich and meaningful data on personal topics (Drabble et al., 2016).

The lack of ethnic diversity within the sample is a notable limitation. The sample consisted largely of White British participants. While the recruitment site was based in an ethnically diverse area of the country, this was not reflected in the sample. Recruitment via different avenues such as charities and social media may hold a higher number of patients and therefore, opportunities to attract participants from ethnically diverse backgrounds whose cultural beliefs and experiences of mental health and the menopause could be captured. There may be variations in cultural norms and values which may shape the perceptions of the menopause which were not captured (Williams, 2024). This may also be true for mental health experiences where stigma may persist. Some degree of openness is required during qualitative interviews and perhaps a mixed methods approach involving online questionnaires using a likert scale could have been used. For example, asking participants to rate statements

from strongly agree to strongly disagree, statements such as, ‘I feel able to access support to manage my menopause alongside CHD’ or ‘menopause has increased my worries about my CHD’. This may have captured those participants affected by the menopause but who may not want to participate in a formal interview. There were some participants who also had expressed an interest in participating in the study, but due to life factors and time constraints, were unable to. An online survey may have offered more flexibility.

Implications of the Study

This research study was undertaken in the context of the increase in survival rates for patients living with CHD (Gurvitz et a., 2016). Individuals living with CHD are surviving into menopausal age, meaning that adult CHD teams will see a growth in CHD patients seeking care during the menopause transition. Research is therefore required to understand the experiences of this transition and needs. Participants in the present study offered unique and new insights into the menopause journey for someone living with CHD. Their experiences build upon existing knowledge relating to reproductive health. The findings of this research study highlighted the ways in which the menopause and CHD impact mental health. This research seeks to inform clinicians and services on what to pay attention to, why it matters to women living with CHD and how care can be improved.

Clinical Recommendations

The NHS Congenital Heart Disease Standards (NHS England, 2016) state that written advice about sexual, reproductive health and safe forms of contraception must be provided for those living with CHD. The present research study has clearly highlighted the need to include a focus on the menopause in the current standards. Information leaflets and knowledge around safe forms of HRT were considered as an idea from participants as well as discussions about possible supplements that they could consider. Further clinical

recommendations are detailed in Table 6 based on the results of this research study to support with addressing the research aims.

Table 6.

Summary of Clinical Recommendations

Recommendations
Clinical
• Routine discussions about menopause during cardiology appointments for patients who are approaching the menopause age. • Offering the choice of a female clinician if preferred to discuss menopause with. • Incorporate discussions within cardiology appointments about menopausal treatments and the cardiovascular risks, where appropriate. • To continue to offer specialist psychological support within CHD teams. Psychological practitioners could proactively ask about menopause symptoms (if appropriate) which may co-exist with mental health related symptoms. This may help to reduce stigma and fear of bringing up the topic of first. • Create information leaflets with checklists around the differences and similarities between menopause, cardiac and mental health symptoms. • Provide signposting to reliable websites, apps and charities that can support CHD women through the menopause. • Consider curated peer led initiatives to promote the discussion on menopause for women living with CHD. • Management and team lead to support teams to hold conversations around menopause and challenge unhelpful narratives that may perpetuate stigma.

- Psychological practitioners to support teams and healthcare professionals with managing anxiety and uncertainty around the topic of menopause.

Training

- Mandatory training for all staff working in CHD teams to understand the menopause and the cardiac interactions.
- Ongoing clinical discussions within teams around menopause symptoms that may mimic cardiac concerns.
- Menopause awareness to be provided in mental health/psychological doctoral training programmes.

National Policy

- To update the Congenital Heart Disease Standards (NHS England, 2016) to include menopause awareness and support.
- Formalise support pathways for GP's to access timely advice on whether HRT or other medical interventions are suitable for their patient.

Research

- Research and evaluation into understanding what therapeutic interventions are supportive for CHD women transitioning through menopause.
- Consider research into understanding the risks/benefits for women living with CHD accessing different forms of HRT.
- Use both quantitative and qualitative methods for research studies to ensure patient experience is captured.

- Consider research into healthcare providers' experience and confidence of discussing the menopause with CHD patients to explore the strengths and challenges that they face working within these systems.

Psychological support is seen as an essential part of CHD teams throughout the lifespan (Kovacs et al., 2022). The integration of physical and psychological health is something that has been recognised within the UK, based on the CHD standards (NHS England, 2016). With medical advances and surgeries improving the lives of people living with CHD, the introduction of the menopause in this guidance should now also be thought about. The lack of understanding and training on the menopause, is not solely located within medical professionals. Psychological understanding of menopause is not commonly thought about in psychology training programmes. This could be considered by the British Psychological Society (BPS) when planning core training competencies. Pastor and Elder (2023) recognised that amongst teenagers living with CHD there needs to be an emphasis on understanding both the physical and psychological impact of living with CHD. The biases, stigma and possible shame around discussing menopause within the psychological profession may also be experienced. This is because beliefs, attitudes and experiences will vary from different countries, cultures and regions (Dashti et al., 2021). Therefore, continuous work to educate and remain curious amongst all professionals is needed.

Dissemination

This thesis was submitted to the University of Essex as part of a doctoral degree in clinical psychology. All participants confirmed that they would like to read a copy of the thesis once it has been finalised and successful completion has taken place. The thesis will be uploaded to the University of Essex research repository which will be accessible to the

public. Possible journals have been explored to consider publication to a peer-reviewed journal, which includes the International Journal of Cardiology Congenital Heart and *BMJ Open*. The systematic review which forms part of this thesis has been submitted to *BMJ Open* and accepted for publication (See Appendix A). An infographic poster will be created and shared at the recruitment site as they support patients throughout their life living with CHD. Disseminating the findings to the recruitment site could contribute to refining aspects of their existing work, as well as the continued development of menopause related resources and discussions. This research aimed to support early discussions on the menopause and may prompt professionals on a multidisciplinary level to reflect on the gaps within this topic area to both improve patient experience and consider further research. The findings can also be shared with other hospitals nationally that support CHD patients throughout their life as well as charitable services. The findings of the research may shape policies within the NHS for example, updating the CHD Standards (NHS England, 2016) to include discussions and guidance on navigating the menopause.

Future Research

This research highlighted the need for discussion and support for women living with CHD who are transitioning through the menopause. There was an interest from participants to share their experiences in the hope of shaping the support for future generations. The exploration of the therapeutic assessments, formulations and interventions offered to those transitioning through the menopause, has yet to be explored. A further research study or service evaluation may be particularly important in populations where there are restrictions on medical interventions. Such research may offer insight into shaping evidence-based guidelines specifically that supports this population. This could be explored both quantitatively to look at both outcomes and reliable and clinically significant change as well as qualitatively to explore the patient experience. Research into healthcare providers'

experiences and confidence in addressing the topic of the menopause could enhance understanding of both the facilitators and barriers to these discussions. These experiences are likely shaped by service level structures, personal experience and professional confidence. Such findings may help to promote thinking within professional training programmes to better equip staff. From a medical perspective, research into understanding the risks and benefits for women living with CHD accessing different forms of HRT or vitamin supplements may support women with tangible information they need to help make an informed decision. Of course, it is important to acknowledge the heterogeneity of CHD and, as the menopause is a not a singular event, the experiences may change over time and place and be dependent upon individual intersecting identities.

Final Reflections

When embarking on this research, I was mindful of exploring a topic that I had no personal or professional experience of. It brought out of me a genuine curiosity to learn and understand, particularly from the participants themselves. It was valuable to provide participants with a dedicated time and space to share their experiences of their own bodies which they have become experts in. The value of being personally distant from the topic enabled this research to not become about me and my experiences, I felt a genuine curiosity and interest hearing each participant's experience. Listening to moments and stories of being dismissed or navigating uncertainty, was something that felt personal and emotionally challenging throughout this research. The reflective journal helped me to recognise my feelings of anger towards the experiences that these women had, and I have personally experienced similarities of being unheard. The sensitivity of the topic and my own reflexivity reminded me the importance of this not just being an academic study, but something that people must navigate daily. Throughout the three years, I was balancing some of my own frames of being a young, female, trainee clinical psychologist and a researcher. It felt

important for me to be aware of the ethical and relational aspects of interviewing participants and my role as an interviewer and a researcher.

I valued the role of co-production within the interview schedule at the very start of this research. It helped to ease my own worries and anxieties about 'getting it right' or making sure I didn't ask a 'silly question' during the interviews. However, it also reminded me that this research wasn't about me, but it was about the people who live with these experiences daily. The co-productive nature of the interview schedule meant that the questions hopefully felt relevant to the participants but also enhanced trust and safety during the interview, to support with gathering authentic experiences. Jamieson et al. (2023) asks researchers to reflect on "what did I gain from this research?" For me, I developed qualitative research skills in a topic that was unknown to me. I gained an awareness into the recurring patterns felt by a group of people with shared characteristics along with the common strengths, challenges and coping resources. I also learnt how valuable it felt to represent an underrepresented cohort of people, and it has made me consider how important it is to represent marginalised perspectives. Finally, I learnt that the experiences of the menopause transition may not be isolated to those living with CHD but may be felt by women generally due to societal narratives (Dhanabalan et al., 2023).

Conclusion

To the author's knowledge, this was the first research study which explored the mental health impact of women living with CHD who were transitioning through the menopause. The results highlighted the psychological impact of transitioning through the menopause as well as gaps in the knowledge and support for women who already struggle to feel 'normal' or 'accepted' (Tylek et al., 2024). The study's findings offered new insights into the experiences of transitioning through the menopause for women living with CHD. The intention was that this work will propel further research within this field. Some of the

recommendations included: CHD teams to incorporate discussions about the menopause with both patients and staff, CHD teams to create information leaflets around the similarities and differences between cardiac, mental health and menopause symptoms and to signpost to reliable website, apps, charities that can support with the menopause transition. CHD teams to consider peer led initiatives to support discussions around the menopause. CHD teams to formalise support pathways to GPs to work in collaboration, so that patients can receive timely advice on appropriateness for medical interventions. Further research into the healthcare professionals' experiences and confidence of discussing the menopause with CHD patients may strengthen the implementation of some of the recommendations from this research study. These recommendations and future research can begin to contribute to national change in the UK to improve the care of women living with CHD as they enter a new life stage. The menopause impacts everyone worldwide, from women themselves to the family and friends of women and the professional's supporting women. It is, therefore, vital that a shared understanding and responsibility is considered.

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Appendices

Appendix A

Systematic Review Publication

Open access Original research

BMJ Open

Reproductive journey in women with congenital heart disease: a systematic review of mental health implications

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ABSTRACT

Objectives Advances in medical care have led to increased survival rates among individuals with congenital heart disease (CHD), enabling many women to pursue pregnancy and motherhood; however, their reproductive journey remains complex, involving intertwined medical and psychological challenges that are still not fully understood. This review aimed to explore the lived experiences of women with CHD as they navigate these reproductive challenges.

Design Systematic review of qualitative studies using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The Critical Appraisal Skills Programme checklist was used for quality assessment.

Data sources APA PsycArticles, Medline Ultimate, APA PsycInfo, APA PsycTests and CINAHL Ultimate were searched on 10 March 2025.

Eligibility criteria Studies were included if they examined the lived experiences of women with CHD, focused on reproductive health, used qualitative methods and were published in English without time or geographical limits. Exclusion criteria were studies focusing on family members, men or healthcare professionals; reproductive health in other non-communicable diseases; acquired cardiac disease; single case studies; or quantitative designs.

Data extraction and synthesis The data extracted from qualitative studies included author(s), aims, location, design, method, analysis, results and clinical implications. The synthesis followed the Thomas and Harden thematic synthesis approach to answer the review question.

Results Eleven studies met the inclusion criteria. Thematic synthesis identified four analytical themes: (1) the need for psychological support in high-stakes decision-making, including the emotional burden of parenthood; (2) challenges of receiving conflicting medical guidance; (3) balancing reproductive autonomy with health risks, including the influence of social norms and comparisons with peers; and (4) the impact of geographical location on access to support.

Conclusions Women with CHD face unique challenges within their reproductive health which is shaped by medical uncertainty, challenges with healthcare systems and high-stakes decision-making. Holistic care is crucial to support women through this journey and improve their outcomes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Diverse geographical locations and experiences of women, which captured various cultural and socio-economic experiences of congenital heart disease.
⇒ The included studies were largely focused on the experiences of pregnancy and motherhood, with only four studies referring to contraception or puberty.
⇒ No additional input for the thematic synthesis may lead to methodological bias.

INTRODUCTION

Congenital heart disease (CHD) affects 1 in 100 live births globally and was the leading cause of death in the first year of life in 2021.[1 2] CHD is defined as any structural abnormality of the heart or great vessels present from birth, excluding cases associated with syndromic illnesses, including extracardiac or neurocognitive manifestations in addition to cardiac malformations.[1] In recent years, the life expectancy of individuals born with heart defects has significantly increased due to advances in medical management, and as a result, there is a demographic shift, with the adult congenital heart disease population now surpassing the number of children living with CHD, growing at an estimated rate of 5% per year.[3] This remarkable medical success, while life-saving for countless individuals, has concurrently created psychological implications for women in this population. The intersection of CHD and reproductive health remains an underexplored area of research, leaving significant gaps in our understanding of how these women experience their reproductive journeys.

Women face a higher cumulative effect from CHD,[4] in part due to the distinct set of reproductive challenges faced throughout their lifespan. From adolescence, those with complex cardiac lesions or on anticoagulation therapy report menstrual irregularities.[5] Yet, clinical discussions surrounding sexual

health, contraception and family planning are frequently insufficient or entirely absent in routine practice, potentially leading to unplanned pregnancies.[6 7] Pregnancy causes substantial physiological stress on the cardiovascular system, marked by increased blood volume and cardiac output, which can significantly exacerbate pre-existing CHD.[8] During menopause, the cardioprotective effects of oestrogen diminish, posing additional risks.[9 10] For women with CHD, this transition can precipitate a worsening of their existing condition, heightening the risk of thromboembolism, weight gain, elevated cholesterol, diabetes and atherosclerosis.[9 10] Even hormone replacement therapy, a common intervention for managing menopausal symptoms, presents a complex therapeutic dilemma, as it may contribute to further cardiac complications in those with moderate to severe CHD.[11]

Beyond medical complexities, women with CHD encounter unique psychosocial challenges throughout their reproductive years.[12] The transition from paediatric to adult healthcare systems frequently occurs during adolescence and early adulthood, coinciding with critical periods of reproductive development and decision-making. Many women report inadequate preparation for reproductive health discussions, having received healthcare focused primarily on cardiac management rather than comprehensive reproductive planning.[13 14] Family planning decisions for women with CHD involve multifaceted considerations extending beyond conventional reproductive counselling. These women must balance personal desires for motherhood against potential health risks, consider genetic implications of their condition for future offspring (if applicable) and navigate complex contraceptive decisions accounting for cardiac medications and haemodynamic considerations.[15] The intersection of chronic illness identity and reproductive desires creates complex emotional terrain that women must navigate, often with limited specialised psychological support.

Existing research in this field has focused on clinical outcomes and risk stratification, especially quantitative measures of maternal and fetal morbidity and mortality. Although this clinical perspective is essential for medical management, it provides limited insight into the lived experiences of women with CHD as they navigate their reproductive journeys. The voices and perspectives of these women have been largely absent from research literature, creating a significant gap in understanding their needs, challenges and experiences beyond clinical risk assessment. Qualitative research approaches offer valuable insights into subjective experiences of illness and healthcare that quantitative measures cannot capture, thereby providing deeper understanding of how individuals make sense of their health conditions within their daily lives.

Given the physiological and psychological challenges in managing CHD throughout the reproductive lifespan, coupled with current gaps in research and clinical practice, there is an urgent need to understand the lived experiences of women with CHD during their reproductive years. Here, we review the qualitative literature on reproductive health in women with CHD to identify key experiential elements and critical gaps across puberty, menstruation, contraception, pregnancy, childbirth and menopause. Our objective is to inform clinical practice and support more integrated, patient-centred care.

METHODS

The review was in accordance withthe Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines[16]

Search strategy

A comprehensive search was conducted across multiple databases including APA PsycArticles, Medline Ultimate, APA PsycInfo, APA PsycTests and CINAHL Ultimate on 10 March 2025. Prior to the main search, the Cochrane Library was searched to determine whether a systematic review had already been conducted on this topic. The search strategy employed three main concept groups combined using Boolean operators: (1) "reproductive health" OR "pregnancy" OR "sexual health" OR "family planning" OR "contraception"; (2) "congenital heart disease" OR "congenital heart defect"; and (3) "qualitative research" OR "qualitative study" OR "qualitative methods" OR "interview". The final search combined all three concept groups using AND operators (#1 AND #2 AND #3) (see online supplemental appendix table 1 for more details).

Inclusion and exclusion criteria

To determine the inclusion criteria, the sample, phenomenon of interest, design, evaluation and research type[17] were used to determine inclusion and exclusion criteria.

Studies were included if they (a) included the lived experience of women with a congenital heart disease, (b) focused on any element of reproductive health for these women, (c) qualitative data studies, (d) published in English, (e) published in any time period and (f) published in any geographical location. Papers were excluded if they (a) focused on the experiences of family members or healthcare professionals or men; (b) focused on reproductive health in relation to other non-communicable diseases, such as cancer and diabetes; (c) did not focus on the lived experience of women with congenital heart disease going through a reproductive journey; (d) single case studies; (e) focused on acquired cardiac diseases during pregnancy; and (f) quantitative studies.

Study selection and data extraction

Title and abstract were independently reviewed by two reviewers (MEL and MA). Inconsistencies and conflicts in assessment were resolved by discussion and, if needed, resolved by a third reviewer (MDC). Full-text screening was performed by two independent reviewers (MEL and

MA). Data extracted included author(s), aims, location, design, method, analysis, results and clinical implications.

Quality assessment

To assess the methodological quality of the studies included in this review, the Critical Appraisal Skills Programme checklist[18] was used. As this review focused on qualitative studies, the qualitative checklist was used to assess the relevance, credibility and rigour of each study.[18] The checklist has ten broad questions which aim to systematically assess the relevance and trustworthiness of each study. The guidance on whether to accept or reject a study for synthesis based on its quality has been debated.[19 20] Given that the guidance remains unclear and there are few studies in this area of research, the current review included all selected studies for synthesis regardless of their methodologies to prioritise gaining a comprehensive understanding of the topic (see online supplemental appendix table 2 for Critical Appraisal Skills Programme checklist).

Data synthesis

The synthesis followed the Thomas and Harden[21] approach which involved line-by-line coding of the full results sections of the selected studies. Codes were organised to develop descriptive themes. The descriptive themes did not go beyond what the studies reported but rather summarised the findings from the primary studies. This enabled a summary of what different studies have found in relation to this topic area. Analytical themes were then generated to provide a deeper insight into the findings. These were generated by interpreting the descriptive themes to answer the review question.

RESULTS

A total of 223 papers were identified, 222 in APA Psyc Articles, Medline Ultimate and CINAHL Ultimate and 1 was manually identified (figure 1). After removing duplicates, 165 title and abstract papers were assessed, of which 35 were included for full-text assessment. A final 11 studies met the inclusion criteria and were included in the systematic review (table 1). The studies were based in the USA (n=4), Italy (n=2), the UK (n=1), Australia (n=1), Taiwan (n=1), Japan (n=1) and Jordan (n=1). A total number of 152 women were interviewed across the studies. The sample sizes of the studies ranged from 7 to 25. Four studies used the telephone or an online platform to conduct the interviews, while the rest were conducted face to face. One study conducted the interviews in person where possible but offered telephone if face-to-face was not viable.[22] All studies carried out one-to-one interviewing except one which conducted a focus group discussion.

The thematic synthesis of the included studies led to the development of four analytical themes.

The need for psychological support in high-stakes decision-making

Across all studies, multiple women highlighted the emotional implications of having to make high-stakes decisions about their reproductive health. Within this theme, women alluded to having to make life and death decisions about their health and their babies' health due to their CHD.[22–28] The lifelong implications of choosing whether to have a child or not appeared to be held within cardiology care where there was an emphasis on medicalising decisions with little offering of psychological

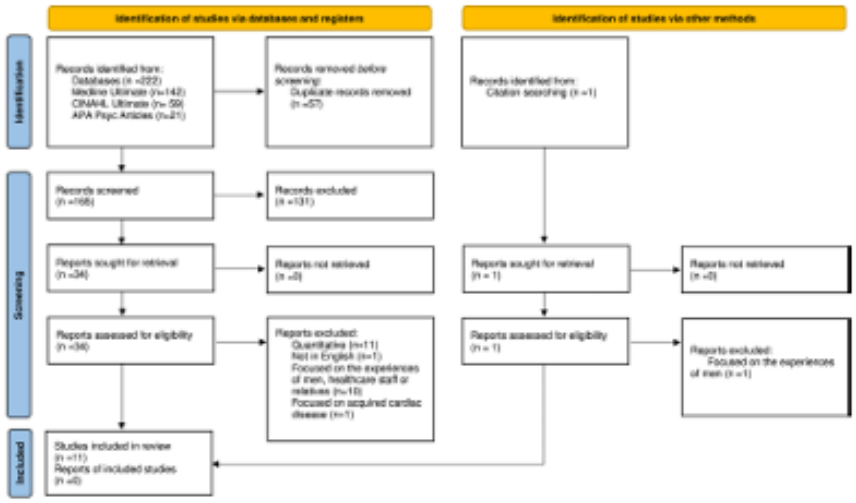

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart.

Table 1 Summary characteristics of included studies

Author(s)	Aim	Location	Method	Analysis	Results	Clinical implications
Flocco *et al*[23]	To explore the lived experiences of women with CHD during pregnancy and early motherhood.	Italy	F2F 12 semi-structured interviews recruited using purposeful and consecutive sampling	Interpretative Phenomenological Analysis (IPA)	Three key themes were identified: (1) 'being a woman with CHD'; (2) 'being a mother with CHD'; and (3) 'don't be alone'.	Individual support is needed for women with CHD. Specialist prenatal and postnatal care which covers both physical and mental health support should be offered for CHD women. Family members should be involved in care, if appropriate.
Gant[32]	To explore what young women with CHD perceive as the impact of their disease on their sexuality, body image, sexual decision making and potential pregnancies.	USA	F2F 13 unstructured interviews using theoretical sampling	Grounded Theory	Three categories were identified: (1) 'growing up heartsick'; (2) 'growing up female'; and (3) 'living against the body'.	HCPs should be trained to understand these women's reproductive needs. HCPs to help CHD women with knowledge about contraception, pregnancy and childbearing to make their own decisions.
Ghizzardi *et al*[29]	To explore the barriers and facilitators impacting CHD mothers' experiences in pregnancy and early motherhood.	Italy	Secondary data analysis of Flocco[23] study	Interpretative Phenomenological Analysis (IPA)	Barriers: (1) 'need for careful management of clinical risk during pregnancy'; (2) 'fear that children may have CHD'; (3) 'need for physical and psychological support in childcare'; (4) 'carrying the burden of their parents' concern'; and (5) 'uncertainty about future prospects'. Facilitators: (1) 'positive mental attitude'; (2) comparison with non-heart disease mothers'; (3) 'search for inner strength and hope in facing difficulties'; (4) 'involvement of children in dealing with the disease'; (5) 'acceptance of support from the partner and family of origin'; and (6) 'trusting relationship with healthcare providers'.	Psychological support is needed as women expressed worries around passing their condition on. Trusting relationships with clinicians and nurses is important.
Harb *et al*[30]	To explore the healthcare needs and experiences of Jordanian women with CHD during pregnancy.	Jordan	F2F 15 semi-structured interviews recruited using purposive sampling	Colaizzi Data Analysis	Three themes were identified: Three themes were identified: (1) 'a broad spectrum of health needs during pregnancy'; (2) 'not being cared for'; and (3) 'the healthcare journey'.	A holistic approach in healthcare is needed. Knowledge about CHD should be incorporated in the HCPs' training curriculum. HCPs should be skilled to work with CHD during pregnancy.
Liu *et al*[31]	To explore the lived experience of first-time mothers with CHD.	Taiwan	F2F 11 semi-structured interviews recruited using purposive sampling	Giorgi's Phenomenological Analysis	Six themes were identified: (1) 'recognising pregnancy risks'; (2) 'performing self-care for health'; (3) 'building self-worth from my baby'; (4) 'adapting to postpartum life and adjusting priorities'; (5) 'enjoying being a first-time mother'; and (6) 'the factors contributing to success in high-risk childbirth'.	Appropriate social support and psychological interventions are important. The findings highlight the emotional burden experienced by women with CHD during their pregnancy.

Continued

Table 1 Continued

Author(s)	Aim	Location	Method	Analysis	Results	Clinical implications
Nakamura *et al*[21]	To examine the perceptions of pregnancy and childbirth among adolescent girls with CHD.	Japan	F2F 12 semi-structured interviews recruited using purposive sampling	Grounded Theory	Three categories were identified: (1) 'the realisation that I live with CHD'; (2) 'I want to be someone who has sufficient knowledge of CHD'; and (3) 'the awareness of getting pregnant and birthing a child while having CHD'.	HCPs should assess adolescent girls' awareness of their disease before discussing pregnancy and childbirth risks. HCPs to provide support specific to the timing, stage and degree of pregnancy and childbirth. HCPs should continuously assess concerns around pregnancy and psychological issues alongside their CHD.
Ngu *et al*[22]	To explore the motivations of women with CHD to conceive.	Australia	F2F or telephone 20 semi-structured interviews using purposive sampling	Thematic Analysis	Four themes were identified: (1) 'influence of existing relationships'; (2) 'personal influences'; (3) 'biological influences'; and (4) 'cultural and social influences'.	Discussions with HCPs should begin in adolescence to support women with decisions about contraception and pregnancy.
Osteen *et al*[23]	To understand the childbearing decision-making and adaptation experiences of women with CHD.	USA	Telephone 17 semi-structured interviews using convenience and snowball sampling	Narrative Thematic Analysis	Five stages of childbearing decisions: (1) 'stimulus to consider childbearing'; (2) 'exploring childbearing options'; (3) 'considering childbearing options'; (4) 'choosing to bear or not to bear a child'; and (5) 'adapting to the childbearing decision'.	There is a need for HCPs to validate and support women's concerns, fears and grief around childbearing decisions.
Steiner *et al*[24]	To understand adults with CHD expectations for and experiences with pregnancy, including factors that influenced patients' perceived quality of care.	USA	25 semi-structured telephone interviews recruited using purposive sampling	Thematic Analysis	Four themes were identified: (1) 'expectations about pregnancy'; (2) 'testing, education and planning'; (3) 'balancing recommendations with logistical reality' ; (4) 'importance of clinician confidence and communication'.	The confidence of the clinician caring for pregnancy in adults with CHD is important. Strong communication skills, multidisciplinary collaboration and counselling should be provided to all patients with CHD.
Stokes *et al*[21]	To explore women's perceptions of pregnancy and family planning care as related to CHD	USA	20 semi-structured telephone interviews recruited using purposive sampling	Thematic Analysis	Five key themes were identified: (1) 'CHD impacted their reproductive health goals and decisions'; (2) 'women with CHD perceived a lack of safe contraceptive methods for their condition'; (3) 'women desired tailored, disease-specific sexual and reproductive health (SRH) information'; (4) 'women viewed their cardiologist as the primary source for SRH information and preferred provider-initiated discussions starting in adolescence'; and (5) 'women desire coordinated pre-pregnancy and intrapartum care between their cardiologists and women's health providers'.	Women with CHD may have limited information in relation to their reproductive health. Cardiologists should play a role in counselling, pre-pregnancy counselling and peripartum management. This should begin in early teenage years and continue through and after transition to adulthood. Interdisciplinary communication is important for successful patient experiences.

Continued

Table 1 Continued

Author(s)	Aim	Location	Method	Analysis	Results	Clinical implications
Tylek *et al*[27]	To explore, examine and identify the experience that women with CHD face as they transition through adolescence to into womanhood.	UK	Three focus groups on Microsoft Teams with seven participants recruited using snowball sampling	Thematic Analysis	Three themes were identified: (1) 'the impact of womanhood and the potential influence of motherhood on the young women themselves transitioning through adolescence with CHD, within medical and sociocultural contexts'; (2) 'the challenges of being a woman and undergoing heart surgery during adolescence on the young women's health before, during and after surgery'; and (3) 'the effect of existing online/offline healthcare and social structures on women's health during transitioning through adolescence'.	HPCs should provide CHD patients with practical, psychological and social support. Care plans should address women-specific issues and offer psychological support. Psychological support may be beneficial for young women transitioning through adolescence and should be embedded throughout the lifespan.

CHD, congenital heart disease; F2F, face-to-face; HPCs, healthcare professionals.

support in that process. The lack of psychological support in recognising the emotional burden of having to make such big decisions was detailed in multiple studies.[25–25 27 29 30] Two studies suggested that women often used their own inner strength or support systems to seek emotional support during this time[23 29] and this was their primary source of psychological support.

Subtheme: The emotional and psychological burden of parenthood

This theme expands further on the need for psychological support in high-stakes decision-making, highlighting how not only did participants describe having to make life-changing decisions but also their concerns about potentially passing on their CHD to future offspring.[22 23 25 28 29 31] There were also fears of being in situations where their own or their baby's survival was at risk and having to make life or death decisions if complications arose.[26] This was later echoed in studies where fears and worries were translated into women not being alive long enough to see their child grow up and the burden of their own health needs exceeding their child's needs and health.[25 29] The opportunities for parent-child interactions were another dimension which was perceived as important, in particular in relation to the potential physical limitation of their CHD to keeping up with the physical demands of playing with their children.[31] The emotional impact of having to face these dilemmas appeared to exacerbate the usual anxieties that come with parenthood.

The challenge of receiving conflicting medical guidance

Several studies described conflicting medical advice among the healthcare teams.[25–27 29 30] Some women recalled being told that having children would never be possible due to their CHD, yet later went on to have children after being informed that it was, in fact, possible.[27 29 31 32] Others reported having no conversations or discussions about contraception or pregnancy in relation to their CHD, which led to unplanned pregnancies that put their heart health at greater risk.[28 31] There was a focus on these women needing professional expertise in understanding their CHD and how it impacts their body and their life, and this was not always available or was conflicting.[23–27 29 30] There appeared to be a strong focus on the support from cardiologists which was often described as someone the women trusted for their understanding of their CHD.[22 23 25 29 31] However, the understanding of their health needs and risks across different departments such as gynaecology and obstetrics was less understood and often participants reported a feeling of insecurity.[26 27 30 31] Women felt that the complex nature of their CHD became even more confusing when other healthcare professionals did not have a good understanding of their needs. Studies which focused on contraception or puberty similarly highlighted the limited information around contraception from their GP and shared examples of being put on contraceptive pills that were associated with cardiac risks.[24 27 28 31] The consideration of the intersections of participants' health needs (physical health, psychological health, reproductive health, medical care and personal circumstance) should be important factors in understanding the reproductive journey of women with CHD.

Balancing reproductive autonomy and health risks with congenital heart disease

Concerns around having little or no control over participants' decision to have children or not were often removed from their agency due to their CHD.[24 28 29 31 32] Women felt that the decision to have children or not

was very personal and they wanted to have autonomy over their body and the decisions that they made for their family, which was not always possible.[27 30] There were also concerns about the overall medicalisation of their pregnancy, and there was an overreliance on medical interventions compared with their own concerns or experiences.[26 28] This was particularly relevant when women's birth plans had not been followed, or their hopes were not considered.[26] It was broadly suggested that women wanted healthcare professionals to hold optimistic and hopeful views so that they could feel empowered in their own ability to make the right decision.[26 30] However, participants emphasised the importance of acknowledging their own limitations specifically on what would be safe for them.[23 24 31] Therefore, placing greater emphasis on person-centred care could help women better manage the challenges of tolerating uncertainty, particularly if they are supported in making their own informed decisions.

Subtheme: social norms and comparisons of pregnancy experiences

Many women reported on the social comparisons between them and their non-CHD peers.[22 24–27 29 30 32] Aligning with this, the concept of womanhood and societal expectations of being able to carry and birth a child were major concerns. This was apparent in two non-Western studies[24 28] where there was a desire to become a mother, which could reflect cultural gender norms where women provide for children and household duties and men provide financial stability. This suggested an 'othering' that women with CHD may feel in relation to their identity and cultural norms. Despite the concerns with pregnancy, the desire to become a mother appeared to outweigh the potential fears of parenthood and the possible health implications.[29]

Impact of geographical location on access to support

Several studies highlighted the importance of location in relation to having access to resources, with differences in support available depending on location. Women who lived in rural areas described having to travel far to be able to access specialist hospitals to manage the safety of their pregnancy and childbirth.[26 30] Three studies[27 28 30] highlighted the importance of a social network for these women which included family members, friends and peer support. The idea of having to move away for childbirth appeared to contribute to feelings of fear and isolation from their support network.[26 28 30] This then contributed to some concerns of finances and employment which were detailed in two studies.[26 30]

DISCUSSION

Globally, over 3 million women of reproductive age live with a congenital heart condition, one million more than in 1990. This is the first systematic review of qualitative studies exploring the lived experience of women with CHD and the mental health burden posed by their reproductive journeys, from puberty to menopause. Overall, our findings identified a gap in the provision of psychological-based support for patients with CHD in their reproductive journey. The results highlighted the complex nature of health needs for women with CHD around their reproductive health.

There are clear health risks for this group of women such as increased risks of heart failure, arrhythmias, stroke and pulmonary hypertension during pregnancy.[33] As a result, women's desires and wishes may not always be accommodated, particularly around pregnancy. There is ultimately an ethical dilemma faced by healthcare providers which needs to balance patient safety and responding to reproductive choices. However, there did appear to be little consideration or support for the emotional and psychological impact of having to make critical decisions about reproductive health. Themes relating to 'the need for psychological support in high-stakes decision-making' and 'the challenge of receiving conflicting medical guidance' appear to overlap because receiving conflicting medical guidance is likely to exacerbate the emotional impact of the decision-making process. This may lead to doubt and uncertainty, ultimately diminishing confidence in the decision. To address these issues, previous studies have suggested a collaborative approach where women and their partners engage in conversations with cardiology about safe pregnancy.[34] Healthcare professionals and providers may be able to mitigate some of the stress experienced by this group of patients by increasing their own confidence and knowledge around reproductive health for women with CHD.

A common concern throughout the reproductive cycle included the woman's decisions around contraception. Results showed the frequent reports of contradictory advice around hormonal contraception, and examples were shared of women being on contraceptive pills that had risks for their CHD. Previous studies have highlighted the need for early consultation with healthcare providers regarding family planning decisions.[35] Women also reported that they relied on their own inner strength or support network. The emotional toll of having to make life-changing decisions appeared to be reinforced by the healthcare systems because of the limited emotional support available. While in some studies, women described their inner strength as a protective factor in their reproductive journey, other studies focused on the strength provided by other people, for example, family, friends or other women with similar experiences. Previous studies which have focused on other chronic conditions share similar findings in that sharing experiences with others with similar lived experiences is a major supportive factor.[36] However, due to the unique and complex nature of CHD, peer support needs to be integrated with professional guidance.

Despite studies recognising the importance of cardiology care for CHD, the same understanding within other disciplines, such as gynaecology and obstetrics, was not

always visible. Previous studies have found that family planning decisions are not consistently addressed for this population.[37]

Our results showed a high degree of inequality in the lived experience of these patients both driven by social norms and geography. On the one hand, previous studies have found that individuals with chronic or long-term conditions strive to move away from feeling 'different' and aim to achieve a sense of normality.[38] The ability to have children may contribute to having a sense of normality[39] which reinforces the societal expectation that motherhood is a key aspect of womanhood. On the other hand, access to specialist support varies based on geographical location, with women who have limited access to healthcare facing greater challenges in attempting to achieve normalcy.

Finally, our results have shown an important gap in our understanding of the mental health burden of transitioning to menopause in this group of women. Women with CHD are more likely to experience a deterioration of their condition during menopause[40] with a higher risk of blood clots, weight gain, increased cholesterol and glucose and an increased amount of fat around the heart.[41] Deterioration of the cardiovascular profile paired with hormonal changes associated with menopause may play a major role in the mental health profile of this group of patients. While a recent review[42] suggests that increased risk of major depressive disorders during the menopause transition is observed predominantly in individuals with previous major depressive disorder, our understanding of the experience in women with CHD is minimal to nonexistent.

While this review was the first to explore the lived experiences of women with CHD through their reproductive journey, there were notable limitations. The majority of studies focused on pregnancy and motherhood, with only four referring to contraception or puberty.[24 27 28 31] The decision to focus on the entirety of reproductive health was to capture all possible qualitative studies that focused on reproductive health for women with CHD. This was aimed at generating a comprehensive overview of the reproductive health experience for women with CHD and offering a holistic view of their reproductive journey. While the diversity of geographical locations and variations of cultural and socioeconomic experiences and norms of the studies included can be considered a strength, differences within healthcare systems across countries and regions as well as cultural norms and access to resources may result in the themes or subthemes not being of relevance in other contexts.

Lastly, although there was input from a second reviewer (MAd) to screen studies, there was no additional input for the interpretations of the findings. This may have led to methodological bias. This was due to the nature of this research being conducted independently due to time restrictions under the conditions for which the review was being conducted.

In conclusion, this systematic review highlighted the significant role that healthcare providers play in women's childbearing decisions and reproductive health among CHD patients. Despite the clear medical implications for these women, medical advances are not the only significant factor in decision-making for reproductive health concerns. This review highlighted the gap within healthcare for the psychological support available for women making life-changing decisions, not only for their health but for their families. The review revealed the importance of cardiologist care but also the need for a multidisciplinary understanding of reproductive health for women with CHD. Based on the findings of this review, consideration should be given to education and discussions about women's health within healthcare teams. Alongside this, psychological support should be available for women throughout their reproductive journey, for example, when going through puberty, decisions around contraception and pregnancy and postpartum periods.

Contributors MA and MDC conceived and designed the study. MA and MAd performed literature searches and independently screened studies. MA extracted data, conducted the analysis and drafted the initial manuscript, with the support of MAd. All authors critically revised the manuscript for important intellectual content. No authors were prohibited from accessing the data. All authors reviewed and approved the final manuscript. MDC is responsible for the overall content as guarantor and had final responsibility for the decision to submit the manuscript for publication.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. Systematic review.

ORCID iD

Melissa Amato https://orcid.org/0009-0005-7038-4948

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Appendix B

EBSCO was used to access five databases, namely - APA PsycArticles, Medline Ultimate, APA PsycInfo, APA PsycTests, and CINAHL Ultimate. EBSCO (https://www.ebsco.com) is a widely used academic research platform that provides access to a vast collection of peer-reviewed journals, scholarly articles, ebooks, and other research materials across multiple disciplines in the UK EBSCO is the chosen NHS platform.

Three independent searches were conducted and combined using the Boolean operator AND. The terms used were searched across the five databases whether they appeared in the title, abstract or keyword/subjects/MesH terms.

Search strategy

Search no.	Search term	Results
1	"reproductive health" OR "pregnancy" OR "sexual health" OR "family planning" OR "contraception"	1,740,238
2	"congenital heart disease" OR "congenital heart defect"	114,889
3	"qualitative research" OR "qualitative study" OR "qualitative methods" OR "interview"	1,621,970
4	S1 AND S2 AND S3	222

Appendix C

Qualitative Critical Appraisal Checklist

	Qualitative Critical Appraisal Checklist Key: Y= Yes N= No ? = Cannot tell									
Author(s)	1.Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4.Was the recruitment strategy appropriate to the aims of the research?	5.Was the data collected in a way that addressed the research issue?	6.Has the relationship between researcher and participants been adequately considered?	7.Have ethical issues been taken into consideration?	8.Was the data analysis sufficiently rigorous?	9.Is there a clear statement of findings?	10. How valuable is the research?
Flocco et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gant (1992)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Ghizzardi et al. (2023)	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Harb et al. (2024)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Liu et al. (2022)	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Nakamura et al. (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ngu et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Osteen et al. (2024)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Steiner et al. (2022)	Y	Y	Y	Y	Y	N	?	Y	Y	Y
Stokes et al. (2023)	Y	Y	Y	Y	Y	Y	?	?	Y	Y
Tylek et al. (2024)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Appendix D

Co-designed Interview Schedule

Introductions

- Introduce yourself and explain the purpose of the interview. Confirm the participant's consent.
- Explain the recording process, the right to withdraw at any time, and the confidentiality of their responses.
- Encourage the participant to share their experiences in as much detail as possible, emphasising that there are no right or wrong answers. Let them know it's okay if they feel like they are talking a lot, as open ended questions will be asked.
- Check if the participant has any questions before beginning the interview.

1. **Tell me about your experience of having a congenital heart disease?**

   Prompts: What was day-to-day life like prior to menopause? How has your congenital heart disease changed as you have gotten older? Were you included in hospital visits?

2. **Tell me about your experience of transitioning through the menopause?**

   Prompts: What changes in your body did you notice? Did you notice changes in your mental health? How did it impact your sense of self?

3. **At what point did you or did you not access support for your menopause?**

   Prompts: Think about factors: social support from family, friends, external agencies, professionals etc. Get a timescale of how long it took to reach out? Timescale of how long it took to recognise these as possibly menopause symptoms?

4. **What was your experience of asking for support during this time (menopause)?**

   Prompts: What did you find challenging / manageable? Do you feel you needed support? Did you seek the support? What point did you seek support?

5. **Tell me about your experience of accessing or not accessing support for menopause?**

   Prompts: How did you feel about the support you received? Did you feel appropriate support was offered? Considering asking why?

6. **Tell me about your experience of accessing or not accessing support for your mental health** (emotional support included)?

   Prompts: How did you feel about the support you received? Did you feel appropriate support? If you did seek support for your mental health, what were the triggers?

7. **Were there any barriers to accessing support for your mental health because of your congenital heart disease?**

   Prompts: think about the different forms of support: professional, social, psychological, lived experience?

8. **Were there any barriers to accessing support for your menopause because of your congenital heart disease?**

   Prompts: think about the different forms of support: professional, social (family, friends), psychological, lived experience?

9. **Was there positive experiences of accessing support for your mental health?**

   Prompts: this can be related to menopause, congenital heart disease or general life stressors?

10. **Was there positive experiences of accessing support for your menopause?**

11. **What support do you feel is needed to help you, as an individual with congenital heart disease who has transitioned / is transitioning through the menopause?**

12. **Are you able to reflect on the interactions between your congenital heart disease, menopause and mental health?**

    Prompts: this may not relevant currently

13. Ending question: Is there anything you would like to add? Were you expecting me to ask you any questions today that I haven't asked?

Appendix E

Participant Poster

Calling at women with congenital heart disease

What is the research about?

We want to understand your experience of accessing healthcare whilst transitioning through the menopause as well as the impact it has on your mental health.

Who can take part?

You can take part if you:

- Are a women with a congenital heart disease.
- Are currently or have recently transitioned through the menopause and are aged 40-60 years old.

What will happen?

You will be invited to take part in a 1-hour interview which will take place online on Microsoft Teams.

Why should I take part?

Contribute to the understanding of the impact of the menopause on women with congenital heart disease.

How to take part?

If you would like to take part in this research, please email the primary researcher (Melissa Amato) on ma23460@essex.ac.uk or scan this QR code

We will give you a £20 voucher following the interview to thank you for your participation.

Participant poster (version 1) Date: 11.10.2024 Page 1 of 1
ERAMS reference: ETH2425-0600
IRAS Project ID: 343439

University of Essex

Appendix F

Participant Information Sheet

University of Essex

[redacted]

Participant Information Sheet

Research title: Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease.

Study Sponsor: University of Essex

My name is Melissa Amato and I am a Trainee Clinical Psychologist in the Department of Health and Social Care at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

I will be interviewing women with congenital heart disease who are currently or recently transitioning through the menopause. The aim of this research is to develop an understanding of the impact of menopause on the mental health of women with congenital heart disease. Previous research has focused on the reproductive health amongst women with congenital heart disease mainly focusing on puberty and pregnancy with little to no research specific on the menopause.

This research is being conducted as part of Clinical Psychology Doctoral research and will run until the end of September 2026 and will be supervised by Professor Mariachiara Di Cesare. Ethical approved has been sought by the University of Essex Ethics Committee and NHS ethics.

Why have I been invited to participate?

You have been invited to participate in this research to contribute to the understanding of the impact of the menopause on mental health for adults with congenital heart disease. In order to take part in the study you need to be a woman with a congenital heart defect who has also gone or going through the menopause.

Do I have to take part?

It is up to you to decide whether you wish to take part in this research study. If you do decide to take part you will be asked to provide written consent. You are free to withdraw before or during the interview without giving a reason. Withdrawal will have no impact on existing treatment or access to services.

University of Essex

[redacted]

What will happen to me if I take part?

The study involves taking part in a confidential online interview through Microsoft Teams which will last approximately 60 minutes. The online interview will be audio recorded and transcribed by the primary researcher. You can choose to whether or not to keep your camera on during the interview.

What are the possible disadvantages and risks of taking part?

Taking part in this study will not affect the care or treatment that you are currently receiving. Participating will involve around 60 minutes of your time.

What are the possible benefits of taking part?

We hope that you find it beneficial to have your voice heard and share your experiences to inform future service provision. You will be able to stop the interview at any point should you feel upset or need to take a break. In addition, we will offer you a £20 voucher following the completion of the interview.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your name will be replaced with a pseudonym to ensure anonymity. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study. We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by emailing one of the research team; Melissa Amato: ma23460@essex.ac.uk, Professor Mariachiara Di Cesare: m.dicesare@essex.ac.uk
- by emailing the University of Essex's Research Integrity Manager Mantalena Sotiriadou: ms21991@essex.ac.uk. The University of Essex's Information Assurance Manager can also be contacted on dpo@essex.ac.uk.

University of Essex

[redacted]

Will my information be kept confidential?

All data collected will remain confidential throughout the research process and a pseudonym will be used for the write up. Confidentiality will only be broken if you disclose information where I may be concerned about your safety or the safety of those around you. I will discuss this with you first if confidentiality needs to be broken.Your data will be kept securely within a encrypted folder on the University of Essex network and will only be accessible by the research team. The data collected about you may be used to support other research in the future, and may be shared anonymously with other researchers. Should you have any concerns or questions regarding the data collection, you can contact University Information Assurance Manager dpo@essex.ac.uk

What will happen to the results of the research study?

The data will be transcribed, analysed and written up into a thesis as part of the Clinical Psychology Doctorate Programme at the University of Essex. The study may be published in journals and disseminated to hospitals and mental health services to inform current practices. The data will be anonymised and therefore, participant information will not be identifiable. If you would like to receive a copy of the findings, please contact the research team.

Who is funding the research?

The research is a student project which is being carried out as part of the Clinical Psychology Doctorate course at the University of Essex.

Who has reviewed the study?

A favourable ethical opinion has been given by NHS Research Ethics Committee.

What is the legal basis for using the data and who is the Data Controller?

The General Data Protection Regulation (GDPR) states that your consent must be freely given, specific, informed, and unambiguous. This will be given by you signing the consent form should you wish to take part in this study. The data controller for this study is the University of Essex and the University's Information Assurance Manager can be contacted on dpo@essex.ac.uk.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules. Universities, NHS organisations and companies may use patient data to do research to make health and care better.

Universities and the NHS are funded from taxes, and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'. If they could do the research without using patient data, they would not be allowed to get your data.

University of Essex

[redacted]

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checked before this research study started to ensure that the use of your data will meet GDPR rules.

Concerns and Complaints

If you have concerns or complaints about this study please contact the primary researcher, Melissa Amato and/or supervisor.

If you are still concerned or feel your complaint has not been addressed, please contact the HSC Research Director, Professor Konstantinos Roussos (k.roussos@essex.ac.uk).

If you are still not satisfied, please contact the University of Essex Research Integrity Manager, Mantalena Sotiriadou (email: ms21994@essex.ac.uk).

Name of the Researchers

Primary Researcher – Melissa Amato (Trainee Clinical Psychologist, University of Essex) – ma23460@essex.ac.uk

Primary Supervisor – Professor Mariachiara Di Cesare (Director, Institute of Public Health and Wellbeing) – m.dicesare@essex.ac.uk

If anything is unclear, please do not hesitate to ask any questions. Thank you for taking the time to read this participant information sheet. Should you wish to take part in the study, please contact the Primary Researcher by email.

What should I do if I want to take part?

If you would like to take part in this research, please email the primary researcher (Melissa Amato) on ma23460@essex.ac.uk

Appendix G

Participant Consent Form

University of Essex

Consent Form

Title of the Project: Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease.

Research Team: Melissa Amato (Primary Researcher), Professor Mariachiara Di Cesare (Primary Supervisor).

Please initial box

1. I confirm that I have read and understand the Information Sheet dated 14.11.2024 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project without giving any reason and without penalty. Once the interview has ended, I can no longer withdraw my data. ☐
3. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
4. I agree to my interview being audio recorded. ☐
5. I agree to the use of anoymised quotes in the research reports and publications. ☐
6. I understand that the study may be published as a journal article. ☐
7. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. Yes ☐ No ☐
8. I understand that the study will be written up as a thesis for the Clinical Psychology Doctorate Programme at the University of Essex. ☐
9. I agree to take part in the above study. ☐

Participant Name _____ Date _____ Participant Signature _____

Researcher Name	Date	Researcher Signature
_____	_____	_____

Appendix H

Favourable Opinion Letter

Health Research Authority

London - Bloomsbury Research Ethics Committee
Health Research Authority
2 Redman Place
Stratford
London
E20 1JQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 December 2024

Miss Melissa Amato
University of Essex
Wivenhoe Park
C04 3SQ

Dear Miss Amato

Study title:	**Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease.**
REC reference:	**24/LO/0826**
Protocol number:	**N/A**
IRAS project ID:	**343439**

Thank you for your letter of 10 December 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair, along with Committee Member Ms Victoria Cover.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Participant poster]	1	11 October 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance document]	1	16 October 2024
Interview schedules or topic guides for participants [Interview schedule for particiapants]	1	17 September 2024
IRAS Application Form [IRAS_Form_18102024]		18 October 2024
Letter from sponsor [Letter from sponsor]	1	16 October 2024
Organisation Information Document [Organisation Information Document]	1	16 October 2024
Other [Letter to GP]	1	14 November 2024
Other [Ethical Review- Further information required]	1	14 November 2024
Other [Ethical Review- Further information required]	2	10 December 2024
Participant consent form [Participant Consent Form]	2	14 November 2024
Participant information sheet (PIS) [Participant information Sheet]	2	14 November 2024
Research protocol or project proposal [Thesis Proposal]	1	17 October 2024
Schedule of Events or SoECAT [Schedule of Events]	1	16 October 2024
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	17 October 2024
Summary CV for supervisor (student research) [Summary CV for supervisor]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Melissa Amato
University of Essex
Wivenhoe Park
C04 3SQN/A

Email: approvals@hra.nhs.uk

13 December 2024

Dear Miss Amato

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease.**
IRAS project ID:	**343439**
Protocol number:	**N/A**
REC reference:	**24/LO/0826**
Sponsor	**University of Essex**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

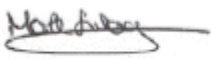
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **343439**. Please quote this on all correspondence.

Yours sincerely,



Mark Sidaway
Approvals Specialist
Email: approvals@hra.nhs.uk

Copy to: *Dr Mantalena Sotiriadou*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Participant poster]	1	11 October 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance document]	1	16 October 2024
Interview schedules or topic guides for participants [Interview schedule for particiapants]	1	17 September 2024
IRAS Application Form [IRAS_Form_18102024]		18 October 2024
Letter from sponsor [Letter from sponsor]	1	16 October 2024
Organisation Information Document [Organisation Information Document]	1	16 October 2024
Other [Letter to GP]	1	14 November 2024
Other [Ethical Review- Further information required]	1	14 November 2024
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User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 343439 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Mary Lowth
Vice Chair

Email:bloomsbury.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: Dr Mantalena Sotiriadou

Lead Nation England: approvals@hra.nhs.uk

IRAS project ID	343439

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Research activities and procedures as perthe protocol and other study documents will take place at participating NHSorganisations.	Research activities should not commence at participating NHS organisations in England orWales prior to their formal confirmation of capacity and capability to deliverthe study in accordance with the contracting expectations detailed.	An Organisation Information Document hasbeen submitted and the sponsor is not requesting and does not expect any otheragreement to be used with participating NHS organisations of this type.	Please note that the SoECAT submitted has not been authorised by an AcoRD specialist as this is a non-portfolio study but is acceptable in the place of a Schedule of Events. This does not constitute authorisation of the content of the SoECAT or confirmation that the cost attribution is appropriate. Study funding arrangements are detailedin the	A Principal Investigator should beappointed at participating NHS organisations.	Where an external individual who does not already hold an NHS employment contract will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold an Honorary Research Contract. External staff holding pre-existing NHS employment contracts should obtain a Letter of Access. These should confirm Occupational Health Clearance. These should confirm enhanced DBS checks appropriate barred list checks

			Organisation Information Document		

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they donot intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix I

University of Essex Ethical Approval

University of Essex

19/12/2024

Miss Melissa Amato

Health and Social Care

University of Essex

Dear Melissa,

Ethics Committee Decision Application: ETH2425-0600

We are writing to advise you that your application to register an external ethical approval of your research project entitled "Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease." has been reviewed by the REO Research Governance Team. We are pleased to inform you that the University of Essex will accept the ethical approval granted by HRA NHS REC for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Research Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

Appendix J

Capacity and Capability Site Approval

[redacted]

Dear PI and all,

Study: Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease

Full Study Title:	Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease
Site PI/LC	[redacted]
Protocol version & date:	Version 1.0 Dated 17/OCT/2024
Latest HRA Approval date:	13/DEC/2024

This email confirms that [redacted] NHS Trust has the capacity and capability to deliver the above referenced study.

This approval is for [redacted].

This approval is given on the assurance that all appropriate staff support and resources are in place.

Please see original signed Contract attached.

[redacted] NHS Trust agrees to start this study on a date to be agreed when you as sponsor confirm this. Please ensure the R&D office is provided with this date.

Any amendments should now go to [redacted]

If you wish to discuss further, please do not hesitate to contact us.

Appendix K

Debrief Sheet

University of Essex

Debrief sheet

Title of the Project: Navigating menopause: a qualitative exploration of the mental health implications for women with congenital heart disease.

Research Team: Melissa Amato (Primary Researcher), Professor Mariachiara Di Cesare (Primary Supervisor).

The aim of this research was to develop an understanding the mental health impact on women transitioning through the menopause who have a congenital heart disease with the hope that your experiences will inform future service provision.

Your data will help with our exploration of this. The write up and results of this research will not include your identifying information.

The research did not use deception. You may request a copy of the research findings once the project is complete.

Below is signposting information for services that you may wish to access:

Sommerville Foundation: https://sfhearts.org.uk

British Heart Foundation: https://www.bhf.org.uk

Little Hearts Matters: https://www.lhm.org.uk

British Menopause Society:https://thebms.org.uk

Your adult congenital heart disease team which may include psychological support

Your GP

If you have any further questions please contact me, Melissa Amato on ma23460@essex.ac.uk

Thank you for your participation in this research.

If you have concerns that the primary researcher is unable to address, please contact the Health and Social Care Research Director, Dr Camille Cronin (camille.cronin@essex.ac.uk) or the university's Research Governance Officer, Sarah-Manning-Press (sarahm@essex.ac.uk).

If you are still not satisfied, please contact the University of Essex Research Integrity Manager, Mantalena Sotiriadou (email: ms21994@essex.ac.uk).

Appendix L

Letter to GP

University of Essex

[redacted]

Dear GP,

This letter is to notify you that I have taken part in a research study which explored the mental health implications for women with congential heart disease who are transitioning through the menopause.

The aim of this research was to develop an understanding of the mental health impact on women transitioning through the menopause who have a congenital heart disease. The study has been reviewed and approved by the Health Research Authority, Research Ethics Committee (reference:343439) and adheres to all applicable regulatory and ethical standards.

This research is being conducted as part of Clinical Psychology Doctoral research and will run until the end of September 2026.

Participation in this study does not interfere with ongoing care.

Participants may request a copy of the research findings once the project is complete.

Below is signposting information for services that has been provided to all participants.

Sommerville Foundation: https://sfhearts.org.uk

British Heart Foundation: https://www.bhf.org.uk

Little Hearts Matters: https://www.lhm.org.uk

British Menopause Society:https://thebms.org.uk

Adult congenital heart disease team which may include psychological support

GP practitioner

If you have any further questions please contact the researcher, Melissa Amato on ma23460@essex.ac.uk

Appendix M

15-point checklist by Braun and Clarke (2006;2022)

Number	Process	Steps
1	Transcription	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
2	Coding	Each data item has been given equal attention in the coding process.
3	Themes	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
4		All relevant extracts for all each theme have been collated.

5		Themes have been checked against each other and back to the original data set.
6		Themes are internally coherent, consistent, and distinctive.
7	Analysis	Data have been analysed – interpreted, made sense of - rather than just paraphrased or described.
8		Analysis and data match each other – the extracts illustrate the analytic claims.
9		Analysis tells a convincing and well-organised story about the data and topic.
10		A good balance between analytic narrative and illustrative extracts is provided.

11	Overall	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
12	Written report	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
13		There is a good fit between what you claim you do, and what you show you have done i.e., described method and reported analysis are consistent.
14		The language and concepts used in the report are consistent with the epistemological position of the analysis.

15	The researcher is positioned as active in the research process; themes do not just 'emerge'.

Appendix N

Anonymised Participant Transcript

Interviewer started transcription

Interviewer

So before we begin the interview questions, there is a debrief information sheet that I'll send to you now. So, it contains information about services should you wish to seek out some support after today's interview for signposting purposes. I send it just at the start of the interview in case we lose connection. I have also attached a letter to your GP. So, it's completely up to you whether you want to notify your GP know that you've taken part in this research, so there's a draft letter if you want to give that to them. I will send that over to you now by email.

Participant

Yeah thank you.

Interviewer

That should be in your inbox now.

Just to start with the demographic information. So, are you able to tell me your age please?

Participant

Yeah, I'm 50.

Interviewer

50 and then what age were you diagnosed with your heart condition? Was it at birth, or was it later picked up?

Participant

I think it was at birth.

Interviewer

OK, thank you. Do you know the name of the heart condition that you have?

Participant

Yeah, it was well before it was corrected. I had pulmonary valve stenosis.

Interviewer

Pulmonary valve stenosis. OK, thank you. And then where are you on your menopause journey, would you say?

Participant

I mean, I would say I'm in menopause. I wouldn't have said I'm necessarily in perimenopause. I hadn't had periods for a little while before I started taking HRT, although on HRT and now I don't know whether I'm coming or going, I seem to have been now I'm experiencing a very long period. So I don't know what's going on, but I would say I am, I would say I am in menopause.

Interviewer

OK, thank you. And then just your ethnicity and nationality?

Participant

I'd say white British.

Interviewer

OK. And then any religious beliefs?

Participant

No.

Interviewer

OK. So we'll begin with the questions then and then also at the end there is £20 Amazon voucher as well. So I'll speak to you about that at the end if that’s OK?

Participant

Yeah.

Interviewer

So the first question is can you tell me about your experience of having a congenital heart disease?

Participant

Yeah. I mean, I think I've been relatively lucky because I think my defect as defects go was a relatively minor one, but I was born in 1975 and I had the operation in about 19 eighty 1981.

Interviewer

Mm-hmm.

Yeah.

Participant

And I was entirely reliant on my parents telling me about what I had and of course, of course, because I was a child when I had the surgery, but my parents didn't know it was called pulmonary valve stenosis. I've only found out, I would say, to be honest with you maybe in the last 10 years when I started re attending so I had the operation when I was about 5.

Interviewer

Mm-hmm.

Mm-hmm.

Participant

And my parents always talked to me about that, and I was given a little card by the doctors after I'd had the operation saying I need to take antibiotics if I was having dental work. I did start to feel tired before the operation and then I've always been appreciative of being able to move my body and whatever. But I mean, I don't know whether that's as a result of that or whether you know, you're so young, I mean anyway. So I had the operation and I suppose I'm quite an anxious, nervy person, that is by personality. I'm a bit of a worrier, so it's very difficult to know whether anxiety or whether because I know I have a heart defect. Whether that then made me feel anxious, I never considered myself to be a sporty person I like

dancing. It never stops me from doing things that I wanted to do, but on the other hand, I never really considered myself to be particularly, you know, I didn't really push my body and maybe I would have been more inclined if I'd had a gift for that kind of thing, to push my body. My parents were anxious. My mother would worry a bit, and she'd be like, you know, your heart, your heart kind of thing and I was aware of it, but I didn't really know. And then my father would take me for annual check ups when I had the operation, my father told me that the surgeon said, look she'll be fine. She may need another operation in old age, but it was very successful. And then I went annually until I was about 17 to [my hospital], which is where I had my operation and I see a different person every time. I think they give me an ECG and an echo and that was it. And then they said to me, you don't need to come anymore. So then I had no contact in relation to my heart with the health from the ages of about 18 till I suppose my early 30s is this OK? Is this what you want to know?

Interviewer

Yeah. Yeah, yeah, yeah, yeah.

Participant

Stop me if I'm like, if I'm not telling you information you need. So in my early 30s, I was working, I'd gone on a residential and I played rounders with the kids and I fainted and I was also thinking I want to have a baby, and I know that this is genetic, but I didn't even really know what it was that I had. I didn't really know much about it because I've been relying on my parents. My parents had no technical language for what it was. There was no documentation. There was just this little card saying I had to have antibiotics anyway, so I went to the my GP and initially my GP said to me, are you depressed? I said no, I'm not depressed. I said I have a heart defect. And I just want to be sure. So he sent me to [a hospital] and they gave me an echo and I think they got in a bit of a panic because even though what I have is relatively minor, I have quite a loud murmur and I think if you're not, if

you're, if you're a General practitioner or a more general person, you might be like, oh, what is this? The girl said to me she said, oh, do you know you've got a bit of a hole in your heart. I was like, no I don't think so. But I felt fine. I felt absolutely fine otherwise.

Interviewer

OK.

Mm-hmm.

Participant

Anyway, so then [the hospital] eventually referred me to [a hospital]. So then when I was about, I can't even remember how old I was, I would have been 32. Maybe I was younger than 34. Maybe I was only 32. So it's quite a lot a long time ago now come to think of it, they said, oh, no, you should be under us. You should be coming to us every year to 18 months. I remember the first time I went, they checked me out. They explained to me all about it, they said, well, when you were five, what they would have done and they would have just opened you up, put their hand in and just opened the valve physically. Which has resulted in regurgitation, which is their concern now, because there'll be a back flow of blood basically through that valve, which can put pressure on the heart and can be corrected in time, which is I think now why they're monitoring me basically. So now I have a barrage of quite expensive tests every 18 months or so, and I'm under a consultant, but I wouldn't have known. I mean, maybe if I'd fallen pregnant, perhaps somebody at the hospital where

I went then might have referred me, but I don't know.

Interviewer

Mm-hmm.

Yeah.

Participant

So because I was just out of the thing and I don't know if the hospital's even there anymore. A

lot of the women that I met when we had the menopause, everybody got together, many of them and maybe most of them were younger than me and a couple of the women had only recently been diagnosed with heart defects.

Interviewer

Yeah.

Participant

But the women that were those women that were had been children, they'd all gone to [a specialist children's hospital], none of them mentioned [my hospital] but I don't know, there's probably. I mean there must have been kids like me. They weren't at [my hospital]. Anyway, that is that it.

Interviewer

Yeah. That's really helpful to hear about your experience. And I guess following on from that, thinking about your experience of then transitioning through to menopause, are there any changes in your body that you've noticed?

Participant

I think, yeah, the menopause, I would say I always used to have quite painful periods and I always used to have like the mood swing, like the classic thing that we go through. So the mood swing before, you'll feel like you're losing your mind, you know, and you'd be like, why am I losing my mind? And then your period will be like, OK, when period started and sometimes occasions, I've had really, really, really unpleasant, painful periods, which is quite common. So to be honest with you, that I don't miss, it's actually a real relief to not to have to go through that anymore, but I was getting my periods after I had my son, so I had my son quite late. I was 37 when I had him, and not long after I had him. My periods I I've always had really regular periods but that I was getting a period every three weeks and that lasted for about, I would say two or three years. Then I think it's around the pandemic. My periods just

kind of tapered off.

Interviewer

Mm-hmm.

Participant

Same time I was getting very hot flushes and just my mood, my personality. I felt like my personality had changed and my mood really, I was really short tempered and just not be able to things, I didn't feel like I could cope as well and to be honest.

I suppose I still feel a little bit like that now, so eventually I went on HRT, I've got patches and there was a brief period because I was bleeding a bit and my periods were a bit sore, when I was having them even on the HRT, I thought oh well, let me maybe come off the patches and see how I feel. I probably shouldn't, but anyway I'll tell you but then the symptoms came back. I was like, actually, no, I'd rather have the periods and not have the symptoms because it was it was the hot flushes. It was the generally being very short tempered more than I used to be.

Interviewer

Yeah.

Mm-hmm.

Participant

But it was, you know, the mood swings and the just and not being able to sleep. Poor sleep was a real problem and now I do sleep through. I do the night. I'm not. I'm not woken up.

Interviewer

Mm-hmm.

Mm-hmm.

Mm-hmm.

Participant

So for me, HRT has been, you know it’s been fantastic. So yeah, and that's been about well I suppose 2020. I suppose that's only really in the last couple of years that I've been using it and I kind of went to the GP and but the GP she was a bit reluctant initially I had to try a few times. I contacted a couple of different GPs they were both female. The GPs that kind of were a bit reluctant and then they were like, wow, we don't think your symptoms, you know, they kind of felt that I wasn't really bad enough. They didn't say anything about my heart.

Interviewer

Yeah.

Yeah.

Participant

But obviously there is that link between clotting and an increased chance of clotting, although I've never really been on the pill. But of course, if I'd gone on the pill, there would have been that in risk, and obviously I wasn't being seen by a consultant or anything for years, and no one had said to me when I was younger. Oh, you shouldn't go on pill or you know, so it's difficult, isn't it? You kind of think about things now you're like, oh, so I'm not really concerned about clotting. Well, what can you do? I think I'd rather the trade off is and I'm healthy, you know.

Interviewer

Yeah, yeah. And how long would you say it took you to reach out for that support for the menopause or even maybe recognise that this might be the menopause? Did it take a while or did you recognise that quite quickly?

Participant

No, it took a while it took, I would say it did take about at least a year, 18 months, even though it's difficult to remember now, even though I'm sure your period stopping or fewer periods or whatever is a very obvious sign that you're going through menopause. So then if

you've got the symptoms on top, it's obviously quite clear that that's what it is. But I think sometimes what can happen is that you're aware of the physical symptom. OK. My periods have stopped, but maybe the other symptoms you're like, is it because I'm tired? And of course, I have my son, he was still very small when I was perhaps going to the early stages, he was only maybe about four or five and he was just starting school and it was all so you kind of think, oh, well, I'm tired or whatever. There are other things going on.

Interviewer

Hmm.

Mm-hmm.

Yeah.

Participant

But yeah, I would say I would say that took me a year and then to get the help took me another, maybe it took me another year, you know, I tried a few times and then because you're told no, you're a bit like, well, they know what they're talking about they're the expert, you know. I'll just wait and see and, you know, hold off.

Interviewer

Yeah.

Mm-hmm.

Participant

And I've heard similar stories from, you know, female friends, women they've had similar in this area. A friend of mine, she did it. She stopped me in the street a few months ago. And she's like what was it like for you? Because I talked to her all about my menopause. And she said, oh, I said, have you, did you have trouble? I said, yeah, I said I had to ask a couple of times, she said yeah, because I'm having the same, she was in really quite a desperate state. You know, some people don't really talk, so I thought well, that she must be pretty bad if

she's talking to me about it, you know, she must be. So I think my experiences from people I've spoken to, I mean she doesn't have a heart defect that you know and no one really mentioned that. They were cautious, they've obviously took my blood pressure and my blood pressure was high so I had to go on blood pressure pills and they did want to do a quick echo, they got a nurse to do a echo, and then they spoke to my consultant. So they were, you know, wanted to just check me out, check my heart. But yes, I would say a year at least a year. And then could also been a year to try and get help.

Interviewer

OK. That that kind of follows on to the next question about what did you find challenging about seeking that support? Was it the kind of length of time that it took or was there other things as well that was quite difficult but?

Participant

I would say the length of time that it took and also. I don't remember there being a leaflet or information. I mean, statistics are always dangerous and it is very difficult brain to a layperson what the risks are, but there didn't seem to be that you can go on in the Internet I suppose now and seek help, but I think what a lot of women find is you have private doctors and as a middle-aged woman on Instagram or on social media you have a profile so you will automatically be exposed if you're a woman of a certain age to certain accounts because that's, you know like menopause, you know women who are menopausal, talk about menopause.

Interviewer

Yeah.

Mm-hmm.

OK.

Participant

So there are obviously private doctors who have kind of moved into the space to kind of maybe fill a gap for women and I mean my menopause really, it's not been great, but it's not been horrendous. I mean there are I think other for whom it's worse, but I would say the challenging thing was is you there is that element of trust with the NHS and if I'd had an NHS booklet talking about the menopause, although I'm sure there is that information to access, then that might have made life a bit easier, and I think also contacting a GP and then initially saying no and then contacting someone else and then saying no and then contacting someone else and then going I'm really saying now I really am losing my mind and they're like, OK. Like feeling like you have to really be quite firm about your symptoms and be really like, I would like to try this please, because when things are great rather than going and saying I don't feel this isn't the horrendous. Like I'm not in a desperate state, but I feel like my quality of life could be improved. Could you please can we please give it a try? And I feel that. If you're in that category, a doctor might say, well, there are risks and then that's very difficult for you as an individual. You're like, OK, are the risks so great that unless I'm really fit, you know, things are really helpful. I shouldn't be risking using it. It's tricky, isn't it? Because you're relying on the expertise of a General practitioner, some of whom are women, some of them who may have been post menopausal.

Interviewer

Yeah

Participant

I don't know. I think also there's such a wide range of experience of women in menopause. In the same way that there's a wide range of experience for women who have maybe postpartum depression, even within that area, you'll have people who have psychosis.

Interviewer

Yeah.

Participant

You are very, very seriously, dangerously ill and people who were just really blue for, you know, and people talk about the baby blues and it's kind of diminished a bit because maybe because it relates to women, who knows, probably, but it is.

Interviewer

Yeah.

Participant

And similarly for women. There's that huge spectrum experience like my mother had an awful menopause, and she didn't really have any other women around her to talk to. So of course she talked to me about it so I knew about it because she'd gone through an awful and I don't think mine was has been as bad as hers.

Interviewer

Yeah.

Hmm.

Participant

But you know, it's difficult. I mean the HRT for my mum was like it turned her life around within a very short space of time. It was it was miraculous for her and that, you know, if she'd been born generation earlier, she wouldn't have had access to it. So, you know, it's difficult, but I would say in terms of seeking help, if you're feeling, a bit blue anyway, so if you're knocking on the door and you're not getting what you need and you're not having that support, and GP's are stressed, they have very limited time to talk to you and you're having to do that a few times kind of just add to your list of problems. You know, and there are some people that can afford private care, but there are a lot of people that can't. They can't afford

the private care and they can't afford the time to be going to the doctor every 5 minutes. They're busy, you know,

Interviewer

Yeah.

Participant

Yeah. So I think that it is difficult, they didn't specifically say to me you have a heart defect, you're might slightly more likely to clot. You know your valves a bit sticky, there is a concern there, how bad are your symptoms? And, of course, statistically I can't make a decision. I'm like, well, obviously I'd rather have hot flashes and be a bit blue than, you know, have a stroke or whatever. So you're like, you know.

Interviewer

Yeah.

Participant

And you haven't really got the information and of course, and there's that whole thing about the misinformation, of course. Then at that time, maybe I got the impression that the doctor was a little bit, maybe she'd been inundated with women ringing up, having seen Davina McColl on television banging on about the menopause. I've got a little bit like I got the impression for her that there was a degree of fatigue, she was like all these women have seen Davina, now they're all wanting patches, you know, and so I don't know. It' and of course they are reliant on you, it's not like you can do a blood test.

Interviewer

Yeah.

Participant

So they are reliant on you saying, I feel like this and I think the doctors and the medical profession and the NHS is fantastic in so many ways. But when it comes to relying on

individuals providing evidence of their pain or of their symptoms, that's not an area in which it excels for a variety of reasons and that, I think, is a contributory factor.

Interviewer

Yeah.

Yeah.

Interviewer

OK thank you, that's, that's helpful to hear your experiences with your menopause journey. Just thinking about then in terms of mental health what has your experience been of accessing support for your mental health or maybe not accessing it?

Participant

I would say I haven't really sought. I had to be fair. I haven't sought support. I haven't really, I suppose because I'm aware of the fact that waiting is too long and support. In terms of availability would probably be, you know, quite limited. I haven't sought support for my mental health via the NHS, I think if I did seek that kind of support, I'd probably just automatically go down the private route I'd probably. Somebody, a counsellor and have a chat with them about it, I think.

Interviewer

Mm-hmm. Mm-hmm.

Participant

Yeah. I mean, I think the HRT has definitely improved. It's put me on a more even keel and I think just being able to speak better has probably helped with that. But I don't, I mean to be fair. When I went to the GP the last time when she gave the HRT like, I feel like I'm losing it, but I think at that point there was no mention of me having additional kind of support for my mental health. It was just, well, let's put you on HRT, see how you, you know and then hope that'll be it. And it has helped.

Interviewer

Mm-hmm.

That's good. But and would you say there are any barriers to access in mental health support because of your heart condition or not really?

Participant

I wouldn't. No not because of my heart condition.

Interviewer

OK. And any barriers for accessing menopause support because of your heart condition?

Participant

I would say that's slightly more complicated because of the link between the kind of taking the hormones and clotting, and of course, there's not really much information.

There's no information, there's not a leaflet about pulmonary or about regurgitation, for example, or people that have had BVS saying, oh, you know, these are slight risk factors. You should be careful if you're taking something that might be make your blood more likely to clot, or maybe you should take blood thinners. There's just

not any information really. So I suppose that as you say, that's a decision that I feel like I've kind of had to make kind of myself and assume that the doctors think it's all right.

Interviewer

Yeah.

Hmm.

Participant

You know that it's not. I mean, I do remember, this isn't my own experience, but again, I remember when I was at that meeting with the other women, a few, one of the women saying she really wanted HRT, but she couldn't get information she couldn't get to the bottom of, whether it was safe to take it, and I think she'd recently had a stroke because she was in a

much worse, you know, I mean, her situation was wasn't was pretty tough. So for her, you know, that's tricky. So that's the thing for me. Like I think I may be at slightly increased risk, but no one's spelt that out to me and I don't know if there's anything I could do. Could I take a blood thinner? No one suggested that I need to so you know, I've kind of left it.

There's kind of limited information, isn't there, but then again, I do feel like my GP has been cautious in a way. I did actually mention it to Doctor [cardiologist] and to be fair, whenever I've contacted them they have been responsive when I've had concerns. So I did contact them even though my GP didn't say oh, maybe you should give them a ring. I did and I think I mentioned it when I had a consultation and I think she did say to me as long as your patch is below your waist, you know she she might have mentioned that there's a bit of a concern around potting, but she didn't seem to think that it was a, you know, a risk, so you know.

Interviewer

Mm-hmm.

Yeah.

OK. And in terms of support, you've mentioned about like family, your mum and maybe socially, was that kind of your go to for support when speaking about the menopause? Was the people around you or?

Participant

I would say I would say so. Yeah, I would say so. I would say really the GP was a gateway to be getting some HRT rather than I mean I described my symptoms but I kind of had already decided pretty much that it was menopause by the time I went to the GP, so I hadn't gone to the GP and said, oh, but this, this, that and the other. And so I would say, yes, it will be that way around.

Interviewer

OK, thank you. It sounds like we're you were able to speak to some people that had maybe

gone through it or had experience of the menopause as well. What do you feel is needed to help you as someone with a congenital heart condition who is transitioning through the menopause or who has transitioned through the menopause?

Participant

I don't know. It's difficult. I think. I mean, my heart defect as heart defects go is a, you know, is a relatively minor one. I mean, I would say perhaps, for the someone who say, 20 years younger than me, who's in the same situation as me, I suppose it would be helpful to have that information. I mean, now there's an awful lot of discussion about menopause and that kind of happened around the same time as I've. It's like women my age really have started talking about it but I would say that for younger women, it's always helpful to know what's coming down the road and to be able to say, you know, menopause can hit, can hit a can here relatively young age kind of be aware of these, you know, the possibility of these symptoms and you know, and having access to HRT readily available really because it really can improve your quality of life. So I think not for women not to have to suffer.

Interviewer

Hmm.

Yeah.

Participant

I think that I mean, maybe I'm being a bit over optimistic, but I think that has generally in the general population. I think that had it now there's a lot more openness. I suppose an understanding of how your heart defect could be impacted then by any hormones you're taking or any additional medication. And I think I get the impression that we're some of the first. I mean, depending on your heart defect. But I think for most of these heart defects, we're one of the first generations. So to be fair you know, they're kind of finding out to a certain extent as they go, information just might not be available, you know. So hopefully for

women that are younger than us that information will be available at least there will be. They will have examples of women you know who've taken HRT and it's successfully, and it's all been fine.

Interviewer

Mm-hmm.

Yeah.

Yeah, that's good and would come in towards the end. Just a couple of more questions, but this is quite a big question, but are you able to reflect on the interactions between your heart condition, the menopause, and your mental health.

Participant

Yeah, I would say.

Umm.

I would say an area where our mental health was particularly affected as a result of my heart condition that isn't necessarily related to the menopause. It was around having children because I knew that there was genetic risk that I would pass a slightly increased risk that I would pass the defect on to my child, or maybe a defect on to my child, that was a concern. I was anxious about having a baby and that the pregnancy would be healthy and that I'd be OK and the baby would be OK and I think that was slightly increased that it was maybe and also an awareness because my mother had obviously had a child with a heart defect and she'd had difficulties when she'd had children and like cetera, et cetera. I was maybe a more, I was maybe more aware of what could go wrong than perhaps a woman who hadn't had those experiences. So that affected my mental health. And I was quite down when I was pregnant. And then I have my son and everything was fine. I was hugely relieved and it was wonderful. And then quite soon went into menopause. Some of that anxiety that I'd had when I was pregnant and trying to have him resurfaced a bit when I went through menopause and I don't

know whether I would have had that anyway, regardless of the heart defect. I mean, I suppose there It's difficult because I was born with it. It's hard to know how I what I'd be like if I hadn't had a heart defect because you're kind of well. It's just what? It's just the way I am. Particularly when I was first diagnosed with menopause and then I discovered that my blood pressure had gone up, possibly as a result of menopause, I was quite anxious about that and I suppose the interplay between this, I suppose there is a slight additional concern about taking HRT and that probably does make me more anxious than I would be ordinarily and maybe I am a bit more aware of my body and how I'm feeling than someone who didn't have a heart defect. I don't, I don't know. But then on the other hand, I'm getting excellent you know, I am getting care and then maybe women walking around who have things going on that they're not aware of.

Interviewer

Yeah.

Mm-hmm.

Participant

Yeah.

You know, and because I get the impression when I see my consultant that my heart defect, as far as you know, the things that she sees, what I've got is really small potatoes. It's like, don't worry about it. But then when I go out into general practice, they're like, you know, they get a bit nervy, so I get that kind of contrasting experience depending on where I am and in some ways that's not such a bad thing and sounds an awful thing to say, but it's not such a bad thing for me because.

I feel like people are like, oh, OK, we better just keep a bit of an eye in the way that for some women, they might not have. They might need that, they might not know that they need that and they might not guess it so.

Interviewer

Yeah.

Participant

It's a kind of a it's a double edged sword, isn't it? You've kind of got to be grateful, really, in the in the in the grand scheme of things. I'm very fortunate, exceedingly fortunate. So you know, so I think that perhaps in terms of my mental health, yes, on the one hand, maybe I worry about, I suppose, in if you're talking about kind of psychologically, my mental health, it's as much about the relationship I have with my parents that ever may have affected in terms of being a child and feeling that I wanted to reassure my parents that I was OK that sense to kind of compensate and my brother, my brother had bad asthma so he was in that hospital a lot. I was born with a cleft lip. So my parents had a lot to kind of deal with and they were recent immigrants country. So although my mother's Irish, I mean she's not her family, are far away. They were quite isolated. It was just the four of us. That's quite an intense experience. So that desire from if anything, I would say that shaped me as much as my contact with doctors.

Interviewer

Yeah, yeah, that makes sense.

Interviewer

It's unique to each person. I'm wondering if the HRT had any impact on your mental health, you said about the sleep. Your sleep has improved?

Participant

Definitely. Definitely, yeah, definitely because I just, you just don't feel like yourself. You just, I felt like, I mean, it's hard to remember. Isn't it funny how when you're going through something, it's so vivid and then as not much time has to pass and you kind of forget.

Interviewer

Yeah.

Participant

And also it's very difficult, it's difficult as well because I think as I've moved into middle age, I've become a little bit more. I don't suffer things as much maybe as I used to. You get a little bit more grumpy anyway, a bit more kind of you know, you don't want to put up with nonsense as much, but also it's difficult to know how much of it was that and how much of it is this. But I was much quicker to cry, I was much more emotional, I was much snappier and more short tempered, and I felt less in control and I felt like I had less kind of fight in me, like less of a desire to go out and do things and plan my life and, you know. I think when you're younger, It's kind of you would get excited about things in a way that I'd it was dull, that sense of enthusiasm was dulled and I think that's definitely come back over time. And I I'm pretty sure that that's the HRT that's done that for me. And then of course it becomes a self fulfilling, so if you feel like you've got the energy to do a bit of exercise or whatever, then that becomes you feel better and then you continue doing and all that kind of thing. Whereas if you're bumping along the bottom, even getting the motivation to do those small things, which might make you feel better anyway, is very difficult to do. So I would say, yeah, I'm definitely on a much more even keel using the HRT.

Interviewer

Yeah.

That's good. It sounds like it was difficult to access it initially, perhaps different reasons why that was, but it's good to hear that you, you have had a positive experience.

Participant

Yeah.

Interviewer

So the final question is just thinking about, is there anything else you'd like to add or

anything you were expecting me to ask today that I haven't asked?

Participant

I don't think so. No, I don't think so. Is there anything that you would any further information you would like?

Interviewer

No, I think that is it. It's been really, really helpful to hear about your, your experience. So thank you.

Thank you for taking the time to participate. So there's a £20 Amazon voucher that I will ask the university Finance Department to send that to you. Are you OK for me to share your name and e-mail address to send that to you?

Participant

Oh, yes and you're very welcome. You're very welcome. Good luck with it all.

Interviewer

Thank you for your time.

Participant

Yeah, fantastic. Well, lovely to meet you anyway, take care of yourself.

Interviewer

Oh, thank you so much. Take care. Bye. Bye.

Participant

Take care. Bye.

Interviewer stopped transcription

Appendix O

Thematic Map

Appendix P

Codebook Template

Theme	Subtheme	Code	Code definition	Examples
The Cumulative Impact of Health Factors	Overlapping Symptoms	•Hard to tell difference between heart, mental health and hormone symptoms	Difficulties knowing what different symptoms relate to	"I think it is because my mental health, the anxiety, I think the hormones are playing havoc in my body and I think that's called creates the anxiety which then obviously creates the pounding in the chest, which then you think to yourself, is it the heart? Is it the anxiety? So yeah, I think they do all interlink and all that and really to be honest you I think that it consistently In the back of your mind is your heart. You know, when I see like, if I get very hot, I sweat a lot and I'm thinking to myself, oh gosh, I've got to try and stay hydrated because the heart will suffer and i've

Theme	Subtheme	Code	Code definition	Examples
				noticed like I've got the swelling in legs, I don't know if that's menopause, pre-menopausal but and then I'm like well, is that first signs of the heart struggling so yeah it is. I think everything, in my body that I suffer with or anything, I always think always go back to what's it going to do to the heart, is it going to damage it further? So I mean, I think what I find is really I just feel like at the moment my whole mind body and everything is just the one big jumble, so yeah, I mean it's crazy what's going on."
		•Menopause symptoms	Experiences of psychological/physical health difficulties,	"My body is changing in a big way. I'm suffering with night sweats and hot sweats or hot flushes. I say more night sweats, but it just come out of the

Theme	Subtheme	Code	Code definition	Examples
			attributed to the menopause	blue. It just completely come out of the blue. There was no warning at all and I went through a stage of about a week of constant night sweats and then it calmed down a bit. So yeah, I'd say it's come on along quite quickly. I have spoken to my GP about it and it's not being sort of like officially diagnosed that I'm actually menopausal because I have I have the coil and I had that in place a few years after my son and literally changed it for me after my recent surgery. My heart surgery, they were going to do it before, but they didn't want to do any intervention prior to my surgery. I don't know what stage I'm at the moment to be honest. My body's a bit more sluggish. I generally feel exhausted and very much so losing my memory. I

Theme	Subtheme	Code	Code definition	Examples
				would say definitely the night sweats because that just come out of nowhere. So I would say definitely the night sweats. Yeah, I didn't know what to expect because I never, ever. Well, I've never, ever experienced anything like that before. It's like it just comes over. Like women say it's literally like just the hot, hot feeling from the head down. It's just awful. It's a horrible feeling."
		• Hormonal changes	Perceived experiences of hormonal changes	"I think the change of hormones; it's kind of affected me a bit again. So yeah, so I've had a bit more of a struggle around health over the last few years."

Theme	Subtheme	Code	Code definition	Examples
		• Heart palpitations	Awareness of rapid heart rate	"What was it probably about five years ago, six years ago. It was the first time I'd had trouble with the rhythm going out again and being aware of palpitations."
		• Sleep difficulties	Difficulties with maintaining usual sleep pattern	"Poor sleep was a real problem and now I do sleep through. I'm not, I'm not woken up."
		• Vicious circle of problems	Interacting health issues that exacerbate one another	"Yeah sometimes I panic when my heart goes too fast, I start having a panic attack, its like a vicious circle."
		• Lots of things impact my CHD	Multiple health factors which affect their CHD	"Well, having a congenital heart disease impact everything."

Theme	Subtheme	Code	Code definition	Examples
				"Yeah, it everything effects my heart".
		• More impact as I've got older	Increasing health or emotional impact with aging	"I probably maybe noticed it more as I've got older. Generally I could keep up with everyone…Yeah. I feel like just my stamina is like, less, like, very slowly. My oxygen levels have kind of gone down compared to how they were like 20 odd years ago.."
				"So and that's hard to do. It's like it's really hard to do because it's like, firstly, like, ****. I'm getting older, you know. How did that happen?...and I'm going to be 50. It like, that's just all mental to me. But then it's like, OK, but 10 years ago or even, you know, 8-7 years ago I felt amazing. Like, I

Theme	Subtheme	Code	Code definition	Examples
				felt amazing. Like it was one of the best times. So what happened in that time? You know, like how can you how can you quantify that? And that's really difficult, but I think if there was an understanding of what that link is more like these are you know and I and I know it'll be different for every person because I have quite a unique heart defect like, you know, mine's very complex, but actually, there'll be others that are similar to me, And just that support in navigating it and I know having taken HRT, I do feel there's a bit more balance in my life, you know but then on top of that, it's like, yeah, OK, well, now I get more out of breath, you know, now I do this is that is that just getting older or, you know, it's just it's a

Theme	Subtheme	Code	Code definition	Examples
				constant kind of having to work out and never really getting the actual answers.”
		• Bigger health issue	A health condition which is perceived as more serious than menopause	“Also, I wonder if there's something to do with because I had a bigger health issue I didn't focus on the menopause and just bear with me on this because I'm not one of those people, I am not a mental health denier, I am not a menopause denier…”
		• Limits of my body	Recognising the physical restrictions of CHD	“So I'm really, I want to get stronger. I want to get fitter and I want to do what I used to do like I used to walk four to five miles every day and I'm struggling with doing those distances.”

Theme	Subtheme	Code	Code definition	Examples
		• Medication restrictions	Limitations on medications due to CHD	"…Well, I mean, I don't know. I mean other than therapy, I don't want to say 'cause I know that medication can trigger or may have a huge side effect on someone and this you know with that condition. I really don't know to be honest. I don't want to say something and then you know, because I might be lucky or someone might and get away with something. But like it could be fatal. If it's not, you know, managed properly." "…I don't realise what I can and can't take. but I wouldn't know what it is, what it is that I need without someone being there that I can relate to and would understand my condition."

Theme	Subtheme	Code	Code definition	Examples
		• Heart medication management	Adjusting to and monitoring cardiac medication	"For heart medication, which I wasn't on before, but since 2022 I don't want to say that that's what it is, but there is a little chance that that did do something in that manner of traumatising me and you know, and this is the same time that the menopause started to get quite intense."
		• Menstrual difficulties	Painful periods prior to menopause	"You'll feel like you're losing your mind, you know, and you'd be like, why am I losing my mind? And then your period will be like, OK, when period started and sometimes on occasion, I've had really, really, really unpleasant, painful periods, which is quite common. So to be honest with you, that I don't miss, it's actually a real relief."

Theme	Subtheme	Code	Code definition	Examples
				"You worry them because of how the heart is taking it all because there's so much loss and you just then get doctors saying, well, yes, you can. You know, you can lose a lot in your period. And I'm like do you not realise that I'm bleeding pretty much three weeks of every month? I only get like a week off and they're like, yeah, but that's OK. And I'm like, no, not really".
		• Unexpected menopause	Menopause occurring earlier or differently than anticipated	"Oh, that's just another it's terrible. It was during COVID. I think I was only about 42 age 42 and my period just stopped suddenly and I've thought I was pregnant, so I had about 12 to 15 pregnancy test, done all very negative, and then after I went into the GP asking what's going on my period

Theme	Subtheme	Code	Code definition	Examples
				stopped, I had nothing. I had a blood test and that wasn't showing anything. So they said, well, it's not menopause...”
		• Not suffering from menopause	Minimal impact from the menopause	“I'm quite robust and I don't consider myself to be suffering from the menopause at all.”
		• Normal life until menopause	Stable life prior to the menopausal transition Experiences of incorrect or delayed diagnosis	“Can I be honest? I don't really know anything much about that. I haven't really. I haven't really found any difference whatsoever really.”
				“It's difficult to describe because I've had it all of my life, so I don't know any different. I sort of spent a good part of my life in the middle of my life. So far not struggling with it, but in my 40s I

Theme	Subtheme	Code	Code definition	Examples
				became poorly again. So that's been a bit more difficult over the past sort of eight years than it has been in previous years."
				"In some ways it's been great in the sense that I have been very well so It's not really stop me doing a lot of things and actually, I think as you know things were there were other sort of I can't think of them specifically now, but there were other as I'm getting older, I'm thinking you know I will need more medical attention for other things that are not related to my heart, but just to relate to old age in the future so I need to sort my problem out with doctors and to be to be really blunt, I've felt violated by them…."

Theme	Subtheme	Code	Code definition	Examples
		• Misdiagnosed	Beliefs around earlier support would have prevent worse experiences/outcomes	"My experience of having a congenital heart disease is with trauma. The misdiagnosed I experienced misdiagnosis, from the age of 21 through to 31, where all my symptoms of fatigue were labelled as hypochondria and fibromyalgia and post viral fatigue and all those labels"
		• Early intervention needed	Early support needed to reduce bigger impact	"I think that it needs to be thought about much earlier than the onset of menopause. I think there should be a care plan that looks we have a female here. I think questions about periods and emotions should be asked from 35 onwards. It should be standard because it affects the heart, so you shouldn't ignore it and it would lead to a lot less unnecessary A&E visits…'

Theme	Subtheme	Code	Code definition	Examples
		• Being aware of menopause symptoms early is needed	Need for early education about menopausal changes	"It's always helpful to know what's coming down the road and to be able to say, you know, menopause can hit, can hit a can here relatively young age kind of be aware of these, you know, the possibility of these symptoms." "But even if it could be some, self-help guides in the congenital heart disease clinic as simple as that. Are you 35 and over? These are things you need to watch out for. If you get any of these things, it's really worth speaking to your GP. It could be the signs of perimenopause. Just like giving women, pre warning."

Theme	Subtheme	Code	Code definition	Examples
	Anxiety and Bodily Vigilance	•Health anxiety	Excessive worry about health status or symptoms	"So I've yeah, had a lot of anxiety and health related panic, yeah" "…Is that something or you don't want to be so paranoid is trying to find that balance, you know, like, why am I having this anxiety attack now and my mum says it's your hormones, your hormones are all over the place. You just don't know what you're doing and I was like, well, could it be another reason? If you're like, no, it's your hormones, it's just trying to find that balancing act in, in, in coping with your symptoms and not letting them overcome you."

Theme	Subtheme	Code	Code definition	Examples
		• Anxious person	Self-identify as generally anxious	"I've lived with anxiety on and off throughout my life anyway. So it did sort of slightly compound things to be fair."
		• Anxious parents	Parental anxiety influencing them as an individual	"So I had the operation and I suppose I'm quite an anxious, nervy person." "My parents were anxious. My mother would worry a bit and she'd be like, you know, they were taught all your heart. I wanted to reassure my parents that I was OK that sense to kind of compensate…"
		• Worried about menopause for my CHD	Concern that menopause symptoms	"Yeah, yeah. I've always feared the condition because I thought, what if my heart goes too fast or what of it? You know what? If I get too hot and

Theme	Subtheme	Code	Code definition	Examples
			may negatively impact CHD	I know. So I'd always make sure I'm feeling cooler and if I get too hot, I go and stand outside or I have a fan on or I have a handheld fan with me to come calm me down, because then I start feeling I'm getting panicky.”
		• Worry about doing damage to my CHD due to lack of knowledge	Fear of doing harm to CHD due to insufficient information	“I don't know if I'd be making stuff worse. You know, if you if you want to get rid of veracious veins, you rub the essence of conquers onto it and it stops you veracious only because it hardens your veins. It's like, well, I'm not going to take the stuff that's in conquers, because that sounds like a really potential problem. So I've just got some varicose veins on my legs. Fine, not a problem, but I worry that other people would go take that

Theme	Subtheme	Code	Code definition	Examples
				because there's no information. I also worry that I'm not taking extra vitamins and stuff that I should be taking, but I'm not taking collagen like all my friends are because collagen, also in your arteries and veins. But I don't know whether I should or I shouldn't. I'm not a vain person, I don't care how I look, I just don't want to shorten my life by taking the wrong decision, I genuinely don't know if taking or not taking these things is the wrong decision."
		• Investigate health concerns	Importance of healthcare providers taking health concerns seriously	"Just understanding, some knowledge of what's going on in your body at the same time as your heart condition, research into supplements that can help you but not affect your medication or your

Theme	Subtheme	Code	Code definition	Examples
				heart. Yeah, you know, that sort of thing, just understanding and research into what what's going on in your body and how's it affecting your heart at the same time and how we can we help out women who are going through the menopause by giving them, you know, well, we know you're on this medication but it's alright to take that as a supplement and we know that you're, you know you're suffering from IBS because of this, but let's not make you worry about it. Let's investigate it, let's see if there is any other problems going on in your stomach. Not just letting you think. Oh God, I've got something terrible wrong with me, listening to us about these changes. And you know all these pains and that you get."

Theme	Subtheme	Code	Code definition	Examples
		• Needing reassurance	Seeking validation from professionals	"…It's about gaining the reassurance, but I think what I have to you know, sometimes you have to, you have to create that for yourself and like and I do, you know." "No, I did actually mention it to Doctor [cardiologist] and to be fair, whenever I've contacted them they have been responsive when I've had concerns. So I did contact them even though my GP didn't say oh, maybe you should give them a ring. I did and I think I mentioned it when I had a consultation and I think she did say to me as long as your patch is below your waist, you know..."

Theme	Subtheme	Code	Code definition	Examples
		• Own mortality	Heightened awareness of death or life expectancy	"…Yeah, I have to go to [hospital] every year and he's done an amazing job because I think that because he looks at my heart and that when I've had worries about dying, he's put my mind at rest and stuff like that…" "…it's just like gosh, what I've been through in life without knowing that I'm carrying this atom bomb inside me, how could I? How did I survive? I've just the way I'm balanced my mental health. OK. I just feel like I'm. I'm blessed to be here, to be honest and when I do feel like on my lowest, I just remind myself like, you know I'm just grateful for every day and you know."

Theme	Subtheme	Code	Code definition	Examples
		• Hard to remain positive	Struggles remaining optimistic	"For me, my journey isn't over. I need open heart surgery again. So it's still a long process and it's about trying to remain positive. For you know for what you go through and I think the menopause is a really difficult part of your mental health in trying to stay positive during that time and knowing in the back of my mind in a few you know."
		• Difficulties coping	Challenges managing emotional stress	"Growing up, it was OK. It was always in the back of my mind, always treated slightly differently with a congenital heart condition But as I've got older, it's a lot more difficult to cope with."

Theme	Subtheme	Code	Code definition	Examples
				"It's been it's been a hard journey."
		• Mental health difficulties	Experiences of poor mental health	" I did have some psychology support. It's related to my congenital heart disease but yeah. So we did meet up, had quite a few sessions. When I went through quite a few bereavement, my close family members, my, my sister, my father, and obviously with my congenital heart disease, my emotions were all over place. So yeah, I did get some help through that."
				"Whereas now there is definitely what happened over the last year, a kind of mental health burden of, OK, this is limiting me now. I think the only thing to add on the mental health stuff is I got no

Theme	Subtheme	Code	Code definition	Examples
				mental health support until I was 47, whatever it was. A long time to have all this **** and no one talked to you about it."
		• Mental health medication felt safe to take as there was trust with the professional	Use or not of psychiatric medication from a trusted source	"And when they prescribed me tablets for depression. Yeah, I did take them. It was alright for my heart 'cause, I trusted this doctor."
		• Mental health unrelated to menopause	Poor mental health prior / unrelated to menopause Difficulties with memory, concentration, organisation	"I've always had mental health support. I'm known locally to the trust. I've been part under the community mental health team. But that's nothing to do with the menopause. That's something I'm always going to have to live with, unfortunately. It wouldn't be fair. Wouldn't be fair to put something

Theme	Subtheme	Code	Code definition	Examples
				down because I don't think I don't think that's where I am at the moment. But again, I'm 55."
		• Brain functioning impacted	Brain/cognitive health impacting their mental health	'Yeah, the executive dysfunction changes in menopause. 'Cause very competent women to collapse, you know, walking into room. Don't know why you're there. Walking into the supermarket. No idea what you're going to buy. No ability to control your temper and not being able to link ideas anymore. I look at some of the project work I did in my career. Pre menopause and I don't know who that person is because that's not the person I am now. There's no way I could do the work I did in my 40s now. I wouldn't even try. So the loss of that person who functioned

Theme	Subtheme	Code	Code definition	Examples
				socially, ish. Cognitively has gone, and that is such a loss for me. If only congenital heart clinics had a list of comorbidities that could be looked at."
		•Neurodevelopmental conditions and menopause	Presence of ADHD, Autism or other neurodevelopmental disorders impacting menopause	"The genetic conditions are also highly correlated with ADHD and autism, so those things became very apparent in perimenopause. And so I've been on that journey as well."
		• Traumatic healthcare experiences	Distressing or harmful medical encounters	"At 12 I wasn't growing, so it was obviously causing problems and I had I think it was the 3rd balloonoplasty in the UK. So where they balloon up, but they tried for two hours unsedated on a 12

Theme	Subtheme	Code	Code definition	Examples
				year old playing me Disney music and then my blood hit the ceiling. So it was a somewhat traumatic experience.”
				“The whole thing's really frightening. You know, when you first find out about it. Surgery itself is naturally quite frightening to explain the risks to you, but genuinely now I don't let it bother me on a day-to-day basis. I'm not on any medication. I know I'm always in the system, but plodding along.But getting over the heart surgery was difficult. I wasn't ready, so it took me a while to sort of accept that I needed to have other operations.”

Theme	Subtheme	Code	Code definition	Examples
		• Shock diagnosis [CHD]	Emotional impact of initial CHD diagnosis	"Well, I mean, obviously when I first found out it was a bit of a shock. So it took me a while to come to terms with it."
				"So yes, it was a bit shocked. It was a bit a bit, a bit shocking, obviously upsetting."
		• Being unwell as a child	Memories of childhood illness	"It wasn't identified at birth, but it I had issues as from a very young age. I wasn't born here, so back home. Where I'm from, as I remember, I was a sick child, family members, me, my parents they just obviously used lots of different method of just to give me relief from continuous cough and things that I don't remember because I was very young."

Theme	Subtheme	Code	Code definition	Examples
		• Hard to live with CHD	Ongoing burden of CHD	"Very limiting, limiting life limiting. Very just, I would, I would just say life limiting very can be tedious on times, just, you know, causes a lot of anxiety and depression and just constant hospitals and things like that. So yes, it's just very I think the biggest life limiting I would, I would say."
		• More impact as I've got older	Increasing health or emotional impact with aging	Repeated code, example quotes already provided.
Physical change as an emotional reminder		• Loss due to CHD	Bereavements of close people due to CHD	"At the age of 20, I did so. I had a sibling who had the same a congenital heart defect as well, and he lived for 16 years and then when I was 20, he passed away."

Theme	Subtheme	Code	Code definition	Examples
		• Couldn't have children	Restrictions of having children due to CHD	"It made me make decisions that a lot of women didn't have to make, so I chose not to have children, so I was sterilised at 20 because I wasn't going to get pregnant and taking the risk away was the best option at the time. You know, I've got a husband, you know, I was lucky enough to find a man who was willing to take me on with how I am and not have children. Yeah, so got married. Gosh, it's 16 years ago now."
		• Wanted to start a family but had worries about CHD	Desire to have children, impacted by CHD and mental health	"…I was also thinking I want to have a baby, and I know that this is genetic, but I didn't even really know what it was that I had."

Theme	Subtheme	Code	Code definition	Examples
				“I would say an area where our mental health was particularly affected as a result of my heart condition that isn't necessarily related to the menopause. It was around having children because I knew that there was genetic risk that I would pass. A slightly increased risk that I would pass the defect on to my child, or maybe a defect on to my child and I said that was a concern. I was anxious about having a baby and that the pregnancy would be healthy and that I'd be OK and the baby would be OK and I think that was slightly increased that it was maybe and also an awareness because my mother had obviously had a child with a heart defect and she'd had difficulties when she'd had children and like

Theme	Subtheme	Code	Code definition	Examples
				cetera, et cetera. I was maybe a more, I was maybe more aware of what could go wrong than perhaps a woman who hadn't had those experiences. So that affected my mental health. And I was quite down when I was pregnant. And then.Yeah, I have my son and everything was fine. I was hugely relieved and it was wonderful. And then quite soon went into menopause and."
		• Did not want to have children	Personal choice not to have children	"So another thing you may need to know is that I consciously never wanted children, ever, ever, so there wasn't the potential loss of fertility issues…"

Theme	Subtheme	Code	Code definition	Examples
		• Menopause is hard when you haven't been able to have children due to CHD	Menopause intensifying grief around infertility	"I feel it's quite difficult to say because the menopause is something for women who have had their children and effectively done with their body, what they were born to do. Well, I couldn't have children, so I have to go through something that was completely pointless in my whole life anyway. So going through the menopause is quite frustrating because there was no there was no joy of having a child through going through all of this…"
Gaps in Knowledge and Holistic Understanding	Caught Between Conflicting Advice	• Conflicting advice	Receiving inconsistent professional recommendations or advice	"…so it depends on who you see and what. Yeah, their take on the medication…" "So three years ago I said to the to the clinic. Should I go on to HRT or not go on to HRT I

Theme	Subtheme	Code	Code definition	Examples
				want to remain stable. How do I do this? And they said go on to HRT if you want to and I thought well, I'm not really suffering from anything. My body wants to get older, not sure that I really want to fill it with hormones if I don't need to, so I didn't. Then last summer I spoke to her [cardiologist] about HRT and just said would this have been prevented? Would the changes that have happened because some have happened? Would they have been prevented if my body wasn't changing? And is this something that I should go onto HRT to stop changes getting worse and she said you should never go onto HRT if she said if your hormones get really low we might put you on a very small amount, but you should never

Theme	Subtheme	Code	Code definition	Examples
				go onto HRT and I was like well that's not what I was heard. I was told three years ago."
		• Conflicting information on menopause	Mixed messages about menopause management	"…Then it's quite confusing because there's a lot of information as well that's out there on Instagram and everything else giving you slightly conflicting information, shall we say..."
		• Lack of knowledge on CHD and menopause	Perceived professional knowledge or lack of on CHD	"They didn't specifically say to me you have a heart defect, you're might slightly more likely to clot. You know your valves a bit sticky, there is a concern there statistically I can't make a decision. I'm like, well, obviously I'd rather have hot flashes and be a bit blue than, you know, have a stroke or whatever. it's almost put on your shoulders to

Theme	Subtheme	Code	Code definition	Examples
				decide and decipher. I would say that's slightly more complicated because of the link between the kind of taking the hormones and clotting, and of course, there's not really much information…'
		• Limited understanding of my CHD	Personal uncertainty or knowledge on own condition	"I think more understanding on the heart condition. I think I know there's a lot of multiple heart conditions and that, but I'd let you know. I'd like to see a basic understanding of heart conditions so that you know, if you say transposition of the great arteries, they may not know what that intricately means, but if they've got an idea of general what it means."

Theme	Subtheme	Code	Code definition	Examples
		• Too much info online on menopause	Overwhelming or confusing online resources	“I think that's really important because as soon as you get to this age, you get bombarded with ****. Like my wife brings all the time because she is more interested in menopause, stuff her Facebook page. They're just trying to sell her bottles of crap. it's very hard to get evidence, and then there needs to be something about this non medical but seemingly medical industry which absolutely attacks you as you turn about 48 years old. It's all over everything and it's unregulated so and because it's unregulated, it's full of AI crap, It’s terrible, they definitely need to somehow protect somehow, protect people from that.”

Theme	Subtheme	Code	Code definition	Examples
		• Seeking out information about menopause	Actively researching menopause information	“ I know that it sort of learnt subsequently that at the beginning of perimenopause it's actually the progesterone levels that go down.”
		• Doing own research	Perceived absence of guidance	“I think I've had to do my own research, but I think understanding that actually you know they're just replacing the hormones that you're meant to have rather than it being a synthetic thing and everyone worrying about this and that. And you know all the stuff that came out like, you know, 20 years ago. I mean, I even remember it, you know, so I think it's I think you have to be quite proactive yourself to be honest. Yeah, I think I've kind of been able to kind of work out now. So like, I know like when I get my period or just

Theme	Subtheme	Code	Code definition	Examples
				before, like I'm really tired and that's just because like, you know, my period's coming and my body. I think I think also with me it's like because my body works so hard anyway like it just works extremely hard. So I think then it added bit of hormonal stuff periods I think just tyres it out."
		• Lack of trust in professionals	Scepticism towards healthcare professionals	"But I have found the medical side really hard. And I would say it's only in the last few years that I've really sought help with them with the mental health side of it all. I mean, really, I don't like doctors. I don't like medical people. I've really really struggled."

Theme	Subtheme	Code	Code definition	Examples
		• Trust that medication contradictions are checked before being prescribed	Feel safe in taking medications prescribed by the doctors.	"Well, I think usually they know if there's any contraindications before they prescribe. Anything else I would may run it by the card cardiology team".
		• More trusting of cardiologist	Greater confidence in heart specialists than others	"Perhaps I could ask them about it, because at least I know I feel that they know about the heart, so they would be able to give me the right answers. Yeah, I trust them more than I trust local doctors because they know all about the conditions."
		• No jargon	Preferences for clear and accessible information	"I need easy words. Like, I don't know. I don't know. I can't explain. Yeah, what I mean, but I do know what I mean. Yes, I do. Because of

Theme	Subtheme	Code	Code definition	Examples
				the way I don't understand things as well. Like. Yeah. So I find that that makes it more harder for me."
		• Relied on parents for information	Dependent from a young age on family for health knowledge	"I was reliant on my parents telling me about what I had and of course, of course, because I was a child when I had the surgery, but my parents didn't know it was called pulmonary valve stenosis."
		• Women are not listened to	Perception of gender bias in healthcare	"Yeah, because I think we're all going through it the same. So we don't all feel like we've completely lost the plot. I mean, there's not a lot anyway for like the everyday woman going through the perimenopause there's like, it is

Theme	Subtheme	Code	Code definition	Examples
				actually disgusting, you know? And I remember hearing, like, someone say if men were going through that be all sorted, you know, it is absolutely appalling. You know, it's not like we're just suddenly going through the this has been going on for, like, ever since women, you know, came to creation, you know, and I just think it's. It's almost sad like in 2025 that we're just not on it at all, you know, and there's been lots of documentaries about, I mean, women have killed themselves because they've been, you know, it's just, it's desperate, It's really desperate and just it's really sad, it's really sad."

Theme	Subtheme	Code	Code definition	Examples
		• Women's health generally not well understood	Recognition of gender specific health issues	"… I just don't think there are enough doctors or people available to help because actually if I if there was a specific like, you know, trained menopause then that they could work well with like the doctors that I have like it would come to better, it would come together a bit more but they're all kind of different things, so I don't think I think just generally getting that access is just difficult for women, heart problem or no heart problem, I just don't think it's really there.Yeah, it's really rubbish…"
		• Scientific research is needed	Evidence based guidance is needed for	"I think people do need to be and there absolutely needs to be some studies on whether people with congenital heart, women with condenser heart

Theme	Subtheme	Code	Code definition	Examples
			CHD, menopause and mental health	defects should take HRT. I don't know how they do those studies without putting some people at risk, but there must be ways they can do metadata studies from people where they have been cohorts with people with heart disease or something in there. There needs to be something because people don't know and it's very hard to get evidence, and then there needs to be something about this non medical but seemingly medical industry which absolutely attacks you as you turn about 48 years old.”
	Siloed Services	•Separated care	Fragmented treatment across specialities	“The other experience that I feel is relevant is that it's not just about the heart. It's about me holistically. So that means it affects other systems of the body and I've never been looked at as a

Theme	Subtheme	Code	Code definition	Examples
				whole person. I've had my stomach looked after by over here and my eyes over there and my heart over here, and no one's put me together, which has meant things have been missed and I've nearly died several times…'
		• Joined up care is needed	Desire for more co-ordinated care amongst different teams	"…The things that we've already talked about, like a more joined up service even between the GP and the cardiologist and I didn't really get a real opportunity to cross that bridge at the moment with the GP."
		• Lack of holistic care	Absence of whole person approach	"The other experience that I feel is relevant is that it's not just about the heart. It's about me holistically. So my menopausal rage effects my

Theme	Subtheme	Code	Code definition	Examples
				heart with spikes in blood pressure, which is detrimental to my condition and that rage is often triggered by my mental health. Which I never had a mental health problem, but the history of a congenital heart condition from a young age is traumatic. So even if I'm the most stoic person on the planet, I am traumatised by my experiences. So previous trauma comes into it and my experience is that each thing has been treated separately, so heart menopause and mental health have been treated separately with without it should be like a Venn diagram. It's not being looked like by a biopsychosocially. So my experience is fragmented, confusing, lonely because I've had to work it out myself.'

Theme	Subtheme	Code	Code definition	Examples
				"Yeah, I mean, I don't, I just don't think people join the dots I don't think people, I don't think I've ever heard the word. You've got congenital heart disease and menopause linked and you are the age or even think of it as, I mean, you know, I was 52 and even when I went to [the hospital] as brilliant as they are, they didn't say in all of those consults I had hours and hours of consultations."
		• Hard to reach out to CHD team	Barriers with communicating with CHD team	"Sometimes it's a bit, you know, sometimes it's like, for example with the cardiology team. It's not very easy to get hold of them. So unless you have a specific query regarding your heart condition. They're almost impossible to reach. Yeah, which

Theme	Subtheme	Code	Code definition	Examples
				in some ways is good. Maybe in some ways is you feel a little bit cut off. So there are those two factors. I have like the heart check and the discussion with the with the consultant and that's it, you know, and you have to quickly take your 5 minutes."
		• Changes in medical care	Alterations in treatment over time	"…so I had my first operation at 22 months, but I don't remember it, although I went into hospital as a completely normal kid and I came out and did not cry 'cause I'd learnt in the 70s in hospital that if you cried, **** all happens. Because medicine in the 70s and 80s wasn't exactly caring, it was definitely plumbing. My experience every major operation, they've all got

Theme	Subtheme	Code	Code definition	Examples
				better pain relief and better at thinking about the fact that you're a person, not just a body, but in the 70s and 80s and even in the 90s..."
		• First generation of menopause and CHD	Lack of previous experiences for this life stage and CHD	"I suppose an understanding of how your heart defect could be impacted then by any hormones you're taking or any additional medication. And I think I get the impression that we're some of the first. I mean, depending on your heart defect. But I think for most of these heart defects, we're one of the first generations. You know, they're kind of finding out to a certain extent as they go, information just might not be available, you know. So hopefully for women that are younger than us.

Theme	Subtheme	Code	Code definition	Examples
				That information will be available at least there will be. They will have examples of women you know who've taken HRT and it's successfully, and it's all been fine.”
		• Barriers to all health due to CHD	CHD limits access to broader healthcare	“There's barriers to access in any health cause of my heart condition, you know. I feel that I'm not entitled to support for mental health because not that I'm not entitled, it's not priority in my health, you know, it's so many years and it's been in the heart condition, so you sort of become. You put up with it. You know, you put up with it.”

Theme	Subtheme	Code	Code definition	Examples
		• No barriers to mental health support due to CHD	Perception that CHD does not restrict access to mental health/psychological support	"I wouldn't necessarily say there were barriers because of the heart, no." "I wouldn't say my heart condition will stop me from accessing, the same way that on teams I can talk to you." "No, I don't not felt not mental health. No, no, not the mental health, everything else, yes, but not mental health. Mental health is I've never had any problems with access and mental health with my heart. It's they've it's been very good with that."
		• Poor communication	Ineffective information exchange with professionals	"And getting everybody to communicate and doctors saying they can't speak to me and then other doctors say they've emailed doctors nothing happening and so a lot of red tape."

Theme	Subtheme	Code	Code definition	Examples
				"Well, that like I said with the yeah, the GP didn't do anything without speaking to [the hospital] so it's just how long that will take. She'll write to them, how long it takes to respond, I guess, yeah. I don't know how long it's going to take. Is it going to take a three weeks or is it going to take six months? I just don't know".
	Insufficient Access to Comprehensive Menopause Support	• Difficulties getting HRT	Barriers getting HRT	"Yes, it took far longer than it should. Yeah. GP wasn't going to prescribe HRT. They weren't prescribing much at all, actually and it waiting lists were a big barrier. but when I got to the right people, I got amazing care."
				"Some of it you see different GPS at different times and some GPS are very quick to offer it to

Theme	Subtheme	Code	Code definition	Examples
				you and others. Others will say look well to be honest, it's not that great.”
		• Cautious with HRT	Hesitant about HRT due to CHD risk	“I do feel like my GP has been cautious in a way. And I suppose the interplay between this, I suppose there is a slight additional concern about taking HRT and that probably does make me more anxious than I would be ordinarily…”
				“Recently I've been to the GP because I've had a load of joint pain in other joints which I know can be a menopausal symptom and my GP wanted to try HRT but she won't do it without [the cardiologists] permission, so she's written to them…”

Theme	Subtheme	Code	Code definition	Examples
		• HRT helpful	Perceived benefits of HRT	"HRT has been, you know it's been fantastic. think the HRT has definitely improved. It's put me on a more even keel and I think just being able to speak better has probably helped with that, having access to HRT readily available really because it really can improve your quality of life. It's kind of you would get excited about things in a way that I'd it was dull, that sense of enthusiasm was dulled."
		• Taking supplements for menopause	Use of non-prescription remedies	"Yeah, I don't know. I just feel like this is very, very difficult for me and at times, I feel like I know how to carry on and, but yeah, I'm trying things, vitamins you know, I really, I look up on things like, you know, when I whenever I get

Theme	Subtheme	Code	Code definition	Examples
				advice online like magnesium and I'm doing all of that and taking those things and you know."
				"I mean, I take bio cult. I have been taking that, which is like a lot of bacteria it has like the magnesium in it and maybe all the extra B12 and all that in it. But yeah, you know, it's just not having someone I can relate to that's going through the same thing is twice as hard."
				"So, like I'm thinking of taking magnesium. Luckily, I'm going to see my [cardiologist] on Monday, so I'm going to talk to my doctor there and just check."

Theme	Subtheme	Code	Code definition	Examples
		• GP support for menopause	Positive experience with GP support for menopause	"I have a nice GP who seems to know, you know, a lot about HRT. She was on it herself and she was able to advise me. I mean it was appropriate for what I asked for, I guess, I mean, you know, yeah. I mean even the GP was like very comfortable to give it to me. You know whether that was correct or not, who knows. But that that was, you know, that's what they decided." "She [the GP] was with me for about 40 minutes. It was really nice and she was happy to talk through everything and talk about risks and benefits and option."

Theme	Subtheme	Code	Code definition	Examples
		• Lack of support from GP	Perceived insufficient GP support	"…I think menopause wise it's just my GP, but then most of the time it's somebody you don't really, you don't really see on a regular basis, so they don't really understand you as a person, you know, and what you've gone through, what you're going through. I mean, I've I saw a doctor not so long ago when she said to me it could be menopause, but she didn't confirm it. So I'm still kind of guessing it's actually happening now…" "I actually went to the doctors and got a blood test because I said I just couldn't cope with it anymore and then they did the blood tests to them be told that they couldn't actually detect somebody who was peri-menopausal and that I would literally

Theme	Subtheme	Code	Code definition	Examples
				have to wait until I’m menopausal before they could help me…”
				“ I've never had any support for menopause. I've had a few, a little bit from the GP. I won’t get it because the my GP is petrified of me. If I go to the GP, she doesn't know what to do with me. That's why she sends me off to the menopause clinic because she can't deal with it…”
				“She was a bit reluctant. Initially I had to try a few times. I contacted a couple of different GPs and they were both female. The GPs that kind of were a bit reluctant and then they were like we don't

Theme	Subtheme	Code	Code definition	Examples
				think your symptoms, you know, they kind of felt that I wasn't really bad enough…"
		• Would like to go GP for support for menopause	Desire to seek menopause support from GP	"I would say that I would prefer to go to the GP and feel a little bit more confident in day-to-day subjects. You don't want to have to go to cardiology over menopausal issues or any other issue that isn't heart related. Or even just a little bit more of an understanding, but I get it. In this modern culture where they have to be so cautious on everything I do understand, but it just makes it difficult for the patient asking for help."

Theme	Subtheme	Code	Code definition	Examples
		• Specialist menopause advice helpful	Benefits of expert menopause guidance	"…The specialist Menopause clinic, which there should be more of, liaised with my cardiology clinic and kept me informed and like problem solved. It didn't say you're too difficult, which is my usual experience. They were like, oh, you're difficult. We need to think about this and my cardiologist, making space in our appointments for other parts of my body, and I invited that conversation…"
		• Specialist person is needed for managing menopause and CHD	Call for dual specialist expertise	"I got permission to up my oestrogen patch, which has helped. So again, if somebody with expertise in menopause had been with me during this journey, either from a clinical psychology

Theme	Subtheme	Code	Code definition	Examples
				perspective or a specialist nurse or somebody, I could have been saved a lot of this,…"
				"I just would like to have a specialist doctor. I could talk to you that could monitor you more regularly. Do you know what I mean? That's the thing with the menopause. You need to be monitored quite regularly, you need to actually be have that, what's the word continue, continuation…"
		• Targeted support needed	Need for tailored advice/guidance for menopausal CHD population	"I don't know whether it's something maybe you could target women of a certain age bracket, when they're leaving hospital, when they're in the

Theme	Subtheme	Code	Code definition	Examples
				hospital system, you know, just then that could be really insulting."
		• Limited resources in NHS	Perceived scarcity of public health support generally	"I think they're quite strapped for everything, cash and time. And so, I mean, they're lovely, they're lovely and great when you for that 5 minutes every 18 months or whatever that you see them on."
		• Accessed private care	Use of private healthcare	"I think so. It's when you couldn't really access the GP. So I kind of went private, I just paid for it through a menopause clinic. So I just booked a kind of nurse specialist. Yes, it was private, but then I got it transferred to the GP…"

Theme	Subtheme	Code	Code definition	Examples
		• Information leaflets needed	Desire for written educational materials	"So I think I absolutely think there should be some leaflets on. These are the thing, these are the supplements you should absolutely avoid, because they know which ones have an impact on cardiovascular health or could an impact on the changes in from a cardiovascular point of view. I mean, I genuinely don't know and you can buy all these things now and I think it would be incredibly helpful if they would just write down a list of the following things can impact your cardiac health, do not take them without consulting your cardiologist, even if they just said that it would give people some comfort. But at the moment I don't, I have no information. So I genuinely don't know what to do."

Theme	Subtheme	Code	Code definition	Examples
Seeking Safe Choices	Specialist Psychological Support Living Safely with System Delays	• Specialist mental health support is needed for CHD	Need for mental specialist CHD mental health support	"… I think there should be more of a mental health presence within physical healthcare settings, not it being separated because the clinical psychologist or therapist need to understand the physical health conditions, a specialist level to help me, I needed a clinical psychologist or therapist who worked within a heart team, not primary care, not saying I'm special, but I feel that about diabetes. I feel that about epilepsy. I don't think it should be seen separate to the people's specialist clinics, You need knowledge and the clinical psychology training and the CBT long term health conditions training is not enough…" "…For me to see someone at [the cardiac hospital] and they then could work together with

Theme	Subtheme	Code	Code definition	Examples
				the cardiac team. So that was really, that was really helpful because they knew who I was talking about. Yeah, they could get in touch. It was a much more joined up service, so. so that really helped…"
		• Mental health support offered from CHD team	Experiences of being provided with mental health support	"I didn't really ask for mental health support from the GP, but actually [the cardiac hospital] was able to offer that. So I had at one point but more recently as I said, it was [the hospital] that just volunteered it…"
				"… I just sort of think I didn't really feel like I needed it. I'm all for therapy, but I didn't feel like I needed it. But my God, it opened up something

Theme	Subtheme	Code	Code definition	Examples
				and really brought out the best in me. Yeah. Cognitive therapy was brilliant. Yeah, absolutely. Yeah, it was beyond what I actually thought I needed because I didn't really feel like I needed anything…"
		• Waiting too long for mental health support (psychology)	Delays accessing therapeutic support	"I haven't really, I suppose because I'm aware of the fact that waiting is too long for support. I haven't sought support for my mental health via the NHS I think if I did seek that kind of support, I'd probably just automatically go down the private route I'd probably."

Theme	Subtheme	Code	Code definition	Examples
		• Professional help is needed	Professional support is needed to manage	"I suppose I reached out to family members and close friends, but how often you feel like you need. Yeah, more professional help."
		• Integrated care was helpful (CHD and psychology)	Positive experience of co-ordinated services (CHD and psychological)	"…For me to see someone at [the cardiac hospital] and they then could work together with the cardiac team. So that was really, that was really helpful because they knew who I was talking about. Yeah, they could get in touch. It was a much more joined up service, so. so that really helped…"
		• Heart service helpful for mental health	Cardiac service supportive with psychological support	"I would say the only thing I can say is that [the psychologist] saved my life, she she'd managed me get to get me to open up to things that I have

Theme	Subtheme	Code	Code definition	Examples
				never told my parents and talk about things that had happened to me when I was young and I managed to explain stuff to my family, my siblings and people that they wouldn't. I would never have spoken about. So [the psychologist] really made me, more at ease with my family and just literally saved my life…"
		• Combination of medication and psychological strategies	Use of both pharmacological and therapeutic approach	"Medication and calming techniques helped"
		• Knowledge on CHD and menopause isn't available yet	Lack of available healthcare information on CHD and menopause	"They're just coming to terms with it themselves, so there's nothing, there's nothing for women in with menopause with CHD you know so, and I

Theme	Subtheme	Code	Code definition	Examples
				think they're trying, you know they are trying, but it's just I think this it's a bit late for me, but I think this should be offered and should be at a much younger age."
Personal Coping Resources	The Strain and Strength of Self-Advocacy Menopause in the Context of Serious Health Conditions	•Bodily Awareness • Self help	Actively aware of own bodily symptoms Independently managing health	"I am a bit more aware of my body and how I'm feeling than someone who didn't have a heart defect." "Like exercise is a big thing as well, and I drink a lot of water anyway, so I'm just trying to go more natural route until the time comes where maybe I do need something more." "So and because no one can find a reason for me having a bit, they couldn't directly link it. Well, they couldn't direct me a hole in the heart because

Theme	Subtheme	Code	Code definition	Examples
				of the stroke. They couldn't directly link. Why? I'd had the clot in the 1st place, if you know what I mean. I just thought that I have to focus and do this on my own. So I think that was that became a mental issue I think, but I just out with it by reaching out just managing it myself."
		• Hard to reach out to CHD team	Barriers with communicating with CHD team	Repeated code, example quotes already provided
		• Hard to ask for help	Difficulties asking for support	"I mean, they're denying that it's happening so I wouldn't bother attempting to get support…."

Theme	Subtheme	Code	Code definition	Examples
				"Yeah, it is with everything, with any health condition and it becomes when you're already, especially from a hormonal point of view, you're already in a position of asking for help, which is a big thing to then hit every single wall and barrier. Where it's not as easy to get help, you know it, it becomes disheartening."
		• Hard to accept support	Difficultly receiving help from others	"I mean always I've approached that sort of through talking therapy, not through medication or anything. I've not. I've never. I've been offered it times but never been never wanted to accept anything."

Theme	Subtheme	Code	Code definition	Examples
				"Well, I know actually that I can talk to someone through Gooch, my hospital like they have mentioned it to me, sometimes I think I should, but then, It's just a weird it's a weird. It's a weird fight you have because you kind of think. Well, I'm fine. I'm like, I've got through it all, you know, like, like, you know, I don't know…"
		• Seeking out information about menopause	Actively researching menopause information	Repeated code, example quotes already provided "… I think you have to be quite proactive yourself to be honest.Yeah, I think I've kind of been able to kind of work out now…."
		• Left to figure it out	Perceived absence of structured guidance	"… I think I've had to do my own research, but I think understanding that actually you know they're

Theme	Subtheme	Code	Code definition	Examples
				just replacing the hormones that you're meant to have rather than it being a synthetic thing and everyone worrying about this and that….”
		• Looking after my health	Active engagement in self-care/managing health behaviours	“Whereas somehow when I found out about my condition, I became much healthier and I my I started exercising much more. So yeah, I think generally I've been much healthier in some ways, which is interesting, but yeah”
		• Learning about my body	Developing an understanding of own bodily changes	“I'm learning to manage that's a bit better and trust that my heart knows what it's doing, even if it's a bit different from everybody else's, but yeah through talking therapy really you know and my own reading and research on nervous system and stuff and learning.”

Theme	Subtheme	Code	Code definition	Examples
		• Needing reassurance	Seeking validation from professionals	Repeated code, example quotes already provided
		• Inner strength	Perceived personal resilience	“I feel so determined to keep pushing through it and that's just, that's just the way I am, I think because of the battle I've come this far, my heart.”
		• Self advocacy	The need to speak up for own health/rights	“I'm really angry, but I have good care now, but I still have to advocate for me as a whole body system.”
		• Bigger health issue	A health condition which is perceived as	Repeated code, example quotes already provided.

Theme	Subtheme	Code	Code definition	Examples
			more serious than menopause	
		• Not suffering from menopause	Minimal impact from the menopause	Repeated code, example quotes already provided
Social Connectedness as Support	Intergenerational support, family and partner relationships	• Family support	Emotional or practical help from family	"No, no. Only support from my husband. He's actually been really good. But other than that, and friends who are going through similar things. But it's very difficult when you have a congenital heart disease as well."
		• Peer support helpful	Benefits of connecting with similar others	"When I attended this menopause again, someone was doing a research and I think write because it is kind, it was nice and it was a kind of, you know, opened your eyes a lot because there's so many

Theme	Subtheme	Code	Code definition	Examples
				people going through this, but in a different way and how it's been affecting them and I would just feel like when I came out of it that day I was quite emotional"
				"We did the tree of life thing, and I've never been in a room with a load of people who've got congenital heart defects before, unless it was a waiting room, everyone sitting there shooting themselves. So that was actually kind of liberating, also I mean I was the only one who'd had multiple surgeries but that was probably just the cohort of that group. I know lots of people about to have happened…"

Theme	Subtheme	Code	Code definition	Examples
				"There is one online that was really useful on Facebook. That was really helpful and it's also really helpful with practical stuff beforehand. Like, what do I need to take to hospital and to do and what can I expect? That was really good. But now beyond that no"
		• Peer support needs to be carefully Considered	Caution regarding connecting with similar others (due to prognosis etc)	"So the [CHD charity], which is a CHD for adults charity, used to help the trustees on that, I think it's a really good charity. But I've always been worried about going to their events because I didn't want to see people who were in the late stages of heart failure or, you know, I actually, I I don't want to see where I might end up.I mean, I'm sure they did other cohorts, it was sort of curated.

Theme	Subtheme	Code	Code definition	Examples
				And I think that it was a more positive experience than it might have been. I'm still not sure I'd go to their event."
		• Not understood by others	Feeling misunderstood socially	"No one understands, my partner wouldn't understand. No one. Because you know, they see you as. OK. You're getting on with life. You're not moaning. You're not in bed continuously."
		• Anxious parents	Parental anxiety influencing them as an individual	Repeated code, example quotes already provided

Theme	Subtheme	Code	Code definition	Examples
		• Relied on parents for information	Dependent from a young age on family for health knowledge	Repeated code, example quotes already provided
		• Female consultant understood	Positive experience based on gender	"Well, the, you know, they did let me go on the HRT which was positive. I got a female consultant. She was quite understanding about it. She saw that my age and yeah."

Appendix Q

Thematic Schema