

Cardiomyopathy: Exploring cardiologists' and patients' lived experiences of diagnosis

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Declaration

I can confirm that this thesis and the research reported within it, is my original work. It was written and submitted in part fulfilment of the degree of Doctor of Philosophy (PhD) at Liverpool John Moores University. It has not been submitted for any other degree or academic qualification.

In line with Liverpool John Moores University's guidance on the ethical use of assistive technologies, I have used EndNote reference management software to organise and format citations and references. I have also used ChatGPT in a limited, supportive capacity to seek general guidance on document structure and formatting approaches only. At no point was generative AI used to create, edit, or analyse the substantive content of this thesis, nor to develop any arguments, interpretations, or findings.

The intellectual content, critical analysis, and conclusions presented in this thesis are entirely my own.

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Signature

08/09/2025
Date

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Abstract

Background:

Cardiomyopathies are a group of chronic cardiac conditions affecting the structure and/or pumping efficiency of the heart muscle, affecting a significant proportion of adults worldwide.

Cardiomyopathy (CM) research has predominantly focused on clinical pathways and biomedical outcomes, with limited attention given to the lived experience of the diagnostic journey. This study addresses this gap by exploring how CM diagnosis is experienced by both adult patients and cardiologists.

Aim:

To explore patients' and cardiologists' lived experiences of cardiomyopathy diagnosis.

Method:

Full NHS ethical approval was obtained for all phases of this research. An interpretivist, phenomenological design was adopted. Semi-structured interviews were conducted with consultant cardiologists and newly diagnosed adult CM patients from NHS trusts in England.

Cardiologists were recruited directly or via their NHS Trusts. A supplementary quantitative participant identification tool supported a purposive, self-selecting sample of patients to interview.

Data were analysed using interpretative phenomenological analysis. A final integrative phase examined convergence and divergence across perspectives.

Results:

Diagnosis was experienced as a complex, multi-layered process shaped by systemic, interpersonal, and intrapersonal factors. Cardiologists described tensions between ideal and real-world practice, highlighting systemic constraints, diagnostic uncertainty, and emotional labour. Patients

experienced diagnosis as disruptive, characterised by loss, identity renegotiation, and an ongoing search for certainty. Across both groups, communication, uncertainty, and power dynamics emerged as central, with notable differences in how diagnosis was understood and experienced.

Conclusions:

CM diagnosis extends beyond a single clinical event and can instead be understood as a psychologically and relationally significant process. By integrating cardiologist and patient perspectives, this study provides a novel, multi-perspective account of diagnosis, highlighting both shared challenges and critical divergences in meaning-making.

Implications:

Findings extend existing cardiology and health psychology literature by viewing diagnosis as an experiential process. They support the development of more psychologically informed, person-centred diagnostic practices, improved communication, and greater integration of psychological support and third-sector services within cardiology care pathways.

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Key Terms and Abbreviations

Term/ Abbreviation	Definition
BNP / NT-proBNP	Cardiac natriuretic peptide biomarkers used in HF diagnosis and monitoring.
Cardiomyocytes	Heart muscle cells responsible for contraction, leading the heart to beat.
Care pathway	Coordinated sequence of services and appointments across settings.
CM	Cardiomyopathy (disease of the heart muscle).
CME	Continuing Medical Education
CPD	Continuing Professional Development
DA	Decision Aids
DCM	Dilated cardiomyopathy.
Diagnostic uncertainty	Recognised limits of knowledge in establishing a diagnosis.
ECG	Electrocardiogram (electrical activity tracing of the heart).
Echo / TTE	Transthoracic echocardiogram (ultrasound scan of the heart).
EF / LVEF	Ejection fraction / Left ventricular ejection fraction (percentage of blood ejected from the heart with each beat).
ESC	European Society of Cardiology (guidelines body).
DA / Decision Aids	Decision Aids – tools used to support communication between clinicians and patients, and to structure thoughts and concerns when weighing up clinical decisions.
HADS	Hospital Anxiety and Depression Scale (14-item screening of anxiety and depression).
HCM	Hypertrophic cardiomyopathy.
Herceptin	Targeted cancer drug used to slow tumour growth.

HF	Heart failure (clinical syndrome due to cardiac dysfunction).
HFpEF	Heart failure with preserved ejection fraction (LVEF $\geq 50\%$).
HRQoL / QoL	Health-related quality of life / Quality of life.
ICB	Integrated Care Board
ICD	Implantable cardioverter-defibrillator (shock device to treat dangerous arrhythmias).
IPA	Interpretative Phenomenological Analysis (qualitative approach exploring lived experience).
KCCQ	Kansas City Cardiomyopathy Questionnaire (patient-reported health status in heart failure/cardiomyopathy).
LV	Left ventricle/ Left ventricular
MDT	Multidisciplinary team (e.g., cardiologists, nurses, physiologists, geneticists).
MI	Myocardial infarction (heart attack).
NICE	National Institute for Health and Care Excellence (UK guidance).
NYHA	New York Heart Association functional class (I–IV dyspnoea scale).
RCM	Restrictive cardiomyopathy.
SCD	Sudden cardiac death.
SDM	Shared decision-making (clinician–patient partnership in choices).
Takotsubo	Takotsubo syndrome (stress-induced cardiomyopathy) characterised by transient LV dysfunction.

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1. Introduction

This thesis explores how cardiomyopathy diagnoses are experienced in practice, beyond their clinical definition and formal diagnostic pathways. This opening chapter introduces the topic and the perspective taken, before setting out the researcher's positionality and the research aims. It then provides a brief overview of the topic, the study and a roadmap for how the thesis is structured.

1.1 Cardiomyopathy Diagnosis: Burden, Complexity, and Lived Experience

Cardiomyopathies are a diverse group of disorders characterised by structural and functional abnormalities in the muscular tissue of the heart (Kian *et al.*, 2021). These abnormalities impair the heart's ability to pump oxygenated blood effectively throughout the body. As a result, individuals with cardiomyopathy (CM) may experience a range of non-specific cardiac symptoms, including breathlessness, chest pain, arrhythmia, fluid retention, and fatigue (Kian *et al.*, 2021). However, some individuals may remain asymptomatic, complicating the diagnostic process (Ciarambino *et al.*, 2021). The various phenotypes of CM reflect distinct structural or functional presentations of the disease. Chapter 2 will introduce CM in greater detail.

Epidemiological studies estimate that up to one in every 250-500 individuals across Europe have been diagnosed with a form of cardiomyopathy representing a considerable strain across health services across Europe (McKenna and Judge, 2021). Given the familial nature of many cardiomyopathies and their frequent under-diagnosis, the true prevalence is likely to be significantly higher. The economic burden is also notable, with acute treatment episodes involving hospitalisation for CM patients estimated to cost between €17,337.75 - €39,425.13 per episode (Wiethoff *et al.*, 2023). Consequently, early detection programmes and strategies could offer substantial cost savings for healthcare systems like the NHS (Temedie-Asogwa *et al.*, 2024). Over the past 30 years, advancements in drug and device therapies have dramatically improved the prognosis for cardiomyopathy patients, however, there remains no definitive cure for the disease (Bauersachs, 2021; Xu *et al.*, 2022). As a result of earlier diagnosis and increased longevity, the impact of CM on patients' daily lives and psychological well-being is gaining greater attention (Arbelo *et al.*, 2023; Freedland, Rich and Carney, 2021; Heidenreich *et al.*, 2022).

The multiple aetiologies and considerable variability in symptomology mean that CM diagnoses are complex and challenging for both patients and clinicians to navigate. Despite this, the lived experience of CM diagnoses is rarely explored in detail from either perspective. Current understandings of the CM diagnostic journey usually involve mapping objective clinical pathways and referencing symptom classification guidelines (Arbelo *et al.*, 2023; Heidenreich *et al.*, 2022). However, these frameworks fail to capture the practical, day-to-day realities of making or receiving a CM diagnosis. Exploring qualitative perspectives from both patients and clinicians provides valuable insights that can be used to inform and improve future service provision, that ultimately benefits both parties. To fully understand and interpret these perspectives, it is important to consider the positionality and motivations of the researcher undertaking this work.

1.2 Researcher position: Background and motivations for research

Having been diagnosed with dilated cardiomyopathy at just six weeks old, medication, medical consultations, and interventions were woven into the fabric of my reality from a very early age. As I grew, I noticed that my perspective and outlook on life differed significantly from those of my peers. I found this both confusing and intriguing.

This curiosity ultimately led me to pursue a degree in psychology at university, driven by a desire to explore whether my sense of self was shaped by my lived experiences or rooted in my genetic makeup. I have always experienced high levels of anxiety, prompting me to question whether this was a consequence of the physical uncertainty I experienced during my formative years or an innate aspect of my personality that developed independent of my cardiomyopathy diagnosis. My own journey with cardiomyopathy introduced me to the psychological implications of living with chronic illness and highlighted the lack of resources and support available to individuals with cardiomyopathy.

At the age of 16, I became a voluntary peer support worker for young people living with cardiomyopathy through the national charity, *CardiomyopathyUK*. By the time I was 20, I had taken on the role of patient advocate, addressing Members of Parliament at the House of Commons to campaign for greater psychological support services and educational resources for cardiomyopathy and heart failure patients

and their families (Vickers, 2013). In 2014, my family and I established a local cardiomyopathy support group on behalf of the national charity, Cardiomyopathy UK. I was struck by the overwhelming number of patients, family members, and healthcare professionals who reached out, seeking more information and support regarding the condition. The group has since expanded and now provides support across Cheshire and Merseyside. Through my interactions as a support group leader, I came to understand that most cardiomyopathy patients were diagnosed in adulthood. These individuals often faced unique physical and psychological challenges, as well as a period of adjustment that differed to my own lifelong experience of the condition. I was therefore keen to explore the lived experience of CM populations diagnosed in adulthood in more detail. I have progressed my career in psychology, working for several physical health and mental health NHS services as an Assistant Clinical Psychologist. I now aspire to pursue a career as a qualified Clinical Psychologist in the future, allowing me to continue both clinical work and further research.

1.3 The Research

This study has a qualitative multi-perspective design, as it explores a series of different perspectives around a single phenomenon (Larkin, Shaw and Flowers, 2019), in this case the cardiomyopathy diagnosis process. The aim of this study was to explore the lived experiences of consultant cardiologists and newly diagnosed adult CM patients. Therefore, this study is also dyadic in that it focuses on both the shared and distinctive features of this process from the perspective of both cardiologists and patients. Larkin, Shaw and Flowers (2019) metaphorically described this type of multi-perspective design as understanding the ‘two sides to every coin’. While there are many examples of clinician-patient dyadic designs within health literature generally (Borg Xuereb, Shaw and Lane, 2016; Brooks *et al.*, 2020; Campbell *et al.*, 2024) currently no such examples exist relating specifically to cardiomyopathy diagnosis. The study considers both perspectives equally and is therefore, split into three main branches of exploration: cardiologists, patients, and an integration of these perspectives (Figure 1). Morse (2003) proposed that all research studies have an over-arching theoretical thrust driving the theoretical focus and aim of the entire study. In this case the study is inductive and qualitatively focussed. Morse (2003) further proposed that each individual phase of the study has a theoretical drive dictated by its unique methodology which may differ to the overarching

thrust of the entire study. In this case, the study in its entirety is inductive and qualitative despite using quantitatively driven means of identifying patients to interview.

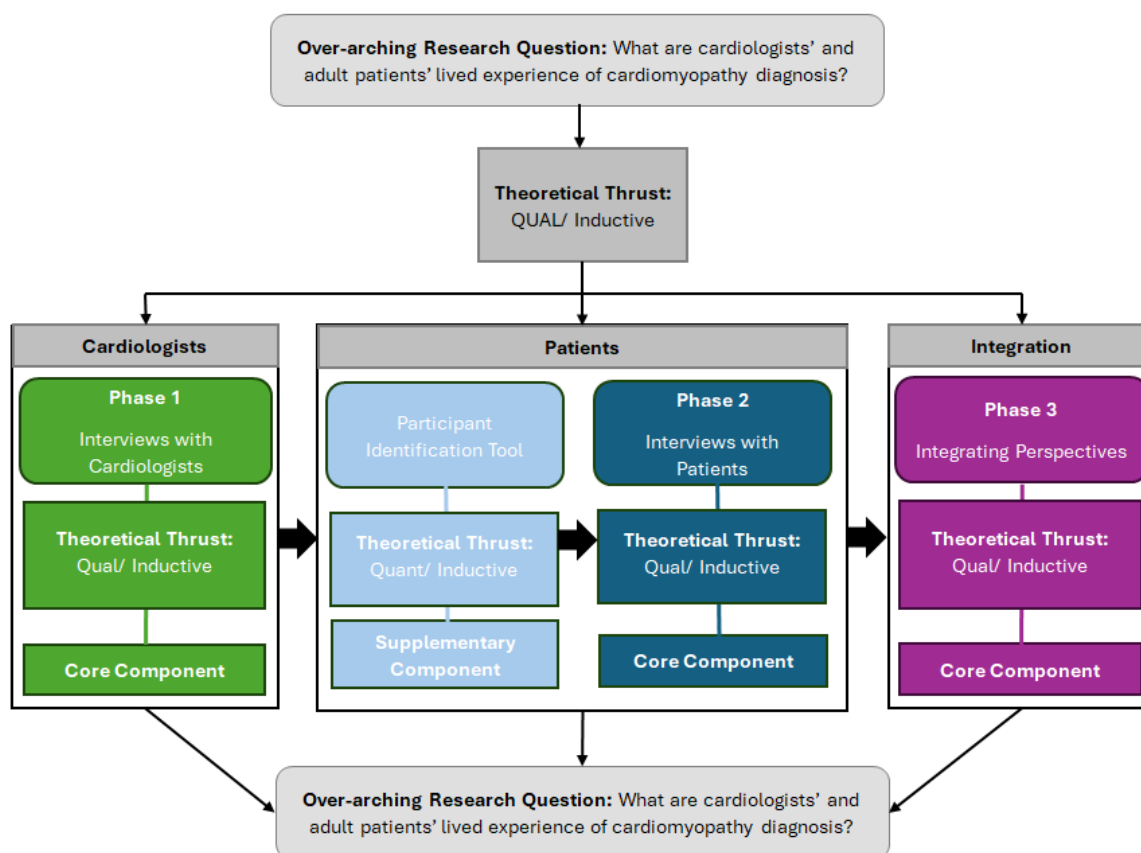


FIGURE 1. THEORETICAL DRIVE VERSUS THEORETICAL THRUST - ADAPTED FROM MORSE (2003).

1.3.1 Research Contribution

Experiential research is integral to deepening our understanding of the lived experiences of specific populations (McIntosh and Wright, 2019). In healthcare, the inclusion of ‘expert patients’ has become a cornerstone of best practice, with policies increasingly recognising their value in shaping service development (Chen, Croft and Currie, 2025; Wale *et al.*, 2021). It has been argued that to ensure health services are person-centred, they must be held accountable to the patients they serve (Larson *et al.*, 2019), making patient insights extremely important in ensuring health systems adequately meet patients’ needs. Health service evaluations now routinely incorporate qualitative feedback from service users (e.g. PREMs – Patient-Reported Experiential Measures) alongside quantitative outcomes, enriching the data with greater depth and nuance (Shunmuga Sundaram *et al.*, 2022). Cardiomyopathy patients represent an

under-researched population, particularly in the context of qualitative accounts (Shore *et al.*, 2024a). Rarer still are research exploring the lived experience of the CM diagnosis process. Existing qualitative research in cardiac care often extrapolates findings from broader heart failure populations, resulting in conclusions that lack specificity for CM. The limited research that does focus on CM specifically tends to focus on particular phenotypes, leaving less prevalent forms of the condition underexplored. This research will be inclusive of multiple CM phenotypes, and self-selection purposeful sampling will ensure the inclusion of often under-represented phenotypes to ensure data reflects the lived experience of a range of CM diagnoses. This research is explorative in nature to open the door to future, more nuanced or focused CM-specific research.

Additionally, the diagnostic journey from the perspective of consultant cardiologists is notably absent from the literature. While the patient-clinician relationship is a well-established and critical component in the management and diagnosis of chronic illness (Berger *et al.*, 2022; Campbell *et al.*, 2024; Náfrádi *et al.*, 2018), the lived experiences of cardiologists involved in CM diagnoses remain unexplored. Given the interconnected nature of patient and clinician experiences, a deeper understanding of both perspectives will provide valuable insight into the systemic, interpersonal and intrapersonal dimensions of CM diagnosis. Insights gained from the dyadic nature of this research can be used to inform and enhance future service provision, enhancing the diagnostic experience for both patients and cardiologists alike.

1.3.2 Research Aims and Objectives

Over-arching research aim: To explore patients' and cardiologists' lived experience of cardiomyopathy diagnosis.

Broad research objectives for each phase of this study are listed below. These objectives were developed through a preliminary scoping review of current research, with input from a patient and public involvement group, and from feedback from a preparatory interview (all of which will be discussed in Chapters 2 and 4). The resulting objectives were then used to inform the interview topic guides for both cardiologist and patient interviews.

Phase 1 Aim: To explore cardiologists' lived experience of cardiomyopathy diagnosis.

Objectives:

- To explore level of cardiomyopathy education and training cardiologists receive
- To map a typical diagnostic pathway
- To reflect on how a new diagnosis of cardiomyopathy is communicated to adult patients
- To understand the needs of cardiologists during diagnosis

Phase 2 Aim: To explore the lived experiences of newly diagnosed adult cardiomyopathy patients.

Objectives:

- To explore individual diagnostic journeys
- To explore patients' understanding of cardiomyopathy
- To consider the implications of diagnosis of patients' lives
- To understand the needs of patients during diagnosis

Phase 3 Aim: To explore how multiple perspectives of cardiomyopathy diagnosis relate.

Objectives:

- To identify and discuss any points of convergence.
- To identify and discuss any points of divergence.

1.4 Structure of the Thesis

This thesis has been purposefully structured to reflect the interactive nature of the research's qualitative and interpretative design. Qualitative research is a co-construction of the researcher-participant relationship and therefore "*must confront the subjective nature of the researcher in connection with the process of research*" (Kirn *et al.*, 2017, p. 4). Particularly given the somewhat subjective nature of interpretative analysis, it is important to be forthcoming about my own position as a researcher coming into the research process. Interpretative phenomenological analysis acknowledges that there will be an inherent

bias and subjectivity in the researcher's interpretation of the participants' data and therefore positionality should be clearly stated and reflected upon (Kirn *et al.*, 2017). This thesis therefore begins with an introductory chapter, introducing myself as the researcher and the topic in hand. The thesis has been written primarily in a first-person narrative to take ownership of the research content and acknowledge the somewhat subjective nature of research process and its' findings. Throughout the thesis, I have written reflexive contemplations, which I refer to as, 'Researcher Reflections'. These reflective stop-offs provide the reader with a snapshot into my lived experience as a researcher to acknowledge my own position on issues relating to the research such as the methodological framework and the analysis process. The thesis has been split into ten chapters as outlined below.

Chapter Overview:

Chapter 1: *Introduction*

Chapter 2: *Literature Review*

Chapter 3: *Methodology*

Chapter 4: *Method*

Chapter 5: *Interviews with Cardiologists: Findings*

Chapter 6: *Interviews with Cardiologists: Discussion*

Chapter 7: *Interviews with Patients: Findings*

Chapter 8: *Interviews with Patients: Discussion*

Chapter 9: *Integrating Perspectives*

Chapter 10: *Thesis Conclusion*

2. Literature Review

2.1 Chapter Introduction

This chapter critically examines existing literature relating to cardiomyopathy (CM) diagnosis in order to situate the present research within its theoretical and empirical context. It aims to identify key areas of existing knowledge, highlight gaps within the literature, and establish the rationale for the current study. The review focuses on research relevant to the diagnostic process in cardiomyopathy, with particular attention to the experiences of both patients and clinicians. In doing so, it brings together literature from clinical, psychological, and health service perspectives to develop a more comprehensive understanding of the factors influencing diagnosis.

The chapter begins by outlining the rationale for, and approach to, both a preliminary review of the literature (conducted during the research design phase) and a narrative review (completed following data analysis). The process of undertaking the scoping review is then described in more detail, before a contextual overview of cardiomyopathy diagnosis is provided, followed by the main body of the narrative literature review. The narrative review is structured around three interrelated domains: systemic, interpersonal, and intrapersonal components of care. These domains reflect the multi-layered nature of the diagnostic process and provide a framework for organising the literature. Finally, identified gaps in the literature are outlined, providing the rationale for the current study.

2.2 Preliminary Review

As the primary narrative review was conducted post-analysis, a simple preliminary scope of current literature was conducted during the research design phase. While some researchers advocate for systematic and comprehensive engagement with prior literature (Muthanna, 2019), qualitative approaches, particularly those grounded in interpretivism, take a more flexible approach, acknowledging that preconceptions are both inevitable and, when reflexively managed, informative (Charmaz, 2014a; Charmaz, 2014b). A simple preliminary review therefore provided an initial overview of the existing literature to inform

study design and ensure the research addressed a meaningful gap, without unduly influencing the subsequent inductive analysis.

Preliminary reviews are particularly useful where the evidence base is emerging or not yet comprehensively reviewed, as they allow researchers to map key concepts, clarify the scope of current literature, and identify gaps to inform future research (Munn *et al.*, 2018; Tricco *et al.*, 2018). A preliminary review of the literature was conducted during the research design phase to assess the scope and nature of existing literature, and to ensure that the current study would contribute to new knowledge.

Initial search terms were developed using the SPIDER framework (Cooke, Smith and Booth, 2012), which is relevant to both qualitative and mixed-methods research. This provided a structured way of identifying key components of the research question, including the sample, phenomenon of interest, and methodological focus. A summary of the resulting search terms is provided in Table 1 below.

TABLE 1. ‘SPIDER’ TOOL AND RESULTING INITIAL SEARCH TERMS – ADAPTED FROM COOKE, SMITH AND BOOTH (2012)

S	<i>Sample</i>	“Clinician(*)” OR “Cardiologist(*)” OR “Cardiomyopathy Patient(*)” OR “Patient(*)”
PI	<i>Phenomenon of Interest</i>	“Cardiomyopathy Diagnosis(*)”/ “Lived Experience(*)”
D	<i>Design</i>	“Phenomenology(*)” OR “Interpretative Phenomenology(*)” OR “Interpretivism(*)”
E	<i>Evaluation</i>	“Thematic Analysis” OR “Interpretative Phenomenological Analysis”
R	<i>Research type</i>	“Mixed methods” OR “Qualitative”

Search terms were then refined iteratively in relation to each phase of the study. For example, Phase 1 was originally focused broadly on all clinicians' roles within the cardiomyopathy diagnostic process, leading to combinations such as "*clinicians AND diagnosis AND cardiomyopathy*". Additional terms were incorporated as relevant concepts emerged (such as "*communication*" or "*shared decision-making*"), allowing the search to remain responsive to the developing scope of the literature.

Searches were conducted across multiple databases, including Web of Science, PsycINFO, CINAHL, and MEDLINE, using a combination of free-text terms and subject headings where appropriate. Citation tracking and grey literature searches were also used to identify additional relevant sources. While this process was exploratory rather than systematic, the search process is described transparently to allow replication and clarity. The description of the search process was informed by PRISMA scoping review guidance (Tricco *et al.*, 2018).

Findings from the preliminary scoping exercise (conducted in 2017) indicated that existing research was heavily weighted towards the clinical and biomedical aspects of cardiomyopathy, including diagnosis, classification, and treatment pathways (Bozkurt *et al.*, 2016; Japp *et al.*, 2016; Maisch *et al.*, 2012). In contrast, there was comparatively a limited amount of attention given to how diagnosis was experienced in practice, either from patient or clinician perspectives. Where patient experience was considered, it tended to focus more broadly on living with cardiomyopathy as a long-term condition, rather than on the diagnostic process itself (Subasic, 2013), or only included specific phenotypes (Dekker *et al.*, 2016). Similarly, clinician-focused research largely addressed diagnostic criteria (Grothoff *et al.*, 2012; Maisch *et al.*, 2012), with little exploration of the interpersonal or experiential aspects of forming or delivering a diagnosis. These findings highlighted a clear absence of qualitative research exploring the lived experience of cardiomyopathy diagnosis, supporting the rationale for the current study and the use of interpretative phenomenological analysis (Smith, Flowers and Larkin, 2009).

Consistent with the principles of interpretative phenomenological analysis (Smith, Flowers and Larkin, 2009), the more comprehensive narrative literature review presented later in this chapter was completed

following data analysis. This approach was adopted to minimise the influence of pre-existing literature on the interpretation of participants' accounts, while the preliminary scoping review ensured the study's focus was grounded within, and contributed to, the existing field of study.

The preliminary scoping of the literature provided an initial overview of the evidence and confirmed a gap in research addressing the lived experience of cardiomyopathy diagnosis. Building on this, the following narrative review examines the literature in greater depth. It begins by outlining key contextual and clinical features of cardiomyopathy diagnosis before reviewing the literature across three interrelated domains: systemic, interpersonal, and intrapersonal components of care.

2.3. Narrative Review

The primary literature review adopted a narrative approach, allowing for a flexible and critical synthesis of research across a broad and multidisciplinary field (Sukhera, 2022). Given the relatively limited research found specifically addressing the lived experience of cardiomyopathy diagnosis, a narrative review was considered most appropriate, as it enabled the integration of diverse sources of evidence, including clinical, psychological, and health service research, and supported the development of a more conceptually driven understanding of the topic.

In contrast to systematic reviews, which aim to identify and synthesise all available evidence addressing a narrowly defined question, narrative reviews are better suited to areas that are conceptually complex, or current only have a limited evidence base (Sukhera, 2022). This approach aligned with the research's aim to explore a relatively under-researched phenomenon rather than evaluate the effectiveness of any specific interventions.

The narrative review targeted searches of databases including PsycINFO, PubMed/MEDLINE, CINAHL, and Scopus, supplemented by grey literature and manual reference checking. Studies were selected based on their relevance to the research aims and findings, and their contribution to understanding chronic illness diagnosis and the associated psychosocial dimensions of care.

Methodological consideration was given to the approach to the literature review to ensure alignment with the chosen method of analysis for this study - interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin, 2009), which is discussed further in Chapters 3 and 4. Consistent with IPA, the narrative literature review was completed following data analysis. IPA emphasises an inductive and idiographic approach, where themes are developed from participants' accounts rather than being shaped in advance by existing theory or literature (Smith, Larkin and Flowers, 2021; Smith, Flowers and Larkin, 2009). Conducting the review at this stage helped to minimise the influence of pre-existing frameworks on the interpretation of participants' experiences, while still allowing the findings to be situated within the wider evidence base.

2.4 Cardiomyopathy Diagnosis: Overview and Context

The term, cardiomyopathy was first used by Brigden (1957) to describe patients with myocardial disease in the absence of any coronary artery disease. All cardiomyopathies were initially described as being idiopathic - defined as heart muscle disease without a known cause (Arbustini *et al.*, 2014).

Cardiomyopathies are now understood to be caused either by genetic predisposition or mutation, or by external factors causing excessive strain on the heart, such as childbirth, severe stress, substance abuse or infection (McKenna, Maron and Thiene, 2017), as illustrated in Figure 2 below.

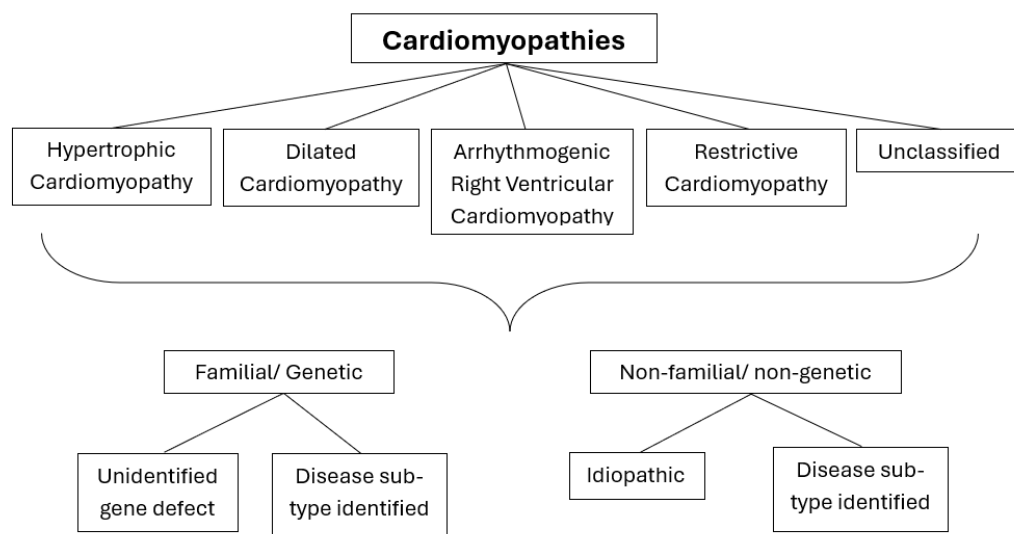


FIGURE 2. EUROPEAN SOCIETY OF CARDIOLOGY CLASSIFICATION OF CARDIOMYOPATHIES AS CITED IN MCKENNA, MARON AND THIENE (2017) AND ELLIOTT *ET AL.* (2007).

Cardiomyopathies are associated with an array of clinical symptoms which can vary in severity from patient to patient. The New York Heart Association (NYHA) classification system (Fisher, 1972) provides common assessment criteria and language in which to describe a patients' symptom severity and dysfunction. The NYHA classification includes varying degrees of common cardiomyopathy symptoms such as shortness of breath and fatigue, which along with physical measures of heart function are used to inform treatment and monitor progress. Cardiomyopathies are associated with dysrhythmia and is the leading cause of sudden cardiac death among people under the age of 35 years (Kian *et al.*, 2021).

2.4.1 Cardiomyopathy phenotypes

The structural abnormalities of the myocardium can vary between cardiomyopathy diagnoses, resulting in the presentation of different phenotypes of the disease. The most prevalent phenotype is dilated cardiomyopathy, where the pumping chambers of the heart are enlarged, weak and thin (Heymans *et al.*, 2023). Hypertrophic cardiomyopathy, which is characterised by a thickened heart muscle resulting in

restricted pumping function, is estimated to affect one in every 200-500 people, however only around 20% of cases are estimated to be clinically identified (Maron *et al.*, 2022). Robust data on the epidemiology of dilated cardiomyopathy is lacking however estimates suggest a prevalence rate of up to twice that of hypertrophic cardiomyopathy (McKenna and Judge, 2021; Fatkin *et al.*, 2021). Less commonly, restrictive cardiomyopathy is diagnosed when the lower chambers of the heart become stiff and restrict the amount of blood flow (Rapezzi *et al.*, 2022). Arrhythmogenic right ventricular cardiomyopathy is diagnosed when the heart muscle cells are replaced by scar tissue or fat cells, increasing the likelihood of cardiac complications (Krahn *et al.*, 2022), but this is proportionately rare. Other relatively uncommon cardiomyopathy phenotypes do exist. For example, peripartum cardiomyopathy is a form of cardiomyopathy that develops in women during the final month of pregnancy or within 5 months of giving birth (Sliwa *et al.*, 2021). Reported rates of peripartum cardiomyopathy varies across the world but latest research estimates a prevalence rate of between 1:968 to 1:4000 (Christiansen *et al.*, 2019). Takotsubo cardiomyopathy is an extremely rare form of stress-induced cardiomyopathy whereby the left ventricle drastically changes shape to resemble a Japanese octopus pot also known as a Takotsubo (Matta and Carrié, 2023). Furthermore, myocarditis has also more recently been recognised as an inflammatory cardiomyopathy (McKenna and Judge, 2021). ESC guidance supports a phenotypic approach to the identification and management of cardiomyopathies, reflecting an increase in understanding of the distinct characteristics, clinical considerations, and underlying mechanisms associated with each phenotype (Arbelo *et al.*, 2023). The physical distortion of the left ventricle found within three of the most common cardiomyopathy phenotypes are illustrated in Figure 3 below.

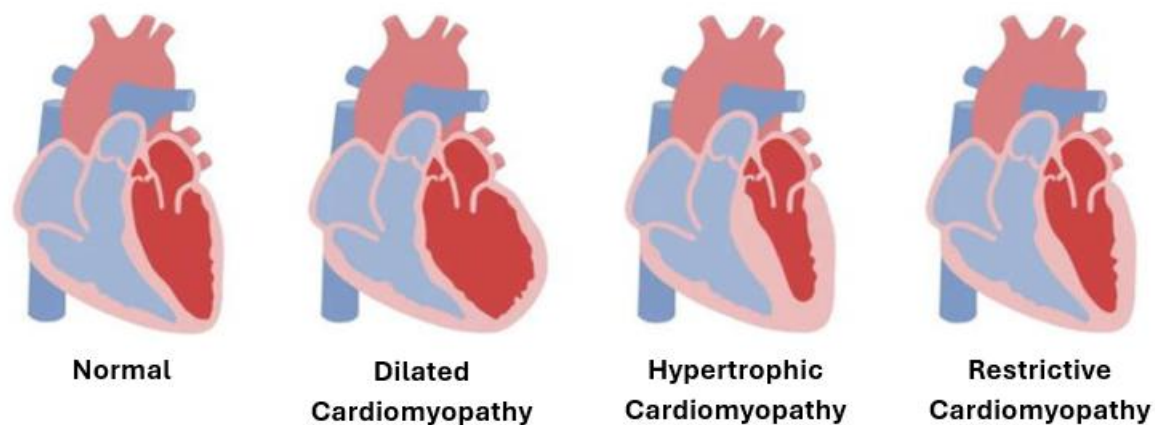


FIGURE 3. REPRESENTATION OF DIFFERENT CARDIOMYOPATHY PHENOTYPES AS PRESENTED IN SINGH, MISHRA AND MONI (2024).

2.4.2 Diagnostic pathways

Many cardiomyopathies are caused by mutations in genes that encode various cardiac proteins (Ciarambino *et al.*, 2021; Walsh *et al.*, 2022). However, in clinical practice patients are rarely first identified through genetic testing. Often, the first clinical indicator of cardiomyopathies are the presentation of heart failure symptoms or abnormal screening test results found incidentally during routine care (Arbelo *et al.*, 2023). Early identification and diagnosis of inherited cardiac conditions (ICC) such as cardiomyopathy is paramount in the prevention of sudden cardiac death and achieving effective symptom management (Bueser, 2018). It is for this reason that the European Society for Cardiology (ESC) recommend a multidisciplinary approach to diagnosing patients with a confirmed or suspected cardiomyopathy (Arbelo *et al.*, 2023). In a revision to previous protocols, ESC advised clinicians to move away from purely morphological diagnoses and incorporate a more comprehensive, multidisciplinary diagnostic approach involving consultant cardiologists, clinical geneticists, nurse specialists, genetic counsellors and physiologists. This approach provides multiple opportunities for reanalysing clinical data as new information emerges throughout the diagnosis process (Arbelo *et al.*, 2023). Specialist Inherited Cardiac Conditions (ICC) clinics have been established at heart centres to address this need. However, these services often rely on family doctors to identify suitable patients and provide a prompt referral to the

specialist ICC service for diagnostic testing: *“Central to this is the need for clinicians to consider a diagnosis of cardiomyopathy as the cause of several common adult and paediatric clinical presentations. However, the identification of a cardiomyopathy phenotype is only the beginning of the diagnostic process and should prompt a systematic search for the underlying aetiology...”* (Arbelo et al., 2023, p. 3519).

Bueser (2018) provides a clinical decision tool (Figure 4) to help practitioners identify patients to refer for diagnostic testing of ICCs such as cardiomyopathy.

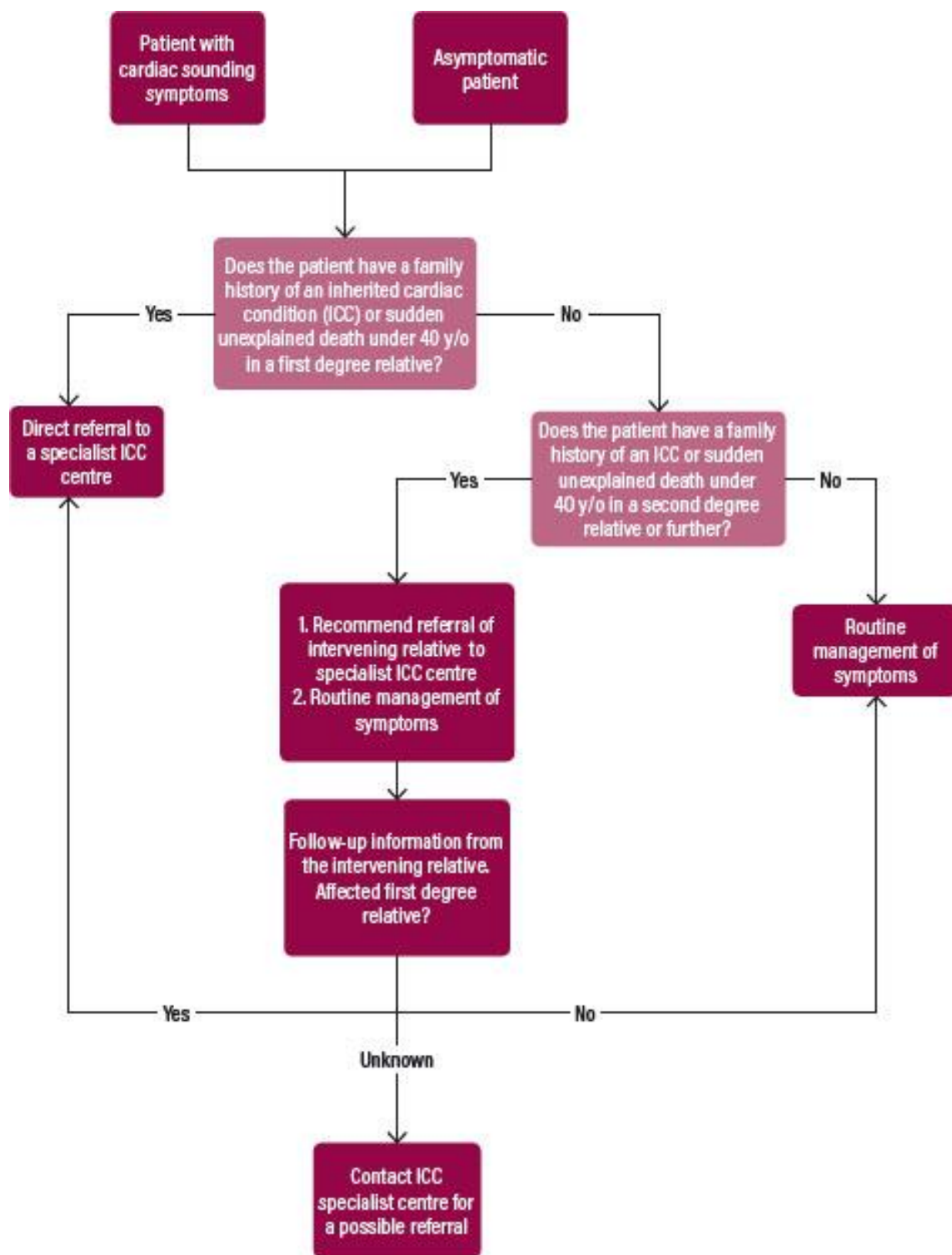


FIGURE 4. DECISION TOOL FOR REFERRAL TO SPECIALIST INHERITED CARDIAC CONDITIONS (ICC) CLINIC FROM BUESER (2018).

As seen in Figure 4, a detailed clinical and family history is one of the most important factors to consider when assessing a new patient for a potential inherited cardiac condition. ESC cardiomyopathy guidance (Arbelo *et al.*, 2023) further explain that a comprehensive clinical and family history is vital in cases where other causes such as valve dysfunction, hypertension or environmental pathogens have already been excluded. A family tree outlining a pattern of inheritance should be made, with particular attention paid to the presentation of autoimmune disorders, any sudden cardiac death, unexplained myocardial disorders or instances of stroke at a young age, as all these features could indicate a genetic predisposition to cardiomyopathy (Arbelo *et al.*, 2023).

Physical symptoms of cardiomyopathy often include shortness of breath, excessive fatigue, fluid retention, palpitations and a cough (Singh, Mishra and Moni, 2024). A diagnosis of cardiomyopathy can be reached with or without the presentation of symptoms. Echocardiograms, cardiac MRI and nuclear imaging are also important tools used to diagnose cardiac conditions such as cardiomyopathies (Stokes and Roberts-Thomson, 2017; Arbelo *et al.*, 2023), although access to these tools are limited outside of specialist heart centres such as within ICC clinics (Nelson *et al.*, 2019), with access further restricted by the backlog of patients awaiting diagnostic testing following the global pandemic (Merriel, Lee and Neal, 2021). This further highlights the need for clinical education and prompt referrals to specialist cardiology centres where these diagnostic tools are more readily available.

2.4.3 Heart Failure and cardiomyopathy

Fundamentally, a heart with any form of cardiomyopathy is a heart that is failing to function as well as it should, therefore '*cardiomyopathy*' and '*heart failure*' are terms that theoretically could be used interchangeably. However, according to ESC guidance for heart failure, in clinical practice, '*heart failure*' refers to a clinical syndrome resulting from structural and/or functional abnormalities that impair the heart's ability to fill with, or eject, blood effectively (McDonagh *et al.*, 2023). Heart failure is commonly classified according to left ventricular ejection fraction (LVEF) in three sub-classifications: preserved (HFrEF $\geq 50\%$), mildly reduced (HFmrEF 40%–49%), and reduced (HFrEF $< 40\%$) ejection fraction (Tsutsui *et*

et al., 2021; Singh, Mishra and Moni, 2024). Like many cardiac conditions, cardiomyopathies can lead to heart failure and often cardiomyopathy patients initially present with symptoms typical of those relating to heart failure (Singh, Mishra and Moni, 2024). A limitation of current trials (Merkely *et al.*, 2023; Molloy *et al.*, 2023) is that participants are often generically classified as having ‘*heart failure*’, without clearly specifying the individual diagnoses of the patient cohort. The findings of these studies are then applied to cardiomyopathy patients regardless of how many cardiomyopathy patients were represented within the study. Research populations with a broad diagnosis of heart failure may only include a small fraction of cardiomyopathy patients, if any at all. This means that most studies rarely represent cardiomyopathy patients in any meaningful way.

Heart failure (HF), and by extension cardiomyopathy, are such broad terms which encompass a range of individual conditions, varied pathologies and phenotypes, that a broad-scale model fitting all HF diagnoses has proved increasingly difficult to produce (Udelson and Stevenson, 2016) however, broad guidance does exist (McDonagh *et al.*, 2023; Tsutsui *et al.*, 2021). Heart failure guidance from the National Institute for Health and Care Excellence (NICE) outlines a standard of care for diagnosing and treating heart failure generally (Doherty, Docherty and Gardner, 2024) but as the guidance is applied very broadly, some of the guidance may not apply to cardiomyopathy populations specifically. However, the number of patients receiving an early diagnosis of HF, either through genetic testing or screening, has vastly increased in recent years and HF is now estimated to affect around 900,000 people within the UK (Naraen, Duvva and Rao, 2023). With this dramatic increase in patients, clinicians are starting to turn their focus to symptom management and quality of life as a primary focus of interventions (Jaarsma *et al.*, 2021; Camafort, Park and Kang, 2023). To ensure patients’ needs are being met in this way, it is imperative that more research is carried out to truly understand the diagnosis and treatment process within all forms of heart failure. The current study builds upon this HF research and applies the same focus specifically to cardiomyopathy care, exploring the diagnosis process from both the cardiologists’ and the patients’ perspective.

2.5 Systemic Factors in Cardiomyopathy Diagnosis

Having outlined the broader clinical context, the review now turns to the systemic factors that shape cardiomyopathy diagnosis in practice. These include the organisation of healthcare services, access to diagnostic resources, and the influence of clinical guidelines and policy on how diagnosis is recognised, investigated, and managed.

2.5.1 Healthcare Infrastructure and Resource Availability

Access to diagnostic tools and specialised cardiology centres is crucial to ensuring timely diagnosis of CM. Despite the availability of guidelines from NICE (2025) and the European Society for Cardiology (ESC) (McDonagh *et al.*, 2023), adherence is inconsistent in practice. General practitioners (GPs) are often responsible for recognising possible symptoms of HF and CM. However, Bottle *et al.* (2018) reported that only 23.6% of patients presenting with HF symptoms over a five-year period were investigated in line with current guidance. The presence of comorbidities, such as chronic obstructive pulmonary disease (COPD), complicates the diagnostic process, leading to hesitation in attributing symptoms to a cardiac rather than a respiratory cause. Further complicating diagnosis is the overlap of CM symptoms with other common conditions, including anxiety, asthma, and heart attacks, which can delay the identification of CM (Smeets *et al.*, 2016; Taylor *et al.*, 2021). Diagnosis is also shaped by patients' ability to recognise, interpret, and communicate their symptoms effectively, which can itself become a barrier to timely identification (Lee and Oh, 2022).

Resource constraints also affect diagnostic pathways. Research has found that some GPs hesitate to refer patients to secondary cardiology services, due to concerns about losing their own clinical skills or appearing inadequate in the eyes of specialists (Tzartzas *et al.*, 2019; Davies, 2022). Furthermore, referrals may lead to fragmented care, as the infrastructure for information sharing between primary and secondary services are not always adequately in place (Byrd *et al.*, 2020).

Limited knowledge and diagnostic uncertainty are not confined to primary care. Wong *et al.* (2021) found that HF and CM were misdiagnosed in 68% of cases referred from GPs and 16% of cases referred by other

cardiologists. However, these data may also reflect the natural process of differential diagnosis, whereby patients are referred to specialist cardiologists in order to rule out HF or CM, rather than simply indicating poor clinical knowledge. Regardless, the diagnostic process is complex and further hindered by a lack of recognition or consideration for rarer CM phenotypes, which often present similarly to more common forms, delaying accurate identification (Migliore *et al.*, 2021; Cui, Wang and Zhao, 2020).

These findings suggest that delayed or inconsistent diagnosis is shaped not only by symptom complexity, but also by systemic limitations in referral pathways, inter-service communication, and access to specialist expertise.

2.5.2 Policy and Guidelines

Current NICE (2025) and ESC guidance (McDonagh *et al.*, 2023) provide a structured framework for diagnosing CM. These guidelines emphasise the role of biomarkers such as brain natriuretic peptide (BNP) and N-terminal pro-brain natriuretic peptide (NT-proBNP) in identifying suspected heart failure (HF). However, their relevance to CM diagnosis is debated, as BNP levels are often lower in patients with heart failure with preserved ejection fraction (HFpEF), potentially leading to missed diagnoses (Gevaert *et al.*, 2022; Rabkin and Tang, 2021). Factors such as obesity, prescribed medications, and ethnicity can also influence BNP levels, further questioning the reliability of BNP as a diagnostic marker for heart failure (McDonagh *et al.*, 2023) and its relevance in diagnosing CM specifically. Given that guidelines are primarily based on heart failure, their applicability to CM remains in question. A more tailored approach, integrating genetic testing and advanced imaging and diagnostic screening tools, may be necessary to improve diagnostic accuracy and ensure clinical guidelines align with the complexities of CM (Rozenbaum *et al.*, 2021; Seghda *et al.*, 2020). Although more specific cardiomyopathy guidance has since been produced (Arbelo *et al.*, 2023), it is not always considered alongside broader HF guidance within primary care and some secondary care services.

Healthcare policies also shape access to specialist services and diagnostic pathways. Policies governing genetic testing, for example, can influence referral patterns and the ability to screen for the early detection

of CM. Although genetic screening is recognised as an important tool for diagnosing inherited cardiomyopathies, access remains inconsistent, with variations in funding and policy implementation across health care systems (Alway *et al.*, 2024; Huang *et al.*, 2024). This suggests that policy-level guidance alone is insufficient if implementation remains variable and access to specialist pathways is inconsistent. Streamlining and standardising referral processes and ensuring that guidelines are reflective of the reality of diagnostic practice could help bridge the gap between policy and clinical practice.

2.6 Interpersonal Factors in the Diagnostic Process

2.6.1 Shared Decision-Making

Shared decision-making (SDM), rooted in the principles of patient-centred care, is being increasingly utilised in clinical practice and being included in cardiovascular clinical guidelines (McDonagh *et al.*, 2023; Arbelo *et al.*, 2023). Its purpose is to foster more equitable relationships between patients and their clinicians, by ensuring that clinical decisions are informed by the patient's individual needs, values, and health-related goals (Dennison Himmelfarb *et al.*, 2023). SDM values contributions by both clinicians and patients, with clinicians sharing relevant research and clinical expertise, and patients sharing their personal values, preferences and lived experience (Probst *et al.*, 2018).

Excellent patient care therefore considers patients and their families as core members of the care team, however, specific guidance on the use of SDM in CM, and the impact SDM has specifically on CM health outcomes, has yet to be fully explored (Dennison Himmelfarb *et al.*, 2023). Communication skills are central to the success of SDM, not just from clinicians but also from patients. SDM requires patients to be health literate, be able to comprehend complex medical information, able to articulate their needs and advocate for themselves. SDM may also require a shift in mindset and flexibility from both parties when viewpoints do not align (Dennison Himmelfarb *et al.*, 2023). Unique research authored by patients suggests that although priorities and viewpoints may differ, continued effective communication remains key to the success of SDM (Lamontagne, 2023).

2.6.2 Patient-Clinician Communication

Effective communication between patients and clinician is essential for fostering understanding and trust yet several barriers complicate this process (Lamontagne, 2023). Research has consistently highlighted that medical jargon, patient anxiety, and time constraints during consultations often impede clear communication (Danaher *et al.*, 2023). For example, studies have shown that patients frequently struggle to comprehend complex medical terminology, which can lead to confusion, less trust and more difficulty navigating shared decision-making (Vinson, 2016). This issue is particularly relevant in cardiology, where diagnoses and treatments often involve intricate details that patients may not easily grasp without clear explanations (Harris and Stefan, 2025). In addition to language barriers, patient anxiety and associated cognitive dysfunction can significantly affect communication, behaviour and engagement (Contrada, 2025). When patients are anxious, they may struggle to absorb information or feel overwhelmed during consultations, which can lead to reduced participation in decision-making (Villena *et al.*, 2025). This is compounded by the often time-limited nature of consultations, which may leave patients feeling rushed and unable to fully engage with their cardiologist (Shersher *et al.*, 2021). These constraints can result in important details being overlooked, and patients may feel excluded from discussions about their care.

To address these challenges, research has highlighted the importance of patient-centred communication techniques, such as the teach-back method. This approach involves clinicians asking patients to repeat key information in their own words to demonstrate their understanding and has been shown to improve patient engagement and comprehension (Denysyuk, Pires and Garcia, 2024). Furthermore, intentional non-verbal communication, such as eye contact and observing patients' body language, can enhance the clinician-patient relationship and make patients feel more comfortable and understood (Danaher *et al.*, 2023). Efforts are continuously being made to improve communication skills amongst clinicians, with contemporary digital training tools making training more accessible for greater numbers of clinicians (Harris and Stefan, 2025).

Despite these strategies, power dynamics between cardiologists and patients can create barriers to open communication. Cardiologists often hold significant authority in the diagnostic process, which may lead to patients feeling passive or disempowered, particularly if they perceive themselves as having less control over decisions related to their care (Chen, Croft and Currie, 2025). This power imbalance can impact the quality of communication, making it essential for clinicians to acknowledge and mitigate these dynamics by fostering a more collaborative approach (Clancy and Clancy, 2024).

2.6.3 The Impact of Uncertainty

As previously discussed, clinical communication plays a critical role in shaping how patients understand and engage with their condition. Uncertainty is a natural part of the diagnostic process, particularly in chronic and complex conditions such as cardiomyopathy (Taylor *et al.*, 2016; McGovern and Harmon, 2017). Even when a clear diagnosis is given, patients often fluctuate between moments of certainty and lingering doubts or worries about their prognosis and condition management (Jönsson *et al.*, 2021; Hess and Donnenwirth, 2022). This underscores the importance of clear, consistent communication from clinicians to minimise distress and support informed decision-making; however, this process is under-researched in relation to cardiomyopathy specifically.

The impact of uncertainty extends beyond immediate distress, influencing long-term outcomes such as psychological well-being, self-management, and quality of life (Chen *et al.*, 2018; Xia, Yu and Wu, 2022). Studies examining illness-related uncertainty have identified links between unclear diagnostic processes and adverse emotional responses, including depression and a reduced confidence in patients' ability to self-manage their chronic condition (Chen *et al.*, 2018; Xia, Yu and Wu, 2022). Adopting a communication style that focuses on transparency and collaboration may therefore improve both patients and clinicians' experience of shared decision-making and could improve clinical outcomes.

2.6.4 Emotional Support and Empathetic Care

A cardiac diagnosis can significantly disrupt a patient's sense of self, particularly when symptoms are vague or non-existent prior to diagnosis (Palmer, Bowles and Morphet, 2023). Many individuals hold deeply

ingrained beliefs about health, ageing, and illness, only to have these assumptions challenged by their new diagnosis. Asymptomatic heart failure, and HCM in particular, can remain undetected, reinforcing the misconception that serious illness must always present with obvious symptoms (Kosmala and Marwick, 2020; Ciarambino *et al.*, 2021). This disconnect can leave patients feeling overwhelmed and vulnerable, making emotional support an important part of promoting wellbeing post-diagnosis.

Studies have highlighted how chronically ill patients sometimes use metaphors that externalise their illness as an unpredictable or even threatening force (Piburn, 1999; Wohlmann, 2022). While this linguistic distancing can serve as a coping mechanism, it also suggests a need for clinicians to approach communication with empathy, acknowledging not just the medical realities of the disease but also its impact on identity that affects patients' daily lives.

2.7 Intrapersonal Factors Affecting Cardiologists and Patients

2.7.1 Cardiologists' Cognitive and Emotional Responses to Diagnosis

NHS staff morale has been in steady decline even before the COVID-19 pandemic and has only worsened since, with increasing burnout contributing to staff absences and low retention rates (Onyejesi, James and Kharicha, 2026). Within cardiology specifically, one study examined staff retention over a ten-year period (2010-2020) and found that 43% of staff who left the NHS during this time left for opportunities abroad, citing workload pressures, financial concerns, and the inability to maintain a work-life balance within the NHS (Crossland *et al.*, 2021). These systemic challenges, combined with the emotionally demanding nature of their role, contribute significantly to professional fatigue (West, Dyrbye and Shanafelt, 2018).

The emotional labour that is inherent to cardiology care has been widely recognised, with clinicians required to balance compassion with clinical detachment (Hochschild, 1983). Hochschild's concept of emotional labour has been applied to healthcare to describe the psychological effort required to manage both patient care and personal wellbeing (Darko, Bediako and Tawiah, 2023). Furthermore, cardiologists often experience moral injury, particularly when systemic constraints prevent them from delivering what they consider to be ethically appropriate care (Dean, Talbot and Dean, 2019). This was exacerbated during

the COVID-19 pandemic, when many clinicians were forced to make difficult triage decisions due to resource limitations, leading to distress and, in some cases, PTSD (Williamson *et al.*, 2021). British Medical Association (2021) has highlighted the extent to which a lack of clinical agency, insufficient resources, and witnessing substandard care contribute to this moral injury. The emotional toll of these pressures is reflected in high turnover rates and an increased prevalence of mental health conditions among physicians, including depression, anxiety, and suicide (Shanafelt *et al.*, 2019). Furthermore, moral distress, exacerbated by ongoing professional frustrations and burnout, has been linked to increased substance misuse among healthcare professionals (Ryan *et al.*, 2023a; Murri *et al.*, 2021). However, the stigma associated with seeking support means the extent of this issue is likely underreported (Gold, 2020). Cardiologists often work in high-pressure environments and hold significant clinical responsibility within services that are often constrained by systemic challenges (Nicholls, 2019). It is therefore critically important to illuminate the lived experience of people working within this professional field in order to better understand their needs.

2.7.2 Patients' Psychological and Emotional Responses to Diagnosis

A diagnosis of CM is life-altering, affecting not only physical health but also mental wellbeing (Stanca *et al.*, 2024). Research has recognised a clear bidirectional relationship between psychological distress and heart failure, with anxiety and depression both contributing to, and resulting from, cardiovascular disease (Stanca *et al.*, 2024). Despite this, access to psychological support within cardiac care remains inadequate (Collopy, Cosh and Tully, 2021; Thomas, Quilter-Pinner and Verma, 2020). Less than 24% of UK cardiac rehabilitation services had a permanent psychologist in 2018, and many patients report wanting to discuss their mental health but feeling unable to do so within their consultations (Doherty and Harrison, 2018).

The social and behavioural implications of poor psychological wellbeing further complicate patient outcomes (Thompson and Pedersen, 2023). Mental health conditions are associated with higher rates of substance misuse, lower levels of physical activity, and reduced adherence to medical advice, all of which

negatively impact cardiac health (Park and Oh, 2021). While cardiologists increasingly recognise the influence of psychological and social factors on physical health, the absence of integrated mental health services limits their ability to address these concerns effectively (Patel *et al.*, 2019). The lack of funding for psychological support within cardiology means that clinicians are often left managing the psychological aspects of their patients' conditions without the necessary training or resources (Burger *et al.*, 2020). Some have argued for routine mental health screening in cardiology settings, particularly at key intervention points such as post-diagnosis or following the implantation of cardiac devices, where patients are at greater risk of anxiety and depression (Celano *et al.*, 2018). However, a lack of funding and a broader prioritisation of physical health services have so far prevented widespread adoption (NHS England, 2019; Anderson, McGuire and Mossialos, 2025). The psychosocial implications of diagnosis on CM populations are not currently well-researched outside of the broader context of heart failure studies but could inform future provision in cardiomyopathy care.

2.7.3 Health Beliefs and Personal Factors

An increasing awareness of 'behavioural cardiology' has highlighted the complex interrelationship between mental health and cardiovascular health (Rozanski, 2017). Research has demonstrated both the direct biological effects of psychological distress on heart function and the indirect social and behavioural consequences that further impact cardiac health (Jilani *et al.*, 2021). However, the integration of mental health services into routine cardiology care remains limited (Thompson and Pedersen, 2023).

A key barrier to progress is the lack of training among cardiologists regarding mental health (Patel *et al.*, 2019). Many clinicians report not feeling equipped to address psychological concerns during consultations, particularly when formal psychological support services are either unavailable or difficult to access (Collopy, Cosh and Tully, 2021). Some have suggested that normalising discussions around psychological wellbeing within cardiology consultations could encourage greater uptake of psychological support by patients, but further research and an increased availability of psychology services is needed to substantiate these claims (Celano and Huffman, 2018). Cardiologists must balance the need to prioritise

their patients' cardiac health while recognising the wider social and psychological impact of a diagnosis (Burger *et al.*, 2020).

2.8 Identifying Gaps in the Literature

Despite being a critical component of the cardiomyopathy journey, the process of receiving a cardiomyopathy diagnosis remains an understudied area within the literature. Much of the existing research on cardiomyopathy focuses on clinical management, genetic predispositions, and long-term physical health outcomes, yet little attention has been paid to the lived experience of diagnosis itself. This diagnostic period is not merely a technical step in medical care but a pivotal moment in which patients begin to navigate their condition, form relationships with clinicians, and engage with the healthcare system in deeply personal ways. As Jeske, James and Joyce (2024) note, *"The diagnostic journey is an overlooked or bracketed period in the illness experience literature even though it may be when patients begin to test illness management strategies, develop relations with health-care providers and intimately interact with health-care institutions"* (Jeske, James and Joyce, 2024, p. 226). This gap in research leaves critical questions unanswered about how individuals perceive, process, and respond to their CM diagnosis experience on systemic, interpersonal, and intrapersonal levels.

2.8.1 Systemic-Level Gaps

While quantitative studies provide insight into diagnostic accuracy, prevalence, and systemic inefficiencies, qualitative research exploring the lived experiences of clinicians and patients navigating CM diagnosis within the NHS is lacking. Understanding the systemic challenges faced by healthcare professionals, including guideline adherence, resource limitations, and interprofessional dynamics, could lead to targeted policy revisions. Additionally, investigating patient perspectives on diagnostic delays, fragmented care, and accessibility issues could help shape more patient-centred approaches to CM management. Future research should prioritise these qualitative dimensions to bridge the gap between policy and practice, ensuring the development of more effective and timely diagnostic pathways for CM.

2.8.2 Interpersonal-Level Gaps

The importance of effective communication between clinicians and patients is being increasingly discussed, however significant gaps remain in understanding the nuances of emotional support and shared decision-making, particularly in cardiomyopathy contexts. Existing literature provides valuable insights into the barriers to achieving effective clinician-patient communication but does not address the interpersonal and emotional dimensions of these interactions specifically in the context of cardiomyopathy diagnoses. Future research should focus on understanding lived experience and the realities of these dynamics in practice in order to develop communication frameworks that considers emotional support, manages diagnostic uncertainty, and empowers patients to participate in shared decision-making.

2.8.3 Intrapersonal-Level Gaps

Despite growing recognition of the psychological dimensions of cardiovascular disease, there remains a notable gap in the literature regarding the psychological toll of diagnosing and managing CM from the perspective of both cardiologists and patients. Existing research has documented cases of burnout (Dominic, Gopal and Sidhu, 2021), moral injury (British Medical Association, 2021; Reis and Lesandrini, 2025) and emotional labour (Kim, Kim and Byun, 2020) among clinicians, particularly within the NHS where systemic pressures increase professional fatigue (Anderson, McGuire and Mossialos, 2025). However, specific studies examining the internal lifeworld of cardiologists when diagnosing CM, and the ways in which they process the emotional burden of delivering life-altering diagnoses, remain underexplored. The role of intrapersonal factors in shaping clinical decision-making and patient interactions warrants further investigation, as does the impact of these stressors on long-term professional wellbeing.

There is also an urgent need to understand how patients internally process receiving a diagnosis of a chronic cardiac condition and how their health beliefs, fears, and coping strategies evolve throughout their CM journey. Current studies focus predominantly on the broader context of heart failure, leaving the specific emotional and psychological burden of CM diagnoses underexplored. More research is needed to

assess whether patients' personal narratives during diagnosis and psychological responses to diagnosis, influence their engagement with treatment, their adherence to medical advice, and their overall disease management.

An additional gap in the literature is the lack of research on how cardiologists and patients navigate discussions about mental health in the context of CM diagnoses. While there is increasing recognition of the importance of integrating psychological support within cardiac care, the lack of formal training for cardiologists in addressing psychological concerns remains a barrier to effective communication and intervention. Further research is required to determine how cardiologists can be better supported in facilitating conversations about mental health and whether integrating routine psychological assessments at key intervention points, such as diagnosis, could improve patient outcomes.

2.9 Chapter summary

Overall, addressing these research gaps is crucial for improving both clinician wellbeing and patient care. A more nuanced understanding of the internal narrative that unfolds during CM diagnosis, both for the diagnosing cardiologist and the patient receiving the diagnosis, could inform targeted interventions aimed at reducing psychological distress, improving communication, and enhancing overall care quality.

3. Methodology

3.1 Chapter Introduction

Building on the literature review presented in Chapter 2, this chapter outlines the philosophical and methodological foundations of the research. Adopting an interpretivist, phenomenological approach, the research explores the lived experience of cardiomyopathy diagnosis from both patient and cardiologist perspectives. This chapter presents the ontological and epistemological assumptions guiding the study, evaluates the suitability of alternative theoretical perspectives and methodologies, and justifies the use of interpretative phenomenological analysis (IPA).

The structure of this chapter is informed by Michael Crotty's (1998) framework of four key elements of research design: epistemology (and ontology), theoretical perspective, methodology, and methods. As illustrated in Figure 5, this chapter focuses on the first three elements, while the final element, 'methods', is addressed in Chapter 4. This provides a clear framework for situating the study's philosophical assumptions and methodological choices.

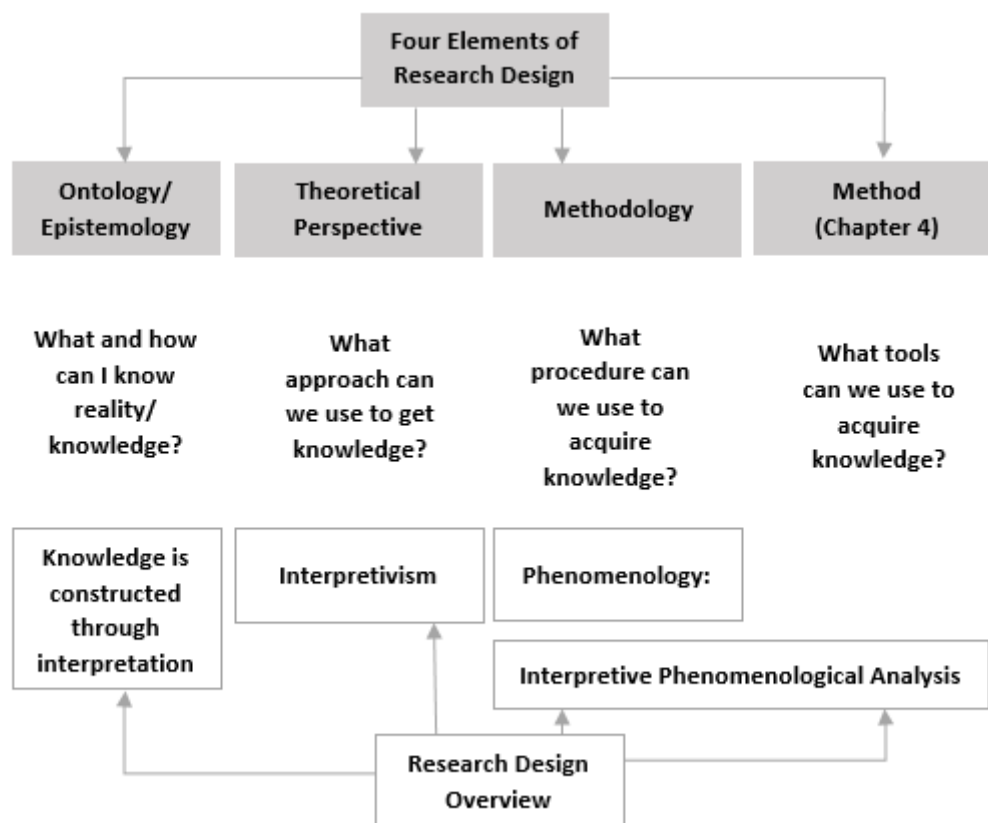


FIGURE 5. DEFINITION OF TERMINOLOGY AND OVERVIEW OF RESEARCH DESIGN - ADAPTED FROM CROTTY (1998) AND PATEL (2015).

3.2 Ontology and Epistemology

When designing the study, consideration was given to my own philosophical position and beliefs. Through my personal experience with cardiomyopathy (CM), alongside my work with the charity, *CardiomyopathyUK*, I had witnessed how differently people experienced and made sense of a CM diagnosis, with individuals describing markedly different meanings, impacts, and interpretations of what the diagnosis represented in their lives. This led me to adopt a relativist ontological position, where reality is understood as subjective and shaped by individual experience, rather than fixed or uniformly experienced (Crotty, 1998; Willig and Rogers, 2017). The idea of a single objective reality did not reflect what I had observed in practice.

Epistemologically, the study aligned with an interpretivist position, which assumes that knowledge is co-constructed through interaction between researcher and participant (Willig and Rogers, 2017; Smith, Flowers and Larkin, 2009). The aim was therefore not to identify a single account of the diagnostic process, but to explore how individuals understood and made sense of their experiences.

This combination of a relativist ontology and an interpretivist, emic epistemology provided the foundation for the study, supporting an in-depth exploration of lived experience while acknowledging both the subjectivity of participants' accounts and my role in interpreting them.

3.3 Theoretical Perspective

A theoretical perspective, sometimes referred to as a research paradigm, reflects a set of philosophical assumptions about the nature of reality (ontology), how knowledge is generated (epistemology), and the approaches used to investigate it (methodology) (Lincoln and Guba, 1985; William, 2024). These perspectives provide a framework for understanding the research process, shaping the study's design, aims, and the type of knowledge that is ultimately produced. Within health research, differing ontological and epistemological positions enable more nuanced understandings of complex phenomena, with each perspective offering distinct ways of conceptualising experience, meaning, and the role of the researcher.

In the current study, the theoretical perspective was determined through consideration of both the research aims and my own positioning within the research process, grounded in a relativist ontology and an emic epistemology. This required consideration of a range of approaches, each underpinned by different philosophical assumptions and analytic priorities ((Willig and Rogers, 2017; Braun and Clarke, 2025). These theoretical perspectives, and their suitability for addressing the research aim, are summarised in Table 2 below.

TABLE 2. COMPARISON OF THEORETICAL PERSPECTIVES AND THEIR SUITABILITY - ADAPTED FROM PATEL (2015). BASED ON EARLIER WORKS OF CROTTY (1998).

THEORETICAL PERSPECTIVE	ONTOLOGY	EPISTEMOLOGY	RESEARCH FOCUS	TYPICAL RESEARCH APPROACH	STRENGTHS	LIMITATIONS FOR CURRENT STUDY	OVERALL FIT
POSITIVISM	Single, objective reality	Knowledge is observable, measurable, and independent of the researcher	Explanation, prediction, causality	Quantitative, experimental, hypothesis-testing	Strong for measurement, objectivity, and generalisability	Does not adequately capture subjective experience, meaning, or context	Poor fit
PRAGMATISM	Reality may be singular or multiple, depending on the question	Knowledge is judged by usefulness and practical consequences	Problem-solving and action-oriented inquiry	Mixed methods: “what works” approach	Flexible and practical; useful for applied research	The current study was exploratory rather than action-oriented and did not aim to generate solutions or interventions	Partial fit
CRITICAL THEORY	Reality is shaped by historical, social, and political structures	Knowledge is used to critique and challenge power and inequality	Emancipation, critique, and social change	Qualitative, participatory, critical inquiry	Useful for examining power, systems, and inequality	The study focused more on understanding lived experience than on critiquing or transforming wider social structures	Partial fit
CONSTRUCTIVISM	Multiple realities constructed through interaction	Knowledge is actively constructed through social engagement	Meaning-making processes	Qualitative, interpretive inquiry	Captures subjectivity and context	Greater emphasis on how meaning is constructed than on interpreting the meanings of a specific lived experience	Partial fit
INTERPRETIVISM	Multiple, subjective realities	Knowledge is co-constructed between researcher and participant	Understanding lived experience and subjective meaning	Qualitative, interpretive inquiry	Emphasises depth, context, and meaning	Limited generalisability and relies on interpretation	Strong fit

Positivist approaches, while historically dominant in healthcare research (Bonell *et al.*, 2018; Chalmers and Cowdell, 2021), prioritise objectivity, measurement, and causal explanation. However, this emphasis limits their capacity to capture subjective meaning and the complexity of lived experience (Pyo *et al.*, 2023), making them unsuitable for the aims of the current study.

Pragmatism offers a more flexible alternative, emphasising the use of methods that best address the research question (Feilzer, 2023). While this approach has practical value, particularly within applied

healthcare research, it is typically aligned with outcome-focused or intervention-driven inquiry. The current study, by contrast, was exploratory in nature and sought to develop a deeper understanding of lived experience rather than generate practical solutions. As such, pragmatism was considered only partially aligned with the study aims.

Researcher's Reflection:

In practice, some elements of the study were shaped by pragmatic decision-making, particularly the use of a quantitative questionnaire to support the identification of a diverse interview sample. This decision was driven by what was most effective for recruitment rather than strict adherence to a single methodological tradition. My personal ideology also aligned with Dewey's (1941) notion that experience, beliefs and actions are cyclical.

However, upon reflection, pragmatism was not fully aligned with the aims of the study. Pragmatic inquiry is typically oriented toward problem-solving and action, involving the identification of an issue and the development of practical solutions (Morgan, 2014). In contrast, the current research was exploratory in nature and did not seek to define or resolve a specific problem within the cardiomyopathy diagnosis process. Instead, the focus was on developing a richer understanding of lived experience, particularly in an area where existing research remains limited. While the findings may inform future applied or intervention-based research, generating action was not the primary aim. Pragmatism was therefore considered only partially aligned and not adopted as the overarching framework.

Critical theory, originating from the Frankfurt School (Horkheimer, 1947), focuses on critiquing and challenging the social, political, and historical structures that shape human experience (Crossman, 2024). While aspects of power and relational dynamics were relevant to the current study, particularly within clinician–patient interactions (Brown *et al.*, 2023; Pilgrim, 2015), the primary aim was not to critique or transform social structures but to understand individual experience. Critical theory was therefore not adopted as the overarching framework.

In contrast, interpretivist and constructivist perspectives both recognise that reality is subjective and constructed through experience (William, 2024). While closely related, constructivism places greater emphasis on how meaning is constructed through interaction, whereas interpretivism focuses more directly on understanding the meanings individuals attribute to their experiences (Tanlaka and Aryal, 2025; William, 2024). Interpretivism was therefore selected as the overarching paradigm, as it most directly supports the

exploration of subjective meaning and lived experience, which are central to the research aim. This perspective also aligns with the study's emphasis on co-construction of meaning between researcher and participant and the importance of reflexivity within the research process (Smith, Flowers and Larkin, 2009; Ugiagbe *et al.*, 2025). This felt particularly relevant given the variability in how individuals experience and interpret a cardiomyopathy diagnosis.

Although interpretivist approaches are sometimes criticised for limited generalisability and potential researcher bias (Alharahsheh and Pius, 2020; Pathak and Thapaliya, 2022), such critiques often reflect positivist assumptions about knowledge production. Within qualitative research, reflexivity and transparency are used to acknowledge and manage researcher influence, rather than eliminate it (Buetow and Zawaly, 2022). Strategies used to ensure rigour and trustworthiness in the current study are discussed in Chapter 4. This interpretivist positioning directly informed the selection of a phenomenological methodological approach, which is further explored within this chapter.

3.4 Paradigmatic Compatibility

A further consideration when determining the theoretical orientation of this study was the inclusion of a quantitative participant identification tool within an otherwise qualitative, interpretivist design. This raised questions about whether these approaches could sit comfortably alongside one another from a paradigmatic perspective.

Historically, methodological purists have argued that qualitative and quantitative paradigms are underpinned by fundamentally incompatible ontological and epistemological assumptions (Liu, 2022). However, more recent perspectives take a more flexible view, suggesting that combining approaches can be appropriate when guided by the research aim rather than strict adherence to a single philosophical position (Della Porta, 2024). Within this more pragmatic stance, coherence is maintained so long as the overall analytic framework remains grounded within a clearly defined paradigm.

In the current study, interpretivism remained the primary theoretical orientation, with interpretative phenomenological analysis (IPA) guiding both data collection and analysis. The quantitative component did

not function as a separate methodological approach but instead acted as a practical tool to support participant identification and sampling for the patient interview phase. It therefore did not alter the interpretivist foundation of the study nor the interpretative nature of the findings.

Phenomenological approaches themselves are always evolving, and there has been increasing recognition of designs that incorporate supplementary quantitative elements to support qualitative enquiry. In particular, 'quan-PHEN' and 'PHEN-quant' sequential designs have grown in popularity (Mayoh, Thompson and Davis, 2023; Toyon, 2021). These approaches remain fundamentally phenomenological but use quantitative data to help build a broader picture of the phenomenon being studied. This can be especially helpful in relatively underexplored populations, where preliminary quantitative data can support the identification of participants who are best able to offer rich, detailed accounts (Mayoh, Thompson and Davis, 2023; Mayoh and Onwuegbuzie, 2015).

In this study, the participant identification tool also served as a form of phenomenological orientation, helping to highlight variation within the patient population prior to more in-depth qualitative exploration (Greene, Caracelli and Graham, 1989; Morgan, 1998). While phenomenology enables detailed examination of individual experience, it does not inherently provide a means of identifying which experiences may be most relevant across a wider group. The inclusion of a preliminary quantitative phase therefore supported a more informed and purposeful selection of participants, without compromising the interpretivist and phenomenological integrity of the study.

Researcher's Reflection:

In relation to the current study, I decided that phenomenological orientation was of particular importance when it came to the patient participants. Due to our shared experience as CM patients and my prior knowledge of CM, I was aware that my own agenda and experience may subconsciously direct the research focus if steps were not taken to mitigate this risk. I was diagnosed with CM during childhood and although I have some level of shared understanding with the patient participants in the study, my own views could not reflect the views of those diagnosed in adulthood. Therefore, a quantitative participant identification tool, used to broadly identify experiences relevant to the patient population being studied, was not only justified as a means of phenomenological orientation and participant identification, but a necessary guard against bias.

3.5 Methodology

Interpretivist research encompasses a range of methodological approaches that aim to explore how individuals make sense of their experiences (Alharahsheh and Pius, 2020; Van der Walt, 2020). When selecting an appropriate methodology, it was important to consider not only procedural differences, but also the extent to which each approach aligned with the study's focus on lived experience. Several interpretivist methodologies were considered, including ethnography, grounded theory, discourse analysis, and phenomenology. A comparative overview of these approaches and their suitability to the current study is presented in Table 3.

TABLE 3. COMPARING INTERPRETIVIST METHODOLOGICAL APPROACHES AND SUITABILITY TO CURRENT STUDY - ADAPTED FROM STARKS AND BROWN TRINIDAD (2007).

METHODOLOGY	PRIMARY FOCUS	DATA/APPROACH	STRENGTHS	LIMITATIONS FOR CURRENT STUDY	SUITABILITY
ETHNOGRAPHY	Cultural practices and shared meanings within groups	Prolonged immersion, observation, fieldwork	Rich contextual insight; captures social processes	Requires access to early-stage diagnostic settings; focus on culture rather than individual experience	Limited
GROUNDED THEORY	Development of explanatory theory	Iterative data collection and constant comparison	Generates theory grounded in data; flexible design	Aims to produce theory rather than explore lived experience	Limited
DISCOURSE ANALYSIS	Language and construction of meaning through discourse	Analysis of spoken/written communication	Illuminates power, communication, and social norms	Focuses on language rather than holistic experience	Partial
PHENOMENOLOGY	Lived experience and meaning-making	In-depth interviews; interpretative analysis	Captures depth, meaning, and subjective experience	Does not inherently identify variation across populations	High

As summarised in Table 3, ethnography and grounded theory were not well aligned with the research aim. Ethnography prioritises cultural immersion, which was neither feasible nor central to the focus of this study, while grounded theory was oriented towards the development of explanatory theory rather than the exploration of experience. Discourse analysis offered some relevance in understanding communication

within the diagnostic process, but its primary focus on language limited its applicability to the broader experiential focus of the research aim.

Phenomenology provided the strongest alignment with the research aim as it focused on exploring how individuals experienced and made sense of a particular phenomenon (Neubauer, Witkop and Varpio, 2019). Given the study's focus on the lived experience of cardiomyopathy diagnosis, this approach offered the most appropriate methodological foundation. Phenomenology has been defined as *"an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it"* (Neubauer, Witkop and Varpio, 2019, p. 91). The goal of phenomenological inquiry is to understand both what it was like and how it was experienced (Van Manen and Van Manen, 2021; Williams, 2021). Central to this approach is an idiographic commitment, whereby individual accounts are explored in depth before considering shared patterns across participant groups. This allowed meaning to be understood within the specific context of each person's experience, rather than assumed to be universal.

A key concept within phenomenology is bracketing, whereby the researcher attempts to suspend prior assumptions in order to attend closely to participants' accounts (Sass, 2021). However, the feasibility of fully bracketing one's own perspective has been widely debated (Sass, 2021; Crotty, 1996; Raphael, 2023). In practice, bracketing is often understood not as the elimination of bias, but as an ongoing process of reflexive awareness (Creswell and Creswell, 2017; Fischer and Guzel, 2023). Again, this was viewed to be particularly relevant to the current study, given my own positionality as a researcher and cardiomyopathy patient.

Whilst a number of phenomenological approaches exist, this study draws primarily on transcendental and hermeneutic traditions, as these are often considered the broadest and most influential approaches within phenomenological research (Khatri, 2022) and together form the philosophical foundation for interpretative phenomenological analysis (IPA).

Hermeneutic phenomenology shifts the focus from description to interpretation. Influenced by Heidegger (1962), this approach emphasises the role of context in shaping experience, particularly through the

concept of the individual's socially and historically situated understanding of reality, or their 'lifeworld' (Neubauer, Witkop and Varpio, 2019). From this perspective, individuals cannot be separated from their lifeworld, as their experiences are shaped by prior knowledge, relationships, and cultural context (Galanti Grollo, 2022). Meaning is therefore not simply described but interpreted, both by the participant and the researcher.

This aligns closely with an idiographic approach, as understanding is rooted in each individual's account, situated within their own unique context rather than assumed to reflect a universal experience. In contrast to Husserl's notion of bracketing, Heidegger argued that it is not possible to fully set aside one's own perspective. Instead, the researcher engages reflexively with their own assumptions, acknowledging their role in the interpretative process (Neubauer, Witkop and Varpio, 2019). Hermeneutic inquiry therefore recognises meaning as co-constructed and context dependent. This approach positioned my personal experience and researcher positionality as important context that can uniquely contribute to the development of new knowledge rather than limit it.

These philosophical positions underpin interpretative phenomenological analysis (IPA), which explicitly integrates phenomenological exploration, hermeneutic interpretation, and an idiographic commitment to analysing individual cases in depth before identifying patterns across participants (Smith, Flowers and Larkin, 2009). Further justification for the use of IPA is outlined below.

3.6 Interpretative Phenomenological Analysis

In determining the most appropriate phenomenological approach to adopt for this research, I first considered the broader purpose of the research. The over-arching research question: '*what are cardiologists' and patients' experiences of the cardiomyopathy diagnosis process?*' lends itself to a phenomenological approach concerned with lived experience. Given the differing perspectives of cardiologists and patients, analysis needed to remain grounded within each participant's lifeworld. Although hermeneutic phenomenology developed from transcendental phenomenology, these phenomenological approaches differ in their emphasis on description and interpretation, and neither is

considered inherently superior (Neubauer, Witkop and Varpio, 2019; Squires, 2023). I therefore used the decision tree outlined in Figure 6, adapted from original version in Ismail and Kinchin (2023) to consider the alignment of the purpose of the research and found it to align most with that of interpretative phenomenological analysis. Pietkiewicz and Smith (2014) recognised that interpretative phenomenological analysis (IPA) draws upon both transcendental and hermeneutic traditions, “...resulting in a method which is descriptive because it is concerned with how things appear and letting things speak for themselves, and interpretative because it recognizes there is no such thing as an uninterpreted phenomenon” (Pietkiewicz and Smith, 2014, p. 8).

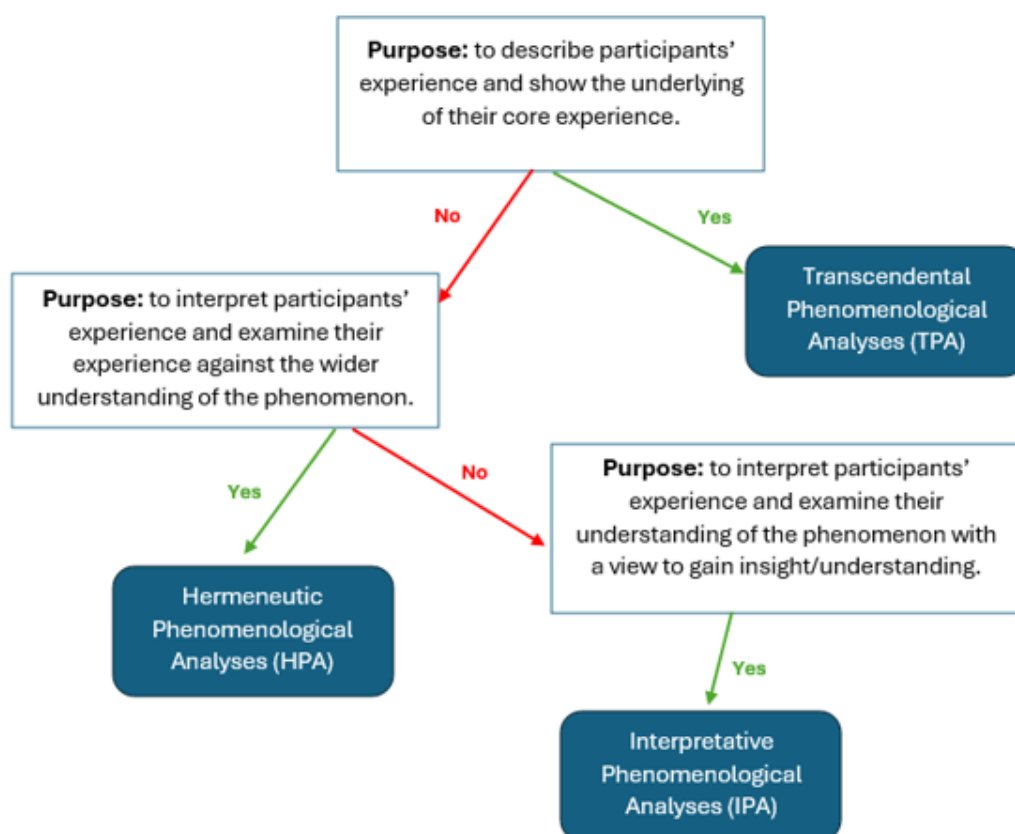


FIGURE 6. PHENOMENOLOGICAL APPROACH DECISION TREE - ADAPTED FROM ISMAIL AND KINCHIN (2023).

To confirm this decision, I further considered the other differences between the three phenomenological approaches (Table 4). IPA is based on the assumption that people are ‘self-interpreting beings’ (Bordogna,

2021; Heidegger, 1962), actively engaging with, and interpreting, the world around them. This assumption that individuals actively interpret their experiences aligned closely with the aims of the current study.

TABLE 4. COMPARING THREE PHENOMENOLOGICAL APPROACHES TO QUALITATIVE INQUIRY - ADAPTED FROM SIMILAR TABLES FOUND IN MILLER, CHAN AND FARMER (2018) AND BACHKIROVA, ROSE AND NOON (2020).

	<i>IPA</i>	<i>Transcendental</i>	<i>Hermeneutic</i>
History	Experiential qualitative approach in health psychology; integrates phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009)	Rooted in Husserl's philosophy of consciousness (Husserl, 1965)	Rooted in existential philosophy and interpretation (Heidegger, 1962)
Philosophy	Reality is interpreted; focus on how individuals make sense of experience within context (Smith, Flowers and Larkin, 2009)	Assumes an essential structure of experience that can be uncovered through bracketing (Lopez and Willis, 2004)	Reality is always interpreted; meaning is shaped by context and lifeworld (Lopez and Willis, 2004)
Goal	To interpret how participants make sense of their experience (double hermeneutic) (Smith, Flowers and Larkin, 2009)	To describe the universal 'essence' of a phenomenon (Lopez and Willis, 2004)	To interpret the meaning of lived, embodied experience (Starks and Brown Trinidad, 2007)
Research Question	"How does this person make sense of this experience in this context?" (Larkin and Thompson, 2012)	"What is the essential structure of this experience?" (Lopez and Willis, 2004)	"What is the meaning of this lived experience?" (Starks and Brown Trinidad, 2007)
Participants	Small, purposive, relatively homogeneous sample with shared experience (Smith, Flowers and Larkin, 2009)	Individuals who have experienced the phenomenon	Individuals who have experienced the phenomenon
Data Collection	Semi-structured interviews; flexible, guided by researcher and participant meaning making (Smith, Flowers and Larkin, 2009)	Semi-structured interviews; researcher aims to bracket assumptions; may include member checking	Semi-structured interviews; researcher engages interpretatively with data
Analytic Approach	Idiographic, case-by-case analysis → emergent themes → cross-case patterns; descriptive and interpretative (Smith, Flowers and Larkin, 2009)	Thematic description of experience; identification of meaning units → essence of phenomenon	Interpretative analysis using hermeneutic circle; no single prescribed method
Role of Researcher	Active, reflexive interpreter; meaning co-constructed with participant (Larkin and Thompson, 2012)	Researcher attempts to bracket assumptions to minimise influence (Lopez and Willis, 2004)	Researcher's perspective acknowledged; interpretation shaped by both participant and researcher

Smith, Flowers and Larkin (2009) describe how IPA is informed by concepts and debates from three key philosophies of knowledge: phenomenology, hermeneutics and idiography. Each of these theoretical approaches contribute to IPA's distinctive epistemological framework and research methodology and will be further explored below in relation to the current research study.

3.6.1 Phenomenology

As discussed, Husserl's (1965; 1977) phenomenology aimed to identify the unique or distinguishable components of a phenomena or experience, from the participants' perspective. Phenomenological studies therefore focus on participants' perceptions of the phenomena or experience rather than the phenomena itself. Husserl argues it is necessary for researchers to take a step back from their 'natural attitude' of unilateral and unreflective thinking in order to take on a more 'phenomenological attitude', whereby the world around them is examined and reflected upon, rather than just witnessed. This aligned well with the aims of the study as the focus was not on the diagnosis itself but rather how consultant cardiologists and adult patients experienced the diagnostic journey.

Husserl (1977; 1931) further suggested that shifts in attitude are achieved through a methodical process of 'phenomenological reduction' or 'bracketing', whereby prior assumptions of the researcher are set aside in order to attend closely to participants' accounts (Sass, 2021). Whilst I agreed with this notion in principle, the assumption that interpretation could occur independent of the interpreter did not align with the interpretivist framework adopted in this study. Although I agreed that the primary focus was, and should have been, the lived experience of the participants within their individual worldview, I adopted a more Heideggerian, interpretative stance to analysis. This reflected the view that interpretation could not be fully separated from the interpreter, as understanding was always shaped by prior experience, context, and positioning. Within qualitative health research, this position has been widely recognised, particularly in studies exploring complex and emotionally significant experiences, where meaning was not simply reported but actively constructed and negotiated (Smith, Flowers and Larkin, 2009).

In practice, this meant engaging reflexively with the data throughout the analytic process (outlined in Chapter 4). This approach supported a co-constructed understanding of the data, whereby meaning was developed through an iterative engagement between participant accounts and researcher interpretation. In the context of the current study, this was particularly important given my prior knowledge and personal

connection to cardiomyopathy, ensuring that interpretation remained grounded in participants' accounts while recognising the active role of the researcher in interpreting these experiences.

3.6.2 Hermeneutics

Building on the work of Husserl, Heidegger (1962) offered an interpretative approach to phenomenology, emphasising that lived experience is always situated within a particular temporal and contextual framework (Smith, Flowers and Larkin, 2009). IPA aligns itself with the Heideggerian view that phenomenological inquiry is primarily an interpretative process (Bordogna, 2021). Heidegger views phenomenology as a process by which meaning is uncovered or revealed through interpretation (Shinebourne, 2011).

An important feature of IPA is recognition that there are multiple layers of interpretation, which Heidegger refers to as 'double hermeneutics' (Tomkins and Eatough, 2013). In contrast to some other qualitative approaches, when conducting IPA research both the participants' and the researcher's interpretation of the phenomena are considered. This layered interpretation enables engagement with both participant meaning making and the researcher's interpretative role (Smith, Flowers and Larkin, 2009; Ugiagbe *et al.*, 2025). Considering my positionality as the researcher and the multiperspective design of the study, acknowledging the multiple layers of interpretation that would contribute to the understanding of the whole cardiomyopathy diagnostic experience, felt particularly relevant and important.

The 'hermeneutic circle' refers to a process of interpretation and reflection whereby knowledge is built up over time by considering each part individually in order to better understand the whole (Smith, Flowers and Larkin, 2009). As each individual part is examined, prior interpretations are expanded, and a greater depth of understanding is achieved about the phenomenon as a whole.

Researcher's Reflection:

The 'hermeneutic circle' is a challenging concept to communicate and explain via typed words on a page. The way I visualise the hermeneutic circle is not as a circle but more of a spiral staircase. If you consider this in the context of analysing a transcript using IPA: You read each line of a transcript word by word, describing, interpreting and analysing as you go. Each line offers new insight into the experience of the participant. With each line, or 'part', your understanding of the participant's experience as a whole expands. A phrase that was read and interpreted on page one, may take on new meaning as you read on throughout the transcript. Imagine that with each line you read, you take another step up on the staircase. Although there is arguably a limitless number of stairs, as you could read and re-read the transcript an infinite number of times, once you reach the top of the staircase (or the end of the analysis process, wherever that may be), you have achieved a higher level of understanding than when you started. Therefore, I argue that a circle is not appropriate, as you do not return to where you started, but rather you spiral to higher levels of understanding and reflection through the dynamic and iterative process of interpretation.



3.6.3 Idiography

The term idiography was first introduced by German philosopher Wilhelm Windelband (1998). Idiographic knowledge describes knowledge of a unique event, entity or trend, whilst nomothetic knowledge describes knowledge of general laws (Shinebourne, 2011). Idiographic research therefore prioritises in-depth understanding of individual experience and is central to IPA's analytic approach and the aims of the current study (Smith, Flowers and Larkin, 2009).

3.6.4 Positioning IPA within Phenomenology

The positioning of IPA within phenomenology has been subject to debate (Smith, 2018; Zahavi, 2019; Van Manen, 2017). Critics have questioned whether IPA aligns with traditional phenomenological principles (Van Manen, 2017; Zahavi, 2019), while proponents argue that its focus on lived experience and

interpretation is consistent with hermeneutic traditions (Smith, 2018). These debates reflect broader tensions within qualitative research regarding methodological boundaries and philosophical purity.

In the context of the current study, IPA's integration of phenomenological, hermeneutic, and idiographic principles provided a coherent framework for exploring lived experience within applied health research. Its emphasis on meaning-making, reflexivity, and contextual interpretation aligned closely with both the research aims and epistemological position. IPA was therefore considered the most appropriate methodological approach.

3.7 Chapter Summary

This study adopted a phenomenological approach, with a central focus on exploring individual lived experiences of the cardiomyopathy diagnosis process. It was underpinned by hermeneutic and idiographic principles, prioritising in-depth understanding of individual perspectives rather than seeking to generate generalisable claims about the phenomenon. Interpretative phenomenological analysis was identified as the most appropriate method of data analysis, given its integration of phenomenological, hermeneutic, and idiographic foundations. This approach enabled a detailed and contextually grounded exploration of how participants made sense of their diagnostic experiences within their individual life-worlds.

The findings generated through this study do not represent a singular or exhaustive account of cardiomyopathy diagnosis. Instead, they offer a nuanced insight into the personal experiences of a small number of individuals across differing perspectives, each contributing to a broader understanding of the phenomenon.

Overall, this study contributed to a more in-depth understanding of how the cardiomyopathy diagnosis process is experienced in practice, providing a foundation for future research and potential developments in clinical understanding and service provision. The following chapter sets out how data were collected and analysed in practice, showing how this methodological approach was applied within the study.

4. Method

4.1 Chapter Introduction

To ensure the trustworthiness of the findings, it is important to clearly outline how data were collected and analysed, demonstrating a transparent and rigorous research process (Johnson, Adkins and Chauvin, 2020). This chapter describes the practical steps taken at each stage of the research (Figure 7). It begins by outlining the ethical considerations of the study, before detailing the process of data collection and analysis using Interpretative Phenomenological Analysis (IPA), and the steps taken to ensure rigour throughout.

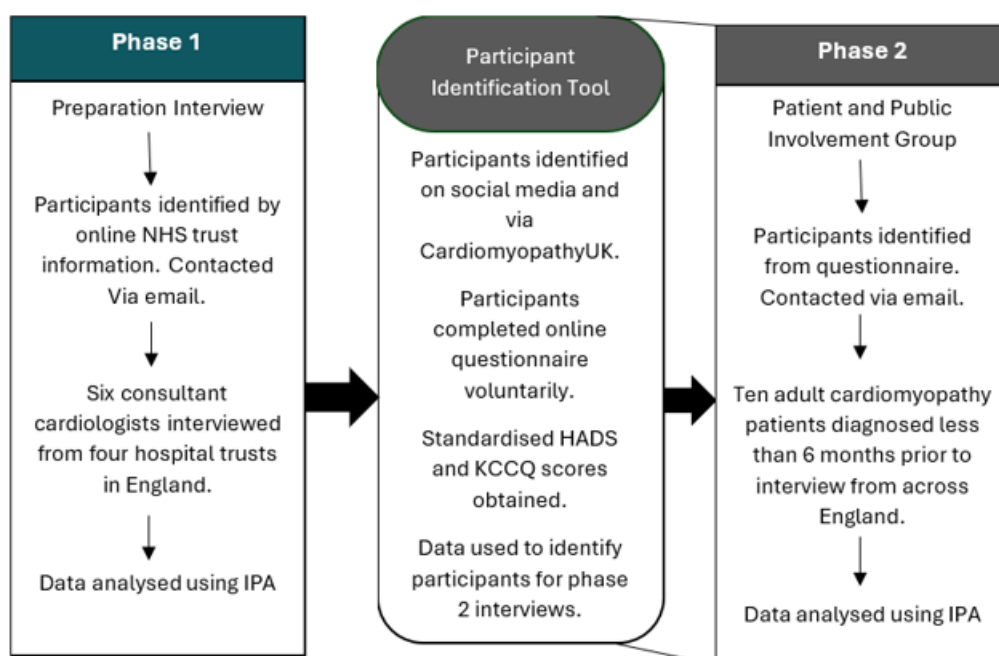


FIGURE 7. OUTLINE OF STUDY PHASES DETAILED WITHIN THIS CHAPTER.

4.2 Research Ethics and Governance

Ethical considerations informed the design and conduct of this research. The study followed guidance from the Health Research Authority (HRA), the British Psychological Society (BPS), and the university's code of practice. NHS ethical and governance approvals were obtained for all phases of the study. Full ethical approval was granted by the HRA on 7th June 2017, with subsequent governance approvals ratified on 16th June 2017 (REC no. 17/NI/0099). Evidence for this can be found in Appendix 1.

4.2.1 Minimising Harm

Given the sensitive nature of the research topic, some level of participant distress was anticipated. This was particularly relevant for patient participants who had recently received a cardiomyopathy diagnosis, where discussing their experiences may have brought existing fears or concerns into focus. Participation also offered an opportunity for reflection, which some individuals may have experienced as beneficial.

To manage potential distress, a protocol was established prior to data collection. If a participant became distressed during an interview, the discussion (and any recording) would be paused, and the participant reminded of their right to withdraw or end the interview at any point. All participants were also provided with information about relevant support services, including cardiomyopathy-specific charities, at the end of each study phase.

Researcher's Reflection:

One patient interview highlighted the complexity of managing distress within the research process. During the interview, the participant became visibly upset, and the distress protocol was implemented. The recording was paused, time was given for the participant to recover, and she was reminded of her right to withdraw. She chose to continue, explaining that the interview had provided an opportunity to express feelings about her diagnosis that she had not previously been able to articulate. She reflected that, within this space, she did not feel the need to minimise her experience or present herself in a particular way.

This experience prompted reflection on the role of emotional discomfort within qualitative research. While distress is typically viewed as something to be minimised, this interaction suggested that, in some cases, it may also reflect meaningful engagement with difficult experiences. However, this does not imply that distress is inherently beneficial or that it should be encouraged. Rather, this example highlighted the importance of carefully balancing participant welfare with the potential value of providing space for open reflection, ensuring that participants remain in control over their level of engagement throughout.

4.2.2 Confidentiality

Maintaining confidentiality and protecting participants' privacy were key ethical considerations (British Psychological Society, 2021). All identifiable data were removed from interview transcripts and analysis documents, and participants were assigned pseudonyms. Data were accessible only to the research team.

For the online questionnaire, participants were asked to provide an email address if they wished to be considered for interview. While this meant full anonymity was not possible at this stage, contact details were used solely for recruitment purposes and were deleted if participants were not interviewed.

Recruitment of clinicians required additional consideration. Where initial contact via NHS Research and Development departments was unsuccessful (as will be discussed in section 4.3 below), clinicians were approached via email using publicly available contact details, in line with BPS guidance regarding the use of information in the public domain (British Psychological Society, 2021). Interviews with clinicians were conducted in private settings to ensure confidentiality. Patient interviews took place in locations chosen by participants, typically their home, workplace, or a quiet public setting, balancing participant comfort with privacy.

4.2.3. Consent

Informed consent was obtained from all participants prior to their involvement in the study. A detailed information sheet outlined the purpose of the research, what participation would involve, and participants' rights, including the right to withdraw.

For the online questionnaire, the information sheet and consent form were embedded within the first pages of the questionnaire, alongside eligibility screening questions. For interviews, written consent was obtained in advance, with verbal consent reconfirmed at the start of telephone and in-person interviews.

4.2.4 Data Security

All data were handled in accordance with data protection guidelines. Audio recordings and raw data files were stored on a password-protected, encrypted device and deleted following completion of the analysis. Hard copies were stored in a locked cabinet within a secure office and retained for five years in line with university policy.

Interview recordings were transcribed by a university-approved professional transcriber, who signed a confidentiality agreement. Files were shared via a secure transfer system. Participants were informed that anonymised extracts from their interviews may be used in the thesis and related publications.

4.2.5 Lone Worker Policy

A lone worker policy was implemented in line with university safety procedures, as data collection involved travelling to interview participants across different locations, including private homes. A buddy system was used, whereby a designated member of the research team was informed of the time and location of each interview and expected completion time. Check-ins were conducted at the start and end of each interview.

On occasions where interviews overran, the buddy contacted the researcher to confirm safety. While this resulted in a brief interruption during one interview, the participant understood the need for these precautions. This approach ensured researcher safety while maintaining participant comfort and continuity of the interview.

4.3 Patient and Public Involvement

Patient and public involvement (PPI) is widely understood to enhance the quality and relevance of health research by ensuring that study design and materials reflect the perspectives of those with lived experience (Aiyegbusi *et al.*, 2023). In the context of this study, which aimed to explore lived experiences of cardiomyopathy diagnosis, PPI was used to inform the development and accessibility of research materials and to inform the interview topic guides.

A small PPI group was convened, consisting of four cardiomyopathy patients and two volunteers from *CardiomyopathyUK*. These individuals were identified through existing contacts with the charity and invited to provide feedback on study materials. Four contributors responded and reviewed documents remotely due to geographical spread. In addition, research materials were reviewed by the 'Service User for Research Endeavour' (SURE) group at Liverpool Heart and Chest Hospital prior to ethical submission.

Feedback from these groups informed several practical revisions. Participant information sheets were reformatted into PDF documents to improve accessibility across devices, and QR codes were added to recruitment materials to facilitate easier access to the online participant identification tool. The cardiomyopathy-specific group were further asked to review the interview topic guide for patient interviews to ensure questions and prompts were appropriately worded and considered. Within written materials contributors highlighted issues with formatting, such as font size and spacing, and identified areas where technical language and acronyms required simplification. These changes were incorporated into the final materials, resulting in documents that were more accessible, user-friendly, and appropriate for the target population. *CardiomyopathyUK* played a significant role in facilitating patient recruitment and increasing visibility of the study within CM communities. This support was invaluable in accessing a geographically dispersed and relatively under-researched population. However, reliance on charity networks may also have shaped the sample in important ways. Participants engaged with *CardiomyopathyUK* may have been more proactive in help-seeking, more engaged in advocacy or peer-support communities, and potentially more reflective about their experiences than individuals not connected to support services.

4.4 Phase 1: Interviews with Cardiologists

This subsection outlines the preparatory work undertaken and the recruitment strategy used for recruiting cardiologist participants. The development of the phase 1 interview topic guide, and the process of data collection is also summarised.

4.4.1 Aim of the Research

Phase 1 Aim: To explore cardiologists' lived experience of cardiomyopathy diagnosis.

Objectives:

- To explore level of cardiomyopathy education and training cardiologists receive
- To map a typical diagnostic pathway
- To reflect on how a new diagnosis of cardiomyopathy is communicated to adult patients
- To understand the needs of cardiologists during diagnosis

4.4.2 Preparation

In preparation for conducting interviews with cardiologists, I created a topic guide (Appendix 2). I also conducted a preparation interview to assess the suitability of this topic guide, to test recording equipment, and to improve my interviewing skills.

A preparation interview was undertaken in August 2017 with a practising heart failure nurse working for the national charity, *CardiomyopathyUK*. The 30-minute interview took place in a local hotel foyer café and was audio-recorded. The pilot person offered some new topics that had not previously been considered such as, the level of cardiomyopathy education that clinicians receive, and the difficulties some clinicians face when accessing local services for their patients. As a result of the preparation interview, a small number of changes were made to the interview topic guide to allow better flow of topics (as discussed in section 4.3.4) and I reflected and improved upon my own interview practices. I found that I spoke quite quickly and at times didn't allow for natural silences. I also found myself speaking over the pilot participant on occasion and having to apologise and refocus on what they were trying to tell me. I reflected that I needed to be more 'in the moment', be more responsive and listen to what was being said rather than focus on the interview topic guide.

4.4.3 Participants

The preparation interview provided insight into the diagnostic pathway of CM that indicated patients' diagnoses were not usually confirmed prior to being seen by a consultant cardiologist, often at a tertiary cardiac centre. This was later supported by findings from demographic data from the patient participant identification tool whereby 77.8% of newly diagnosed CM patients reported being diagnosed by a consultant cardiologist (Appendix 3). It was assumed that cardiologists working at a tertiary cardiac centre would more likely have had the required experience with diagnosing cardiomyopathy than those working within secondary care settings including district general hospitals. I therefore decided to interview consultant cardiologists, specifically those working in tertiary cardiac centres.

4.4.3.1 Identification and Recruitment

An online search was conducted using publicly available information from NHS England web pages to identify hospital trusts with tertiary cardiac centres. Ten NHS hospital trusts were identified due to their geographical spread and named as ‘participant identification centres’ (PIC’s) for this study. The hope was to collect data from consultant cardiologists about their experience of diagnosing cardiomyopathy from sites across England so that the findings were not perceived as being ‘representative’ of one specific region, NHS Trust or cardiac centre. The geographical spread of the chosen participant identifications centres also helped to protect participant’s anonymity.

Recruitment was first attempted via each site’s Research and Development Officers (R&D’s) however this was largely unsuccessful due to poor engagement. I contacted the R&D officers at each site and asked them to distribute a pre-written recruitment email to all consultant cardiologists on my behalf. Three R&D officers responded and forwarded the recruitment email to a total of 26 consultant cardiologists. This resulted in seven responses from potential participants, of which five completed an interview.

I then searched online through each PIC’s website for publicly available contact information (namely email addresses) for consultant cardiologists from each site. Often the consultant cardiologists listed on the trust’s website also stated each cardiologist’s specialisms, sometimes labelled, “special interests”. Consultant cardiologists who provided an email address and listed a special interest in “heart muscle disease”, “heart rhythm disorders” or “inherited cardiac conditions” were contacted as I felt these cardiologists were most likely to have experience with cardiomyopathy patients, of which there were 48. A standardised recruitment email (Appendix 4) was sent either directly or via their secretaries where necessary to each of the 48 identified consultant cardiologists. This resulted in a further three responses from potential participants, of which one completed an interview.

This study used a combination of purposive and convenience sampling strategies. Consultant cardiologists working within tertiary cardiac centres with experience of diagnosing cardiomyopathy were

targeted (purposive). However, in practice, the final sample was self-selecting (convenience), comprising of those who responded to recruitment invitations and agreed to participate in an interview.

In total, seventy-four cardiologists were contacted, ten cardiologists responded and six completed an interview. Three of the participants were recruited from Liverpool Heart and Chest Hospital, while the remaining three were recruited from Leeds Teaching Hospitals, University Hospitals of South Manchester and Guy's and St. Thomas' Hospitals, London. Of the four respondents who did not complete an interview, three did not respond to further contact, and one was excluded from the study on ethical grounds as they were directly involved with my own healthcare. Table 5 shows the number of potential participants contacted, responses received and interviews completed, with (*) indicating co-operating R&D's. Recruitment of cardiologists combined purposive and convenience sampling approaches. Participants were purposively sought based on their clinical involvement in diagnosing and managing cardiomyopathy, as this aligned with the experiential focus of the research. However, recruitment was also shaped by practical considerations, including accessibility, clinician availability, NHS Research and Development engagement processes, and willingness to participate. As such, the final sample represented a self-selecting convenience sample of cardiologists who met the inclusion criteria and were willing to discuss their experiences. Within IPA, the aim was not statistical representativeness, but the generation of rich, idiographic accounts of lived experience.

TABLE 5. NUMBER OF CONSULTANT CARDIOLOGISTS RECRUITED FROM EACH NHS TRUST. (*) INDICATING CO-OPERATIVE R&D's.

<i>Hospital Trust</i>	No. Contacted	No. Responded	No. Interviewed
<i>Royal Brompton & Harefield</i>	5	0	0
<i>Guy's & St. Thomas Hospitals'</i>	5	2	1
<i>*University Hospitals of South Manchester</i>	14	1	1
<i>Newcastle-Upon-Tyne Hospitals</i>	4	1	0
<i>*Leeds Teaching Hospitals</i>	7	1	1
<i>University of Leicester Hospitals</i>	9	0	0
<i>*Liverpool Heart and Chest Hospital</i>	5	5	3
<i>University Hospitals of Birmingham</i>	12	0	0
<i>University Hospitals of Bristol</i>	2	0	0
<i>University Hospital of Southampton</i>	11	0	0
Total	74	10	6

4.4.3.2 Inclusion and Exclusion Criteria

Cardiologists were selected for interview if they had experience of forming and delivering a cardiomyopathy diagnosis within an NHS trust. Any clinician directly involved with the medical care of any member of the research team were excluded.

Researcher's Reflection:

Difficulties engaging NHS Research and Development (R&D) departments during Phase 1 recruitment prompted important reflection on the practical realities of conducting research within complex healthcare systems. Despite initial plans to recruit consultant cardiologists through formal R&D channels, engagement was limited and response rates were lower than anticipated. This required a shift in my approach, including the use of publicly available contact information to invite participation directly. While this approach provided several more responses, uptake remained low. This experience highlighted the extent to which research access is shaped not only by ethical approval, but by local capacity, competing priorities, and organisational pressures within NHS services. It is also possible that services with a strong research focus, such as specialist tertiary cardiac centres, receive frequent research requests. While this could not be directly assessed within the current study, it may have influenced levels of engagement, particularly where clinicians were managing competing clinical and research demands.

This experience has expanded my understanding of recruitment as an active and relational process rather than a purely procedural step in data collection. In future research, earlier and more sustained engagement with clinical services may be beneficial, including building relationships with key contacts, identifying clinical champions, and aligning research aims more explicitly with service priorities. Greater consideration could also be given to how participation is framed for clinicians, particularly in relation to time constraints and perceived relevance to their practice. I could also have made efforts to have a physical presence or suggest that my research be included in the agenda of existing clinical meetings which may have supported engagement. These reflections highlight the importance of adapting recruitment strategies in response to real-world constraints, and of recognising the organisational context within which clinical research takes place.

4.4.4 Interview Topic Guide

An interview topic guide was used to support the interviews with cardiologists. This functioned as a flexible framework rather than a fixed schedule of questions, allowing participants to lead the discussion while ensuring that key areas relevant to the research aims were explored.

The initial version of the topic guide was informed by a limited exploration of existing literature and discussions with clinical supervisors (Appendix 5). Previous research has explored patient experiences of receiving a cardiomyopathy (CM) diagnosis (Dekker *et al.*, 2016; Low, Lavalley and Lord, 2024; Zytneck *et al.*, 2021), as well as factors such as patient understanding (Nightingale *et al.*, 2019) and access to support services, including psychological support and cardiac rehabilitation (Turner *et al.*, 2017). However, there is limited research exploring the experiential perspective of cardiologists responsible for forming and communicating CM diagnoses. The topic guide was therefore developed to specifically explore clinicians

lived experiences, including their perceptions of patient responses, their approach to diagnostic decision-making, and their reflections during diagnostic consultations.

The guide was designed to remain open and responsive, enabling participants to introduce and prioritise topics relevant to their own experiences. The opening question, “Can you tell me about your experience of diagnosing cardiomyopathy?” was intentionally broad, encouraging narrative accounts. Prompts were used where appropriate, for example, inviting participants to reflect on particularly challenging or rewarding diagnostic experiences.

4.4.5 Data Collection

Interviews were pre-arranged with the participating cardiologists via email. Two of the interviews were conducted in-person while the remaining four were conducted via telephone. The in-person interviews were conducted at the cardiologist’s private offices. The interviews varied in length from 18 minutes to 55 minutes due to variation in cardiologist availability and were conducted between October 2017 – August 2018. The interviews were semi-structured and audio recorded. Although they were predominantly participant-led, references were made to an interview topic guide (Appendix 5) throughout the interviews to ensure proper flow. Each interview started by asking the participants to talk about their professional experience with CM. This descriptive, narrative style question was a technique used to ease the participant into a comfortable interaction about their experiences of the topic at hand (Smith, Flowers and Larkin, 2009). The participants were encouraged to talk at length while the researcher’s input was minimal, only providing prompts and introducing new topics of discussion where necessary.

Due to the recruitment difficulties experienced during phase 1 (as discussed above), further consideration was taken with regards to the recruitment strategy for phase 2 interviews with patients. The decision was taken to identify and recruit patient participants using a participant identification tool that could easily be circulated online and will be discussed in the next sub-section.

4.5 Patient Participant Identification Tool

Due to challenges encountered during Phase 1 recruitment, including limited engagement from some participant identification centres, an alternative approach was adopted for Phase 2. Patient participants were identified and recruited using an online participant identification tool, which could be circulated widely across relevant patient groups. This approach enabled direct engagement with potential participants without reliance on specific clinical gatekeepers. Participation was voluntary, with individuals choosing whether to access the questionnaire and indicate interest in a subsequent interview.

The use of this tool also supported purposive sampling, allowing for the inclusion of participants with a range of diagnostic experiences. The processes of recruitment and data collection associated with this participant identification tool is outlined in this subsection.

4.5.1 Aim of the Participant Identification Tool

The aim of the participant identification tool was to collect quantitative data that could be used to identify and select a purposive sample of cardiomyopathy patients for interview.

4.5.2 Tool Development

The online survey began with a series of screening questions to ensure participants met the eligibility criteria for Phase 2 interviews (detailed in subsection 4.4.3.2). Participants who met the inclusion criteria were then asked to provide general demographic information, including gender and regional location from predetermined lists. Further questions captured cardiomyopathy-specific details, such as phenotype, whether participants were symptomatic prior to diagnosis, and the underlying cause of their condition, if known. Participants were also asked to identify the clinical role of the professional who first communicated their diagnosis to them. These data provided additional context for sampling and offered further insight into the diagnostic process. A summary of demographic and clinical characteristics is presented in Appendix 3.

In addition to demographic and clinical data, the questionnaire included measures of psychological wellbeing. The bidirectional relationship between physical and psychological health is well established (Lossnitzer *et al.*, 2020; Ogunmoroti *et al.*, 2022), as is the impact of chronic illness diagnosis on emotional wellbeing (Huang *et al.*, 2023). Assessing symptoms of anxiety and depression prior to interview provided insight into the context within which participants were making sense of their diagnosis and supported the development of a purposive sampling strategy. This data allowed for a more considered sampling framework - depending on the distribution of scores obtained, this data allowed for either a more homogenous sample (e.g., participants with similar levels of distress) or a stratified sample capturing a broader range of experiences. Participants completed the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) (HADS), a widely used and validated measure of anxiety and depression in populations with physical health conditions (Wu *et al.*, 2021; Annunziata *et al.*, 2020), including cardiomyopathy (He *et al.*, 2022; Suárez-Mendoza *et al.*, 2019). The scale comprises 14 multiple-choice items across two subscales: anxiety (HADS-A) and depression (HADS-D). Each item is scored from 0–3. A score of 8 or above on either subscale is indicative of elevated symptoms (Zigmond and Snaith, 1983).

Existing research examining psychological distress across cardiomyopathy phenotypes remains limited. For example, a narrative review by Suárez Bagnasco and Núñez-Gil (2016) highlighted variation in findings across studies but was restricted to specific phenotypes, predominantly Takotsubo and inherited cardiomyopathies. In addition, variation in measurement tools and definitions of distress, alongside the inclusion of participants at different stages of illness, limits comparability across studies. To date, there is limited research examining psychological distress specifically in newly diagnosed cardiomyopathy patients across multiple phenotypes, supporting the inclusion of this measure within the current study.

Finally, the questionnaire assessed participants perceived health-related quality of life using an adapted version of the Kansas City Cardiomyopathy Questionnaire (KCCQ-12) (Jones *et al.*, 2013; Spertus and Jones, 2015). A licence to use this measure was obtained during questionnaire development. The KCCQ-12 is a shortened version of the original 23-item scale (Faller *et al.*, 2005), with strong correlation between

versions ($r = 0.92\text{--}0.99$), indicating comparable psychometric performance with reduced participant burden (Jones *et al.*, 2013). The measure includes 12 items across four domains: physical limitation, symptom frequency, quality of life, and social limitation. Responses are transformed to produce subscale scores ranging from 0 to 100, with higher scores indicating better health status. A summary score is calculated as the mean of these subscales.

Together, these measures provided a structured yet flexible basis for identifying a purposive sample and for contextualising participants' experiences of diagnosis.

4.5.3 Participants

The survey's distribution feature showed that 6,831 people clicked on the link to the questionnaire but only 186 people continued after reading the participant information sheet and consent form. Of these, 61 were subsequently screened out and a further 44 did not complete the questionnaire. A total of 81 participants completed the online questionnaire. Several factors may have affected the completion rate. The inclusion criteria were quite narrow and only included NHS patients within a small window of time following diagnosis. Furthermore, advertising via social media created difficulty when trying to target a specific population. Although I advertised the study within closed targeted groups online, the posts were then 'shared' globally by the public meaning many of the people who opened the survey were not currently living in England or using NHS services.

Researcher's Reflection:

When advertising the questionnaire online, it was interesting to see the rate at which the web-link was being 'shared' globally. The original post specified the inclusion criteria, yet I still received messages from people wanting to take part from the Republic of Ireland, Scotland, Australia, Canada, Germany and the United States of America. I thanked them for their interest and support of the research and explained that I was only looking for patients from services within NHS England at present. The number of people who took the time to click the link and learn more about the research was truly surprising. For me, it highlighted the need for more understanding of psychological wellbeing amongst cardiomyopathy patients globally, particularly within the first few months of diagnosis. It seems an important topic for research and such global interest suggests the needs of cardiomyopathy patients during and following diagnosis, are not being currently met.

4.5.3.1 Identification and Recruitment

The ten NHS trusts identified as participant identification centres in phase 1 were also asked to advertise the online questionnaire to CM patients in their outpatient clinics using recruitment posters I provided (Appendix 6). Whilst all ten trusts were sent the recruitment materials and had approved my request, it remains unknown whether the posters were displayed as requested. The national charity, *CardiomyopathyUK* also advertised the questionnaire on their website, in their quarterly magazine and via their social media pages. I further promoted the study via closed CM-related patient groups on Facebook. All recruitment materials included a QR code and web-link to provide instant access to the online survey.

Researcher's Reflection:

The various recruitment strategies implemented for the participant identification tool varied in effectiveness. Collaboration with *CardiomyopathyUK* significantly increased the reach of the study through promotion across their social media, website, and magazine. Directly posting within cardiomyopathy-related social media groups was also effective, suggesting that recruitment embedded within existing patient communities may be particularly valuable. However, it was not possible to determine which recruitment pathways were most successful, as no data were collected on how participants accessed the questionnaire. Including this would have allowed for a more systematic evaluation of recruitment methods.

In contrast, clinic-based recruitment was resource-intensive and ineffective. Attendance at an outpatient clinic resulted in only one potentially eligible participant, likely reflecting the narrow inclusion criteria and practical challenges of identifying participants in a busy clinical setting. Overall, these experiences suggest that digital recruitment methods via established patient networks may be more efficient and effective than clinic-based approaches for this population.

4.5.3.2 Inclusion and Exclusion Criteria

Once potential participants had accessed the online survey, they were asked to provide the following information to ensure they met the inclusion and exclusion criteria:

- Confirm they were aged 18 years +
- Confirm they held capacity to consent for themselves
- Confirm they had received a diagnosis of cardiomyopathy
- Confirm their cardiomyopathy diagnosis had been received within six months prior to completing the questionnaire

- Confirm they received health care from an NHS service within England
- Confirm they could understand written English language

Based on the responses provided, those who did not meet the inclusion and exclusion criteria were screened out and directed to a prewritten message explaining their ineligibility and thanking them for their time.

4.5.4 Data Collection

Whilst this participant identification tool did not collect data specifically for independent analysis, the data collected were an important part of the participant identification and recruitment process for Phase 2 patient interviews.

As visually represented in Figure 8 below, the online survey began with an information page and consent page. As previously discussed, the questionnaire then included screening questions to assess eligibility for the phase 2 interviews. At this point, participants were automatically either screened out and thanked or allowed to proceed to the next page. Participants were then asked some brief demographic questions along with some direct questions regarding their cardiomyopathy diagnosis.

Participants were then asked a series of scale questions from pre-validated measures including the Hospital Anxiety and Depression Scale to record a measure of psychological wellbeing, and the Kansas City Cardiomyopathy Questionnaire as a measure of health-related quality of life.

The final page of the survey asked whether the participant would like to take part in an in-person interview to be arranged with the research team at a later date via email. Participants could select either “yes” or “no” and if selecting “yes”, they were prompted to provide their email address. All data were downloaded to into a Microsoft Office Excel Spreadsheet and stored in accordance with the stated ethical and governance requirements previously described.

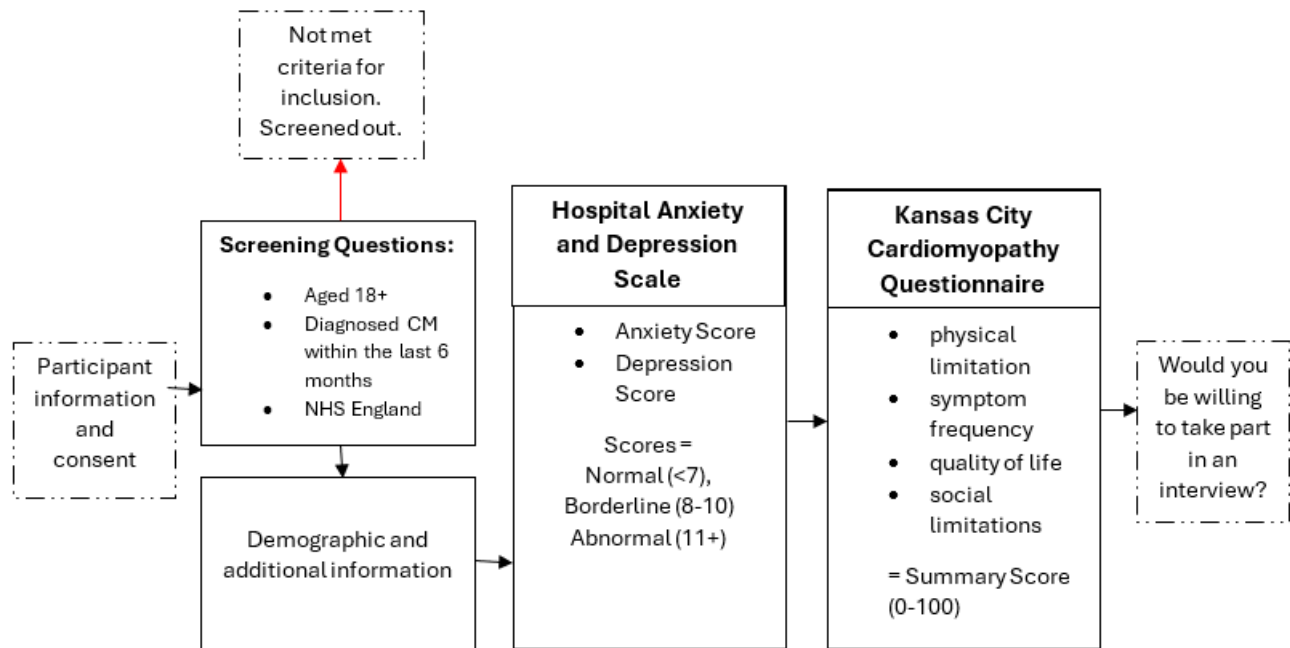


FIGURE 8. PATHWAY DESIGN FOR THE ONLINE QUESTIONNAIRE USED AS A PARTICIPANT IDENTIFICATION TOOL FOR PHASE 2 INTERVIEWS.

4.6 Phase 2: Interviews with Patients

4.6.1 Aim of the Research

Phase 2 Aim: To explore the lived experiences of newly diagnosed adult cardiomyopathy patients.

Objectives:

- To explore individual diagnostic journeys
- To explore patients' understanding of cardiomyopathy
- To consider the implications of diagnosis of patients' lives
- To understand the needs of patients during diagnosis

4.6.2 Participants

As previously discussed, the online questionnaire acted as a participant identification tool. At the end of the questionnaire, participants who wished to take part in an in-person interview were asked to provide an email address for scheduling purposes. Although a purposive sample was initially sought, limited engagement at the point of interview scheduling led to the final sample being self-selecting (convenience),

comprising of those who completed the online survey, confirmed their willingness to complete an interview, provided their contact email address and responded to the invitation for interview.

4.6.2.1 Identification and Recruitment

Of the 81 respondents who completed the questionnaire, 51 provided their email address and agreed to be sent further information about being interviewed for the next phase of the study. All 51 participants were emailed a participant information leaflet (Appendix 7) and consent form along with instructions to contact me should they choose to take part in an interview. Unfortunately, only 11 people responded meaning that the sampling framework had to be reconsidered, and all were offered interviews. One subsequently withdrew from the study due to personal circumstances, and another did not respond to further contact meaning an interview could not be arranged. Nine participants took part in an interview, as shown in Table 6 below.

It was discovered during one participant's interview, whom I assigned the pseudonym, 'Daisy' that she did not in fact have cardiomyopathy and that she had instead been diagnosed with another cardiac condition. Although Daisy answered the online questionnaire truthfully to the best of her knowledge, she did not fully understand the meaning of the term, cardiomyopathy and assumed it was a broad term describing all cardiac conditions. Her data were subsequently withdrawn from the study. The remaining eight participants ranged in age from 32 to 60 years (mean age = 49) and produced scores indicating varying degrees of anxiety, depression and health-related quality of life. There was an equal amount of male and female participants, and five phenotypes of cardiomyopathy were represented in the sample (with one participant unable to identify their phenotype in addition to Daisy). Sampling combined purposive and convenience approaches. Participants were purposively recruited according to their relevance to the phenomenon under investigation (adult cardiomyopathy diagnosis), while recruitment pathways relied on convenience and self-selection, as participation depended on accessibility, clinician gatekeeping, and willingness to engage with the research.

TABLE 6. PATIENT INTERVIEW PARTICIPANTS' DEMOGRAPHIC DATA. *PARTICIPANT DISCOUNTED AFTER INTERVIEW. HADS ANXIETY AND DEPRESSION SCORES CONSIDERED NORMAL (≤ 7), BORDERLINE (8-10) AND ABNORMAL (11+). KCCQ SUMMARY SCORES ARE SCALED 0-100, WHERE 0 DENOTES THE LOWEST REPORTABLE HEALTH STATUS AND 100 THE HIGHEST.

Patient Participant	Cardiomyopathy Phenotype	Region of England	HADS Anxiety Score	HADS Depression Score	KCCQ-12 Summary Score
Henry	Dilated Cardiomyopathy	South East	8	8	51.5
Charlotte	Peripartum Cardiomyopathy	South East	15	10	14.9
Alex	Hypertrophic Cardiomyopathy	South West	11	13	17.2
Jessica	Takotsubo Cardiomyopathy	North West	7	9	42.9
Dominic	Restrictive Cardiomyopathy	South East	7	10	20.1
Carl	Dilated Cardiomyopathy	North	8	4	75.0
Phoebe	Unknown	South East	10	12	33.1
Kate	Hypertrophic Cardiomyopathy	North	9	11	30.2
*Daisy	Unknown	East	13	10	33.6

Smith, Flowers and Larkin (2009) suggest that a small sample size (between 4-10 participants) is required when using Interpretative Phenomenological Analysis (IPA) to allow the researcher to focus on the participants' experience in detail without becoming overwhelmed with data. Sample size is not prescriptive however, as IPA as an analytic approach provides great flexibility so *"there is no right answer to the question of sample size"* (Smith, Flowers and Larkin, 2009, p. 51). Smith, Larkin and Flowers (2021) does however argue that a homogenous sample is necessary to ensure themes can be realised from certain groups of people who have shared particular experiences but reaffirms that IPA is not prescriptive in its' sampling framework. Due to the aforementioned limited uptake, a volunteer sample of eight patient interview data (gained through a purposive sampling framework) were analysed.

Researcher's Reflection:

The inclusion and subsequent withdrawal of the participant known as 'Daisy' highlighted an important limitation of the screening process, as well as a finding directly relevant to the focus of this research. Although Daisy self-certified that she met the eligibility criteria within her responses to the questionnaire, it became clear during interview that she did not have a diagnosis of cardiomyopathy, but rather another cardiac condition. This appeared to reflect a misunderstanding of clinical terminology, with "cardiomyopathy" being interpreted as a general term for heart-related conditions.

While her data were appropriately excluded, this experience is noteworthy in the context of the study's focus on diagnostic experiences that include patient understanding and communication during diagnosis. Daisy's willingness to engage, share her experiences, and make sense of her condition reflects the very challenges faced by patients newly diagnosed with a chronic illness and perhaps reflects general issues with accessibility of information and clarity of diagnostic language.

This case also highlighted the limitations of self-report screening tools in ensuring diagnostic accuracy, particularly where understanding of medical terminology may vary. While the screening questions were necessary and appropriate for large-scale recruitment, this experience suggests that additional verification or clarification may be beneficial in future research. At the same time, it reinforces the importance of not assuming shared understanding of clinical terms when working with patient populations.

4.6.3.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the patient interviews followed those outlined in detail above in subsection 4.5.3.2. Participants were only interviewed if they had met all of these criteria and completed the following additional steps:

- Agreed to be interviewed at the end of the online survey
- Provided an email address
- Responded to the research team when contacted to arrange an interview

4.6.3 Interview Topic Guide

Mirroring interviews in Phase 1, during Phase 2 an interview topic guide (Appendix 8) was used to support interviews with patients. Again, this functioned as a flexible framework rather than a fixed schedule of questions, allowing participants to lead the discussion while ensuring that key areas relevant to the research aims were explored.

Included topics were developed through discussions with the patient and public involvement group, alongside insights from wider literature and reflective discussions with the supervisory team. Topics were phrased as open-ended questions in case a participant fell silent for a prolonged period and struggled to articulate their experience. My first question was, “*Can you tell me about your diagnosis?*”. A further open-ended question was also included: “*What does cardiomyopathy mean to you?*”. This facilitated discussion about participants’ perceptions of their diagnosis and its impact on their lives. These questions were often sufficient to engage participants. Unlike many of the cardiologists interviewed, patients often had a great deal to share, and focusing on their diagnosis appeared to create space for reflection, insight, and emotional expression that they may not previously have articulated. The final question explored participants’ expectations for the future and whether there was anything further they wished to add.

4.6.4 Co-Production of Timelines

During the first interview, it became apparent that patient participants often described their experiences in a non-linear way, moving between different points in their diagnostic journey rather than presenting events chronologically. In response, I adapted my approach and began co-constructing a visual timeline with participants during subsequent interviews.

This involved mapping key events as they were discussed, with minimal notetaking to avoid disrupting the flow of the conversation. The timeline provided a shared reference point, allowing both the participant and me to organise the sequence of events and revisit earlier experiences in a more structured way. This supported a clearer understanding of how participants’ thoughts and emotional responses developed over time, while also prompting further reflection and elaboration.

The use of visual and participatory tools in qualitative interviews has been shown to facilitate recall, support the expression of temporal experiences, and encourage deeper engagement (Glegg, 2019). Similar approaches, such as life story boards (Chongo *et al.*, 2018), photo elicitation (Kyololo, Stevens and Songok, 2023), and structured visual templates (Bravington and King, 2019), informed the development of this method. In the present study, co-producing timelines was mutually beneficial. It supported my

understanding of the chronology and meaning of participants' experiences, while also offering participants a visual representation of their diagnostic journey, which facilitated reflection and validation of their accounts. The timelines were also used to inform subsequent interviews, allowing emerging points of interest to be explored across participants. An example of an anonymised interview timeline is provided in Appendix 9.

4.6.5 Data Collection

Interviews were conducted in person across different regions of England, reflecting the sensitive nature of the research topic and the preference for in-person engagement. Locations were chosen by participants and typically included their home or a quiet public setting, such as a café.

Interviews were conducted between April 2018 – January 2019 and ranged in length from 28 to 126 minutes (mean = 63 minutes). Interviews were predominantly participant led, supported by a flexible topic guide (Appendix 8). All interviews were audio-recorded and transcribed verbatim, with consent. Efforts were made to create a comfortable and informal interview environment, including adopting a conversational approach and minimising formality, to support open discussion of participants' experiences.

4.7 Method of Analysis

Interview data from both study phases were analysed using interpretative phenomenological analysis (IPA), as described by Smith, Flowers and Larkin (2009). IPA is not a prescriptive analytic process and offers flexibility however, it is characterised by a set of common processes and principles through which knowledge is uncovered via an iterative process of interpretation.

As IPA emphasises the co-construction of knowledge and the active role of the researcher, I chose to analyse the data by hand in order to fully immerse myself in the transcripts. This involved reading and analysing each transcript line by line, highlighting words or phrases of interest and making notes throughout. One core analytic principle outlined by Smith, Flowers and Larkin (2009) is that analysis moves from the particular to the shared. That is, understanding developed through engagement with individual transcripts and was then carried forward across the dataset.

For this reason, the analysis process was divided into two distinct levels, as recommended by Smith and Shinebourne (2012): the individual transcript level followed by the multiple transcript level, both of which are discussed below.

4.7.1 Transcription

An independent transcriber transcribed audio recording of the interviews, verbatim. Some qualitative researchers have argued that analysts should transcribe interviews themselves to support immersion in the data (Vanover, 2022). Others have suggested that this is particularly important when the analyst did not conduct the interviews, as transcription facilitates closer engagement with tone, context, and meaning (Rodham, Fox and Doran, 2015).

As I conducted all interviews, and to allow greater focus on analysis, I chose to employ a professional transcriber. The transcriber signed a confidentiality agreement and did not retain any data from the study. Given that transcription is a time-intensive process, research has shown that errors can occur regardless of whether it is completed by the researcher, an external transcriber, or automated tools (Point and Baruch, 2023).

To ensure accuracy, I checked each transcript against the original audio recording, correcting any discrepancies or errors. The data were then anonymised through the removal of identifying names and locations.

It has been argued that transcribing data that will not be analysed may be unnecessary (Point and Baruch, 2023). In line with the interpretative focus of IPA, detailed prosodic features were not included in full (Smith, Flowers and Larkin, 2009). Instead, key non-verbal elements were captured in a simplified form, with pauses indicated by ellipses [...] and utterances such as laughter noted in brackets (e.g., [both laugh]). This approach ensured that relevant contextual detail was retained without overcomplicating the transcription, while allowing fuller consideration of tone and delivery during subsequent engagement with the audio recordings.

4.7.2 Analysis: Individual Transcript Level

Figure 9 shows the template developed and used to analyse each individual transcript. In line with the idiographic nature of IPA, each transcript was analysed in full before moving on to the next (Miller, Chan and Farmer, 2018). This approach ensured that the temporal and contextual integrity of each account was maintained, without being influenced by interpretations from other transcripts (Smith, Flowers and Larkin, 2009).

While Smith and Shinebourne (2012) suggest making initial notes in the margins, I adopted a column-based approach, which suited my preferred visual way of working. The individual transcript analysis was structured into three stages: familiarisation, exploratory coding, and the development of emergent themes.

Step 1: Familiarise with transcript		Step 2: Exploratory coding			Step 3: Emergent themes	
Line No.	Transcript	Coding			Theming	Personal
		Description & Content	Language Use	Interrogative	Emergent Themes	Reflections
1						
2						
3						
4						
5						
6						
7						

FIGURE 9. INDIVIDUAL TRANSCRIPT LEVEL INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TEMPLATE - ADAPTED FROM SMITH, FLOWERS AND LARKIN (2009).

4.7.2.1 Familiarise with the transcript

The first stage involved reading and re-reading each transcript (Smith, Flowers and Larkin, 2009), alongside listening to the corresponding audio recording to support full immersion in the data. This enabled me to develop an understanding of the overall narrative and to retain a sense of each participant's individual 'voice' (Miller, Chan and Farmer, 2018).

I then conducted a detailed line-by-line reading, highlighting phrases or terms of interest using a coloured pen (Alase, 2017). As noted by Smith and Shinebourne (2012), these initial observations reflected points of interest and were not constrained by predefined criteria.

4.7.2.2 Exploratory coding

Exploratory coding formed the most detailed stage of analysis. Following guidance from Smith and Shinebourne (2012) and Willig and Rogers (2017), this process was structured across three layers to support a multidimensional engagement with the data (Figure 9).

First, descriptive comments were made to capture the content of the participant's account, allowing key events, experiences, and contextual details to be identified. Second, linguistic features such as metaphors, emotive language, and patterns of expression were noted, supporting attention to how experiences were communicated (Larkin and Thompson, 2012). These stages align with first-order analysis, remaining close to the participant's account (Pietkiewicz and Smith, 2014).

The final stage involved a shift toward a more interpretative stance, consistent with the hermeneutic principles underpinning IPA (Smith, Flowers and Larkin, 2009; Nizza, Farr and Smith, 2021). At this stage, I engaged more conceptually with the data, considering possible meanings, assumptions, and underlying processes within participants' accounts (Crotty, 1998; Miller, Chan and Farmer, 2018).

An additional column was included to record personal reflections. This provided a space to acknowledge my own responses to the data, including emotional reactions and points of personal resonance (Nizza, Farr and Smith, 2021). This process supported reflexivity and helped to distinguish between participants' accounts and my own interpretations. An anonymised example of this process is provided in Appendix 10.

4.7.2.3 Emergent Themes

The final stage of individual transcript analysis involved developing emergent themes. At this point, the focus shifted from the transcript itself to the patterns identified within the exploratory coding.

Relationships between codes were examined, and clusters of meaning were grouped to form emergent themes (Alase, 2017; Smith and Nizza, 2022).

Theme labels were developed by combining participants' language with psychological concepts and interpretative insight (Smith and Nizza, 2022). These themes were recorded within the analysis template (Figure 9).

To support organisation and visualisation of the data, I created a mind map for each transcript, illustrating how individual codes contributed to emergent themes (Appendix 11). This facilitated identification of overlap and connections between themes in preparation for the next stage of analysis across transcripts.

4.7.3 Analysis: Multiple Transcript Level

The second stage of analysis involved examining patterns across transcripts and developing superordinate themes. At this stage, emergent themes from individual transcripts were brought together to explore shared and divergent aspects of participants' experiences. Superordinate themes represented clusters of related (and, at times, contrasting) sub-themes that captured both the essence of participants' accounts and the interpretative work of the analysis.

4.7.3.1 Compiling Emergent Themes

A table was created in a word document to collate emergent themes from each transcript, alongside relevant extracts and coding notes (Appendix 12). These tables were then examined across cases to identify patterns, similarities, and differences between participants' accounts.

Consistent with IPA, attention was given to both convergence and divergence within the data (Miller, Chan and Farmer, 2018). This involved identifying themes that were shared across participants, as well as those that reflected unique or contrasting experiences. Considering both commonality and difference supported a more nuanced understanding of the phenomenon under investigation.

4.7.3.2 Identify superordinate themes

Emergent themes were subsequently clustered into superordinate themes through a process of analytical abstraction (Smith, Flowers and Larkin, 2009). This involved grouping related themes and developing higher-order labels that captured their shared meaning. In some cases, themes were refined, combined, or reduced, while others were retained due to their conceptual richness.

In line with IPA principles, themes were not selected on the basis of frequency alone, but on their relevance and contribution to understanding participants' experiences (Smith, Flowers and Larkin, 2009). As such, themes represented across a small number of participants were retained where they offered particularly insightful or illuminating perspectives.

To support this process, a separate document was created for each superordinate theme, within which relevant extracts from all transcripts were organised under associated sub-themes (Appendix 13). This facilitated a clear visual representation of each theme and supported consideration of both its coherence and variability across the dataset.

4.7.3.3 Data sufficiency

Rather than aiming for data saturation, which is not typically aligned with idiographic qualitative methodologies, the analysis was guided by the concept of data sufficiency (Smith and Nizza, 2022). Data collection and analysis were considered sufficient when additional cases continued to elaborate on existing themes without substantially altering them. This approach reflects the emphasis within IPA on depth of understanding rather than exhaustive coverage.

4.8 Ensuring Rigour

Assessing the quality of qualitative research remains a debated area (Braun and Clarke, 2025). While some approaches adopt positivist criteria such as validity and reliability (Long and Johnson, 2000), others argue that qualitative research requires distinct frameworks aligned with its interpretative foundations (Noble and Smith, 2025).

In response, structured reporting tools such as COREQ (Tong, Sainsbury and Craig, 2007) have been developed to promote transparency. However, such checklists have been critiqued for imposing overly rigid standards that may not reflect the flexible and interpretative nature of qualitative inquiry (Morse, 2022). These concerns are particularly relevant to ‘big Q’ qualitative research, where meaning is understood as co-constructed and contextually situated, and where quality is better demonstrated through methodological coherence and transparency rather than adherence to procedural criteria (Braun and Clarke, 2025).

This study is aligned with a ‘big Q’ qualitative approach. As such, rigour was conceptualised in terms of transparency, reflexivity, and depth of interpretation, rather than the application of positivist criteria. To demonstrate rigour, this study drew on Lincoln and Guba’s (1985) framework of trustworthiness, which includes the criteria of truth value, consistency, neutrality, and applicability (Table 7). These principles were applied throughout the research process, as outlined below.

TABLE 7. TERMINOLOGY AND CRITERIA USED TO EVALUATE SCIENTIFIC RIGOUR AND CREDIBILITY OF RESEARCH FINDINGS.
(LINCOLN & GUBA, 1985; LONG & JOHNSON, 2000) CITED IN NOBLE AND SMITH (2015).

Quantitative research terminology and the application to qualitative research	Alternative terminology associated with credibility of qualitative research
Validity <i>The precision in which the findings accurately reflect the data</i>	Truth Value <i>Recognises that multiple realities exist; the researchers outline personal experiences and viewpoints that may have resulted in methodological bias; clearly and accurately presents participants' perspectives</i>
Reliability <i>The consistency of the analytical procedures, including for personal and research methods biases that may have influenced the findings</i>	Consistency <i>Relates to 'trustworthiness' by which methods have been undertaken and is dependent on the researcher maintaining a 'decision-trail'; that is, the researcher's decisions are clear and transparent. Ultimately an independent researcher should be able to arrive at similar or comparable findings</i>
	Neutrality (or confirmability) <i>Achieved when truth-value, consistency and application have been addressed. Centres on acknowledging the complexity of prolonged engagement with participants and that the methods undertaken and findings are intrinsically linked to the researcher's philosophical position, experiences and perspectives. These should be accounted for and differentiated from participants' accounts</i>
Generalisability <i>The transferability of the findings to other settings and applicability in other contexts</i>	Applicability <i>Consideration is given to whether findings can be applied to other contexts settings or groups</i>

4.8.1 Truth Value

Within IPA, knowledge is understood as co-constructed between participant and researcher. Several strategies were used to ensure that the analysis remained grounded in participants' accounts. Reflective notes were recorded alongside coding to acknowledge and bracket potential biases, and reflexive 'stop-offs' were used throughout the thesis to maintain transparency regarding my positionality as a researcher. While member checking is often used to enhance credibility (Lincoln and Guba, 1985), it is not considered appropriate within IPA due to the temporal and contextual nature of the analysis (Smith, Flowers and Larkin, 2009). Instead, credibility was supported through in-interview verification processes, such as the

co-construction of timelines, which enabled participants to confirm and clarify the chronology of their experiences. In addition, rich verbatim extracts were used throughout the findings chapters to allow readers to assess the alignment between data and interpretation (Noble and Smith, 2025).

4.8.2 Consistency

Consistency was addressed through maintaining a clear and transparent account of the research process. Detailed descriptions of data collection and analysis procedures were provided to support auditability (Noble and Smith, 2025). Rather than aiming for replication in a positivist sense, consistency within this study refers to the coherence and traceability of analytic decisions. This was supported through systematic documentation of coding, theme development, and analytic progression across both datasets.

4.8.3 Neutrality

Neutrality was ensured through ongoing reflexive practice and collaborative engagement with the research supervisory team. Emerging themes were discussed with supervisors to challenge assumptions and support the development of interpretations grounded in the data. This process did not aim to eliminate researcher influence, which is recognised as inherent within IPA, but to make it visible and open to critical reflection.

4.8.4 Applicability

Within IPA, findings are context-specific and not intended to be generalisable. Instead, applicability relates to the extent to which findings offer insights that may resonate with or inform understanding in similar contexts (Noble and Smith, 2025). The detailed, idiographic accounts presented in this study may therefore provide a foundation for further exploration of diagnostic experiences in cardiomyopathy and related conditions.

4.8.5 Quality in IPA Research

In addition to the broader framework of trustworthiness, the quality of this study was further considered in relation to Smith's (2011a) IPA Quality Evaluation Guide (Table 8). While this framework has been critiqued for its perceived prescriptiveness (Chamberlain, 2011), Smith (2011b) emphasises that it is intended as

guidance rather than a rigid checklist, particularly for supporting methodological clarity in applied research.

TABLE 8. IPA QUALITY EVALUATION GUIDE - ADAPTED FROM THE ORIGINAL WORKS OF SMITH (2011A) BUT INCLUDING THE LATER ADAPTATIONS/CORRECTIONS OF SMITH (2011B).

	Criteria for Assessing Trustworthiness in IPA
Acceptable A paper that meets all four of the following criteria is considered trustworthy. Caveats to this...	1. Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic. 2. Sufficiently transparent so reader can see how research was undertaken. 3. Coherent, plausible and interesting analysis including theme summaries and interpretation of extracts. 4. Sufficient sampling from corpus to show density of evidence for each theme: If N=1–3: extracts from every participant for each theme; If N=4–8: extracts from at least three participants for each theme; If N>8: extracts from at least three participants for each theme + measure of prevalence of themes, or extracts from half the sample for each theme. Compensation – Evidence base and interest factors considered together so that, e.g., a paper with particularly interesting data may gain compensation for a less than ideal evidence base. Partial Acceptability - A paper may be deemed acceptable if it has partial pockets of acceptability, e.g. • Only two of the four themes presented are interesting and well evidenced. Paper considered acceptable if the two good themes make a sufficient contribution. • A number of themes presented but evidence all from the same participant. Research considered acceptable if the account of the individual is sufficiently coherent and read as an interesting idiographic case study. • Paper may present data from two participant groups, e.g., males and females and be deemed acceptable for one participant group but not the other. Borderline – A paper with a sample over eight with extracts from enough participants to illustrate variation, but without detail of prevalence or enough evidence of density of themes, is deemed borderline.
Good Paper clearly meets the four criteria for acceptability and demonstrates three extra qualities.	1. Well-focussed; offering an in-depth analysis of a specific topic 2. Data and interpretation are strong 3. The reader is engaged and finds the paper particularly enlightening
Unacceptable The paper fails to meet the criteria for acceptability and is deemed not trustworthy/ not suitable for publication.	1. Not consistent with theoretical principles of IPA 2. Insufficiently transparent for the reader to understand the analysis process 3. Not of sufficient interest 4. Poorly evidenced themes e.g. • Large number of descriptive/ superficial themes from a large number of participants • Each theme has a short summary with one or two extracts without interpretation • Insufficient extracts from participants to support the themes being illustrated • No explanation for how prevalence of themes was determined • Crude analysis lacking nuance

The present study was designed to meet the criteria for an ‘acceptable’ IPA study as outlined in Table 8, with several features aligning with indicators of ‘good’ quality.

Firstly, the study clearly subscribes to the theoretical foundations of IPA. As outlined in Chapter 3, the research is grounded in phenomenology, hermeneutics, and idiography, with a focus on exploring and interpreting participants lived experiences of cardiomyopathy diagnosis.

Secondly, transparency was prioritised throughout the research process. This chapter has provided a detailed account of participant recruitment, data collection, and analytic procedures, enabling the reader to follow how interpretations were developed from the data. The inclusion of analytic templates, examples of coding, and reflexive commentary further supports this transparency.

Thirdly, the analysis aimed to produce coherent, plausible, and insightful interpretations. Themes were developed iteratively and grounded in participants’ accounts, with careful attention to both convergence and divergence across cases. The use of rich verbatim extracts in Chapters 5 and 7 allows the reader to evaluate the relationship between data and interpretation, supporting the credibility of the analysis.

Finally, the study demonstrates sufficient sampling for IPA. With sample sizes of six cardiologists and eight patients, the analysis remained idiographic while allowing for cross-case examination. In line with Smith’s (2011a) guidance, themes were illustrated using extracts from multiple participants, ensuring sufficient depth and density of evidence. Where appropriate, variation in experience was also highlighted, rather than valuing frequency alone.

Beyond the criteria for acceptability, the study also reflects elements associated with ‘good’ IPA research. The focus on a clearly defined phenomenon, the depth of analysis across individual and shared experiences, and the integration of patient and cardiologist perspectives contribute to a nuanced and engaging account of the diagnostic process.

It is acknowledged, however, that quality in qualitative research cannot be reduced to checklist criteria alone. Consistent with a ‘big Q’ qualitative approach (Braun and Clarke, 2025), the rigour of this study is

best understood in terms of its coherence, transparency, and interpretative depth. The use of Smith's framework therefore serves as a guide for reflection rather than a definitive measure of quality.

4.9 Chapter Summary

This chapter has outlined the methodological approach underpinning the study, including the design, recruitment, data collection, and analysis across two qualitative phases. Phase 1 explored the perspectives of six consultant cardiologists working within tertiary cardiac centres, while Phase 2 examined the lived experiences of eight newly diagnosed cardiomyopathy patients, identified via an online participant identification tool.

Interpretative Phenomenological Analysis (IPA) was used to guide both data collection and analysis, enabling an in-depth, idiographic exploration of participants' experiences. Ethical considerations, research governance, and strategies to ensure rigour and trustworthiness were also detailed, demonstrating how the study was conducted in a transparent and methodologically coherent manner.

Having established the methodological foundations of the research, the following chapter presents the findings from Phase 1, outlining the themes identified from interviews with consultant cardiologists.

5. Findings: Interviews with Cardiologists

5.1 Chapter Introduction

This chapter builds on the research design and procedures set out in Chapter 4 and presents findings from interviews with consultant cardiologists. Using interpretative phenomenological analysis (IPA), I examine how participants made sense of diagnosing and managing cardiomyopathy (CM). The accounts are presented as situated, reflective narratives that address both the practicalities of contemporary cardiology care and the emotional load that accompanies this work.

Two superordinate themes developed from the analysis: ***Ideal Versus Real*** and ***Barriers to Shared Decision-Making***. Together, these themes capture the tensions between professional ideals, service realities, and the moral and emotional dimensions of care.

The first theme, ***Ideal Versus Real***, considers how cardiologists conceptualise ideal care standards and what they perceive to be hindering delivery in practice. It outlines their efforts to uphold professional and ethical standards while negotiating organisational pressures, fragmented inter-service communication, and the emotional labour of working within an imperfect system. Six inter-related subthemes contribute to this superordinate theme. For readability, these are grouped and presented as three broader categories, contextualising the findings within *knowledge and diagnostic contexts*, *communication and relational practice*, and *professional and emotional experience*.

The second theme, ***Barriers to Shared Decision-Making***, examines how patient involvement was negotiated during diagnosis and beyond. It considers how organisational constraints, communication styles, and expectations on the part of both clinicians and patients shaped the extent to which decisions could be shared. This theme can be understood as a practical driver of *Ideal versus Real*, since current practice in shared decision-making was experienced as out of step with cardiologists' ideal care standards. However, shared decision-making was viewed to be a fundamental component of diagnosing CM, and given its centrality to the CM diagnostic experience, it stands as a sufficiently distinct superordinate theme. Six subthemes underpin this superordinate theme. For readability, I group them to show how cardiologists

identified barriers to shared decision-making mainly in *organisational constraints*, and in *relational dynamics*. Within this superordinate theme, cardiologists reflected on authority, responsibility and assumptions about patients. They further demonstrate how trust, empathy, and humility inform relationships and clinical choices.

These interwoven experiences collectively portray the nuanced and multifaceted reality of contemporary cardiomyopathy care, revealing how ideals, constraints, and human responses intersect in everyday clinical practice. The chapter closes with a brief summary of key findings and their implications for understanding how cardiologists balance professional ideals with clinical reality.

Researcher's Reflection:

I chose to display the participant quotes using animated avatars to clarify which cardiologist provided each quote. The avatars also serve as a reminder that there are real people with individual voices behind each participant excerpt. The avatars were randomly selected using an online image search and are used to represent the gender of the participants only. Pseudonyms have also been used to further protect the identity of participating cardiologists. Each quote is followed by closed brackets denoting the pseudonym and transcript line numbers from which the quote was taken.

5.2 Ideal Versus Real (*Superordinate theme*)

This superordinate theme explores cardiologists' perceptions of what constitutes ideal care, the barriers that prevent this ideal standard from being realised, and the emotional and professional consequences of this disconnect. The findings are presented through six interlinked subthemes, that together, illustrate how cardiologists navigate the tension between professional ideals and the constraints of modern clinical practice. These subthemes are organised within three broader contexts of *knowledge and diagnostic contexts*, *communication and relational practice*, and *professional and emotional experience*.

Researcher's Reflection:

In line with IPA, this structure reflects both the patterns I saw emerging in the data and the interpretative decisions I made along the way. As I worked through the interviews, I kept noticing how certain ideas clustered together but were distinctive enough to be considered individual subthemes. This led me to group the subthemes into three broader contexts while still holding onto the ideographic focus of each person's account. I also chose this structure because the number of subthemes risked overwhelming the reader and organising them this way felt truer to how I made sense of the material. In presenting the findings like this, I am acknowledging my position in shaping the narrative as well as my intention to stay close to participants' experiences.

Although participants were not asked directly to describe their vision of an ideal care pathway for patients with cardiomyopathy (CM), comparisons between *what should happen* and *what actually happens* featured prominently throughout their accounts. Cardiologists often spoke about how practice would be in an ideal world when reflecting on the realities of clinical work, describing an implicit vision of a more coordinated, patient-centred service. Their reflections revealed how the quality of care they were able to provide was deeply influenced by factors beyond individual control, including service structures, resource constraints, and variations in professional knowledge across healthcare settings.

The contrast between ideal and real practice became a powerful site of reflection. Cardiologists frequently positioned themselves as striving to meet professional and moral standards of care while negotiating the compromises required by systemic inefficiency and limited time. These tensions shaped how they made sense of their roles and responsibilities, influencing both how they interacted with patients and how they perceived themselves as clinicians.

Figure 10 (below) illustrates the cardiologists' collective conceptualisation of an ideal care pathway during CM diagnosis in contrast to the realities they described. It demonstrates the multiple barriers perceived to limit their capacity to provide, what they considered to be, optimal care. It also highlights how these experiences are situated within a complex system of interacting professionals and organisations.

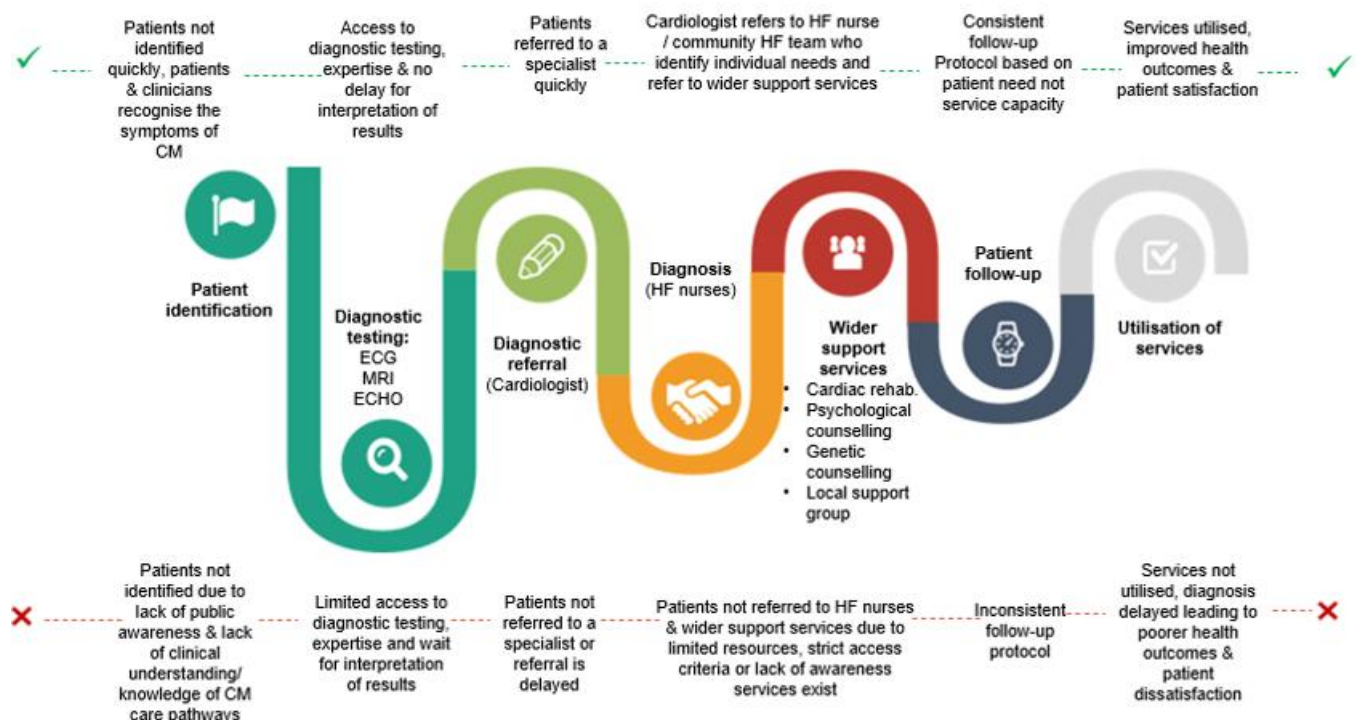


FIGURE 10. THE IDEAL CARE PATHWAY FOR NEWLY DIAGNOSED CARDIOMYOPATHY PATIENTS AND BARRIERS TO ACHIEVING IDEAL CARE, ACCORDING TO THE CARDIOLOGISTS.

5.2.1 Knowledge and Diagnostic Contexts

Cardiologists described significant barriers to achieving their ideal vision of care, including inconsistencies in service delivery, limited clinical understanding of cardiomyopathy (CM), and low levels of public awareness. These challenges were understood not as individual shortcomings but as symptoms of wider structural and cultural problems within healthcare. Participants often portrayed themselves as operating within systems that constrained their capacity to act, where organisational inefficiencies, resource limitations, and fragmented communication diluted responsibility for patient outcomes. The subthemes, **clinical and public understanding of cardiomyopathy** and **working culture**, explore how cardiologists made sense of these constraints; how they perceived knowledge and diagnostic practices to shape patient experiences, and how these realities challenged their ability to provide the kind of care they considered to be ideal.

5.2.1.1 Clinical and Public Understanding of Cardiomyopathy (Subtheme)

Cardiologists identified a lack of awareness and understanding of cardiomyopathy (CM) as a barrier to enacting ideal care. They described this in the context of both clinical and public understanding. First, gaps in clinical knowledge and uncertainty about referral pathways, especially in primary care and emergency departments, were perceived to delay identification and specialist review. Second, low public awareness and confusing clinical language shaped how patients understood what was happening and often heightened anxiety during diagnosis. In these accounts, cardiologists acknowledged that awareness of CM was pivotal in shaping who was investigated, how quickly referrals happened, and how patients made sense of their life-changing diagnosis.

Clinicians described a health system where patients relied on health professionals who might not have been informed about the availability of services and routes to care. Cardiologists highlighted how reliant patients were on General Practitioners (GP) and other healthcare professionals to help them “*navigate the system*” (Dr Nichols, 905), which were described as “*very difficult for patients to try and negotiate*” (Dr Nichols, 897–899). Cardiologists emphasised shared rather than individual responsibility, explaining that even well-intentioned healthcare professionals could struggle to orient patients within a fragmented service that was not well understood.



“Having a huge support network in place for people newly diagnosed with cardiomyopathy or heart failure is completely pointless unless everybody that’s involved with making that diagnosis, from nurse to GP to heart failure physician all the way to the top knows that there are those services are in place.” (Dr Cartwright, 917–923)

Limited familiarity with CM, particularly when symptoms resembled more common conditions, was seen to result in missed or delayed referrals. Participants described how common CM symptoms, such as breathlessness or fatigue, were often attributed to anxiety, asthma or infection, with cardiac causes only considered after deterioration or by chance during routine care. These accounts reflected the uncertainty and frustration cardiologists felt when witnessing what they viewed as avoidable diagnostic delays.

“She started going back to her GP in the summer with breathlessness and she’d been concerned that she’d wake up at night and she just was panicking because she couldn’t breathe. She was given diazepam for several months. Then one of her GP’s just decided to do a BNP which was 1400.” (Dr Christie, 397–404)



Here, Dr Christie expressed her unease with how a lack of specialist awareness or knowledge may have contributed to multiple missed opportunities for investigation or unnecessary progression of symptoms.



“A not uncommon path in this hospital is somebody comes in supposedly having had a heart attack and that kind of faction” (Dr Richards, 108–111)

“There’s a large population of people where heart failures diagnosed incidentally, you know. They come into hospital, they have a chest infection, someone for whatever reason does an echo, the echo shows LV [left ventricular] impairment... Then do those people all end up seeing cardiologists? Well, they should do, but they don’t” (Dr Nichols, 361–369)



Dr Richards and Dr Nichols highlighted a pattern of incidental diagnosis in acute, non-cardiology settings. In these accounts, identification of CM depended on non-specialists ordering cardiac tests, accurately interpreting results, and knowing when to refer to cardiology, creating several points where opportunities for further investigation could be missed. Their examples suggested that attention in busy hospitals was often directed to the most immediate threat rather than a less obvious underlying cause. Several cardiologists described this pattern as troubling, noting concern that identification did not always follow a consistent process.

Taken together, cardiologists described recognition of CM as depending not only on clinical skill but also on awareness, timing and the lens through which symptoms were interpreted. They linked this to a broader pattern in medicine: expertise could illuminate some features while screening out others. They acknowledged their own susceptibility to such blind spots and stressed the value of humility and comfort with uncertainty in day-to-day practice.



“We don’t know about all the diagnoses that we don’t know about, you know” (Dr Nichols, 377–379)

This comment captured a recurring awareness among cardiologists of the limits of their medical knowledge. They acknowledged that uncertainty was an unavoidable part of practice and that gaps in understanding existed at every level of the healthcare system. Rather than positioning themselves as immune to error, they viewed recognising these gaps as a sign of professional maturity and an important part of safe clinical decision-making.

“It was very much something that I found, didn’t understand, went to speak to my bosses who equally I got the impression just, sort of, superficially understanding what was going on.” (Dr Richards, 31–37)



Cardiologists also noted that the first point of contact could set the investigative path because specialists tended to read the same symptom through the lens of their own expertise.



“The first thing I think about is heart failure because that’s my world... the first thing the lung doctor’s going to think about is it must be your lungs. So, the person that you meet is critical” (Dr Nichols, 381–394).

Participating cardiologists diverged on solutions. Some framed the issue as a training deficit across the care pathway, while others questioned the feasibility of expecting more from already stretched generalists. This tension reflected a wider pattern in the interviews, where clinicians acknowledged a need for change but felt the responsibility for enacting change lay beyond their individual remit.

“I think you need better education for GPs. You need better education for people. You need public awareness. You then need better understanding in the district general hospitals and in the tertiary centre, so the network hub and spoke model, so you need each public health, primary care, secondary care, tertiary care, it needs to be better in all those areas” (Dr Garcia, 347–354)



“They’ve [GPs] got so many things that everyone would like to train them on, but actually I’m not absolutely convinced that that’s the solution. They don’t have time. They’re too busy” (Dr Nichols, 439–443)

Clinical language emerged as a second, interconnected arena where knowledge and understanding shaped experience. Clinicians reflected on how broad or emotionally charged labels organised clinical thinking and set patients’ expectations. Several cardiologists considered terms such as *heart failure* and

cardiomyopathy insufficiently specific for clinicians and unnecessarily alarming for patients, requiring translation.

“Heart failure means that your pump is inefficient and is inadequate to maintain a circulation required by the body’s metabolic needs. Cardiomyopathy is one cause of heart failure and it’s a relatively rare” (Dr Wallis, 345–360)



“So, once you’ve explained to them [patients] that the term heart failure, which often by non-heart failure doctors, has been used without thought, once you explain to patients that the heart is a bit weakened and that’s why they get breathless when they try and do stuff but not necessarily mean that the heart is going to stop, then they are often much less stressed than they were” (Dr Cartwright, 160–170)

Similarly, the term *cardiomyopathy* was considered inadequate for physicians and potentially confusing for patients. Dr Cartwright suggested avoiding the term altogether as it was insufficient as a stand-alone clinical label and was *“not specific enough to be that helpful” (Dr Cartwright, 741–742).*

“I would explain that the diagnosis is not really a diagnosis. It’s a descriptive term... cardio/heart, myo/muscle, pathy/problem, technically a heart muscle problem. You often see that people go, oh, okay, I get it.” (Dr Richards, 302–310)



Cardiologists worked to pre-empt patients’ distress when educating them about their CM diagnosis, especially given that service structures required the use of these clinical labels. For example, the inclusion of heart failure nurses within a care team made such terms unavoidable.



“It’s a condition that’s got a very unfortunate name and it’s called heart failure. I have to use that phrase because that’s what it’s called and I’m going to be getting you in touch with our heart failure nurses and they have heart failure on their badge, so it’s a scary term and please don’t switch off when I use it because we have to.” (Dr Christie, 249–259)

“They say, ‘well, you haven’t told me that my hearts failing’ and the problem is that heart failure is such an awful term. It sounds like you’re going to die, to a lot of people, you know, your heart is going to fail, meaning it’s going to stop.” (Dr Nichols, 110–117)



From an interpretative standpoint, these moments captured clinicians' efforts to hold together accuracy, compassion and institutional requirements. Rewording as a "heart muscle problem" or preparing patients prior to encountering emotive labels functioned as small acts of care within constraint. At the same time, participants remained cautious about relabelling services, worrying that local changes might create wider confusion.



"I always put a sort of, proviso on that by saying, 'look heart failure doesn't mean your heart is going to stop. It is just a bad name that we've got, and we have to deal with it.' In fact, you could call them the heart inefficiency team or the heart pumping problem team or something. Actually, people then accept it far better"
(Dr Nichols, 117–129)

Cardiologists highlighted how current awareness, knowledge and language surrounding CM actively shaped (and limited) the CM diagnosis experience. Variability in clinical understanding of CM, service navigation, and the use of terms such as heart failure and cardiomyopathy could determine who was investigated, how quickly referrals proceeded, and how patients made sense of a new diagnosis. These barriers were not expressed in isolation; it was acknowledged that wider NHS working culture and responsibility structures intersected and contributed to these barriers. The next subtheme turned to this NHS working culture and considered how everyday workload, coordination across teams, and role expectations further pulled practice away from idealised standards of care.

5.2.1.2 Working Culture (Subtheme)

A silo working culture was perceived to exist, whereby tertiary cardiac centres were viewed as superior because of variations in familiarity with, and expertise in, CM across other settings. From the outset, cardiologists described a diffusion of responsibility across the pathway: tasks were passed between services, ownership was diluted, and gaps were normalised as systemic rather than individual. Although cardiologists felt these variations led to perceptions of poorer care outside tertiary centres, they often reported being unwilling or unable to overcome them - an issue that could be seen to compound the problem.

CM diagnoses were generally perceived to sit within a hierarchy of services, with tertiary centres valued over primary and secondary care. Dr Garcia indicated a hierarchy of expertise when he described the CM diagnosis process as something that “most of the time isn’t done very well” (Dr Garcia, 44–47).

Cardiologists working within tertiary centres were perceived to have more expertise in CM and to diagnose more accurately than physicians in other settings.

“I certainly see a lot of people who’ve been seen elsewhere who’ve either been given a label of cardiomyopathy that they don’t have or told they don’t have it when they do have, so often people get the diagnosis wrong” (Dr Garcia, 62–68)



Cardiologists noted how this diffusion of responsibility became visible at handover points. Patients were perceived to be lost to follow-up when they were passed back from tertiary centres to local cardiology services, which might not have had the infrastructure to monitor CM unless complications emerged.



“If they (patients) are stable and you have explored the genetic option and they are fully educated then you default back to the local follow-up until they develop a symptom or until they develop something else. If everybody already had a more mature service and has got that in place, then great. I’d be surprised” (Dr Richards, 277–288)

This highlighted how continuity of care could be undermined by inconsistencies in CM knowledge and systems outside tertiary centres. Dr Richards also implied that low case volume and limited exposure contributed to a lack of felt responsibility for managing CM patients and upskilling non-specialist clinicians in community settings.

“They [GP’s] do understand that it’s not something that can be dealt with by everybody because if you see five patients per year you don’t do it very well, you don’t understand it, you don’t keep up to date, you can’t explain things properly, so there is an understanding that everyone will be referred into a specialist unit where you can do these things” (Dr Richards, 180–191)



Researcher's Reflection:

The data was somewhat limited by my inexperience as an interviewer. It would have been interesting to know with certainty whether cardiologists took steps to re-educate those in other healthcare settings about CM following their claims of misinformation for example. However, I didn't explicitly ask this. Upon reflection I think this was due to it being my first set of interviews so inexperience may have limited my appreciation of how rich the data needed to be. I also believe that unconscious social hierarchy may have played a role. Although I did not disclose my patient status to the cardiologists I interviewed, I obviously was aware of that fact which may have subconsciously prevented me from challenging or asking more of the cardiologist – a figure of higher authority and status than myself. Lack of confidence and insecurity due to my inexperience as a researcher probably added to this feeling of inferiority. I had identified that my experience as a patient, and the social structures associated with the doctor-patient dynamic could become a barrier to data collection. It is for this reason that I decided not to disclose my patient status to Cardiologists in phase 1. However, I underestimated the effect this knowledge would have on myself as the interviewer, which is important for me to recognise and learn from when considering future research projects.

Since all participating cardiologists worked in tertiary cardiac centres, their accounts of patient referral pathways may have only reflected those who had successfully been referred. Dr Garcia indicated that some patients were diagnosed locally before referral to tertiary care services.



"Because I'm in a specialist centre half of my work is from other cardiologists outside this hospital, so most of them would have been diagnosed before they come to me. "(Dr Garcia, 361–364)

In Dr Garcia's estimation, only half of his patients had been referred by other cardiologists, implying that the remainder were referred by non-specialist clinicians in services such as primary care. While this could have been read as the pathway functioning well, it did not account for patients who were not identified in primary care and therefore never received a referral. This pointed to an unease felt by cardiologists that risk was accumulating outside specialist settings through missed diagnoses and there being uncertainty about where clinical responsibility for those people should sit.

Where change was enacted, it was described at the level of individual clinics rather than the wider system. Dr Richards reported changing his follow-up protocol to address retention of information and early questions, taking local ownership of one gap in continuity.

“Something that I changed only two weeks ago was this idea that people who are well who get the diagnosis are seen again in a years’ time. Over the course of the last year or so I’ve actually engaged in quite a few follow up phone calls after about six to eight weeks because people never take in everything that you say” (Dr



Richards, 190–201)

By contrast, Dr Garcia highlighted the inadequacy of a 12-month routine follow-up for psychological needs but did not describe implementing a change, illustrating how recognition of a gap did not necessarily translate into local action:



“Where there’s medical need they’ll come back whenever they need to come back. If they’re...straightforward is a bad term, but if they’re straightforward, they might come back in a year and medically that works, but psychologically that doesn’t, and they probably would have lots of questions in the meantime.” (Dr Garcia, 274–280)

Across these accounts, cardiologists identified weaknesses in identification, referral and follow-up yet largely located responsibility elsewhere (primary or secondary care), accepting many issues as system limitations beyond their control. The result appeared as a culture of fragmented working, where services functioned in parallel rather than in collaboration and where accountability thinned as patients moved between settings.

In this subtheme, cardiologists described how siloed working, a centre-based hierarchy of expertise, and handover practices, together with diffused and unclear responsibility for change, pulled care away from ideal standards, particularly around follow-up and psychological support. The next section considered how these structural features interacted with barriers in communication and relational practice during CM diagnosis.

5.2.2 Communication and Relational Practice

This subsection of findings explores how communication, education and collaboration shaped cardiologists’ ability to deliver the service standard they considered ideal. Participants described how fragmented communication between services limited their capacity to respond fully to patients’ needs and

contributed to inconsistencies in diagnosis and follow-up. The subthemes, **multidisciplinary teams** and **disseminating cardiomyopathy education**, outlines how improved service connection via multidisciplinary teams (MDTs) and improved networks of dissemination, could increase continuity of care, promote CM education across services and increase patient satisfaction.

5.2.2.1 Multidisciplinary Teams (Subtheme)

Diagnosing CM was not viewed as a single event but as a process involving multiple professionals, as was shown earlier in Figure 10. Cardiologists felt that networks for sharing patient information needed improvement. Dr Nichols described how issues around data ownership and sharing sometimes compromised care, noting that patients coded with heart failure in GP records were not always referred to a cardiologist. He also explained that scan images were often stored separately depending on who owned the equipment, limiting access and resulting in repeat scans that were both costly and inefficient.

“We know that there are GP practices where there are patients who are coded as having heart failure who have not been referred or have met a cardiologist... Sometimes community echo services are contracted out by commissioners, so a GP, for example, might get a report [but]... the pictures can’t then be looked at...we have to repeat the scan because who knows where they’re stored.” (Dr Nichols, 280–459)



Dr Nichols proposed that a national electronic records system would allow patient data to be accessed across all services and would make it possible to audit who had been reviewed by a cardiologist. He acknowledged that political, legal, and funding barriers currently prevented this from being achieved.



“If there were national systems then you could audit who has and hasn’t had a [heart failure] review, but ... you know, that needs a political will and it needs to be sorted out at a level that is beyond what an individual department could do” (Dr Nichols, 475–489)

Cardiologists described how stronger communication networks could help overcome these barriers. Their vision of ideal care often centred on multidisciplinary teams (MDTs), which were well established in tertiary cardiac centres. These were seen as creating “flexibility in the service” (Dr Christie, 550) and as providing professional support.



“[It’s] how everybody does it, we all pull together, we’re all one big team.” (Dr Christie, 551–553)

Working collaboratively helped cardiologists offset the frustrations of systemic inefficiencies. Dr Christie recalled using personal contacts to accelerate a patient’s care when standard pathways failed to meet her needs.



“I phoned the heart failure nurse up there and she saw the lady in her lunchtime ... I suppose the thing is that when you know people and work with people then you call in favours infrequently, sometimes that can be done” (Dr Christie, 429–441)

This example illustrated how collaboration could bridge fragmented systems and unite professionals across disciplines in both practical and intellectual ways. MDTs also helped patients access additional services by navigating layers of care and addressing gatekeeping barriers. Dr Cartwright described how heart failure nurses often coordinated access to wider support, including psychological care.

“The first stage is to see a heart failure nurse...but often the psychology services are accessed by the heart failure nurses. So, if you don’t know there are heart failure nurses available you won’t know to refer that patient...and then they won’t have access to psychological services...often it’s the first stage the patient needs support from nursing support initially then if that isn’t enough then they go onto the third [next] level of support.” (Dr Cartwright, 985–999)



Dr Cartwright described this as a tiered model of care, but one that depended on efficient communication between services. If patients were not directed to heart failure nurses, they often missed opportunities for psychological or practical support. MDT collaboration was seen as key to ensuring these networks functioned effectively.



“The problem is that often the non-specialist making the diagnosis won’t use these nurses, partly because they don’t know they are available and partly because they don’t have the insight into the complexity that the condition is and they give the diagnosis, tell the GP what to do and move on. And that’s often done incredibly poorly.” (Dr Cartwright, 275–282)

Access to a range of expertise within MDTs was also viewed as a major advantage for both patients and professionals.

“I’m quite lucky I have a consultant geneticist in my clinic, so if there’s PGD or particular specialist genetics they can see. We have a psychologist within our service, so for those who’ll benefit from that we involve her. Then there’s the whole, you know, whatever else they need really” (Dr Garcia, 299–306)



Patients also benefited directly from coordinated MDT working. Clinics designed for inherited cardiac conditions (ICCs) were seen as examples of good practice, enabling patients to see multiple specialists in one visit and reducing the burden of repeated appointments.



“We have very much the concept of an ICC, inherited cardiac condition, an ICC team here and we have a big multidisciplinary clinic where we have pretty much every aspect of care for a patient that you would want, predominantly focusing on medical care, so electrophysiologist, interventional cardiologist, imaging cardiologist, sport cardiologist, clinical geneticist, specialist nurse.” (Dr Richards, 965–978)

Cardiologists saw multidisciplinary collaboration as central to their ideal vision of care. It provided structure, shared responsibility, and opportunities for learning while helping patients access a more seamless and compassionate service.

These accounts positioned MDT working as a practical solution to managing system gaps: it distributed expertise, streamlined handovers, and created clearer routes into psychological and specialist support. In the wider tension between ideal and real care, MDTs functioned as a key facilitator, even though structural constraints limited how far they could go. The next subtheme examined another relational function within CM diagnosis; how CM education was disseminated across services and delivered to patients.

5.2.2.2 Disseminating CM Education (Subtheme)

Another barrier to ideal standards of care was the perceived lack of infrastructure for disseminating ongoing cardiomyopathy (CM) education across settings. Several cardiologists described limited opportunities for re-education and variable motivation among clinicians to engage with it.

“I wouldn’t say there’s none, but it’s still to say there isn’t enough [ongoing medical education regarding CM]...it takes for you to tell them they need to know something for them to appreciate that they need to know something.” (Dr Richards, 880–888)



Dr Richards suggested that more community-based training could support general practitioners (GPs) to navigate local pathways, particularly by knowing where heart failure nurses were based and how to contact them for advice. He proposed that heart failure nurses could deliver local education and training. However, this risked oversimplifying the problem and adding pressures on overstretched clinicians. GPs also could not be expected to maintain specialist knowledge across all conditions while managing heavy workloads. An alternative perspective was that educating GPs on where and how to access specialist input might be more useful than attempting to teach detailed specialty-specific content.



“Yes, one of my to-do lists, which is very, very, very long, was to go into the community. I wanted our specialist nurses to go into the community and educate as well.” (Dr Richards, 813–818)

In line with this, Dr Cartwright indicated that nurses were well placed to attend educational events and share learning, possibly because nurses were perceived to have “more time” (Dr Wallis, 289) than cardiologists.

“I delete almost all emails ... so it’s not going to be per email ... The way to do this was to have organised educational sessions ... governance sessions, audit meetings ... our nurses were encouraged to meet with them on a regular basis ... Face-face meetings ... were the best way to get information across.” (Dr Cartwright, 965–975)



Engagement itself was a considered a recurring difficulty. Dr Richards recalled limited participation in national CM training events, arguing that stronger communication networks and easier access to

education were needed. Without change, the same centres that regularly engaged would continue to be the ones staying current, risking widening gaps between specialist and non-specialist clinicians.



“You went to the national conferences; you saw the same people from the same places at every meeting and this was here supposedly everyone was being updated about developments in this and developments in that and end treatments. The same people went and they were from the same 15 hospitals.” (Dr Richards, 255–263)

None of the cardiologists discussed how they maintained their cardiomyopathy education. Dr Cartwright did identify his need to ‘keep abreast’ of the latest developments in cardiomyopathy care but described how he gave the lectures rather than attended as a listener.

“And as a part of that my job is to keep abreast of what is going on in the field so I tend not to... I mean I go on courses, but I tend to give the lectures rather than listen...” (Dr Cartwright, 63-66)



This provided little insight into the learning practices of consultant cardiologists. It could be argued that the lack of interest or acknowledgement of participants’ own learning needs may be a contributing factor to the problems of expertise sharing that they themselves found problematic.

Dr Garcia agreed that linking physicians in tertiary cardiac centres with colleagues in secondary and primary care could improve access to ongoing CM education. Efficient regional networks were seen as essential to share information about available services, access criteria, and emerging clinical developments. He suggested inviting local cardiologists with an interest in inherited cardiac conditions into specialist clinics or shared learning spaces so they could cascade their learning within their services.



“So, you needed more people trained in it. You needed networks that were efficient. You needed to have bespoke networks where in the general district hospitals you had someone who took an interest in inherited disease, and they linked in with a specialist centre. (Dr Garcia, 96–100)

Dr Richards also believed that hosting education within tertiary centres, where best practice could be demonstrated, would encourage shared standards and approaches to CM care.

“We had a dedicated full session to say this was what [the hospital] offered for all inherited cardiac conditions and it was for all cardiologists, anaesthetists, general medics, all ...came along and saw what was available.” (Dr Richards, 866–873)



Finally, Dr Nichols recalled how incentivising behaviour had improved practice in other areas (e.g., blood pressure checks in primary care). He suggested similar incentive structures could be explored to support CM education and attendance at training, while acknowledging funding constraints.



“I thought the thing that GPs responded to was having targets of income and that did seem to have worked in particular ways. For example, they got additional money for doing certain blood pressure checks and things, so they worked out their practices, they worked out their business to do that and that worked.” (Dr Nichols, 445–453)

In sum, dissemination of CM education was perceived to be hindered by limited infrastructure, variable engagement, and competing pressures on clinicians’ time. Participating cardiologists proposed practical solutions: nurse-led local teaching, stronger local–tertiary networks, cardiac centre-based demonstrations of best practice, and selective incentives, with a view to narrowing knowledge gaps and standardising care. The next sub-theme will explore cardiologists’ felt professional responsibility and emotional demands of working within an imperfect health system.

5.2.3 Professional and Emotional Experience

This subsection explored the emotional and professional demands placed on cardiologists as they strove to balance the physical and psychological needs of patients with cardiomyopathy (CM). Subthemes, **Emotional Labour** and **Moral Injury** outlined how participants described their work as both rewarding and deeply challenging, marked by a constant negotiation between clinical responsibility, personal empathy, and the realities of an imperfect healthcare system. The gravity of their role, coupled with the awareness of systemic limitations, often left cardiologists feeling unable to meet their own standards of ideal care. This internal tension was interpreted as generating significant emotional burden and a sense of moral discomfort that was rarely acknowledged within their professional environment.

5.2.3.1 Emotional Labour (Subtheme)

Cardiologists recognised the psychological and wider social implications that a CM diagnosis had for their patients. Some described how patients must “*carry the diagnosis for the rest of their lives*” (Dr Cartwright, 695–696), identifying it as a heavy burden. They also described the challenge of balancing psychological and physical needs within an imperfect healthcare system, which they perceived resulted in emotional labour that was not often recognised. Dr Garcia highlighted the “*three dimensions of health*” (Dr Garcia, 155–156) and emphasised the need to consider all three (physical, psychological, social) across the CM diagnosis journey.

“What I like is this, sort of, three dimensions to health, so you do the medical, physical side, but you need to do the social side, where do you live, do you need benefits, all of that and you need to do the psychological side, so it’s like this three-part pronged approach to everyone.” (Dr Garcia, 155-161)



This exemplified clinicians’ ongoing work to integrate psychosocial needs into clinical pathways. Cardiologists also considered patients’ individual circumstances, how the diagnosis could affect patients in different ways in different life stages.



“So, it’s very difficult – each person is an individual and you have to respect each individual’s needs, requirements and ...the impact it might have on them...[A diagnosis of CM] has implications for mortgages, insurance and jobs...they are... going to run into trouble going on holiday to Ecuador or going mountain climbing and stuff like that” (Dr Cartwright, 543-701)

Here, emotional labour appeared in the form of anticipatory guidance and practical problem-solving around social consequences of diagnosis. Cardiologists spoke of the need to balance physical care with preserving quality of life and psychological wellbeing.

“You’ve got all these medical worries, but you’ve also got the ones that you’re worried about psychological health” (Dr Richards, 1027-1030)



“Then there’s a group of patients that psychologically really struggle with their diagnosis or their device” (Dr Garcia, 126-128)

These remarks illustrated how cardiologists' routinely monitored mood and meaning making as part of routine care, a core component of emotional labour. Cardiologists recognised particular challenges for patients who required device therapy, especially ICD implantation. Dr Christie described the psychological turmoil associated with actual or anticipated shocks and noted the value of psychology input.

"A lot of people with ICD's... Some people are really desperate for it to go off so they know what it feels like and ... other people if ever it's gone off spend the rest of their life thinking, 'is that ever going to happen again?'"



That's why it's important to have psychology input as well" (Dr Christie, 811-823)

This exemplified the ongoing, anticipatory containment and reassurance work cardiologists undertook. An emotional labour that sits alongside, but is not captured by, procedural checklists. However, not every physician regarded psychological wellbeing as part of their role. Both Dr Nichols and Dr Garcia suggested that routine psychological enquiry was uncommon outside dedicated services.



"I think, so doctors in particular aren't very good at this. So, even at a very simple level just saying, how are you psychologically, most people don't do that. So, I think people need to ask the question" (Dr Garcia, 147-151)

"I think lots of people don't think it's their job. They think it's someone else's job. I think a lot of people are very

busy, you know, GPs are sometimes too busy to do that" (Dr Nichols, 979-984)



Dr Garcia nonetheless viewed psychological wellbeing as equally important to other health needs and expressed frustration about it not currently being embedded within mainstream cardiology care.



"When you see them [patients], you know mental health should be a vital sign in the same way that blood pressure and pulse it, so it's trying to mainstream psychological health really is the challenge, I think." (Dr Garcia, 161-165)

This pointed to mainstreaming psychological awareness as routine clinical work, reinforcing emotional labour as standard healthcare rather than an addition reserved only for exceptional cases. Dr Garcia noted the bidirectional effects between psychological and physical health and drawing parallels with other long-term conditions.

“Anyone with these long-term conditions...40% will have anxiety or depression or something and certainly there’s some good evidence in other long-term conditions...if you treat the underlying psychological issues, sort of, actual physical outcomes are much better.” (Dr Garcia, 173-181)



Here, Dr Garcia again framed attention to distress as clinically consequential, not merely a compassionate add-on to standard care. Dr Nichols echoed the need to consider psychological and physical health together, reflecting on how clinical experience had broadened his view beyond his training which had focused on physical health.



“There is no point of having reasonable physical health and poor mental health or poor psychological health. You have to have both... I’m trained in physical health, but I know that if my patients aren’t happy, well it doesn’t really matter what outlooks I’m giving them.” (Dr Nichols, 911-922)

Dr Richards also recognised these bidirectional effects. He theorised that heightened awareness of chest sensations after diagnosis could fuel anxiety and misinterpretation of benign symptoms, a point developed further in Chapter 6.

“Symptoms that they have that would normally be dismissed all the sudden become a source of anxiety and a source of panic ...I reckon that half of the people that I see with a new diagnosis have...symptoms that are anxiety related disorder” (Dr Richards, 493-507)



This underscored the interpretative work cardiologists undertook to differentiate anxiety-driven symptoms from cardiac symptoms. Dr Richards also used a war metaphor to demonstrate his insight and understanding of his patients’ experience during diagnosis.



“Once you get a bit of distance from ground zero it becomes more manageable... there’s a great analogy about Londoners in the Second World War... when you’re told there’s a bomb coming you panic... but the last 14 bombs landed over there... and didn’t get you, so I’m alright.” (Dr Richards, 590–611)

“Ground zero” positions diagnosis as a significant rupture point in his patient’s lives. He perceived that distress becomes more manageable over time, not because danger disappears, but because people recalibrate their alarm system. “The last 14 bombs didn’t get you” sounds like a pragmatic coping strategy used to create a sense of safety amidst ongoing uncertainty. The analogy validates the scale of

threat and emotional labour CM patients endure, while normalising the shift from acute panic to routine vigilance over the course of the diagnostic journey.

Researcher's Reflection:

I interpret Dr Richards' war metaphor as an attempt to position himself within the diagnostic experience - joining patients to acknowledge fear while normalising how the threat becomes more bearable over time. I recognise that others might interpret the same metaphor as minimising distress, especially given its "Blitz spirit" undertones. This is a double hermeneutic as I am interpreting his interpretive act. My interpretive lens is shaped by my clinical work as an assistant psychologist, where I support patients to identify and *hold* uncertainty. That lens likely sensitises me to metaphors that legitimise ongoing ambiguity rather than promises resolution.

On the availability of wider support services such as psychology teams, Dr Wallis described a robust local service at his tertiary centre but suggested that not all centres prioritised investment in this area.

"I think it's pretty robust at the present time, but I think different centres put a different amount of effort into it."

"We've made a particular effort to make sure that there are appropriate supports for patients here" (Dr Wallis, 459–464)



Dr Christie noted that improved access to psychological support services for CM patients remained on her *wish list*, implying current provision was insufficient.



"That's one of the things that's been put into my wish list of how I would like things to be, would probably be more access to psychology" (Dr Christie. 834–839)

Researcher's Reflection:

The widespread identification and recognition that patients' psychological needs are not being met within the current system indicates a systemic change in what is considered "health", and what responsibilities are involved in a robust healthcare service that is fit for purpose. One example of this shift in attitude was captured during Dr Richard's interview where he was speaking about a "stable" group of patients but then felt the need to clarify that he was speaking about a medically stable group, not necessarily psychologically stable group. This clarification was interesting to note as he considered it was important distinguish that one does not necessarily reflect the other and showed real insight into the psychological wellbeing of his patients.



"We're generally dealing with a quite stable patient group, like, medically stable group." (Dr Richards, 220-224)

Dr Nichols described difficulties accessing psychological services on behalf of his patients, largely attributing these difficulties to funding and historical norms that placed limited emphasis on psychological health within cardiology. He implied that physicians needed to *care* enough to advocate for their patients and invest effort and time into identifying routes of support for them.

"We don't have good counselling services... support organisations are underfunded. All mental health is underfunded, but ...I think it falls on the people who you're meeting that actually you hope that that's someone who's going to care" (Dr Nichols, 990-998)



This suggested that clinicians who sought to address their patients' psychological needs by making a referral to psychological services carried additional work and emotional labour as they navigated systemic barriers. It further implied that the system risked discouraging deeper, empathetic care, as it was easier to focus on narrow professional tasks than to pursue support pathways that were hard to access.

Dr Nichols continued by noting that current services targeted only the most in-need patients, leaving many without support.



“The service only exists for the people who are, you know, the most in need, but there is a lot of people who fall just below that threshold who have got needs that are not being met” (Dr Nichols, 1005–1009)

He argued that wider psychosocial support could strengthen confidence in the diagnostic process for all patients, not only those meeting clinical thresholds.

“I was really thinking about the mental wellbeing for everybody, that you make sure that everybody is okay. There are lots of people who may not be clinically depressed but still need...to feel that they’ve got to have confidence in the process” (Dr Nichols, 950–962)



Overall, cardiologists outlined how gaps in psychological provision affected newly diagnosed patients and demoralised and deterred clinicians. Attempting to balance physical and psychological needs within an insufficient system appeared to generate ongoing emotional labour and extra responsibilities.

5.2.3.2 Moral Injury (Subtheme)

Cardiologists discussed the high level of responsibility felt for their patients’ wellbeing. Holding a position of authority within the physician-patient dynamic, cardiologists felt duty-bound to acknowledge their role in patients’ diagnostic experiences and aimed to care with compassion, empathy, and accountability. Participants reflected on the moral ambiguity of invariably causing some level of harm or difficulty for patients in their pursuit of diagnosing and treating CM. Cardiologists acknowledged the social and psychological implications of care but also the inevitable balance of short-term (or low-level) physical discomfort to gain long-term (or greater) physical health benefits. This insight arguably led to an internal struggle of morality and ethics which could negatively affect physicians’ own wellbeing. For the purposes of this thesis, the term *moral injury* was used to reflect this internal conflict and resulting psychological burden in relation to the cardiologists interviewed.

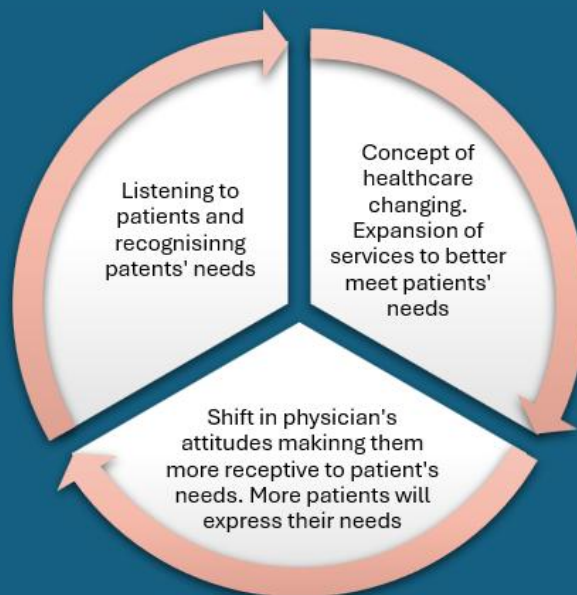
Dr Christie recognised that as physicians have become more knowledgeable about CM over time, they have gained insight into the wider effects of diagnoses and treatment. She further implied that understanding has grown through listening to patients.



"I suppose, with the way we understand cardiomyopathy has changed, how it affects people, how it may affect families. We didn't really have much of an understanding (before)" (Dr Christie, 97-101).

Researcher's Reflection:

Dr Christie's comment suggests a cyclical shift in attitude towards the concept of health. Physicians have listened to patients and recognised the wider impact of the care they provide, both generally and specifically in relation to CM diagnoses. This has led to the expansion of health care services to address these additional needs. In turn, the attitudes of physicians have changed, making them more likely to be receptive to their patients' needs. Subsequently, this creates an environment in which patients feel more comfortable sharing their experiences.



As understanding grew, physicians appeared more aware and reflective about the impact of their care.

This evolution came with added burdens, as empathetic care required personal accountability and human relatedness. Cardiologists pointed to feelings of vulnerability and emotional investment when recalling memorable patients.

"Immediately their faces jump into my head and they're young and they're panicking" (Dr Richards, 520-525)



"She had two young kids, so that tears on your heartstrings, and therefore everybody went slightly above and beyond. We do it for most people, but every once in a while, there's people that stick out" (Dr Christie, 554-561)

They recalled patients who stayed in mind years later. Dr Richards described mental images of young, panicked faces. Dr Christie noted that some patients tore at her “*heartstrings*” and motivated care that went above the usual standard. Physicians’ emotional investment and their resolve to act with empathy affected their own wellbeing.

Cardiologists demonstrated empathetic care in how they described practice. Dr Christie tried to adopt the patient’s perspective and recognised service limits while aiming for honesty and openness.

“It’s hard because I don’t know how I’d cope if somebody told me I’d got cardiomyopathy. I think unless you’re actually in that hot seat you don’t really know...I hope we provide a reasonable service and I hope we try and give a fairly tailored service...at the end of the day, you have to be open and honest about what the diagnosis is and what the potential is” (Dr Christie, 717-723)



Similarly, Dr Cartwright implied concern that patients might feel alone, pointing to a residual ethical discomfort that they carry when care is not of ideal standard.



“I worry a huge amount that they think that they are going to be left on their own.” (Dr Cartwright, 891-895)

One example of insight was offered by Dr Nichols when discussing how he would explain the implications of an implantable cardioverter defibrillator (ICD). He acknowledged wider lifestyle effects and prepared patients for possible downsides despite the physical benefits.

“But now I have to tell you all the downsides about having a device’ you know, which is the shocks are painful and that there are lifestyle implications...I want it to be very clear for people that these devices...although they are lifesaving...they worsen quality of life” (Dr Nichols, 788-796)



Such insight appeared to affect cardiologists’ wellbeing because they felt responsible for consequences that might diminish quality of life, even when interventions were lifesaving.

Dr Christie discussed how moral injury affected physicians. They felt responsible not only for their own decisions but also for historical decisions within the profession. She reflected on medications now known to cause CM and on the current use of agents that carried risk where safer alternatives did not exist.



"I think we understand things more, and also you have to bear in mind I suppose as medics we're causing more cardiomyopathy with things like Herceptin and chemotherapy agents that are new... There's a recognition of the stuff that we gave people 15, 20, 30 years ago actually can cause long term problems and now we're actively searching out for those people" (Dr Christie, 131-152)

She also described feeling uneasy about holding knowledge that patients might not possess, particularly when it was not possible to identify or inform individuals who could need screening.

"As a clinician you feel a bit awkward [knowing] there's someone sitting out there who potentially should have some screening, but you don't know who they are or where they are" (Dr Christie, 228-234)



Dr Nichols described the need to be guarded at diagnosis. He considered that sharing too much information before sufficient data were available could harm wellbeing, so he filtered what he disclosed.



"I tend to be guarded, but I say, 'look, I don't know how this is going to go, but we're going to keep you under review...this is a condition you might die from, but of course you might get completely better', because I tend to feel that because this is a chronic condition time is going to show me which group someone is going to fall into" (Dr Nichols, 569-579)

He provided a further example when discussing treatment options. To protect patients from distress, he avoided raising options they would not qualify for, likening premature discussion to offering something and then taking it away.

"If I don't think someone should have a device I shouldn't, sort of...it's like giving, you know...saying to a toddler, 'look at this thing that you could have, oh but by the way I'm not giving it to you. I'm now taking it away from you' so I wouldn't even present it" (Dr Nichols, 754-759)



Dr Cartwright observed that some form of treatment was usually possible, which implied that a minority received no prognostic or symptomatic benefit. This limitation appeared to weigh on clinicians.



"There is usually most 90% of cases there is usually a change I can make that will have an impact on their prognosis and/or their current symptoms." (Dr Cartwright, 595-598)

These choices and trade-offs captured moral conflict embedded in routine practice. Interestingly, none of the cardiologists directly commented on their own wellbeing or described in detail how professional responsibilities affected their psychological health. This either was not widely recognised within the

profession or was difficult to discuss. Instead, they outlined responsibilities and patient challenges using empathetic language, implying emotional investment in care.

Cardiologists recognised the importance of empathetic care. Moral injury could be seen as arising when clinicians shared the burden of diagnosis yet faced constraints on delivering what they believed to be ideal care. At times, service structures offered relief by enabling referral to colleagues, as when Dr Christie described seeking continuity through nurse specialist input, which also appeared to protect her from sustained exposure to distress. This suggested team-based buffering of moral strain when individual capacity was exceeded.

“If somebody’s struggling a lot then, I’m fortunate in that in several of my clinics I have one of my heart failure nurses in the next room...so if I’ve got somebody who’s cried on me or something like that I tend to go next door and get [them]” (Dr Christie, 300-310)



These sub-themes outlined how diagnosing CM left cardiologists managing professional responsibility and emotional labour. Cardiologists weighed physical benefits against psychological and social harms, navigated scarce psychosocial services, and carried a felt sense of residual responsibility for historical and systemic limits. These tensions illustrated the wider superordinate theme of ideal versus real, in which clinicians aimed for ideal standards of cardiomyopathy care while working within imperfect structures that constrained its delivery in practice.

5.3 Barriers to Shared Decision-Making (*Superordinate theme*)

This superordinate theme explored the challenges cardiologists reported facing when trying to achieve genuine shared decision-making with patients during diagnosis. Participants described how organisational constraints, professional obligations, and differing health expectations shaped their ability to involve patients fully in clinical choices. Limited time, staffing pressures, and funding restrictions often restricted opportunities for meaningful discussion, while medico-legal responsibilities such as informed consent and risk communication further complicated the process. Beyond clinical encounters, cardiologists recognised that decisions were also influenced by external factors such as the impact of diagnosis on employment, insurance, and family circumstances, which lay beyond their control. Six interrelated subthemes made up

this superordinate theme and are presented within the context of two key perceived barriers to achieving genuine shared decision-making when diagnosing CM: *organisational constraints* and *relational dynamics*.

Although participants acknowledged their authority and expertise positioned them as the dominant voice in clinical interactions, many described conscious efforts to involve patients and promote collaboration. They reflected on the importance of recognising and managing their own expectations and assumptions to align clinical recommendations with what mattered most to the patient.

Cardiologists also noted that the nature of medical decision-making had evolved over time. Patients were increasingly well-informed, more confident in expressing preferences, and more likely to question medical advice. For many, this shift represented a positive change towards partnership, but it also required new communication skills and flexibility to balance professional responsibility with patient inclusion.



“We’re hearing things that we probably didn’t hear 20 years ago. If the doctor had told my grandmother to stand in the corner for three hours she would have done without question because, you know, that’s what the doctor said. The generations fortunately are changing massively. If you’ve got somebody who’s vocal and articulate that makes a huge difference, I think.” (Dr Christie, 898-909)

Dr Christie described this change as a fortunate, positive thing which could have reflected a similar movement within clinicians’ attitude to shared decision-making and aligned with the NHS agenda to encourage self-management in chronically ill patients. It could also have explained why some older patients were less inclined to challenge clinicians or seek clarification for information they did not fully understand. It is important therefore to consider age and other factors when encouraging patients to contribute to discussions regarding care decisions. Cardiologists described how there was *“a clear art”* (Dr Garcia, 51) to decision-making, implying that it required practice and a refined skillset.

5.3.1 Organisational Constraints

Cardiologists described how organisational pressures and structural challenges within the NHS, such as short consultation times, lengthy gaps between appointments, and funding priorities, often restricted patient choice. Participants reflected that these constraints shaped not only how decisions were made but

also who had the opportunity to contribute to them. Cardiologists often felt caught between doing what was best for the individual patient and working within policies designed to maximise benefit for the most people. This tension left some feeling conflicted, as professional and ethical ideals of personalised care were frequently compromised by the realities of service demand and limited resources.

5.3.1.1 Professional Responsibilities (Subtheme)

Professional responsibilities such as obtaining informed consent and managing clinical uncertainty were perceived as central to shared decision-making. Patients were reliant on clinicians to provide pertinent information so they could meaningfully contribute to discussions about care. Clinicians were often tasked with deciding what to share and when, balancing the need to inform while protecting patients from unnecessary distress or confusion. Some described pacing information over time rather than providing everything at first contact, noting how prognosis wasn't usually be discussed until *"three to six months later"* (Dr Nichols, 208–219). They also noted an avoidance of giving fixed probabilities when discussing potential prognostic outcomes, reflecting active debate about how best to frame uncertainty.

"I would say, 'someone with your level of heart functioning is at risk of dangerous heart rhythm abnormalities and those heart rhythm abnormalities can result in people dying suddenly and that could be you.'... 'but the greatest likelihood is that won't be you, but it could be you and we know the risk of that happening to you is higher than someone who doesn't have severe heart problems'" (Dr Nichols, 769–781)



This explanation remained deliberately vague to communicate the existence of risk whilst remaining cautious of giving any precise quantifiers. This demonstrated a felt unease at assigning probabilities when prognosis was unknown or subject to change over time.

Shared decision-making relied on a shared understanding of relevant information. Cardiologists stressed the importance of doctor–patient communication during diagnosis, with one participant describing it as *"vital, absolutely vital"* (Dr Wallis, 435). At the same time, they differed on whether communication could be taught effectively across a career, and whether developments in medical training over time had led to increased emphasis on communication skills training.



"I think doctors are much better at communicating... medical schools spend far more time... they are better communicators and worse diagnosticians... when I was training, we had one week... whereas now... close to 30%... So, I'm not sure that more training is what's needed" (Dr Nichols, 1065–1089)

The suggestion was that medical training had shifted towards communication skills, creating a generation of physicians who were stronger communicators than their older counterparts. However, Dr Cartwright considered communication to be an innate skill that either came naturally or never developed.

"It comes naturally, or you just never get it. There are 50-year-old consultants that have been consultants for 30 years and they are crap communicators...they've been on communication courses and they just don't get it" (Dr Cartwright, 242-250)



Dr Cartwright suggested that some clinicians were fundamentally incapable of being good communicators. His statement also implied that poor communication did not necessarily preclude being a good doctor, which sat uneasily alongside his earlier assertion that *"information is key"* (Dr Cartwright, 936) during diagnosis. Dr Nichols shared the view that more training for established consultants was not the primary solution, arguing that improvements at junior level had already raised standards overall, though possibly at the expense of other aspects of training. Both Dr Nichols and Dr Cartwright implied that many modern physicians tended to be either strong diagnosticians or strong communicators, but not often both. Further research was needed to identify gaps and ensure training pathways developed well-rounded consultants.

Communicating information was seen to be especially important (and challenging) when patients chose to disengage. Cardiologists balanced patients' wishes with their responsibility to ensure informed choices.



"There are some people who just go, '...I'll take my chances doc' ... that is what consent process is ... [ensuring patients] ... go into it with their eyes wide open ... the people that decide they don't want to come on the journey have had enough information ... that is an informed choice..." (Dr Nichols, 802–820)

In practice, Dr Nichols indicated that he asked for a brief conversation, stating, *“we should at least talk about it for five minutes”* (Dr Nichols, 821-827) prior to accepting disengagement. This approach demonstrated his need to provide enough information to allow disengagement as an informed choice. However, there was no predetermined amount of information that constituted *enough* for such decisions. A five-minute conversation, while considered appropriate by Dr Nichols, might not have felt adequate to other clinicians, leading to variability in practice.

Cardiologists also acknowledged the weight of holding ultimate accountability for patient’s wellbeing and knowing that blame would be assigned to them should anything go wrong, reflecting the hierarchical structure within health services.

“It’s exactly the same way as...if we went to a hotel and we had a problem it is much more reassuring to go straight to the top, at least just once with our complaint or our concerns” (Dr Cartwright, 297–

306)



Wider consequences of treatment decisions were prominent in accounts. Dr Christie noted how device implantation, while beneficial, had longer-term implications for lifestyle, wellbeing, and future health. This example highlighted the mutual benefit of shared decision-making regarding treatment decisions as it ensures patients are suitably informed but also encourages self-management and renewed ownership of their care, unburdening cardiologists to some degree.



“It’s the whole lifestyle thing, which jobs you can and can’t do, how it’s going to affect you if you’ve got a device in, you know. Your device is going to last eight to ten years, how many box changes are you going to have, the risk of problems of leads and things like that over those years, so there’s all sorts of things to actually consider” (Dr Christie, 866–878)

Stratifying risk was described as one of the most challenging elements of practice, particularly given the constant uncertainty and the felt burden of potential adverse outcomes. Dr Richards described a *safety-net* mindset where probabilities could not be pinned down.

“I usually say what I have to do is assume the worst of whatever these diagnosis is and safety net, so that we are appropriately treating you with tablets, we are appropriately treating you with protection if we need to, things like a defibrillator...you have a risk and we can’t quantify it, therefore my inclination is to be safe with you” (Dr Richards, 670–686)



Here, precaution functioned as a communicative frame for uncertainty management within shared decision-making.

Cardiologists recognised that their position of authority within the clinical hierarchy left them with ultimate responsibility for managing patient risk and for enabling meaningful shared decision-making. This burden was not always acknowledged, generated unease, and contributed to variation in how clinicians disclosed information, paced discussions, and framed choices. The next subtheme considered how limited consultation time operated as a practical barrier that constrained shared decision-making in everyday practice.

5.3.1.2 Consultation Time (Subtheme)

Participants considered certain NHS policy decisions to have created difficulties for shared decision-making, particularly around consultation time. Although the NHS aimed to promote self-management and shared decision-making, cardiologists perceived that limited flexibility and few opportunities for extended discussion indirectly hindered these goals. Time itself was described as *“not an NHS resource”* (Dr Richards, 727), despite being necessary for understanding symptoms and formulating a diagnosis.

Cardiologists suggested that a standard 15-minute appointment was insufficient to provide appropriate care, especially once documentation requirements were included within the same slot. As Dr Richards noted, the expectation to record the consultation further eroded time available to patients.



“So, a standard appointment would be 15 minutes, which doesn’t give you much time to talk about anything, never mind document anything, so it was very much just do the risk stratification and see them next year” (Dr Richards, 48-55)

Time constraints further complicated cardiologist's ability to engage in true shared decision-making.

Participants emphasised that discussing options, particularly involving risk, demanded more time than allotted in a standard appointment because of the cognitive load and need for careful pacing.

"Discussing the risk stratification with people is actually far more challenging and nuanced than actually discussing the diagnosis of heart failure because ... you essentially...say, well, there's a chance that you might drop down dead...and is not something that you can do in a ten-minute consultation." (Dr Nichols, 718–733)



Limited time within and between consultations also introduced pressure on both clinicians and patients to make decisions quickly. In the context of long waiting lists, clinicians sometimes initiated referrals early to secure a place in the system while reserving the option to cancel later, which managed service constraints but risked rushing deliberation and considered discussion:



"Sometimes I'll say to them, 'we'll refer you on so that you're in the system, if your MRI comes back actually that the numbers are slightly better or you're not appropriate then we can always cancel the appointment'" (Dr Christie, 375-381)

These practices may have reduced delays and ensured timely access to treatment, yet they also risked patients feeling coerced or underprepared, with insufficient time to digest information, consider preferences, or ask questions. Participants implied that achieving an effective balance was difficult: insufficient time reduced opportunities for informed participation, while lengthy intervals between appointments were viewed as pressuring decisions to be made while patient and clinician were face-to-face. The next subtheme examined cardiologists' appreciation of the far-reaching social implications of a CM diagnosis and how this shaped their approach to shared decision-making.

5.3.1.3 Social Implications of Diagnosis (Subtheme)

Cardiologists demonstrated understanding of the wider social implications of a CM diagnosis and subsequent treatment. These factors were seriously considered alongside other risk factors during clinical decision-making. For those of working age, Dr Cartwright detailed many ways in which a patient's lifestyle could be negatively affected by a CM diagnosis and subsequent treatment, including the impact on their work, relationships, obtaining life insurance and securing a mortgage.

“The implications of cardiomyopathy...is driving, erm job... for the physical workers... they are often more limited, and they get tired more regularly...it has huge psychological effects. So yeah, that’s it so for younger patients it’s the effect on their job, the effects on their sex life...” (Dr Cartwright, 448-517)



Practicalities such as driving restrictions were also considered to affect younger patients more due to their diagnosis. Dr Cartwright, in particular, felt strongly that people diagnosed with CM were unfairly penalised by the DVLA and insurance companies due to a lack of understanding about the risk factors associated with their health. He argued that penalising those who were regularly monitored and on optimal therapy was counter-intuitive when there were other road users who might have been unaware or unwilling to address health concerns that were not penalised.



“The rules around HGV and PCV licencing don’t change that rapidly and are not based around any symptoms but they are based around cardiac function. So if you are a young bloke that has got no symptoms but are taking a shed load of tablets and have a weakened heart, it is really difficult to maintain your HGV licence even though you may actually be fine” (Dr Cartwright, 472-479)

Dr Cartwright was keen to point out the challenges faced by CM patients because of companies not understanding risk factors or the condition well enough. He claimed that entities such as DVLA and insurance companies were so risk averse that they placed blanket bans on anyone with certain health conditions regardless of their actual risk level. He felt this was due to a lack of understanding about CM and how risk levels are determined. Such companies appeared to operate on a population-based decision-making rather than individualised decision-making which Dr Cartwright felt led to injustice.

This also pointed to a fundamental problem with insurance policies as the current requirements to declare health conditions could lead to patients not wanting to be tested, diagnosed, or treated for life-threatening conditions due to sanctions when obtaining insurance, a mortgage or a driving license.

Lifestyle factors such as these are arguably becoming more problematic for clinicians as testing improves and diagnoses are found earlier in younger populations, such as those who are still of working age. These population-based decisions could deter patients from engaging with cardiac services and lead to additional challenges in shared decision-making. The next subsection discussed how relational

dynamics influenced patient engagement and inclusion, adding another layer of complexity to shared decision-making in practice.

5.3.2 Relational Dynamics

Cardiologists reflected on the central role of communication and trust in shaping how shared decision-making unfolded during clinical encounters. They recognised that their professional authority (being viewed as “the boss” - Dr Cartwright, 294) inevitably influenced the balance of power within consultations, often positioning them as the primary decision-makers. Many spoke about the pride they took in their role and the respect it commanded yet also acknowledged how this hierarchy could limit patients’ confidence to voice concerns or preferences.

In response, participants described conscious efforts to create a sense of partnership and inclusion, using empathy, openness, and accessible language to encourage patient participation. Several likened this to a kind of performance, where patients were “the audience” (Dr Nichols, 567-568) and the consultation was “the show” (Dr Cartwright, 310). This positioned demonstrative care and attentiveness as being both genuine and strategic - a visible expression of empathy that invited trust and engagement.

These metaphors conveyed an awareness that emotional connection and communication were integral to quality care but were not always visible or easily measured. By making these relational elements explicit, cardiologists aimed to reduce the distance between clinician and patient, transforming authority into a source of reassurance and performance into an avenue for participation.



“People who’ve got chronic conditions need to feel that their doctors are interested in them...even just knowing that they’ve got a phone number they can call if things are going wrong can make a massive difference to people.” (Dr Nichols, 887-896)

Cardiologists acknowledged that they were entrusted with patients’ lives and patients expected to be protected from harm. However, this could be difficult when patients had a different level of understanding to them. For example, pain could be considered harmful, however a painful procedure in the short-term carried out in order to gain long-term health benefits ultimately achieved the opposite of harm. As Dr

Nichols suggested, sometimes patients have “*got to have confidence in the process*” (Dr Nichols, 953-962), even though that process may be unfamiliar and frightening to them. As previously discussed, cardiologists have the professional responsibility to manage uncertainty in patients. To do this, physicians needed to build trust, ensure patients’ understanding and empower patients to contribute to discussions about their care. Cardiologists discussed ways in which they purposefully presented information to patients in a way that created opportunities for inclusion and equality between doctor and patient. This was viewed as being psychologically beneficial for their patients and fundamental to joint decision-making and obtaining informed consent.



“I would say that it is about presenting the information” (Dr Nichols, 807-808)

“It’s the way you do it I guess” (Dr Cartwright, 399)



These metaphors served as a unique backdrop from which to understand the reality of shared decision-making in practice and were discussed in relation to three sub-themes: **Inclusion**, **Empathy**, and **Preconceptions**.

5.3.2.1 Inclusion (Subtheme)

Cardiologists purposely manufactured opportunities for patients to contribute to discussions about their diagnosis and treatment. This curated sense of control was seen as necessary for patients to cope and adjust to their new reality with cardiomyopathy (CM). The partnership that this created between patients and cardiologists was perceived to protect patients from feeling victimised by the healthcare process and instead encouraged them to think of their new relationship with health services as an alliance.

“I try to make them feel that they have as much control over this as possible, rather than the heart failure process and heart failure journey is something that is done to them...they’re not just coming to the hospital and being someone who’s prodded and poked and then leaves, you know, making them feel like they are a partner in this.” (Dr Nichols, 685-699)



Dr Wallis purposefully included patients in the dictation of medical notes at the end of their consultation, allowing patients to correct him if necessary. This allowed the patient to feel more included in the process. Rather than discussing patients’ health without them, patients were invited to listen in to the notes being made about them and even invited to contribute to, or amend, them. This switched the

dynamic of the relationship, so the patient had some semblance of authority over the physician in that moment. However, although the aim was to empower patients, it was still clearly an illusion and not genuine authority as that fleeting opportunity was gifted to the patient by the physician. Regardless, this technique was seen to give patients a voice and allow them to hold their physician to account.



“One of the techniques I use for all my patients is that when I’ve finished seeing them, I dictate the letter that they’re going to get in front of them...if I make any mistakes, they correct me, which is brilliant, but also, they hear it all again and they get it in writing” (Dr Wallis, 172-179)

Similarly, Dr Cartwright spoke with intentional delays to allow patients the opportunity to ask questions or make comments. This could have been perceived by patients as a more overt attempt to include them but nevertheless was seen to be worthwhile as it created opportunities for patients’ voices to be heard.



“(I) speak it with pauses to allow them to jump in if they want to” (Dr Cartwright, 202-203)

Much like a teacher with their students, Dr Wallis and Dr Cartwright demonstrated how they facilitated patients’ independent learning to reinforce the information shared with them during the diagnostic consultation. They described ensuring they had the name, ‘cardiomyopathy’ written down, so they had the correct spelling, and then pointed them to pre-approved resources. Whilst this encouraged patients to take ownership of their own learning and provided them with basic information resources to relay information more easily to their family/supporters, it also highlighted the imbalance of power. It clearly reinforced the message that physicians held knowledge about their health that they did not fully comprehend themselves.



“I often give them website information. Some of the cardiomyopathies have the websites, so they can go and get good quality information from the British Heart Foundation of the Cardiomyopathy Society, rather than look up things online in their own way.” (Dr Wallis, 209-216)

Dr Wallis also used his body language to indicate to patients when he expected them to contribute during consultations. When discussing how he assessed patients’ understanding of their diagnosis, he indicated that he would physically sit back and wait for them to recite back the information he had just shared with them. Although this was clearly an attempt to involve patients in the discussion, it could also have been

perceived as intimidating for patients who found comprehension difficult. It did however afford patients the opportunity to consolidate their knowledge and provide time for the patient to digest and comprehend the information more fully.

“I sit back, and I often put my feet on the table to make it clear that I’m sitting back expecting them to tell me and give them plenty of time” (Dr Wallis, 195-199)



Non-verbal communication was also used to tailor conversations to the mood of the individual patient to instil a sense of partnership between physicians and their patients. Patients were made to feel intuitively understood by their cardiologist, but this required a level of attunement and emotional intelligence.



“I usually watch them very carefully as I’m talking to them, and this is why it’s done face-to-face really very well and very poorly over the telephone or even perhaps skype because it doesn’t always give you emotions that well” (Dr Cartwright, 192-200).

Dr Cartwright noted how much easier this was to achieve when speaking directly to patients face-to-face. This was interesting to note as it suggested that this emotional attunement to patients’ needs was lost during online or telephone appointments. Although data were collected prior to the 2020 pandemic, further research should question the quality of care that can be achieved through virtual consultations alone and what effect the lack of face-to-face consultations has had on shared decision-making. The next subtheme considered the role of empathy in shared decision-making during cardiomyopathy diagnosis.

5.3.2.2 Empathy (Subtheme)

Actively demonstrating empathy, often through empathetic language-use, was also perceived to facilitate shared decision-making and help cement a partnership between physicians and their patients. Cardiologists felt responsible for creating a positive experience for their patients by thoughtfully selecting empathetic language and communicating in a way that left patients feeling reassured and hopeful.

“You tell them that actually it’s not that rare, most of these are actually much more common than people think. I think if it’s possible at that point you reassure them, you say things for you don’t look too bad” (Dr



Garcia, 210-215)



“When I break bad news to patients often, in fact most of the time, I can...make the cloud have a silver lining. So, you have heart failure but look we’ve got great treatments...we can sort out your symptoms and...So often the meeting with me is a positive one” (Dr Cartwright, 379-286)

Information was tailored to the circumstances of the patients as this was seen to communicate empathy and understanding on the part of the physician, unifying the physician and patient.

“I mean, it’s very patient specific really. What you say and how you say it depends on why they are there, you know. So, someone who comes to see you because their brother has just dropped dead is very different to someone who’s just a little bit breathless, so their worries and expectations are very different.” (Dr Garcia,



198-205)

Communication was empathetic and aimed to address patients’ individual needs during diagnosis. This was seen to help build trust between physician and patient and create an environment within which patients felt able to communicate their needs and contribute to shared decision-making. Equally, it also created an environment within which patients were more open to hearing physicians’ opinions, so it was considered a mutually beneficial approach to care.



“They generally recognise that you’ve got their best interests at heart, and they generally will, by that point if you build up enough of a rapport, that they want to hear what you want to say” (Dr Nichols, 832-836)

Relational barriers to shared decision-making, such as the inherent power imbalance between physician and patient, were perceived to be mediated by cardiologists’ attempts to form a partnership with their patients. Purposefully creating opportunities for patients to contribute to discussions, empowering patients to take control of their condition and the consultation, being emotionally attuned and reactive to patients’ needs and caring with empathy were all factors that were perceived to help overcome interpersonal barriers to shared decision-making.

5.3.2.3 Preconceptions (Subtheme)

Cardiologists reflected on how their own assumptions and emotional responses shaped the decision-making process. Several described moments when personal beliefs about what constituted “best practice” influenced how they guided patients, recognising that genuine shared decision-making required them to step back from these preconceptions. Aligning their professional goals with patients’ individual values was described as both challenging and necessary for authentic collaboration.

“I often say, ‘have you gone away and read about this on the internet?’ or ‘has anybody spoken to you about this?’ because it’s important to get an understanding of what their thoughts and expectations are. Some people will often lay it out, ‘I’m petrified of dying.’” (Dr Richards, 410-418)



One example of preconception related to the health expectations of different patient age groups. Cardiologists discussed how CM diagnoses negatively impacted young patients more so than elderly patients and resulted in poorer mental health. Dr Cartwright theorised this could have been due to health expectations differing with age. He suggested that whilst elderly people expected to become frail and ill towards the end of their life, younger people were not expecting ill health and therefore struggled more to adjust to life with a diagnosis of CM.



“Psychologically it’s often the younger people that struggle more...they’ll have young children, which weighs on their mind...They’ll have a more active lifestyle...I think when you’re young you think you’re immortal, but as you get older you realise you aren’t, I guess. “(Dr Garcia, 322-341)

The suggestion that older people expected health deterioration was presumptive and although arguably a reasonable assertion, there were likely to be some elderly patients who were usually very healthy and were completely shocked by their diagnosis. Equally, a younger patient may quickly become accepting of their deteriorating health. Patients’ health expectations directly contributed to shared decision-making as physicians needed to understand and align themselves with patients’ health goals and expectations. Dr Christie recalled how on occasion her patients’ and her own expectations for her patients’ health were completely misaligned. However, she acknowledged the need to show understanding and work with patients however uncomfortable it might feel to her.

"It depends what the patient's expectations are...we had a lady who was very poorly in coronary care...and she was dying and we phoned her husband...He turned around and said, 'well, she's 59, she's had a good innings.' That was a realistic expectation. If that's some people's mindset it's, kind of, okay, alright, but what else can you do or say?" (Dr Christie, 789-804)



Another example of clinical preconception surrounded patients' desire for children. Dr Wallis claimed that younger people worried about how CM would affect their decisions to have children whereas older people worried that CM could affect the children they had prior to diagnosis. Although Dr Wallis may have been speaking in general terms about a pattern he had observed, assuming that young people plan to have children could become problematic if not communicated with sensitivity.



"I think it's...when people are young there's often a fear of god how will this affect me having children? Whereas, when people are older they are fearful that it will affect their children. So, there's a huge element of the family unit to consider as well." (Dr Wallis, 255-261)

In-depth discussions surrounding family planning decisions were considered necessary due to the increased risk associated with CM patients during pregnancy, and the potential for CM to be hereditary. Dr Christie revealed that she found it difficult sometimes to conceal her disapproval or surprise when patients were willing to risk their health to achieve their goal of having a biological child.

"[Regarding pregnancy] 'You said it wouldn't work the first time, it has, I want another.' Really, do you really want to risk it?" (Dr Christie, 862-864)



Dr Christie's response to a patient expressing her wishes could have been perceived as judgmental, which could adversely affect her patients' willingness to contribute to future shared decision-making. Cardiologists acknowledged the need to align themselves to meet patient' goals but ultimately had to also consider patient' level of understanding regarding risk. Cardiologists shared how there was sometimes a mismatch in understanding of risk. In the following example, Dr Cartwright suggested that patients were more fearful of the well-known risks associated with diseases such as cancer than they were of the lesser-known risks of CM due to differing amounts of familiarity and understanding.



“It doesn’t scare people as much as cancer does. It’s just the heart muscle – I mean how bad could it be? And of course the reality for some patients is that it is much worse than cancer” (Dr Cartwright, 127-132)

Dr Cartwright described making generalisations about patients’ capacity to engage with and process information about risk. He suggested that individuals perceived as having lower intellectual ability may experience less psychological burden in relation to their diagnosis, as they may be less likely to engage in detailed consideration of associated risks:

“Somebody who is less intellectually gifted, perhaps in a more manual job, they may not have the capacity to appreciate all of the things that might go along with this diagnosis and for them therefore the implications of this diagnosis on their psychology are much less...They are going to go out and have a couple of cigs and go home” (Dr Cartwright, 521-538)



In describing this, Dr Cartwright appeared to draw associations between intellectual ability, occupation, and health behaviours such as smoking. These accounts suggest the use of heuristic assumptions in making sense of patients’ likely understanding and responses to diagnosis.

This was further reflected in his description of adapting communication style based on limited contextual information, such as occupational role:



“Usually within the conversation I have first of all established what their job is or was and what their wife or their partners’ job is or was, thereby...I’ve established at what level I’m going to talk to them, what words I am going to use and how I am going to explain what the problem is” (Dr Cartwright, 185-193)

Although he acknowledged his approach could be viewed as *“arrogant or asocial”* (Dr Cartwright, 277), it was a method Dr Cartwright had developed to ensure his communication style was tailored to the needs of his patients within the confines of a limited consultation time. Additionally, it is important to note that generalisations are often unavoidable when speaking generally about different patient groups in a reflective way. On the other hand, should these preconceptions be voiced to patients it could be considered unethical and risk alienating groups of patients, widening the pre-existing power imbalance within the physician-patient relationship. While Dr Cartwright acknowledged that this approach could be perceived as *“arrogant or asocial”* (Dr Cartwright, 277), he positioned it as a pragmatic strategy developed to tailor communication within the constraints of limited consultation time.

These accounts highlight a potential tension between efficiency and individualised care. While such heuristics may function as a means of navigating time pressures, they also raise questions about how assumptions regarding patients' capacity, background, or health behaviours may shape clinical interactions. If left unexamined, these assumptions may influence how information is conveyed and understood within the consultation.

5.4 Chapter Summary

Two superordinate themes were identified from the cardiologist interview data. The first theme, ***Ideal versus Real***, captured the tension cardiologists experienced when striving to deliver the standard of care they believed patients deserved within the constraints of everyday clinical practice. Participants described feeling caught between professional ideals and organisational realities, expressing frustration at their limited capacity to influence systems they perceived as inefficient or beyond their control. Collaboration and communication emerged as essential to their understanding of good practice, with multidisciplinary teamwork and effective information-sharing networks viewed as key to improving both patient care and professional support. Alongside these structural and relational challenges, cardiologists also spoke of the emotional demands of their work. Feelings of frustration, moral discomfort, and helplessness were common, revealing an often-overlooked dimension of emotional labour that accompanied their efforts to provide compassionate and effective care.

The second superordinate theme explored the ***Barriers to Shared Decision-making*** during diagnosis and beyond, as illustrated in Figure 11. Participants described how organisational pressures, limited consultation time, professional obligations, and the wider social realities of living with cardiomyopathy (CM) sometimes restricted opportunities for genuine collaboration with patients. Cardiologists reflected on the influence of their own authority within consultations and described how they consciously sought to create space for patient engagement through enacted care, open dialogue and empathetic language. Many emphasised the importance of aligning medical recommendations with patients' individual goals and expectations, recognising that this alignment was essential to building trust and partnership. At the same

time, they acknowledged that clinical assumptions and preconceptions could inadvertently undermine these relationships, highlighting the ongoing emotional work involved in ensuring genuine partnership.

The insights gained from participating cardiologists' vision of ideal care carries practical applications to routine practice. Consultations could be improved, through a modulated, flexible protocol used guide diagnostic consultations to ensure cardiomyopathy is clearly defined, clinical terminology and service structure is introduced with sensitivity, and that prognostic uncertainty is acknowledged, normalised and discussed openly. The protocol could ensure time is protected with longer first-contact consultations, routine 'check in' or 'decisional review' appointments after two-weeks to reduce systemic pressures affecting shared decision-making. Their ideal pathway also points to needing an embedded clinical psychologist to co-formulate, support psychologically informed consultations, and distribute emotional labour more evenly across the team. Regular team huddles could also be used to surface and process moral tensions before they accrue as moral injury. Application of findings in practice and future research, including more operational detail is provided in Chapter 9.

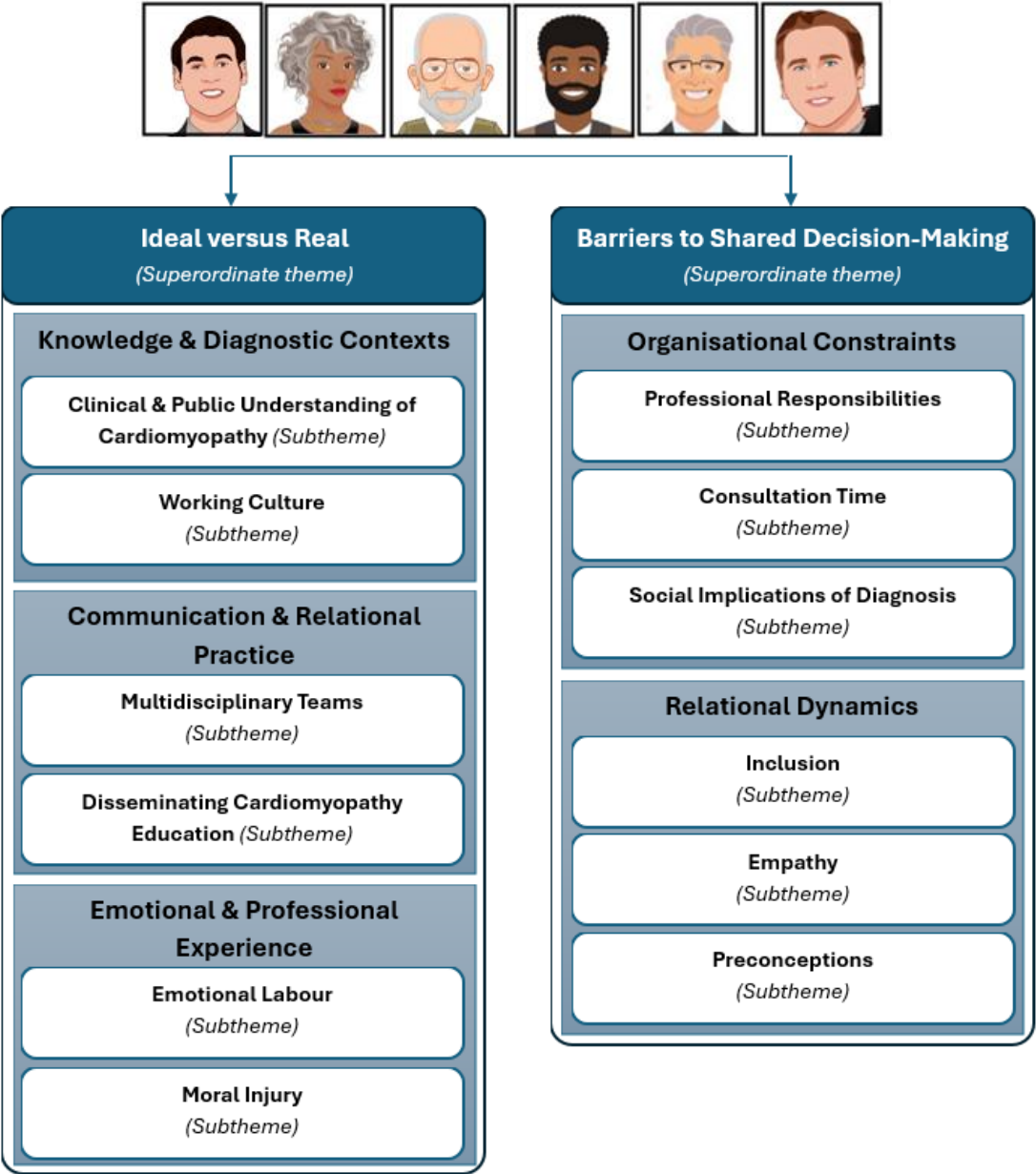


FIGURE 11. INTERVIEWS WITH CARDIOLOGISTS: OVERVIEW OF SUPERORDINATE AND SUBORDINATE THEMES.

6. Discussion: Interviews with Cardiologists

6.1 Chapter Introduction

This chapter critically discusses findings from cardiologist's lived experience of diagnosing cardiomyopathy (CM), as presented in Chapter 5. Interpreting these data through an interpretative phenomenological lens, I remained closely aligned to how participants made sense of their work: not only the practical steps taken during CM diagnosis, but also the elements they experienced as difficult, ethically challenging, or uncertain, and how they navigated constraints within routine practice.

Two superordinate themes were developed: ***Ideal Versus Real*** and ***Barriers to Shared Decision-Making***.

The first captured the tension between cardiologists' aspirational standards of care ('ideal' care) and the practical realities of delivering a CM diagnosis within an under-resourced, fragmented system. The second explored how organisational, relational, and intrapersonal factors limited how much cardiologists and patients could achieve truly collaborative decision-making throughout the diagnostic journey.

Across both themes, cardiologists described 'good' standards of care not as vague, unachievable aspirations, but as the foundations of safe and manageable practice. Their accounts highlight that when those foundations were compromised (through reduced time, staffing, access, or continuity) care isn't just lower in quality but is fundamentally changed. In their accounts, these compromises ultimately affect what can realistically be offered, and what clinicians can 'hold', without the diagnostic process becoming clinically risky or psychologically unmanageable.

6.2 Ideal Versus Real (*Superordinate theme*)

This superordinate theme examines how cardiologists attempted to deliver guideline-based, person-centred care while working within services affected by well-known limitations such as capacity pressures, variable expertise, and inconsistent diagnostic infrastructure (Castelli *et al.*, 2023; Mitchinson *et al.*, 2021). Participants described a persistent gap between what they believe should happen (according to their understanding of formal guidance and their own professional standards) and what they perceive actually happens in routine practice (see visual representation in Chapter 5, Figure.10). Cardiologists' accounts

conveyed an ongoing negotiation: trying to deliver what they understood as safe, good-quality care, while repeatedly working around constraints that made this difficult to achieve consistently. In that sense, “Ideal Versus Real” captured more than just a list of systemic pressures, but also what it felt like to practise within such constraints where compromise was sometimes unavoidable, and where clinicians carried responsibility for the consequences.

Mirroring the presentation in Chapter 5, this superordinate theme is discussed through six interlinked subthemes. For clarity, these were grouped within three broader contexts: *Knowledge and Diagnostic Processes*; *Communication and Relational Practice*; and *Professional and Emotional Experience*. Together, these contexts showed how cardiologists adapted their practice, managed uncertainty, and at times pushed back against the limits of what was feasible within the services they worked in.

6.2.1 Knowledge and Diagnostic Contexts

Cardiologists suggested that CM diagnosis did not often happen neatly or consistently across the NHS. Instead, familiarity with relevant guidance varied, and access to specialist scanning equipment (and the expertise needed to interpret scans) were inconsistent (Thomas, 2024; Smeets *et al.*, 2016; Bottle *et al.*, 2018). Within this context, two subthemes were developed: ***Clinical and Public Understanding of Cardiomyopathy*** and ***Working Culture***. Together, these subthemes captured how gaps in knowledge, variable confidence in recognising CM, and everyday service pressures, affected when symptoms were escalated, which tests were prioritised, and how quickly patients reached specialist cardiology services (Perera *et al.*, 2021; Hancock *et al.*, 2014).

6.2.1.1 Clinical and Public Understanding of Cardiomyopathy (Subtheme)

Cardiologists described CM diagnosis as a complex, multi-step process that did not always map neatly onto clinical guidelines. They suggested that at initial presentation, patients’ cardiac symptoms could sometimes be misattributed to other causes, such as anxiety or asthma. They also suggested that when cardiac causes were identified, broad heart failure guidance were often used to guide initial diagnoses, with cardiomyopathy (CM) being identified more specifically at a later stage. This was viewed to be

problematic as clinical guidance from the National Institute of Clinical Excellence (NICE, Figure.12) and from the European Society for Cardiology (ESC, Figure.13) for suspected chronic heart failure (HF) both use clinical thresholds that don't neatly align with all CM presentations, meaning some CMs might be missed. As discussed briefly in Chapter 2.3.2, natriuretic peptide testing (BNP/NT-proBNP) has often been used as a key trigger for rapid referral in HF guidance (National Institute for Health and Care Excellence, 2025; McDonagh *et al.*, 2023). Yet cardiologists did not describe BNP/NT-proBNP as a significant or routine diagnostic indicator of CM, and this was not featured in their "ideal" diagnostic pathway as shown in Chapter 5. BNP/NT-proBNP are hormones released by cardiomyocytes in response to ventricular stress and are usually elevated in heart failure patients (Patel and Southern, 2020). HF guidance (National Institute for Health and Care Excellence, 2025) suggests referrals should be considered urgently when certain thresholds are met (NT-proBNP $\geq 400\text{ng/l}$). However, cardiologists' accounts suggested that in practice, they relied more heavily on clinical assessment, imaging, and specialist interpretation than on natriuretic peptides during HF diagnosis.

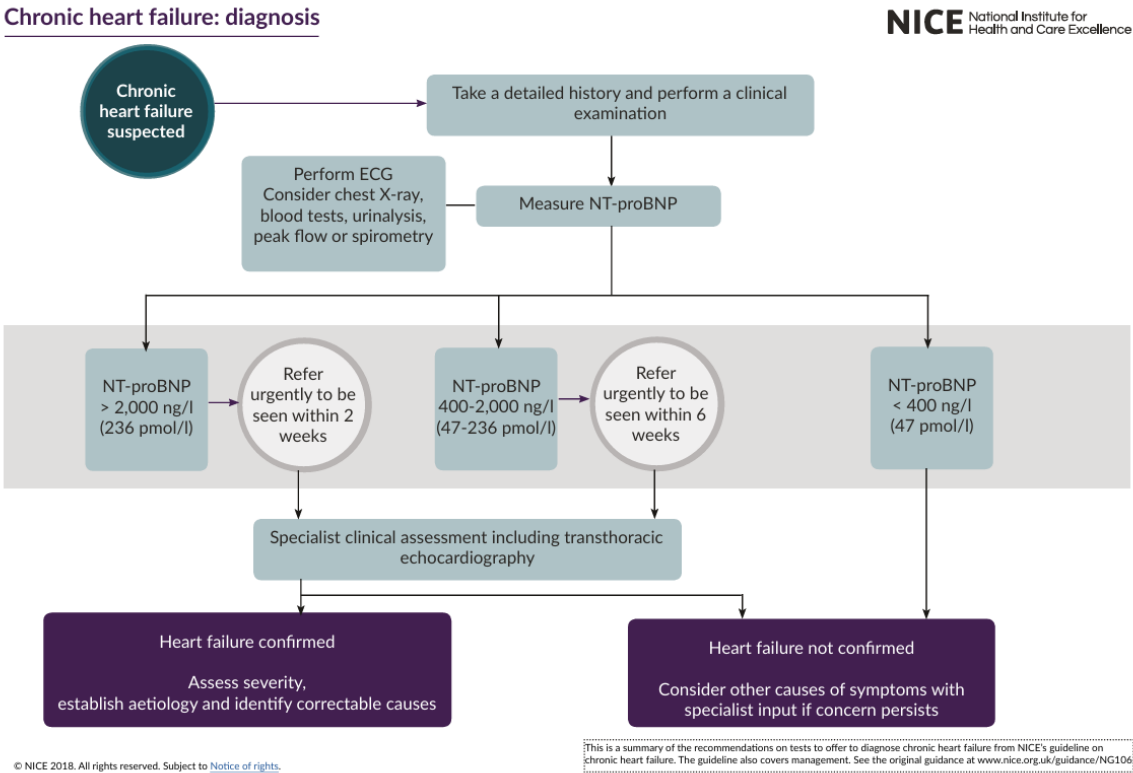


FIGURE 12. NICE PATHWAY FOR INVESTIGATING AND DIAGNOSING CHRONIC HEART FAILURE (NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE, 2025)

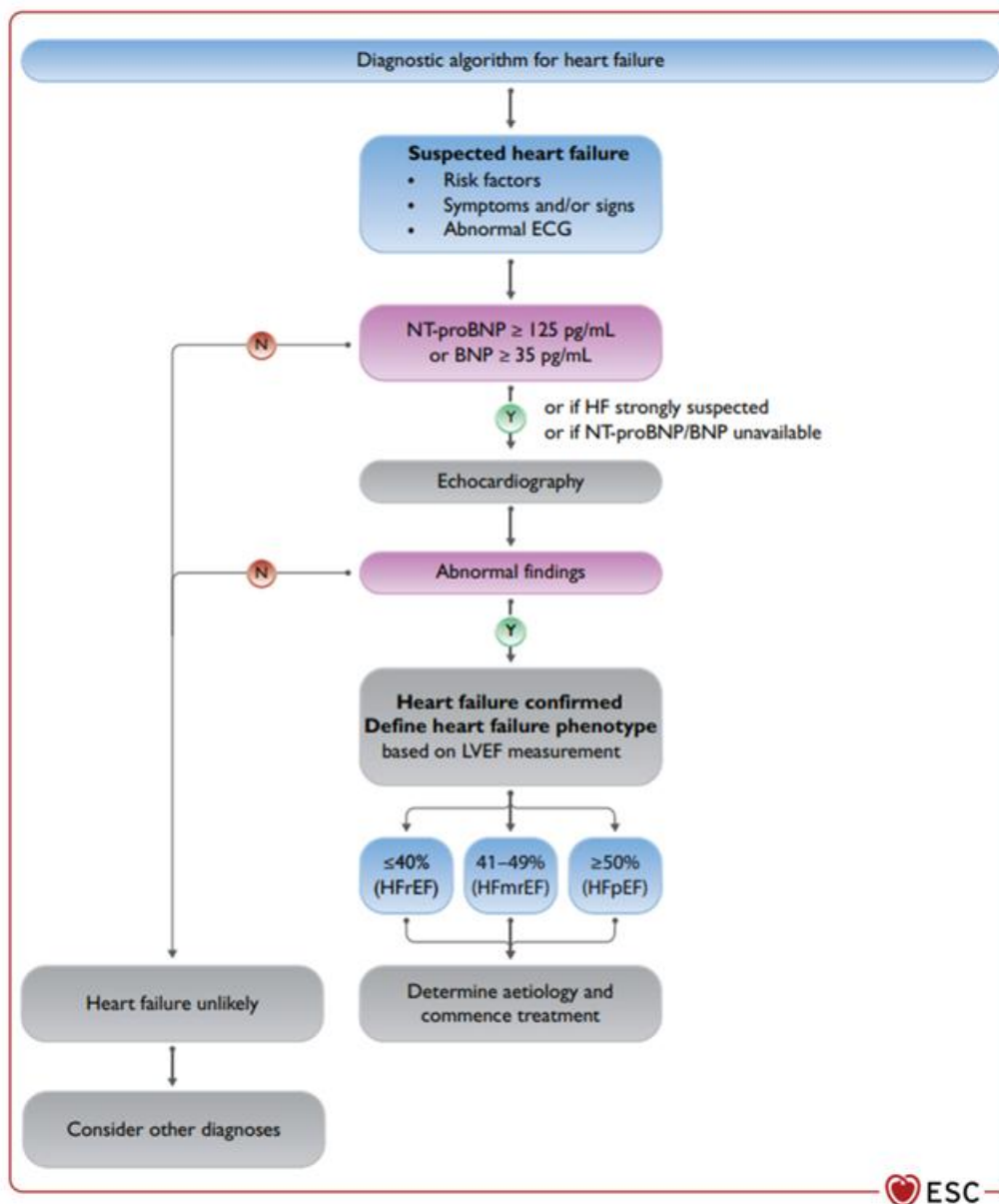


FIGURE 13. ESC GUIDELINES FOR THE DIAGNOSIS AND TREATMENT OF CHRONIC HEART FAILURE - FROM McDONAGH *ET AL.* (2023).

The suggested gap between clinical guidance and practice was contextually relevant when considering the subtheme, *Clinical and Public Understanding of Cardiomyopathy*. Cardiologists suggested that diagnostic work involved holding multiple uncertainties at once: non-specific symptoms, ambiguity regarding phenotype, uncertainty about prognosis, and judgements about how much confidence was *enough* before acting. In cardiologists' accounts of their real-world practice, BNP was viewed less like a

clear-cut threshold and more as one imperfect indicator of HF among many, which added to the uncertainty. This interpretation aligned with research showing how natriuretic peptide levels can be lower in heart failure patients with preserved ejection fractions (HFpEF) than in those with reduced ejection fraction (HFrEF) presentations (Rabkin and Tang, 2021; Sakane *et al.*, 2021). ESC guidance has noted that “*up to 20% of patients with invasively proven HFpEF have NPs below diagnostic thresholds*” (McDonagh *et al.*, 2021, p. 36), linked to obesity and other factors unrelated to heart function. National Institute for Health and Care Excellence (2025) also notes that obesity, African or African-Caribbean heritage, and medications such as diuretics or beta-blockers can reduce serum natriuretic peptide levels. For some CM phenotypes, strict adherence to generic HF thresholds therefore risked false reassurance or missed diagnoses. Cardiologists’ emphasis on specialist review for any suspected CM could, in this sense, be interpreted as an attempt to keep decisions anchored in the broader clinical picture, rather than allowing a single biomarker to hold such diagnostic weight (McDonagh *et al.*, 2023). Understanding this real-world diagnostic reasoning raised questions about the appropriateness and relevance of generic HF guidance when diagnosing some cardiomyopathies.

Cardiologists described how limited clinical understanding of CM across services contributed to delayed or missed diagnoses. Cardiologists felt that primary care physicians in particular lacked awareness of CM services and were more hesitant about making referrals than secondary care clinicians. However, they also described limited familiarity with CM diagnostic pathways in some secondary care contexts and suggested there were services available to CM patients that secondary care clinicians were simply not aware of. Research has acknowledged that in some cases, primary care assessment and management of patients presenting with symptoms suggestive of heart failure is frequently guided by generic heart failure guidance (Dworzynski *et al.*, 2014) rather than CM-specific guidance, despite heart failure pathways not being sufficiently tailored to encompass CM variants (Arbelo *et al.*, 2023). Previous ESC guidance emphasised a combination of diagnostic tests “*due to the diverse aetiology of the disease*” (Elliott *et al.*, 2014, p. 2739) but did not specify who should carry out tests, leaving referral decisions open to interpretation. NICE’s 2018 update (NICE, 2018, recommendation 1.1.1) clarified that although MDT

working is important, a lead physician with subspecialty heart failure training (usually a consultant cardiologist) should take responsibility for clinical diagnosis. However, this revision is not clearly reflected in the widely familiar NICE flow chart (Figure 12), particularly if BNP thresholds are not met, meaning responsibility within the pathway remains unclear in practice. The current study adds weight by highlighting the inconsistent interpretation and implementation of guidance, the existence of uneven referral thresholds, and how cardiologists experienced this ambiguity when diagnosing CM.

Cardiologists perceived GPs to lack confidence in identifying HF symptoms and interpreting test results. Hancock *et al.* (2014) reported substantial differences in clinicians' confidence when using echocardiography to diagnose left ventricular systolic dysfunction, with confidence dropping sharply across roles for more complex presentations involving preserved ejection fraction. A systematic review also reported that rates of HF misdiagnosis ranged from 16.1% in hospital settings to 68.5% in primary care (Wong *et al.*, 2021). These findings should be treated cautiously given their reliance on self-report data and variation in how 'misdiagnosis' was defined across studies, but even so, they reinforce cardiologists' view that clear referral routes into specialist cardiology services, ideally a tertiary cardiac centre, are needed for more accurate and confident diagnoses.

These interpretations sit within a wider context of systemic pressures affecting all settings, including guideline fatigue and limited consultation time affecting clinician confidence and accuracy (Smeets *et al.*, 2016; Perera *et al.*, 2021). Bottle *et al.* (2018) found that only 23.6% of patients repeatedly presenting to GPs with HF symptoms were investigated in line with published guidance, and both the literature and participants in this study highlighted how symptom overlap (e.g., anxiety, asthma, chronic obstructive pulmonary disease, heart attack) can delay escalation and onward referral (Smeets *et al.*, 2016; Taylor *et al.*, 2021). Recent professional HF self-development frameworks have therefore emphasised the need to strengthen HF knowledge across professions, whilst also developing key competencies such as interpreting echocardiograms (ECGs) within HF multidisciplinary teams (Forsyth *et al.*, 2024). This reinforces how long-standing gaps in understanding relate not only to HF generally, but also to more

specific and complex conditions such as cardiomyopathies. Alongside education, technological solutions have also been introduced. Bachtiger *et al.* (2022) trialled an ECG-enabled stethoscope using artificial intelligence (AI) to provide diagnostic information within 15 seconds, detecting signs of reduced ejection fraction and arrhythmia with up to 91% accuracy. If feasible and acceptable in routine primary care, this type of tool could support earlier detection and referral by addressing some of the confidence and interpretation barriers described by cardiologists.

Cardiologists also acknowledged that clinical uncertainty is intertwined with patients' meaning making and communication skills in that clinicians are reliant on patients to identify symptoms, engage with services, and describe physical changes clearly (Lee and Oh, 2022). In that sense, knowing enough to escalate or prompt action is not evenly distributed across settings and may depend as much on when a patient presents, where, and who sees them first, as on the symptoms themselves.

Alongside clinical understanding, cardiologists described how limited public awareness also negatively affected diagnosis. They described how help-seeking was unnecessarily delayed due to a lack of recognition of cardiac symptoms, and that misunderstandings of terminology added distress and confusion during diagnosis. Although CM has occasionally featured in news media (BBC News, 2017; Times Now News, 2024), headlines rarely contextualise the condition and leave the public associating CM primarily with sudden cardiac death rather than broadly understanding associated symptoms or risk. Multiple studies have found that patients frequently normalised cardiac symptoms and delayed seeking help, presenting only once usual activities were disrupted (Phillips *et al.*, 2024; Taylor *et al.*, 2017). This suggests earlier recognition by patients could support earlier engagement with services, and earlier diagnosis.

Cardiologists referenced the value of public health-style awareness campaigns. Following the success of the 'act-FAST' campaign in raising recognition of stroke symptoms (Dombrowski *et al.*, 2013), Taylor *et al.* (2021), in collaboration with the health charity, Pumping Marvellous, developed BEAT-HF (Breathlessness, Exhaustion, Ankle swelling, Time for a simple blood test) to raise awareness of common

HF symptoms. When HF is suspected in primary care, breathlessness, fatigue, and ankle swelling are reported by the majority of patients (Taylor *et al.*, 2017) supporting the use of these symptoms in public awareness campaigns. Cardiologists' emphasis on public understanding therefore positioned symptom recognition as part of their ideal diagnostic pathway, not separate from it.

Public understanding was also considered to be shaped by language. Cardiologists described dissatisfaction with the label 'heart failure', describing it as "*scary*" (Dr Cartwright, 146) and a "*terrible expression*" (Dr Nichols, 129), and linked it to patients "*switching off*" or assuming cardiac death was inevitable (Dr Christie, 258). Stevenson (2017) similarly argued that "*the mission to prevent disease progression is undermined if directed at patients labelled as though failure has already occurred.*" (Stevenson, 2017, p. 1360), proposing alternatives such as "heart insufficiency". Other proposed alternatives include 'cardiac impairment' (Lehman, Doust and Glasziou, 2005) and terms such as 'heart flux', 'heart fatigue' or 'heart stress syndrome' (Launer, 2017). Boulos *et al.* (2022) concluded that "*the term 'heart failure' is outdated, disempowering and negatively impacts quality of care*" (Boulos *et al.*, 2022, p. 284) after reviewing letters submitted by patients in protest of the term. They suggested that referring to illness as a *failure* only perpetuates feelings of hopelessness, discourages self-efficacy, and evokes shame that may discourage patients from engaging with health services. Colucci, Gottlieb and Dardas (2021) described the term as misleading and overly broad, and participants noted terminology may sometimes be used "*without thought*" (Dr Cartwright, 163), leaving patients with uncertainty. Although cardiologists acknowledged the practical difficulty of renaming established 'heart failure' services, Levey *et al.* (2020) demonstrated that consensus-driven revisions to clinical language are possible, as seen in kidney disease terminology, where changes were introduced to reduce misunderstanding and distress, replacing 'end-stage kidney failure' to the term, 'renal failure'. However, widespread renaming risks confusion across services and patient groups unless it is implemented consistently and evaluated carefully, which in the current landscape is unlikely to be prioritised. There may also be reasonable counterarguments for the use of such blunt labels: used alongside a clear, compassionate explanations, they can help some patients quickly grasp the seriousness of the problem

and support timely engagement with recommended action (e.g., monitoring symptoms, adhering to treatment, or engaging with services). Additionally, avoiding the widely adopted clinical label may leave patients unprepared for future encounters with the term (e.g., referral to a 'heart failure nurse'), and may reduce patients' ability to conduct independent research and access resources developed specifically to demystify and contextualise the label (Taylor *et al.*, 2017). On this basis, the issue may be less about the label itself and more about how clinicians introduce it and facilitate understanding.

Cardiologists suggested that patient education during diagnosis was often less than ideal, arguing consultations alone were not always sufficient to ensure understanding. Under time pressure, clinicians described unease that patients were often left without a clear grasp of their condition. Dr Wallis suggested many settings failed to use available educational tools, leaving patients reliant on independent research and the risk of misinformation. Participants described concern about patients consulting "*Dr Google*" (Dr Christie) when there was insufficient time to ask questions during consultation and proposed integrating charitable information resources or clear signposting into diagnostic consultations. While providing materials does not guarantee patients will read or understand them, offering additional resources was positioned as part of their vision of 'ideal care'. Participants highlighted how charities often filled systemic gaps within an overburdened NHS and suggested more formal collaboration between cardiology services and reputable charities such as, *CardiomyopathyUK*, might strengthen resources and increase the offer of support to patients during every stage of diagnosis.

6.2.1.2 Working Culture (Subtheme)

A structural hierarchy was perceived to exist whereby tertiary cardiac centres were positioned as the central sites of CM expertise, because familiarity and confidence in CM were considered to be variable across other settings. Cardiologists linked this to the fact that CM did not always present in obvious or straightforward ways. Some rarer phenotypes could resemble more common cardiomyopathies, which could delay accurate phenotyping (Cui, Wang and Zhao, 2020). In Chapter 5, Dr Richards described dedicated inherited cardiac conditions (ICC) clinics as places where familiarity developed through

repeated exposure and suggested this type of experience was less prevalent in smaller services. In that sense, tertiary expertise was not just about status, but about patient volume, repetition, and the chance to see patterns in clinical features emerge over time.

At the same time, a silo working culture was also perceived from the data, contributing to a diffusion of responsibility and leaving cardiologists feeling unable to overcome the systemic barriers they identified. In other words, participants' accounts suggested a system that was both hierarchical (expertise was assumed to dilute as one moved away from tertiary centres to secondary care, and again to primary care services) and fragmented (care was distributed across services but was poorly integrated). This combination appeared to make responsibility *feel* shared without any one professional experiencing sufficient leverage to actually change the wider pathway. Cardiologists suggested this issue was seen most clearly when things went wrong or when patients were transferred between services.

Researcher's Reflections:

All participating cardiologists were working within tertiary cardiac centres at the time of interview, and their reflections on other settings were therefore best interpreted as perceptions of cross-system functioning rather than direct observations. In describing barriers beyond tertiary care, cardiologists sometimes drew on patient accounts, which may have been shaped by misinterpretation or incomplete understanding. Equally, they may have been combining these accounts with previous professional experience from working in other settings. Either way, these views remained analytically valuable, as long as they were considered in relation to the organisational and temporal context in which participants were situated.

Wider research has highlighted the complex hierarchy that can exist within national health systems (Safaeinili *et al.*, 2020), and how rigid hierarchies can adversely affect efficiency, trust, cohesion, and safety within clinical teams (Brennan and Davidson, 2019; Panhwar and Kalra, 2019). Brennan and Davidson (2019) found that hierarchical cultures could prevent junior doctors from speaking up about safety concerns for fear of repercussions such as confrontation, social isolation, and restricted career opportunities. The Care Quality Commission (2018) also described hierarchical cultures as “*inimical to safety*” (p. 4) in its report, ‘*Opening the door to change*’, and recommended MDT working and ‘universal

levelling measures' (e.g., addressing each other more informally regardless of seniority) as one way of mitigating these effects. However, Brennan and Davidson (2019) also argued that hierarchy of responsibility was not fully avoidable, and that multidisciplinary teams (MDTs) remained susceptible to horizontal hierarchy because consultants retained ultimate authority and responsibility for patient care.

Participants' accounts showed how hierarchy operated in cardiology teams. Cardiologists described the pressure of tertiary work and the sense of being ultimately responsible for patients. They also positioned tertiary expertise as different from what was available elsewhere. For example, Dr Richards suggested GPs recognised CM diagnosis was *"not something that can be dealt with by everybody"* (Dr Richards, 180–191), and Dr Garcia reflected that *"it's nice to do something well that most of the time isn't done very well"* (Dr Garcia, 45–47). These comments placed tertiary care as the gold standard or most aligned with their 'ideal' CM diagnosis pathway, which reinforced the hierarchy participants perceived and the weight of responsibility they then carried.

A *"mature service"* (Dr Richards, 286) was described as one in which tertiary centres diagnosed, educated, and initiated treatment, while local services provided follow-up care and monitoring until referral back to tertiary care was needed. Responsibility in this model therefore remained ultimately located at the tertiary centre, even if care was temporarily delegated elsewhere. Dr Richards was sceptical about whether this idealised model was consistently achieved in practice. The tension between "Ideal Versus Real" was not only felt in relation to accessing resources, but also about whether coordination, communication, and accountability measures were robust enough to make such joined up cross-service care practically viable.

Cardiologists described several systemic barriers, particularly poor communication and a lack of agreed protocols between services, as contributing to fractured care. They suggested that when patients moved between services, it sometimes became unclear who held responsibility for them. Guidance clarifying prescribing responsibility for specialist medications exists and includes transfers of responsibility from secondary/tertiary care to primary care and shared-care prescribing protocols (NHS England, 2018).

However, participants described other responsibilities as less clearly defined. There is a growing recognition of challenges relating to poor transitional care within and between NHS services (Anderson, McGuire and Mossialos, 2025; Carollo *et al.*, 2026). Cardiologists perceived tertiary cardiac centres as better positioned to coordinate outpatient CM care than other settings and suggested that continuity problems may be increased during transitions of care between other services where patient information, and responsibility had to move through poorly integrated systems. Future work could map the pathway of CM patients' transitional care between services using audit data and experiential accounts to examine whether these transfer points are indeed where continuity and accountability most often break down.

Alongside hierarchy, cardiologists described a silo working culture whereby improvements were made to their own local practice but were rarely extended beyond this. Systemic problems were considered to mostly exist outside of tertiary cardiac centres, and barriers in other settings were viewed as unfortunate but beyond the scope of what they as individual clinicians could feasibly change. Participants' accounts therefore suggested a diffusion of responsibility that may discourage the collaborative action required for cross-system improvement. Ray and Clarke (2023) argued that silo working in cardiology could be reinforced by funding allocation processes that leave services competing rather than collaborating. They suggested NHS structures incentivise individual services to focus on their own development to secure income and prestige, rather than coordinate improvement across the pathway. Stevenson and Moore (2019) similarly highlighted how monetary incentives and sanctions associated with performance targets (set by the quality and outcomes framework) may have amplified competition and silo working, shaped by what they described as "*the persistence of a culture of fear and blame in the NHS*" (Stevenson and Moore, 2019, p. 1). The tension between 'ideal care' and reality is therefore not only about resources or expertise but also about service structure. Without changes to how services are developed, run and connected, silo working is likely to continue.

6.2.2 Communication and Relational Practice

Cardiologists described communication, education, and collaboration as essential for delivering the standard of CM diagnostic care they viewed to be ‘ideal’. Consistent with wider concerns about transitional care within the NHS (Anderson, McGuire and Mossialos, 2025; Carollo *et al.*, 2026), participants positioned fragmented inter-service communication as a practical barrier that disrupted continuity and contributed to variation in CM diagnostic processes and follow-up. Two subthemes, **Multidisciplinary Team Working** and **Disseminating Cardiomyopathy Education**, are therefore discussed as ways to strengthen inter-service connection, support a more unified understanding of CM across services, and reduce inconsistency in care.

6.2.2.1 Multidisciplinary Teams (Subtheme)

Cardiologists described multidisciplinary team (MDT) working as one of the clearest examples of what ‘ideal care’ looked like in practice. They considered MDTs to be essential to providing high quality, patient-centred care, particularly during CM diagnosis and management where patients benefit from input from many different specialists: cardiologists, geneticists, specialist nurses and, where available, psychologists. This aligns with wider evidence that MDT working sits at the centre of heart failure care and is linked to improved outcomes and fewer hospital readmissions (Heidenreich *et al.*, 2022; Forsyth *et al.*, 2024). MDT working and integrated care models have been found to be particularly useful for long-term, complex cardiac conditions (Batchelor *et al.*, 2023). This is particularly applicable to cardiomyopathies as Carr-White and Leema (2018) state that *“The complex and chronic nature of inherited cardiovascular conditions (ICCs) require a multi-disciplinary approach to provide holistic care. This ensures appropriate diagnosis, risk assessment, management, cascade screening and/or genetic testing; and psychological support for patients and their families”* (Carr-White and Leema, 2018, p. 817). Cardiologists suggested that MDTs also worked as access infrastructure, creating flexibility and informal routes through the system that helped patients get past gatekeeping points and reach the right services more quickly. For example, Dr Christie valued her ability to *“call in favours infrequently”* (Dr Christie,

429–441) to get a patient seen sooner by another MDT member and described effectively ‘tagging in’ a mental health professional to support a distressed patient on another occasion (Dr Christie, 300–310). This illustrated how MDTs function in practice: not only widening patients’ access to different parts of the service, but also giving clinicians trusted colleagues to call upon when standard pathways were too slow or too rigid to meet patients’ needs.

At the same time, the data suggested that MDTs could only work as well as the wider system allowed. They were perceived to function best when the team sat within one service or centre (e.g., Inherited Cardiac Conditions clinics within tertiary settings), where clinicians shared the same electronic notes system, trust-wide protocols, and expectations about who does what. In contrast, MDT working across different settings was described as harder to sustain, because information did not travel smoothly between services. Participants pointed to incompatible IT systems, incomplete records, and inconsistent coding as practical barriers that limited information sharing and disrupted continuity (Smeets *et al.*, 2020; Conrad *et al.*, 2018).

A key issue was therefore where the ‘ideal’ MDT structure was located. Joined-up working seemed most reliable once patients reached tertiary services, but it did not consistently extend backwards along the pathway. MDTs were seen to be able to reduce fragmentation locally, but not before patients reached these specialist services. Cardiologists essentially described how patients benefitted from coordinated input once they arrived at the right service, while the steps leading up to that point remained more fractured and prone to delay.

Primary care heart failure services have tried to improve how information moves between services, for example through regular record audits and consultant-led reviews (Kahn *et al.*, 2022). That work showed it is possible to tighten the links between primary care and specialist cardiology services. But it also exposed how easily people can be missed when referral routes, coding, and communication are inconsistent in day-to-day practice.

MDT working therefore was seen to be part of the solution because they made joined-up care more achievable, but they also highlighted systemic issues in collaborative working as their benefit depended on whether patients could reach them in the first place, and whether information could move reliably between services.

6.2.2.2 Disseminating Cardiomyopathy Education (Subtheme)

Cardiologists recognised that improving knowledge of cardiomyopathy (CM) at all levels of the health service was not straightforward, as discussed in subchapter 6. 2.1.1. Rather than focusing only on formal teaching, they emphasised strengthening networks between services as a way of improving channels of information, access to expertise, and day-to-day confidence in recognising and responding to CM symptoms.

Dr Garcia suggested that, in an ideal world, each district hospital would have a nominated cardiologist responsible for linking in with a tertiary cardiac centre to gather specialist knowledge and experience, who then would educate colleagues locally. Dr Richards described a similar model but focused on heart failure (HF) nurses. He suggested that HF nurses based in tertiary centres could be given protected time to support community-based HF nurses through outreach and education, with those community nurses then acting as a point of contact for primary care teams. In this model, Dr Richards suggested it was not realistic to train GPs in CM directly due to the many demands of their role, but more practical to ensure they knew how to tap into local expertise through community nursing networks. The collective vision of cardiologists' idealised approach to educational dissemination is shown in Figure 14 below.

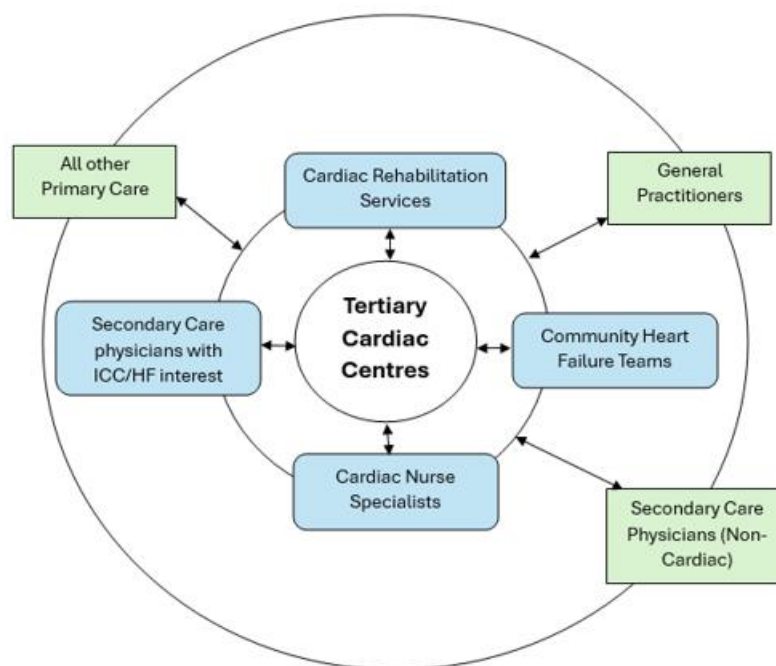


FIGURE 14. CARDIOLOGISTS’ IDEALISED VISION OF EDUCATIONAL NETWORKS.

This model echoed integrated care approaches already described in the wider literature. Hub-and-spoke models are typically defined as a system where a central ‘hub’ provides the most specialist input, supported by ‘spokes’ offering more limited services, with patients routed to the hub when needed (Elrod and Fortenberry Jr, 2017). Participants extended this model for use beyond service delivery. Their focus was not only on where care happened, but on how specialist knowledge travelled across settings in ways that supported earlier recognition, timely referral, and more consistent decision-making.

That said, cardiologists were clear that the ‘education network’ idea would only work if systemic challenges were resolved. Time pressure, staffing shortages, and limited managerial support are established barriers to engagement with continued professional development (CPD), particularly for trainees (Gawne, Fish and Machin, 2020). Those same pressures may help explain the patchy and inconsistent engagement with educational dissemination described participants in Chapter 5 (Dr Richards, 255-263). Research supporting the feasibility of such networked education models do exist, if the infrastructure is in place. For example, specialists at Great Ormond Street Hospital delivered 19

nurse-led education programmes via Zoom to clinicians across 26 network hospitals, with early feedback suggesting increased confidence in recognising and responding to congenital heart disease (Cottam and Robertshaw, 2023). While the longer-term impact on practice is still unclear, this example suggests that a hub-led model can be operationalised if intended attendees can realistically engage.

Engagement itself became part of the ‘ideal versus real’ tension as well. Cardiologists described how current networks for sharing expertise across settings were limited and inefficient (Chapter 5), despite the fact that formal training and governance structures are designed to support ongoing learning. In the UK, there is a legal requirement for doctors to be on specialist registers in order to work as a consultant within the NHS (General Medical Council, n.d.). The General Medical Council and training bodies provide guidance on minimum learning requirements for specialist practice, including cardiomyopathies as a key competency area, evidenced through supervised learning events, workplace-based assessments, multisource feedback, and related procedural experience (Joint Royal Colleges of Physicians Training Board, 2016). Consultants are also encouraged to demonstrate attendance at CME/CPD activities, and some training events are mandatory for progression. However, participants’ accounts suggested that the way CPD is structured can create unintended consequences. Where CPD “points” or certificates are foregrounded, valuable learning opportunities without formal accreditation may be overlooked in favour of activities that more easily evidence compliance.

Charities such as Cardiomyopathy UK have developed accredited CM-specific CPD programmes, which can incentivise learning, particularly for trainees. Yet participating cardiologists described the challenge of sustained engagement among established consultants once formal training is completed. Although CPD remains necessary for appraisal and revalidation, and formal schemes exist requiring a minimum amount of CPD across a range of topics, consultants are not required to subscribe to these schemes and CPD becomes largely self-directed (General Medical Council, n.d.). Dr Richards described how national training days frustrated him because it was “*You went to the national conferences; you saw the same people from the same places at every meeting*” (Dr Richards, 255-263). Dr Cartwright described trying to “*keep*

abreast” of developments but positioned himself more as someone who presents at learning events than attends as a listener (Dr Cartwright, 63-66). These accounts captured a practical barrier (workload and competing demands) but also a cultural one: education was valued in principle, yet participation seemed uneven and, at times, shaped by whether clinicians experienced a topic as still relevant to their own learning needs.

This reflected wider CPD literature: Cullen *et al.* (2019) noted that CPD/CME can fail to meet physicians’ needs in contexts of rapid knowledge growth and increasing demands on time, and they argued for more tailored, needs-led digital content. Remote learning may reduce the time and travel burden, but it does not remove the more basic problem that people do not always recognise their own gaps. Ikenwilo and Skåtun (2014) discussed this in relation to the “*unskilled and unaware of it*” phenomenon (p.196), drawing on Kruger and Dunning’s (1999) work on overestimating competence in familiar areas.

Participants sometimes applied this idea to primary care in their accounts of CM knowledge, but their narratives also raised a more uncomfortable possibility: that specialist clinicians may not be immune to the same blind spots, particularly in areas they feel are already ‘covered’ by experience. This may help to explain the gaps in ‘missing key attendees’ when educational events and inter-service networks are trialled (Hansen *et al.*, 2024).

Overall, participants’ accounts framed robust educational networks as part of the infrastructure needed to reduce avoidable variation in CM knowledge and diagnostic practice. The hub-and-spoke vision (Figure 14) was clear conceptually, but participants’ accounts, and the wider literature, suggested that the real-world challenge are around creating protected time, credible incentives, and workable cross-service links that make education dissemination routine rather than reliant on motivated individuals. More research is therefore needed on the feasibility and sustainability of local education networks, and on the ongoing educational needs of consultant cardiologists themselves, particularly given that confidence and familiarity were described as uneven even within some cardiology services.

6.2.3 Professional and Emotional Experience

Cardiologists spoke indirectly about the emotional burden of their role, particularly their experience of trying to deliver ‘ideal’ standards of care within an imperfect health care system. Research has demonstrated how morale in the NHS has been declining for some time, alongside rising burnout, sickness absence rates and retention difficulties (Cooksley *et al.*, 2023; French, Hanna and Huckle, 2022). In cardiology specifically, one study reported that 43% of cardiologists left NHS roles for work outside the UK over a ten-year period, commonly citing NHS constraints, work–life balance and financial reasons (Crossland *et al.*, 2021). Two subthemes, **Emotional Labour** and **Moral Injury**, were therefore used to capture cardiologists’ experience of meeting patients’ psychological needs throughout CM diagnosis, and the longer-term strain of repeatedly working in ways that often fell short of their own ideal standards.

6.2.3.1 Emotional Labour (Subtheme)

Hochschild’s (2003; 2012) concept of emotional labour, later applied to healthcare contexts (Smith and Lorentzon, 2008), captured the challenge of caring for patients with compassion and composure while also managing and protecting one’s own psychological wellbeing. In this study, cardiologists described CM diagnostic consultations as emotionally demanding encounters. They were often responding to distress, uncertainty and future-focused questions, while also trying to stay clinically clear and keep appointments moving under time pressure. A lack of psychological support for CM patients was one of their major concerns, partly because cardiologists did not always know how to access psychological input and often felt ill-equipped to address mental health concerns within routine consultations.

Cardiologists did not frame the consideration of patients’ mental health as ‘extra’ work or separate from their medical role. Instead, they spoke as though psychological wellbeing was part of their ‘ideal’ cardiology practice, particularly as they recognised how distress, anxiety and low mood can shape symptom monitoring, engagement with services, and longer-term health outcomes. This aligned with emerging ‘behavioural cardiology’ frameworks (Astin, Lucock and Jennings, 2019) and with growing evidence linking psychological wellbeing and cardiovascular health (Levine *et al.*, 2021; Krittanawong *et*

al., 2023). Research has highlighted not only direct biological effects of poor psychological wellbeing on the heart (Sumner *et al.*, 2023), but also the social and behavioural consequences that can indirectly worsen cardiac outcomes. For example, people experiencing psychological distress have been found to be more likely to engage in substance misuse (Niedzwiedz *et al.*, 2021), less likely to be physically active (Rovero *et al.*, 2024), and less likely to adhere to medical advice (Nielsen, Banner and Jensen, 2021). These factors all link back to cardiac outcomes (Thompson and Pedersen, 2023; Rovero *et al.*, 2024). In that sense, cardiologists' emotional work sat alongside the clinical work, rather than outside it. Dr Garcia's emphasis on the need to hold social and psychological context alongside physical health captured this clearly:

"What I like is this, sort of, three dimensions to health, so you do the medical, physical side, but you need to do the social side... and you need to do the psychological side, so it's like this three-part pronged approach to everyone." (Dr Garcia, 155–161)

However, cardiologists' accounts also demonstrated how hard it was to practise in this *"three-part"* way when the service model did not reliably support it. Despite increasing evidence of a bidirectional relationship between poor psychological health and heart failure (Celano *et al.*, 2018; Rashid *et al.*, 2023), fewer than 24% of cardiac rehabilitation services in 2018 had a permanent psychologist (Doherty and Harrison, 2018). CardiomyopathyUK (2023) also reported that only 9% of cardiomyopathy patients surveyed were asked about their mental health by a clinician involved in their cardiac care. Considered alongside participants' qualitative accounts, this suggested that psychological care was widely recognised as important, but inconsistently available and difficult to integrate into short consultations without additional infrastructure.

Emotional labour was described as sustained rather than occasional amongst cardiologists. One reason for this may be due to cardiologists trying to manage psychological needs alongside physical health, whilst also navigating limited pathways for onward support. Dr Garcia described the difficulty of trying to *"mainstream psychological health"* (Dr Garcia, 161–165) within a physical health service and argued that

cardiologists should monitor mental health in the same way as other physical vital signs are routinely monitored. Thompson and Pedersen (2023) made a similar case, suggesting mental health screening should be routine in cardiology services, particularly during certain points in the pathway where strong emotional responses may be triggered, for example, following diagnosis or following implantation of cardiac devices. This raised practical questions about funding and prioritisation, especially when psychological distress is known to influence health outcomes. Alongside screening, research has proposed more structured consultation approaches, including teach-back methods, to help clinicians raise mental health and check understanding in routine appointments (Astin, Lucock and Jennings, 2019). Collopy, Cosh and Tully (2021) also suggested that lack of information and education about mental health in cardiac contexts can be a barrier to accessing support, and that normalising and validating distress may improve engagement and referrals to wider mental health services. However, they also noted the need for more robust evaluation of whether these approaches translate into measurable improvements.

Particularly since the Covid-19 pandemic, emotional labour in healthcare has been increasingly recognised (Lin, Li and Yan, 2022; Javed, Batool and Hassan, 2023). Extended periods of emotional labour have been linked to emotional exhaustion (Adams and Mastracci, 2020), low wellbeing (Van der Heijden, Brown Mahoney and Xu, 2019), and burnout (Kotzé, 2022). Burnout among cardiologists has serious consequences for clinicians and patients (Panagioti, Geraghty and Johnson, 2018), and cardiologists were considered particularly vulnerable given ongoing workplace demands (Ryan *et al.*, 2023a). Inefficiencies, resource constraints and excessive workload have also been linked to cardiologist burnout (Panagioti, Geraghty and Johnson, 2018). A US-based study reported that 42% of cardiologists surveyed felt burnt out, with 83% also feeling low in mood (Sharma *et al.*, 2023). While this is US-based data, a similar picture is emerging in the UK (Ahmed *et al.*, 2022; Camm *et al.*, 2022), and burnout has been more widely associated with depression, anxiety, and suicidal ideation (Ryan *et al.*, 2023a). Cardiologists' accounts implied that gaps in psychological provision do not remove the emotional work that is needed during the diagnosis process, they just relocate it into already time-pressured, medically

focused consultations. This adds to cardiologists' workload, but in a way that is rarely recognised, measured, or properly supported.

Overall, working without the psychological expertise, infrastructure, or resources to support patients' mental health while also addressing physical health needs was experienced as emotionally laborious for cardiologists. Participants' accounts suggested they were trying to provide care that was more holistic and psychologically informed than the system routinely enabled. More research is therefore needed focusing on the effects of embedding psychological support into standard cardiac care, with outcomes measured not only in relation to patient wellbeing, but also cardiologists and other clinicians impacted by sustained emotional labour, as part of efforts to prevent emotional exhaustion and burnout.

6.2.3.2 Moral Injury (Subtheme)

The concept of 'moral injury' was first used to describe the psychological distress experienced by military personnel who were required to act in ways that challenged their personal ethics and beliefs (Patel *et al.*, 2021). This internal conflict has been linked to feelings of guilt and shame and to increased risk of mental health difficulties such as post-traumatic stress disorder (PTSD), anxiety, and depression (Williamson, Stevelink and Greenberg, 2018). Moral injury was also widely documented during the COVID-19 pandemic, when clinicians around the world were at times forced to provide suboptimal care and prioritise certain patient groups due to limited resources (Xue *et al.*, 2022). Far removed from their usual ethos and duty of care, many clinicians developed significant psychological distress, including PTSD (French, Hanna and Huckle, 2022; Khattak *et al.*, 2021).

Within this study, cardiologists' accounts suggested a related, but often more chronic, form of moral strain in cardiology care. Cardiologists were acutely aware of their position of authority within the clinician-patient dynamic and of the responsibility they held over patients' health and wider wellbeing. Cardiologists are often the lead clinician within a cardiac patient's multidisciplinary team and hold ultimate responsibility for care (National Institute for Health and Care Excellence, 2025). This level of responsibility, coupled with the need to make high-stakes decisions in direct care settings, has been

linked to greater vulnerability to moral injury compared to some other health professionals (Thevathasan *et al.*, 2026). Bottle *et al.* (2018) and Cartolovni *et al.* (2021) have highlighted that moral injury (and closely related moral distress) is more likely to arise where clinicians lack agency to enact the ‘right’ decisions, have insufficient resources to provide care to professional standards, or witness poor standards of care and complicity in wrongdoing. This sits against a broader workforce context in cardiology, including high turnover within the NHS (Crossland *et al.*, 2021) and evidence of elevated suicide rates among physicians relative to the general population (Harvey *et al.*, 2021). There is also evidence that moral distress and systemic constraints are associated with increased alcohol consumption among healthcare workers (Savage *et al.*, 2020), though under-reporting is likely given barriers to disclosure and help-seeking (Harvey *et al.*, 2021).

In this study, cardiologists described discomfort in knowing that while diagnosing and treating patients’ physical health (CM), their psychological wellbeing and wider social circumstances (e.g., employment, family planning, and access to life insurance) could also be negatively affected. While participants recognised the necessity of some short-term physical discomfort or restriction in service of longer-term health outcomes, they also spoke about the wider consequences patients may have to carry. This moral tension appeared to intensify when resource constraints prevented participants from delivering the standard of care they viewed as ideal during diagnosis.

Cartolovni *et al.* (2021) highlighted the distinction between moral injury and moral distress: repeatedly knowing what good care should look like but being unable to deliver it due to factors beyond individual control, may be more accurately conceptualised as ongoing moral distress linked to systemic inequalities. At the same time, cardiologists also described more acute, ethically charged episodes that may resemble moral injury more closely, such as Dr Christie’s reflections on cancer treatments that can increase CM risk and the uneasy trade-off of protecting immediate physical health at potential longer-term cost.

Whether framed as moral distress or moral injury, accounts suggested that cardiologists can carry a persistent internal conflict that is not always visible or explicitly acknowledged. This sits within a wider NHS culture where staff may feel unable to raise concerns about wellbeing and workload: Dominic, Gopal and Sidhu (2021) reported that 53% of NHS workers did not feel able to raise concerns relating to wellbeing, workload, or stress, and that 97% considered excessive stress to be the norm. Together, these figures raise questions about how often moral strain is named, supported, or translated into systemic change. Future research should therefore consider the potential value of improved psychological support for cardiologists, and whether this impacts staff retention, wellbeing, and job satisfaction (Dominic, Gopal and Sidhu, 2021; Crossland *et al.*, 2021).

6.3 Barriers to Shared Decision-Making (*Superordinate theme*)

This superordinate theme examined how cardiologists attempted to negotiate shared clinical decision-making during cardiomyopathy (CM) diagnoses, while working within conditions that made genuine partnership challenging. Shared decision-making, described as “*a clear art*” (Dr Garcia, 51), was viewed by cardiologists as being central to the CM diagnosis process. Participants acknowledged how clinical decision-making had evolved over time due to a wider shift from a paternalistic model to a more holistic and person-centred model of healthcare (Tan, 2022). Dr Christie captured this shift by reflecting that, “*If the doctor had told my grandmother to stand in the corner for three hours she would have done without question*” (Dr Christie, 898-909). In contrast, cardiologists described how in modern times, patients’ insights and experiences are valued as meaningful contributions to clinical decision-making. However, they also outlined barriers that continued to limit ‘true’ shared decision-making, raising the question of whether the move away from paternalistic models has always been a genuine shift, or whether it can at times feel like paternalism repackaged under a façade of partnership. It is also important to note that some patients may prefer a more directive style, particularly when frightened or overwhelmed, which complicates assumptions that more involvement is always experienced as better care (Turrini *et al.*, 2025). With natural inequalities in knowledge and experience in healthcare, cardiologists’ accounts also raised the possibility that full equality during diagnosis might be an unachievable goal, even where intentions are collaborative.

Instead, meaningful partnerships were recognised as non-hierarchical in spirit, built on mutual respect for different forms of knowledge, and a held a shared sense of responsibility for agreed health goals (Tan, 2022).

Mirroring the presentation in Chapter 5, this superordinate theme is discussed through six interlinked subthemes. For clarity, these were grouped within two broader contexts that were perceived to be key barriers to achieving genuine shared decision-making when diagnosing CM: *Organisational Constraints* and *Relational Dynamics*. Under *Organisational Constraints*, the subthemes **Professional Responsibilities**, **Consultation Time**, and **Social Implications of Diagnosis** captured how time, funding, staffing and professional responsibility limited what clinicians were able to offer, even when working with the best of intentions. Under *Relational Dynamics*, the subthemes **Inclusion, Empathy and Non-Verbal Communication**, and **Preconceptions** explored how shared decision-making could be both strengthened or undermined through the quality of clinician-patient interactions, including conscious efforts to reduce inequality, while recognising the influence of bias and pre-existing assumptions. Together, these contexts showed how cardiologists attempted to include patients in decisions, while navigating constraints that could made partnership harder to achieve in practice.

6.3.1 Organisational Constraints

Cardiologists perceived organisational constraints to adversely affect shared decision-making and their ability to foster self-management in CM patients. Three subthemes are discussed in this section:

Professional Responsibilities, **Consultation Time**, and the **Social Implications of Diagnosis**.

Participants described how the practical demands of obtaining informed consent, the limited time available during and between consultations, and the wider social consequences attached to a CM diagnosis could all restrict patients' participation in shared decision-making. These constraints left cardiologists feeling pulled between approaching patients in a more uniform, standardised way (as a practical necessity) and tailoring discussions to the needs and preferences of each individual. This tension placed strain on the clinician–patient relationship and could affect patient satisfaction and willingness to engage in shared decision-making (Consolandi, Magnolini and Dragoni, 2023; Roodbeen *et al.*, 2020).

6.3.1.1 Professional Responsibilities (Subtheme)

Cardiologists spoke of the professional responsibilities they held, such as obtaining informed consent and educating patients and discussed how these processes can affect shared decision-making. Informed consent involves sharing knowledge between clinician and patient so that patients are equipped to make informed and autonomous decisions about their healthcare (Agozzino *et al.*, 2019). Although legally and ethically required, informed consent is a complex process shaped by clinician communication, patient comprehension and capacity, and both parties' ability to make sense of risk (Pietrzykowski & Smilowska, 2021).

Informed consent also assumes that patients truly understand what they are consenting to. Even when patients feel informed, understanding may be limited by health literacy, discussing health in a second language, or having a limited education (Nutbeam and Lloyd, 2021). Patients may also not retain all details, which can affect later decision-making. These issues were frequently referenced by cardiologists in the current study and align with wider research. For example, Ruske *et al.* (2021) found that while many patients reported feeling well-informed about an upcoming vascular procedure, only 14% could accurately recall information about risks, benefits and alternative options. This gap is sometimes discussed in relation to the Dunning–Kruger effect, a cognitive bias where people overestimate their ability or knowledge about a specific topic (Canady and Larzo, 2023). Determining whether a patient truly understands the information they are given remains difficult, and no single standardised approach to checking understanding currently exists (Glaser *et al.*, 2020).

Similarly, health professionals can overestimate their ability to communicate in ways patients understand and can be overly confident about patients' understanding (Shore *et al.*, 2024b).

Cardiologists may also overestimate their ability to calculate risk and communicate it clearly, further limiting informed consent and effective shared decision-making (Daily, Dalby and Greiten, 2025). This was alluded to by cardiologists in the current study, who described themselves as good communicators and suggested communication skills had improved over time. Patients' subjective impression of being

well informed, alongside doctors' overconfidence in the quality of information provided, can therefore act as barriers to true shared decision-making and adequate informed consent (Pietrzykowski and Smilowska, 2021).

In terms of wider responsibility, risk stratification was described as one of the most challenging aspects of cardiologists' work, particularly in the context of uncertainty. Participants described three linked challenges: quantifying risk, balancing short-term benefit against longer-term harm, and communicating risk to patients. Dr Richards described having to stratify risk at every consultation and noted that risk tools did not always capture the complexity of real-world variables. The shortfalls of current cardiovascular risk stratification tools are well documented, as they are often based on population norms and cannot accurately factor in co-morbidities as is often the case (De Matteis *et al.*, 2025; Panattoni *et al.*, 2025), leaving the exact method of risk stratification, and how much trust to place in this, the responsibility of the cardiologist. Dr Christie also spoke about the burden of decisions that reduced short-term risk while increasing the risk of longer-term harm, such as chemotherapy eradicating cancer while increasing the likelihood of cardiomyopathy developing later. Clinicians knew these risks when recommending cancer treatment and carried responsibility for balancing the competing outcomes over time.

These responsibilities shaped how cardiologists approached information-sharing. Dr Nichols reported feeling uncomfortable when patients disengaged from conversations about risk or prognosis and saw patient understanding as foundational to care planning (Consolandi, Magnolini and Dragoni, 2023). At the same time, cardiologists described the difficulty of knowing how much risk-based information to share with patients to avoid unnecessary alarm or distress. Cardiologists often relied on their expertise to decide what to emphasise and made recommendations that patients could accept or reject. This raises questions about how truly 'shared' decision-making is when control over information remains largely with the clinician (Timmermans, 2020). More broadly, shared decision-making depends on the knowledge, experience and expectations of both parties. Clinicians may assume a level of health literacy

or prior understanding that patients do not have (Pietrzykowski and Smilowska, 2021), and health goals (short-and long-term) often shape what information feels most relevant to each individual patient. This reinforces the importance of having adequate time during consultations to clarify expectations, responsibilities, and to share the information patients need to make significant health decisions.

6.3.1.2 Consultation Time (Subtheme)

Cardiologists reported that typical consultation length was not enough to build rapport, understand patients' health goals and expectations, assess risk factors, and relay risk information in an accessible way before reaching a mutually agreed decision. Some clinicians also felt that long gaps between consultations added pressure to make decisions quickly, without giving patients enough time to reflect or ask follow-up questions. Clinicians were keenly aware of the impact time constraints had on shared decision-making but felt helpless to change such a widely engrained systemic issue.

Keij *et al.* (2021) found that some patients required more time, particularly following a new diagnosis, to develop 'readiness' for shared decision-making. They argued this included time to process and familiarise themselves with the diagnosis or problem in hand before feeling psychologically ready to engage in clinical discussions. Ten or fifteen-minute consultations, as described by cardiologists in this study, did not allow for such 'readiness' to develop leading to the need for multiple consultations and higher resource burden. However, cardiologists suggested multiple consultations were not the norm and that a CM diagnosis was often communicated within the same consultation as recommending treatment (lifestyle change plus medication and/or surgical intervention).

Dr Richards recognised that follow-up consultations would benefit many of his patients and accommodated this through additional follow-up reviews with himself or a cardiac nurse specialist. He highlighted however that this was not typical and that he was 'fortunate' to be able to facilitate extra appointments in his clinic. Dr Richards also discussed the challenges of stratifying risk within the limited timeframe of a standard consultation. Tsiga *et al.* (2013) found that, under time pressure, clinicians were more likely to rely on intuitive processes rather than evidence-based information when making clinical

decisions, whereas clinicians afforded more time relied more on evidence-based information and felt more confident in their clinical decisions. It should be noted that neither condition considered patients' wishes or expectations, so results may not translate directly to the context of shared decision-making. However, this research highlights the value of having more time between consultations to support clinician confidence and clarity on their own position and recommendations. It could therefore be argued that the process of developing 'readiness' described by Keij *et al.* (2021) should ideally be afforded to both clinician and patient prior to shared discussions around decision-making.

In the absence of adequate consultation time, multiple tools have been developed to streamline parts of shared decision-making process. Sometimes referred to as decision aids (DA), these tools usually involve patients engaging with information via video or written materials about their condition, treatment options and associated risks, which can be digested at home rather than during clinic time. Coronado-Vazquez *et al.* (2020) systematically reviewed 24 studies published between 2007 to 2019 and found overall satisfaction improved in both clinicians and patients when using a DA. For cardiovascular patients, they found improvements in patients' perception of cardiovascular risk factors and higher rates of sustained positive lifestyle changes. During decisional conflict, DAs were also found to increase confidence in decisions and decrease decisional regret in cardiovascular patients (Coronado-Vazquez *et al.*, 2020).

Although potentially beneficial, DAs may not be tailored enough to meet individual needs and circumstances (Backman *et al.*, 2020). Comorbidities or risk factors can make patients ineligible for some options included in standardised DAs. DAs used at home also rely on a certain level of health literacy and memory to understand and retain information. Educating patients about their condition, treatment options and risk forms a crucial platform for shared decision-making. Some may argue that completing this element prior to consultation could free up time to discuss health goals and expectations within clinic time and support the development of 'readiness' described by Keij *et al.*

(2021). Equally, however, it could be argued that DAs can feel impersonal, create distance within the clinician–patient relationship and may not be an accessible option for every patient.

Cardiologists described time-limited consultations as an organisational barrier to achieving genuine shared decision-making. Current consultation length was seen to constrain rapport, decrease patients' and clinicians' 'readiness', and reduce the space needed to explain and reflect on risk, with decision aids being of only partial benefit to some patients. In that same limited time, clinicians and patients must also consider the real-life social implications of a CM diagnosis and subsequent treatment options.

6.3.1.3 Social Implications of Diagnosis (Subtheme)

Cardiologists demonstrated an understanding of the wider social implications of a CM diagnosis and subsequent management, describing how patients must "*carry the diagnosis for the rest of their lives*" (Dr Cartwright, 691-701). Cardiologists spoke of how these factors were seriously considered alongside risk stratification and other factors during clinical decision-making. The social implications of diagnosing CM were understood to be unique to each individual patient. For those of working age, cardiologists considered the impact of the diagnosis on their work, relationships, obtaining life insurance and securing a mortgage, while the impact to other populations (older adults, women of child-bearing age etc.) were also uniquely considered. This represented a general shift in focus from a purely physical health-centred to a more person-centred model of care that has been widely adopted within the NHS (Titheridge, 2025).

Dr Cartwright in particular highlighted key system-level challenges that arise for his patients when they are diagnosed with a CM, as they are obligated to inform organisations such as life insurance companies or the Driver and Vehicle Licensing Agency (DVLA), who use statistical modelling to stratify risk. This can have serious implications for patients, including increased premiums and potentially restricted or revoked driving licenses. Whilst Dr Cartright acknowledged these processes are intended to reduce risk of harm, he expressed frustration that such systems do not factor in known or well-managed risks and instead rely on statistics that may not accurately represent the CM population. For example, the DVLA has published specific guidance on how health conditions affect driving eligibility, leaving some CM

patients with a blanket ban on driving or significant periods of restriction, depending on the type of licence held (personal car versus bus or heavy goods vehicle). With regards to a heart failure diagnosis (with guidance specifically highlighting several cardiomyopathies), even those who are least symptomatic (NYHA1 - New York Heart Association, Level 1) bus and lorry drivers will be immediately banned from driving any heavy goods vehicle unless their left ventricular ejection fraction (LVEF – a measure of the heart’s pumping function) is at least 40% (Driver and Vehicle Licensing Agency, 2025).

Dr Cartwright highlighted how someone with a diagnosed and appropriately managed diagnosis of heart failure is arguably less at risk of sudden cardiac symptoms or acute event during driving than someone with unknown and unmitigated risk factors. This is supported by a growing body of research highlighting the limitations of using LVEF alone as a reliable clinical indicator of risk in heart failure patients (Rosano *et al.*, 2025), with only sporadic correlation between LVEF thresholds and symptom expression. Seckin *et al.* (2023) reviewed sex differences in KCCQ (Kansas City Cardiomyopathy Questionnaire) scores across three heart failure subgroups: preserved, mildly reduced, or reduced left ventricular ejection fraction (LVEF), and incidentally reported how, *“At baseline, shortness of breath and fatigue were the most prominent symptoms in both sexes irrespective of HF subgroups”* (Seckin *et al.*, 2023, p. 695). This demonstrates that, while relative in terms of frequency, symptoms likely to affect driving ability were present across all subgroups, including those with a preserved ejection fraction (LVEF >40%) - the standard at which a licence may be reinstated by the DVLA. Furthermore, health thresholds for retaining a driving licence are inconsistent across the globe (Lusetti *et al.*, 2025), highlighting the challenges of using universal cut-offs such as LVEF for something so impactful on day-to-day functioning and quality of life, particularly as it pertains to employment.

Overall, the points raised by Dr Cartwright, alongside published research, suggest that current risk stratification measures used in non-NHS services are less than perfect and can feel punitive to those with CM diagnoses. Such social and emotional implications of diagnosis must therefore be considered within shared decision-making in order for it to be truly person-centred.

6.3.2 Relational Dynamics

Cardiologists described shared decision-making as relational work as much as clinical work. They acknowledged that patients needed to feel able to ask questions, admit uncertainty, or disagree for shared decision-making to be meaningful. Cardiologists also recognised that these dynamics were not neutral, given the asymmetry of knowledge and gatekeeping power they held in the consultation. Similar relational conditions have been highlighted in other contexts as foundational for effective communication, including empathic attunement, attentiveness, cultural sensitivity and awareness of bias, particularly where power is uneven (Patil, Patil and Katre, 2024). This section discusses three subthemes, ***'Inclusion'***, ***'Empathy'***, and ***'Preconceptions'***, to examine how cardiologists attempted to manage the relational conditions for shared decision-making, and how these efforts could both welcome and restrict patient voice.

Cardiologists also suggested these relational skills were not equally held or equally valued across clinicians, which may help explain variation in the strategies cardiologists used to manage these relational dynamics during CM diagnosis.

6.3.2.1 Inclusion (Subtheme)

Cardiologists acknowledged that their inherent power over patients negatively affected shared decision-making. They recognised the relative authority they hold within the diagnosis process and described deliberate efforts to form partnerships with patients by creating opportunities for inclusion. These strategies were purposeful and aimed to empower patients to contribute to discussions about their care. Some likened this purposeful demonstration of care to that of a theatrical performance, referring to patients as *"the audience"* (Dr Nichols, 567-568) and the consultation as *"the show"* (Dr Cartwright, 310). This framing suggests that inclusion and empathy were not always treated as spontaneous by-products of good care, but as something that had to be made visible, managed, and sometimes consciously 'performed' in order to bring patients into the interaction. These acts aimed to reduce barriers to shared decision-making by making space for patients' questions, reactions and preferences, even within a relationship that remained fundamentally unequal.

Empowering patients has been at the forefront of NHS policy for many years, partly to increase self-management in chronically ill patients and support the sustainability of current health systems (Denysyuk, Pires and Garcia, 2024). Despite this focus, patient empowerment is usually poorly defined and overlaps with neighbouring concepts such as engagement, enablement and activation, creating further ambiguity (Fumagalli *et al.*, 2015). This lack of clarity may help explain the range of inclusion attempts described by cardiologists in the current study. Some cardiologists described using the ‘teach-back’ method to check patients’ understanding and engage them in conversation, others used intentional pauses to invite verbal contributions, and some described purposefully dictating notes and letters in front of the patient so they could access what was being recorded in their clinical notes. Although these methods are popular strategies for engaging patients in partnership with their health care team (Denysyuk, Pires and Garcia, 2024; Shersher *et al.*, 2021), the ultimate power remains with cardiologists who, in performing such actions, allow patients into the conversation and into clinical notations they would otherwise not be privy to.

Cardiologists also described relying on observation and non-verbal cues to judge whether patients were following, whether uncertainty was being tolerated, and whether it was safe to keep going or necessary to pause, revisit, or invite questions. Non-verbal communication plays a crucial role in clinical settings (Sharkiya, 2023), where understanding a patient’s body language can reveal unspoken concerns, emotions or provide insight into interpersonal dynamics between patient and carer or patient and clinician (Bellieni, 2022). In the context of shared decision-making, cardiologists described how these cues helped them to pace information, check understanding, and judge whether a patient felt able to ask questions or express disagreement. Research by Danaher *et al.* (2023) highlighted how clinicians employed kinesics, such as nodding and eye contact, while also observing patients’ posture and facial expressions to gauge their reactions. In practice, this is important because patients may outwardly appear to be in agreement but may inwardly feel overwhelmed, fearful, or affected by ‘constrained compliance’ (Saggese, 2023; Vinson, 2016), particularly in high-stakes consultations where specialist knowledge and gatekeeping power sit with the clinician.

At the same time, non-verbal communication is neither perfect nor neutral. Cues themselves, and the interpretation of cues, vary across individuals and contexts and can be shaped by culture (Moloko-Phiri *et al.*, 2022) neurodivergence (Radford *et al.*, 2025), hearing or vision problems, fatigue, or patients trying to appear as though they are ‘coping’ (Saggese, 2023). This creates a risk that clinicians may misread quietness as understanding or interpret distress in ways that does not match the patient’s actual concerns. The rise of telemedicine, accelerated by the COVID-19 pandemic, adds a further constraint as when clinicians transition to virtual consultations, they often exaggerate or modify their own body language to enhance visibility (for example, ensuring all hand gestures are visible on camera) and connection with patients, as noted by Christensen and Danbjørg (2021) Christensen, Skou and Danbjørg (2021). This adaptation may help bridge the gap created by the absence of physical presence, yet it also limits the clinician's ability to assess non-verbal cues from patients, such as their physical presentation and emotional state. With the evolution of telemedicine, further research is needed exploring how non-verbal communication is affected in virtual settings and its implications for patient care. Understanding these changes is essential for optimising the clinician-patient relationship in an increasingly digital healthcare landscape in the pursuit of more successful shared decision-making.

Chen, Croft & Currie’s (2025) work described how the concept of ‘co-production’ had worked towards levelling the power imbalance during interactions between patients and clinicians. They argued that with expert patients playing key roles in the development and structure of health services, patients who are aware of this collaboration may enter the consultation room as a co-producer of knowledge and healthcare framework, rather than as a mere spectator. Through collaboration patients become more aware of the systemic challenges faced by clinicians and clinical researchers, while clinicians and researchers become more aware of the real-world implications of clinical protocols and expectations on their patients. The researchers acknowledged that in some cases the more dominant actors (clinicians) may engage only in tokenistic involvement, but they argue co-production can still offer less dominant service users’ routes to influence more dominant clinician groups. However, co-production only meaningfully reduces imbalance if patients are aware of the influence they hold and the contributions

they can make, and if opportunities to contribute are distributed fairly. Research has shown that only articulate, educated patients are likely to be invited to participate in co-production activities (El Enany, Currie and Lockett, 2013), which creates equality and diversity challenges for less dominant patient groups who may never feel the benefits of such inclusion.

Even when the clinical agenda is communicated with empathy and framed as ‘patient-centred’ or empowering, it may still produce ‘constrained compliance’ rather than genuine partnership (Vinson, 2016). Further research is needed to understand how these bids for inclusion are experienced by patients and whether they translate into meaningful shared decision-making, rather than reassurance or participation on the clinician’s terms. This theme is further discussed in Chapter 9 from an integrated perspective. It could be suggested that acknowledging power dynamics in the consultation room and attempting to mitigate them is preferable, and likely more effective, than acting as though the imbalance does not exist.

6.3.2.2 Empathy (Subtheme)

Cardiologists highlighted the importance of enacting empathy during diagnosis in order to build rapport and trust. Empathy was described as active, intentional work, using language, tone, pauses, reassurance, and validation to help patients tolerate uncertainty and stay engaged with difficult topics (e.g., risk, prognosis, device decisions, and the family impact of CM), rather than disengaging or simply ‘going along’ with recommendations. One way this appeared in cardiologists’ accounts was through the use of empathetic framing: presenting the diagnosis as manageable and treatable to instil hope and keep patients involved in the conversation, for example, *“I can...make the cloud have a silver lining”* (Dr Cartwright, 379–286). This aligns with wider health research on optimistic framing and its association with increased patient engagement and communication (Forth *et al.*, 2024).

At the same time, framing can create challenges for shared decision-making. While the use of particular language may help patients engage with information, it can also influence how different options are perceived before patients have had the opportunity to consider what matters most to them personally.

Persuasion can occur when the wording, emphasis, or meaning attached to an option makes it appear to be the most sensible choice, or the option most strongly endorsed by the clinician (Engelhardt, Pieterse and Stiggelbout, 2018). Framing can therefore influence which options feel reasonable and which risks feel most important, before patients' own preferences have fully formed. Positive framing is not inherently problematic and, in high-stakes consultations, may be necessary to prevent overwhelm and disengagement. The difficulty arises when reassurance slides into subtly persuasive communication, particularly where patients feel less able to voice different preferences, or where the clinician's view is assumed to carry disproportionate weight (Schoenborn *et al.*, 2024).

More specifically, empathy-based framing where clinicians (1) acknowledge discomfort felt by patients and then (2) present a specific action that is framed as the resolution, has been shown to increase uptake of clinician-suggested choices, particularly amongst patients who are very unwell or have low health literacy (Geurts *et al.*, 2022). This supports the view that empathy can function not only as emotional support, but also as a mechanism of influence within SDM. However, cardiologists' accounts also positioned empathy as a facilitator of participation. Empathy can operate as a relational influence in that once rapport is established, *"They generally recognise that you've got their best interests at heart... they want to hear what you want to say"* (Dr Nichols, 832–836). In this sense, empathic communication may keep patients in the conversation long enough for questions, worries, and preferences to surface, rather than shutting down discussion or defaulting to passive agreement. Research supporting the use of such displays of empathetic communication suggested that *"doing empathy activities"* (Babaei, Taleghani and Farzi, 2022, p. 241) such as sitting alongside patients and giving them the opportunity to share their experiences openly, is fundamental to creating a supportive clinical environment (Babaei, Taleghani and Farzi, 2022). Cardiologists therefore suggest that performative empathy can support shared decision-making by increasing trust and reducing emotional threat, but can also create tension, because framing and reassurance have the potential to slip into persuasive communication that steers patients' decisions.

Cardiologists also used an empathetic approach to pacing and tailoring information to patients' emotional context: *"it's very patient specific... someone who comes to see you because their brother has just dropped dead is very different to someone who's just a little bit breathless..."* (Dr Garcia, 198–205). In other words, how cardiologists shared information was shaped by what they understood the patient to be feeling, fearing, and needing in that moment. This use of empathy as a pacing tool can be read as an attempt to prevent information overload and allow patients to remain psychologically present during complex discussions. At the same time, cardiologists also emphasised the importance of supporting all patients to make an *"informed choice"* (Dr Nichols, 820), which introduced a practical tension within shared decision-making between responding to individual concerns and keeping information-sharing consistent and comprehensive across patients. If not handled carefully, this can reinforce a one-way dynamic, with the clinician positioned as the 'information provider' and the patient as the 'information receiver'. However, cardiologists' accounts also suggest the opposite - that tailoring is often driven by attentive listening, and by attempts to meet the patient's priorities without losing the broader standard of patient education that CM diagnosis requires. This aligns with evidence that individualised tailoring can improve attention to, and understanding of, risk–benefit information when it is framed in terms of how it might affect the individual person, rather than delivered as a blanket script for all patients (Scherer and Matlock, 2024). Empathy therefore becomes part of the clinical judgement involved in shared decision-making itself, shaping not only what is said, but when, how, and in response to which emotional cues or contextual information provided by the patient.

6.3.2.3 Preconceptions (Subtheme)

Cardiologists recognised that, whilst very human, making generalisations and holding preconceptions about patients' needs can significantly affect the quality of care they provide, further limiting opportunities for shared decision-making. They acknowledged that genuine shared decision-making sometimes necessitates setting aside their preconceived notions of best practice in order to align their expectations and health goals with those of their patients. Several cardiologists described needing to pause their own assumptions in order to understand the patient's starting position (i.e., the patient's

preconceptions, fears, and expectations around health). Dr Richards described doing this explicitly by asking whether the patient had read about CM online and inviting them to name expectations that might otherwise remain implicit: “*Some people will often lay it out, ‘I’m petrified of dying.’*” (Dr Richards, 410–418). In this way, preconceptions were not presented simply as bias or prejudice, but as something cardiologists noticed and, at times, tried to correct for to keep decision-making anchored in the patient’s concerns.

Cardiologists often spoke of preconceptions relating to patients’ age, and how age was assumed to change the impact and meaning assigned to a CM diagnosis. A recurring assumption was that younger patients struggle more because the diagnosis confronts an implicit expectation of health, imposes new responsibilities, and disrupts future planning. Dr Garcia’s account captured this clearly, describing the different emotional load younger patients may carry in the context of children, lifestyle, and the shock of no longer feeling “*immortal*” (Dr Garcia, 340). This fits with wider research raising concerns about ageism and diagnostic decision-making, where clinicians’ beliefs about what coping should look like (and what goals are *reasonable*) for different age groups can shape how options are communicated, which risks are deemed important, and how strongly recommendations are presented (Veenis *et al.*, 2020; Agarwal *et al.*, 2025).

Preconceptions about health expectations were therefore particularly relevant to shared decision-making, because they influenced how cardiologists interpreted distress, predicted what mattered to patients, and judged what kinds of outcomes would feel acceptable. Cardiologists highlighted the importance of understanding patients’ psychological states and how health expectations can shape decision-making conversations, particularly when clinicians’ and patients’ assumptions are misaligned (Stewart, Roberts and Brindle, 2023). An illustrative case is presented in Chapter 5.3.3, where Dr Christie reflected on her discomfort when a patient’s husband described age 59 as “*a good innings*” (789–804). Importantly, she did not frame this as something to correct or override but instead, she described it as something she had to negotiate in real time: “*okay, alright, but what else can you do or say?*” (789–804).

This demonstrated that when preconceptions are challenged, cardiologists can respond either with curiosity and recalibration, as Dr Christie demonstrated, or they can default back to their own assumptions about what *should* matter, which risks minimising patient's views and subtly steers discussions towards clinician-led goals.

Gramling *et al.* (2016) reported a similar phenomenon in cancer care, which they described as prognostic discordance - occurring when there is a discrepancy between patients' prognosis expectations and those of their oncologists. They found that discordance not only hindered clinician-patient communication but also reduced patients' understanding of the condition itself. Shore *et al.* (2024b) found similar patterns of prognosis discordance amongst end-stage heart failure patients. Similarly, cardiologists in this study suggested that discordance is not only about factual misunderstanding, but about differences in expectations, fears, and meaning attributed to a CM diagnosis. If clinicians develop a deeper awareness of the biases and preconceptions they bring into consultations, they may better recognise how these influences shape their interpretation and presentation of information (Gopal *et al.*, 2021). This heightened awareness could encourage clinicians to consider the perspectives through which patients interpret and present information, ultimately enhancing communication and understanding during the diagnostic process, but this requires further investigation within the contexts of cardiomyopathy diagnoses.

Preconceptions and assumptions also emerged around family and reproduction, which is particularly relevant to CM because pregnancy risk (Norouzi *et al.*, 2025) and inheritability (Voinescu *et al.*, 2024) are clearly documented. Dr Wallis described a pattern of worry linked to the age of the patient: *"when people are young there's often a fear of god how will this affect me having children? Whereas, when people are older they are fearful that it will affect their [existing] children"* (Dr Wallis, 255–261). While this may reflect a genuine pattern cardiologists encounter, it would be risky to presume this is the case and not ask each patient directly. This is also where the emotional pull of the topic becomes visible in the data. Dr Christie's response to a patient requesting another pregnancy: *"Really, do you really want to risk it?"* (Dr

Christie, 862–864) shows how quickly a protective stance might be communicated and interpreted as surprise or disapproval, affecting what patients feel comfortable discussing. This highlights how preconceptions are not always neutral and are often emotionally loaded responses that shape tone, pacing, and what topics are discussed enthusiastically invited versus shut down.

Dr Cartwright's observations about how educational background and current employment influence patient comprehension raise ethical questions regarding how physicians communicate complex medical information. He described using job roles (including partners' occupations) to decide "*what level I'm going to talk to them*" (Dr Cartwright, 185–193), acknowledging it could be viewed as "*arrogant or asocial*" (Dr Cartwright, 277), but positioning it as a pragmatic response to limited time. Roodbeen *et al.* (2020) found that palliative care oncologists employed similar strategies to gauge their patients' education levels, enabling them to make informed judgments about the language used in discussions, which proved largely effective. However, the difficulty is the epistemic leap from job title to health literacy or emotional capacity, particularly when it leans towards unnecessary stereotyping. Dr Cartwright's linking of manual work, lower intellect, smoking, and reduced psychological impact - "*a couple of cigs and go home*" (Dr Cartwright, 521–538) is one example of how quickly such preconceptions can become an assumed narrative about who will cope and who will not. Easton, Murugesu *et al.* (2022) emphasised the need for clinicians to promptly assess and address communication challenges, health literacy issues, or cognitive impairments and adjust their language-use accordingly. They discovered that, due to the associated stigma, many patients comply with medical advice without fully understanding the provided information. Moreover, patients often attempt to conceal their lack of understanding or limit their interactions with clinical staff to avoid embarrassment, complicating clinicians' ability to accurately assess comprehension (Easton, Entwistle and Williams, 2013). The above excerpt also raises ethical considerations regarding the practice of generalising patient experiences. While some cardiologists use generalisations as a pragmatic communication tool, this practice risks fostering patronising attitudes or making decisions based on incomplete understandings of patients' lives, potentially compromising ethical standards in care.

This subtheme highlights the importance of clinicians noticing and reflecting on the assumptions they bring into consultations, and how these can shape patient care and shared decision-making. If assumptions are not checked (about factors such as risk tolerance, goals, understanding, or family priorities) patients may appear to agree while privately feeling unsure, embarrassed, or unheard (Easton, Entwistle and Williams, 2013). In contrast, when cardiologists actively explore a patient's starting point (as Dr Richards does) and are willing to sit with differences in values or health expectations (as Dr Christie describes), these assumptions can be discussed and adjusted rather than quietly directing decisions. For example, if education level is being used as a proxy for determining health literacy, it may be more appropriate to ask about understanding directly, rather than inferring it from job roles that may not be relevant.

6.4 Chapter Summary

The analysis of interviews with consultant cardiologists revealed two primary themes: ***“Ideal versus Real”*** and ***“Barriers to Shared Decision-Making”***. These themes were discussed in relation to wider research and interpreted through an interpretative phenomenological lens.

Ideal versus Real

This theme captured the perceived tension cardiologists experienced between what they believe *should* happen in an “ideal” cardiomyopathy (CM) diagnosis and what is actually possible in routine NHS practice. Their accounts showed that the issue is not simply that care becomes “less good” under pressure; it changes what the diagnostic process can realistically be, including what can be prioritised, explained, followed up, and held emotionally. Cardiologists described working within uneven knowledge and infrastructure across services, fragmented pathways, and inconsistent continuity. They also highlighted how language and public understanding shape patient distress and engagement (e.g., discomfort with “heart failure” terminology), and how patient education often falls short within typical consultation constraints, leaving charities and informal supports to fill gaps. Across these accounts, the “ideal” was

presented as a practical standard for safe, manageable care, while the “real” was described as an ongoing negotiation with system conditions that repeatedly force compromise and carry consequences.

Barriers to Shared Decision-Making

This theme focused on how shared decision-making (SDM) is constrained in CM diagnosis even when cardiologists value collaboration and try to practise in a person-centred way. Barriers were described as both structural and interactional: time pressure, informed consent demands, and risk-based decision-making place clinicians in a position where they still control the flow and weighting of information, which can narrow genuine collaboration. Cardiologists also described how the wider social consequences of diagnosis (e.g., work, insurance, driving, family planning) are not “extra” considerations but part of what patients are deciding around, and therefore shape SDM in real life. Relationally, cardiologists acknowledged the power imbalance and described deliberate efforts to include patients (teach-back, pauses, dictation in front of patients), yet these efforts can still be tokenistic if participation remains on clinician terms. Empathy was positioned as necessary for keeping patients psychologically engaged during high-stakes discussions, but cardiologists’ accounts also highlighted how reassurance and framing can slip into subtle persuasion, shaping what feels like the “reasonable” choice before patient preferences are fully explored. Finally, cardiologists recognised that preconceptions (age, health expectations, perceived literacy or coping) can contribute to this – potentially steering how options are presented and how patients’ distress is interpreted. In real terms, this means that SDM is more productive and successful when clinician’s implicit bias or assumptions are acknowledged, however, if left unchecked, true collaboration begins to break down.

Together, these themes suggest that cardiologists experience CM diagnosis as a balancing act between what the system allows and what the relationship with the patient needs. The limits of the NHS pathway shape the clinical options available, but perhaps less acknowledged, they also shape what can realistically be held or considered psychologically and ethically during consultations. These findings suggest that shared decision-making in CM isn’t just a neat “communication skill” that clinicians can switch on and “perform” like a script. It is negotiated in real time, often under pressure, in the context of uncertainty, unequal knowledge, and real-world consequences for patients’ lives. The gap between “ideal” and “real” care

therefore isn't just context; it shapes the consultation itself. It can make hierarchy more visible, limit deliberation, and increase reliance on clinician judgement, including assumptions about what patients can cope with or how much they want to know. Chapter 9 takes an integrated perspective by bringing cardiologists' accounts together with patients' lived experience. It examines where understandings of support, uncertainty, inclusion and influence align or diverge, and what this means for making CM diagnostic care more collaborative, consistent, and psychologically safer in practice.

7. Findings: Interviews with Patients

7.1 Chapter Introduction

Following an exploration of findings from interviews with cardiologists in chapters 5, this chapter marks a shift into the exploration of a new perspective - findings from interviews with newly diagnosed adult cardiomyopathy (CM) patients. Three superordinate themes were identified following a detailed interpretative phenomenological analysis of the eight interview transcripts, as evidenced in chapter 4. These superordinate themes labelled, **processing loss**, **evolving identity**, and **seeking certainty** reflect the lived experiences of newly diagnosed adults during their CM diagnosis journey.

The first superordinate theme, **processing loss**, outlined the non-linear stages of emotional adjustment experienced by participants during a CM diagnosis. Seven subthemes emerged from the data, all relating to a profound sense of loss and emotional adjustment over time.

The second superordinate theme, **evolving identity**, outlined the many ways in which patient identity changes during their CM diagnosis journey, and the different influential factors that contribute to this change. Six subthemes were organised within a process arc, illustrating progression from identity disruption, through loss of agency and social recognition, to identity renegotiation.

The third superordinate theme, **seeking certainty**, examined the ways in which patients attempted to make sense of their diagnosis during a period of significant uncertainty and change.

Each theme is presented in detail, supported by illustrative participant quotations.

Researcher's Reflection:

As with the cardiologist excerpts, I chose to use animated avatars to represent each patient participant. The avatars serve as a reminder that there are real people with individual voices behind each participant quote and help to clarify who provided each quote. The avatars were created using Apple's 'MeMoji' feature. Supportive friends and family created their own 'MeMoji' characters reflecting their own physical attributes and submitted them for use in the thesis. I felt this was a novel way to include and honour the people who had supported me during the PhD journey. These avatars represented the gender of the participants only. Pseudonyms were again used to further protect the identity of participating patients. Each quote is followed by closed brackets denoting the pseudonym and transcript line numbers from which the quote was taken.

7.2 Processing Loss (Superordinate Theme)

Newly diagnosed patients experienced a loss of their former conceptualisation of ‘self’ and processed this loss in stages, similar to when grieving or processing other forms of loss such as a death. Patients experienced various stages of emotion throughout their diagnosis journey, starting with shock and denial and ultimately leading to acceptance. However, the stages were not considered to be strictly linear. An overview of the various stages of processing loss during the CM diagnosis process is outlined in Figure 15 below.

7 Stages of Processing Loss During a Cardiomyopathy Diagnosis						
Shock & Denial	Anger & Blame	Loss of ‘Self’	Anxiety & Depression	Testing	Re-evaluating ‘Self’	Acceptance
Paralysis Confusion Denial	Lashing out Guilt/Blame Feeling victimised	Separation of body & self Changing identity: Patients’ role in society, within relationships and their goals have changed.	Isolation Uncertainty Feeling overwhelmed Helplessness	Tentatively finding ways to move forward within new parameters.	Redefining their roles within society/within relationships New conception of ‘self’	Accepting new ‘normal’

FIGURE 15. SEVEN STAGES OF PROCESSING LOSS DURING A CARDIOMYOPATHY DIAGNOSIS - ADAPTED FROM SIMILAR MODELS FOUND IN PRATT (2018) AND KUBLER-ROSS AND KESSLER (2005)

7.2.1 Shock & Denial (Subtheme)

Patients reported feeling shocked about both the seriousness and permanence of their new CM diagnosis.

Kate described feeling immediately overwhelmed by the gravity of her CM diagnosis.



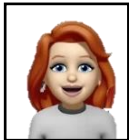
“Oh God, I’ve got a lifechanging heart condition, I’m actually not in a great place for making [decisions].” (Kate, 210-212)

Others felt additionally burdened by a sudden decline in their health or were diagnosed without experiencing many noticeable symptoms. This disconnect led to difficulties comprehending their diagnosis, as these patients grappled with the knowledge that their lived experience of their physical body

was not reflective of the reality of their body's internal health. Patient's prior knowledge, beliefs and models of illness were challenged, and this led to confusion and denial.

"I don't know why they are keeping me here because there's nothing wrong with me, I don't feel ill."

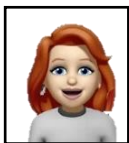
(Phoebe, 474-476)



"I shouldn't be here I said, everyone is so poorly. He said, 'don't you think you're poorly?' and I went no, no I'm not". (Jessica, 418-421)

Although Phoebe and Jessica had experienced symptoms associated with cardiac illness and were hospitalised, their prior conception - that people who were ill should feel poorly, was challenged. This led to them both denying or doubting their diagnosis. Patients often described initial feelings of shock and confusion. Some described a sort of cognitive paralysis where they felt as though they couldn't attend to, nor comprehend the information being relayed to them.

"I have to block it out of my head" (Henry, 1530)



"It didn't really register, I think because of what happened, I was kind of out of it – I was very poorly yes but I didn't really twig honestly, I was kind of like if you give me half an hour I'll be on my way. I didn't really get it. I really didn't see how poorly I was". (Jessica, 306-315)

"I didn't know what that meant, so first thing I remember walking out of there just totally destroyed,

shocked really and I sat in my car, and I was upset" (Henry, 233-236)



7.2.2 Anger & Blame (Subtheme)

Patients described the many ways that anger was felt and exhibited during their diagnosis journey. Anger sometimes stemmed from feeling isolated or helpless and was projected outward.



"It's been a real mental battle I think to try and not take it out on the world" (Henry, 933-934)

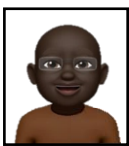
Sometimes anger or hostility was directed at clinicians for using clinical labels that were confronting and difficult to hear.

"I said 'what do you mean I've got heart failure?' and she said 'well look I'll give you a book to read' so I read the first page and the first sentence said 'You have a life limiting condition – your expected outcome is 3 – 5 years' so I told her to take her fucking book and get out of my room." (Phoebe, 394-

403)



Anger was sometimes described as feeling bitter or resentful of others who did not suffer from CM as they did, especially towards those who they perceived to be living unhealthy lifestyles. Patients felt victimised by their diagnosis early on in their journey and raised questions about why they deserved CM, as if it were a punishment or karmic retribution of some kind.



"I was very bitter to my friends, like I would look at them going well they're out drinking and smoking and whatever they were doing, and they've not got this, so why have I got this? I'm keeping myself healthier than any of them in terms of fitness" (Henry, 853-859)

"I get cross, you know I was really angry. I hated everybody at that point. I hated everybody who was overweight, fat, smoked, I actually told somebody off on the ward". (Pheobe, 936-940)



Previously held beliefs that unhealthy lifestyles lead to poor cardiac health were challenged by their CM diagnosis, prompting the frustration, resentment and bitterness described by Henry and Phoebe above. Similarly, Jessica explained that she felt other people might judge her for her illness, perceiving her to somehow be to blame for her poor cardiac health rather a victim of genetic, or environmental factors.

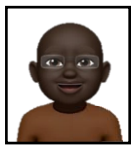


"People who have had cardiac arrests, they are very indignant if people say you've had a heart attack because they're like 'it's not a heart attack it's totally different...heart attacks is poor lifestyle and things...you associate it...with maybe not eating very healthy, maybe smoking, drinking that sort of thing" (Jessica, 364-376)

Jessica expressed feeling victimised by her CM diagnosis and helpless to stop her cardiac arrest from happening. Prior conceptions of illness and the cause of illness continued to play a part in patients' understanding of their diagnosis, and their emotional response to their CM diagnosis.

In some cases, anger appeared as self-blame, blaming stress-levels, poor diet, lack of exercise, or alcohol consumption for their decline in health.

“You think, what have I done? Have I done anything? Was I too stressed?” (Jessica, 245-247)



“You can beat yourself up around what’s probably caused it...I don’t know but either way I’m looking at things like, what have I done wrong?” (Henry, 869-874)

7.2.3 Loss of Self (Subtheme)

Patients’ conceptualisation of the ‘self’ began to change as the roles they played within society, family and their work had to adjust to accommodate new limitations brought on by CM. Patients described feeling ‘lost’ as the pillars of their identity, characteristics, or titles they once used to define themselves were now shifting. They worried about how others may perceive them and felt their entire identity was being redefined by illness and CM. One example of this was Carl who explained that prior to his CM diagnosis, he had tied his identity to his role within the emergency services. Carl’s role as an emergency service worker had given him purpose and a strong sense of self-worth. Following his CM diagnosis, he was unable to continue with his job and struggled to conceptualise his new sense of self. Carl found that he had gone from being introduced as a heroic emergency service worker, to being defined by his chronic illness.

“My aunt introduced me to everyone as ‘so, this is Carl, you know, the one with the dodgy heart’.”

(Carl, 1770-1771)



Patients grappled with their changing sense of self in a variety of ways. Some patients previously valued their independence and had to adjust to accepting physical and emotional support.



“Being an independent kind of person, I’ve had to rely on [his partner] perhaps more than I ever had to rely on anybody in the past and as much as that is a good thing, but it’s a thing I’ve had to adjust to and build on.” (Dominic, 749-755)

Dominic identified as someone who valued traditional gender roles within his romantic relationship. He explained how he struggled to conceptualise himself as being a ‘gentleman’ if he could no longer carry his partner’s bag for her. His CM had made it difficult for him to live up to his values in the usual way, forcing him to reconsider his sense of self and the values he previously held. Dominic had previously viewed

carrying his partner's bag as an act of chivalry but now worried about being perceived as disrespectful or somehow 'unmanly' by not helping to carry the bags.

"Me picking up her bag and, but as a man I think it's something I should be doing and it's natural for me to do it". (Dominic, 894-869)



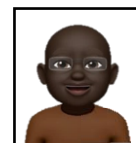
Similarly, Henry described worrying about how others would react to his changing sense of self following his CM diagnosis. Henry described himself to be very confident, active, and a social drinker prior to his CM diagnosis. However, since his diagnosis, Henry had not been able to drink alcohol as he used to, had gained some weight and was no longer feeling confident in his body. Henry described how he would avoid social activities with his usual friendship group so he wouldn't have to explain his sudden change in behaviour, demeanour or appearance.



"I was lucky it wasn't really my close friends, so I could go there and relax a bit knowing that everyone's not scrutinising what I'm doing. Not that they probably would anyway, but it's just in my head." (Henry, 684-689)

Henry recognised that his values had changed following his CM diagnosis, and he no longer shared certain values with his friends anymore. Henry also felt like parts of his identity had changed with his changing health. For example, he described feeling distant from the confident and active 'self' he had previously identified as.

"I felt really low on confidence since I've been diagnosed. I've put on probably a stone and a half in weight". (Henry, 620-623)



7.2.4 Anxiety & Depression (Subtheme)

Although not all patients would have met the threshold for clinical levels of anxiety and depression, patients frequently described experiencing emotional distress and symptoms associated with some level of anxiety and/or low mood. Throughout their diagnostic journey, patients reportedly experienced feelings of helplessness, isolation, and uncertainty.



"I know it's not life-threatening, but it's killed my life. All my choices have been taken away from me. Why can't I be better? Why can't I find something that's going to help me? Who's going to fix me?"
(Henry, 893-898)

"It's destroyed my life. It's upset my whole plans. My future was decided...our plans are up in the air now." (Phoebe, 1030-1043)



Whilst some patients described feeling as though they had progressed to a point they could reflect back on periods of anxiety and depression, others described currently feeling low in mood and overwhelmed with emotion at the time of the interview. This suggests the psychological impact of diagnosis is an ongoing process that does not necessarily resolve before moving on to the next stage.



"You do get bad days and you get bad thoughts...I was a bit suicidal then." (Alex, 504-513)

"I still wake in the night and some nights I wake and I'm away crying." (Phoebe, 858-859)

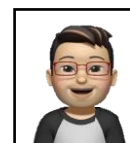


Patients described experiencing physiological symptoms of anxiety and stress when coming out of hospital and returning to their everyday life. Describing the monitoring and care they received in hospital as a 'safety blanket', some patients felt distressed by the lack of monitoring and increased uncertainty when returning to their everyday lives. Patients found it difficult to distinguish whether the symptoms they experienced were cardiac or psychological in nature.



"I went back to work, and I was sitting at my desk, and I was feeling like I'm going to pass out, obviously anxiety has taken over then and stress". (Henry, 380-383)

"Coming out of hospital and being taken home I'd lost my safety net a little bit. I'd had this safety blanket around me for a month being in hospital" (Dominic, 503-506).



7.2.5 Testing (Subtheme)

Patients described a point where they started to tentatively move forwards with their life within the new parameters dictated by their CM diagnosis. Henry described this stage as moving forwards with life whilst

“respecting what the condition is” (Henry, 282-283). At this stage, patients began to exercise or return to work and usual activities in some capacity, often with adjustments.



“I’m going to go back hopefully to get back to full time again which I know I’m going to have to make adjustments... We’ll get the ironing man to do my ironing and we’ll do shopping online and maybe I’ll get a cleaner.” (Phoebe, 1128-1133)

During this stage, patients found ways to make the invisible threat of CM more visible and therefore more able to monitor independently e.g., using fitness trackers, blood pressure machines, and heart rate monitors. These devices also acted to provide immediate reassurance and reduce feelings of uncertainty when patients began to challenge themselves physically. Throughout this testing phase, patients learnt more about what works for them as an individual, which led to increased confidence and more self-management.

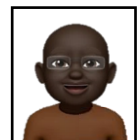
“I’ve got a heart rate monitor now that I wear if I go to the gym. I make sure my heart rate is staying below 150bpm...I don’t feel any shortness of breath whatsoever”. (Henry, 567-574)



“I don’t tend to look at my watch as much anymore and I know I’ve gone over 100bpm and I’m still, you know, they’re only guidelines and whatever.” (Dominic, 731-734)

Patients also found ways to feel more comfortable in their everyday lives and adjusted to resume their valued activities. For example, Henry adjusted to drinking alcohol-free beer when socialising with friends and felt as though he could join in and be sociable but without the negative physical symptoms. This small adjustment allowed him to engage socially with friends again and reduced feelings of isolation.

“I was standing in the sunshine. That feeling of a crisp, cold beer in the sun is still there, but I’m just not getting drunk” (Henry, 697-700)



Others tentatively found ways to regain a sense of control over their health by learning what works for them in terms of symptom management and safety netting, which enabled them to return to their usual activities with more confidence.



"I researched where the nearest heart hospital was [when traveling], I researched who was there, who worked there, you know, had they got the facilities?" (Dominic, 494-498)

"I've had to eat like vegetable and fruit smoothies every morning and porridge oats. I have salads for lunch, and I eat a relatively healthy dinner...my symptoms have eased off with the medication and eating better". (Henry, 4747-4783)



7.2.6 Re-evaluating Self (Subtheme)

In recognising the impact of their CM diagnosis and how their lives had changed since diagnosis, patients described a period of reflection leading to a re-evaluation of the 'self'. Patients started to think about the ways in which they had defined themselves in the past, and how they defined themselves post-diagnosis. Some remained unchanged whereas others perceived themselves to be 'strong' or 'more logical' after diagnosis.



"I'm stronger than I thought I was" (Henry, 2181-2182)

"It's probably the first time I feel like my old self" (Dominic, 723-724)



"I am more logical...I'm thinking alright it's not absolutely rosy but equally I don't think that I'm going to die tomorrow anymore. I think if I do this, I can help myself" (Henry, 756-770).

Patients reflected on how illness was a levelling experience in that it was indiscriminate and affected people from all walks of life. Some found that they no longer identified themselves by the roles they played within society, such as their job. They were forced to find fulfilment and purpose outside of their career and with it the value they placed on their career changed.

"People have said, 'Oh the place will fall apart without me' and I thought, no it won't. I know first-hand now that the place will still go [on]." (Dominic, 689-692)



Others felt a renewed sense of hope at this stage and described the positive impact of engaging with other people with CM who were living and thriving post-diagnosis. Henry felt that seeing how other CM patients

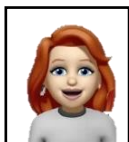
were able to adjust to living with their CM, motivated him to keep going and make adjustments so he could still live a full life alongside his CM diagnosis too.



"I had such amazing respect for these people. It just drove me on that I just want to improve, and I can improve, even though I know I'm not normal anymore in terms I can't do what I could before." (Henry, 837-842).

7.2.2 Acceptance (Subtheme)

The CM diagnosis process ultimately led to patients expressing a level of acceptance of their new reality and new conception of 'self'. Some patients continued to struggle with their diagnosis and jumped from acceptance to other stages of the loss process, but all experienced some level of contentment and acceptance of the reality of their life with CM.



"Today I forgot I had it [CM] until coming to meet you" (Henry, 487-488)



"I'll just get on with stuff now. It's fine and I'm here and that's good." (Jessica, 965-967)

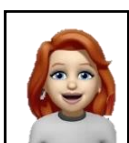
"Actually, I want to look after myself and accept myself." (Kate, 303-304)



"I can start viewing this as something I'm living with, but I can get on with a normal life rather than it dictating how I live my life and what I can't do." (Henry, 737-742).

Patients found a level of acceptance for elements of their diagnosis that had once caused distress. Henry found himself allowing irregular heartbeats to pass without feeling anxious. Jessica found herself accepting the limits of her capacity for work and found a way to work part-time to fulfil her desire to work, without putting pressure on herself to work full-time.

"I don't get panicky or sweaty or anything anxiety-related to them anymore. I just let them do what they're doing" (Henry, 1398-1400).



"I've got a part-time job not a full-time job because I don't think I could do a full-time job at the minute" (Jessica, 465-467).

Patients experienced a shared sense of loss which was emotionally processed in seven non-linear and distinct phases. This process helped patients to navigate through their diagnosis journey to reach a place of acceptance. Patients expressed feeling as though they were at different phases on this journey at the time of interview, suggesting the journey is one that is individual and cannot be predicted by the amount of time since diagnosis.

7.3 Evolving Identity (Superordinate Theme)

Patients frequently acknowledged that their sense of identity moved and evolved over the course of their cardiomyopathy (CM) diagnosis journey. They began their accounts from a presumed monism (body and 'self' experienced as unified) but perceived a disconnect between the physical body and the intellectual or emotional self once symptoms began (a shift toward dualism). Clinicians and the wider health system, in diagnosing and treating CM, were perceived to compound this disconnect by prioritising the physical body over the self during diagnosis. Furthermore, CM was often experienced as an external entity acting on the body and, by extension, the self. Through a process of renegotiation, a balance was found once patients adjusted to, or accepted, a new conceptualisation of the self that included CM and ongoing clinical input. A visual overview of this evolving identity is presented in Figure 16.

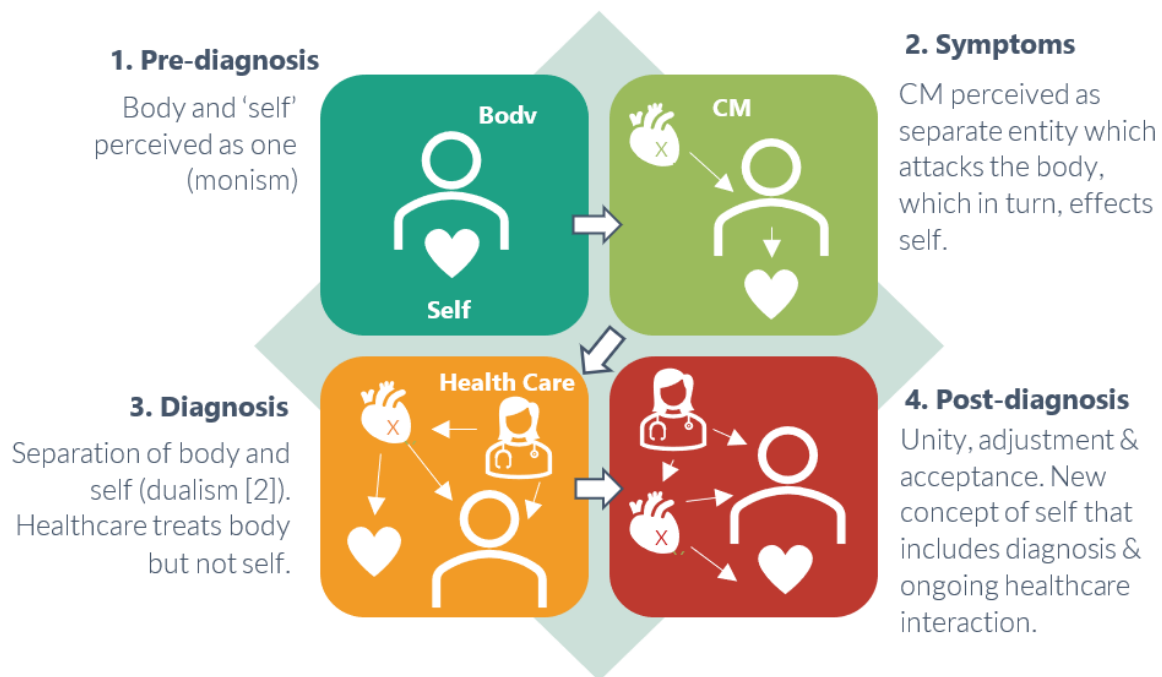


FIGURE 16. AN ILLUSTRATIVE OVERVIEW OF 'EVOLVING IDENTITY' AS DESCRIBED BY NEWLY DIAGNOSED CARDIOMYOPATHY PATIENTS

Patients alluded to identity change over time: an assumed unity was disrupted, agency narrowed amid clinical routines and social misrecognition, and identity was renegotiated through meaning-making. Six subthemes contributed to this superordinate theme and were organised under three narrative headings that represented key experiences and drivers of identity change as described by participants: *Disruption and Objectification, Loss of Agency and Social Recognition, and Meaning Making and Identity Renegotiation.*

Researcher's Reflection:

The subthemes were organised and presented using an illustrative process arc that could imply a linear move from identity disruption through objectification, loss of agency and social identity, to a process of meaning making which results in a renegotiated sense of identity. However, patients did not discuss this process in linear terms, nor were all experiences universally reported. Instead, patients identified small individual moments that accumulated and interacted to nudge their identity evolution forwards. The illustrative process arc therefore acts only as an analytic scaffold, not a prescription, acknowledging that participants looped back, skipped, and moved non-linearly between moments.

7.3.1 Disruption and Objectification

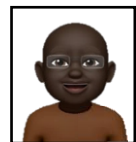
This narrative heading introduces the earliest movements in the process arc of evolving identity.

Participants described how initial encounters with health services disrupted an assumed unity of body and self and objectified their experience, orienting attention toward the body and away from personhood. Two subthemes sat within this heading: **Unconscious NHS Messaging** (small but consequential cues in language, routines, and patient materials that repositioned the self) and **Dr Robot** (technically proficient but emotionally mechanical encounters that intensified body-self separation). Together, these moments marked the shift from presumed monism towards emerging dualism and set up the drift toward reduced agency and social recognition traced in the subsequent sections.

7.3.1.1 Unconscious NHS Messaging (Subtheme)

This subordinate theme described how impactful healthcare workers could be, as they relayed (often) unintentional messages to patients through their word choice and actions. These messages had both positive and negative effects on patients' self-worth and identity during diagnosis.

“He said, ‘normal people (EF) it’s pumping at 55% or higher and yours is at 45%’” (Henry, 178-180)



The phrasing, ‘normal people’ relayed the unconscious message to Henry that he was no longer ‘normal’ and was now in fact, ‘abnormal’. Abnormality could be interpreted as both a positive and a negative characteristic. For example, people could be abnormally gifted or abnormally strong. However, the comparison of the ‘EF’ percentages (referring to Left Ventricular Ejection Fraction – a measure used to explain how well the heart is functioning) also communicated to Henry (albeit unconsciously) that he was somehow *less than* normal as his EF was pumping at 10% below that of the standard for ‘normal people’. Such phrasing could become internalised by patients and have a negative effect on self-worth and identity.

In another example, Phoebe described her experience whilst staying in hospital during her diagnostic journey and how the nurse's apparent inaction affected her perception of safety, self-worth, and trust in the healthcare workers in charge of her care.



“On the ward you see machines going off, the beeps start going, lights flashing red, and no one is coming, and you think, what is going on?” (Phoebe, 831-835)

In this example, Phoebe interpreted danger from her previously engrained symbolic understanding of red, flashing lights and alarm sounds coming from other patients' monitors, which she associated with danger or imminent threat. Indeed, the machinery was most likely designed using this symbolism to quickly alert health professionals of dangerous changes in health status. However, when no-one came running to the patients' aid, as she had expected, this caused confusion for Phoebe, and she interpreted this as a failure on the health care workers' part to respond to a threat. She therefore felt helpless, uncertain, and unsafe, concluding that she too could have been left with no-one running to her aid when she was in danger. Health care workers routinely had remote monitoring of patients' vital signs and could quickly check whether an alarm was indeed a sign of imminent danger for patients. Machinery could sound for lots of different reasons and might have been completely unrelated to patient status. However, the perceived inaction of health care workers relayed the unconscious message to Phoebe in this instance that she might not have been safe. Generally speaking, this could have triggered feelings of anxiety, helplessness and potentially lead to a breakdown of trust between patient and clinicians.

Unconscious messaging could also have affected patients' understanding of their condition and their risk of serious illness. As lay public, patients relied on health professionals to relay information regarding their health and their risk of serious illness. Alex's experience below described an example of how illness can be considered hierarchical. Although he did not suffer a heart attack, he was still experiencing serious illness that was later diagnosed to be CM. The conclusion that 'nothing's wrong' could have led Alex to believe that his symptoms, and diagnosis of CM, was not as serious as a heart

attack, and was therefore less in need of medical attention and perhaps even less worthy of NHS resources.

“I was taken in from work by ambulance because I had chest pains and they checked me all over and said, ‘no, no heart attack’ you know, did all the checks on it, ‘nothing’s wrong’, so that was that.” (Alex, 29-33)



Of course, the paramedics may have meant to provide reassurance with the statement, ‘nothing’s wrong’, or perhaps they were working through differential diagnoses and were relieved to have ruled out a common medical emergency before moving on to other possibilities. However, this example did highlight how, from the patient’s perspective, their very real cardiac symptoms may have been invalidated by the CM diagnosis process. The patients’ perception of these small unconscious messages could have contributed to feelings of being *less than* or no longer being *normal* early on in their diagnosis journey, greatly affecting patients’ sense of self.

Unconscious messages were perceived by patients throughout all elements of their diagnosis experience, including the printed patient information literature they were given by their healthcare team. Charlotte described the emotive response she had when reading the slogan, ‘Fight for every heartbeat’. She described the emotional pain and anger she had when she interpreted the slogan to mean she was unworthy of her heartbeat and then had to fight in order to have it. Although it was possibly intended as a motivational phrase or as a demonstration of patient’s strength, Charlotte perceived the phrasing to suggest she was no longer worthy of living without a fight.



“‘Fight for every heartbeat’ -I was like you’ve got to be bloody kidding me. It literally does feel like you’re doing that, but to be told that as a slogan was a bit like, fight for it, what do you mean fight for it? I should just be allowed to have my heartbeat” (Charlotte, 1000-1006)

Taken together, these small, unintended messages nudged patients from a sense of embodied belonging toward difference, widened the body-self split, and narrowed their felt agency. Through these narratives, clinical attention was experienced as drifting away from personhood. Patients further spoke

of encountering care that was technically proficient but emotionally mechanical, further intensifying moments of disruption and objectification that contributed to identity change.

7.3.1.2 Dr Robot (Subtheme)

The evolution of patient's identity throughout the diagnosis process was also affected by how they perceived their interactions with healthcare workers and their pre-existing beliefs about the medical model of care. As demonstrated in Figure 16, patients felt that health care workers treated the cardiomyopathy and worked directly with their body but did not necessarily direct support to the person occupying the body at times. This furthered their perceived dualism – the separation of their identity into two distinct parts: their 'self' and their body. Kate exemplified this in describing clinicians as *"Looking at bodies as objects rather than people"* (Kate, 1106-1107). The interaction between patient and clinician was sometimes perceived as mechanical and lacking in human connection. This subtheme was therefore labelled as, Dr Robot.

Like robots, some patients felt that cardiologists were not equipped to deal with complex human emotions and were quick to move them along through the diagnosis process without making room for their emotional selves.

"[Doctors] are frightened of patients having feelings and they want to, oh god just shut this one down and get them out." (Kate, 1052-1058)



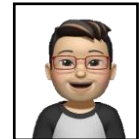
"...treating a person as a whole person rather than just the condition" (Henry, 2126-2127)

Henry's statement demonstrated how his identity had been changed by his diagnosis. He suggested the medical care he was provided treated the condition in isolation and did not treat or acknowledge his personhood, furthering the felt sense of separation of his body and self.

Patients suggested that clinicians sometimes lacked the human connection needed to address their concerns or emotional responses during the diagnosis process. While patients recognised that systemic pressures could contribute to clinician's need for efficiency, it was sometimes perceived by patients that

clinician's also experienced a separation of their body and self, in that they treated patients mechanically with some parts of themselves (their physical clinical skills and their knowledge), but did not allow their human emotional self to be part of the service they provided to their patients.

"[I would have liked] Right let me tell you about the device, not just a pamphlet, let me tell me about what that can and can't do for you" (Dominic, 936-938)



Dominic expressed a desire to connect to his clinician and express himself through discussion and felt somewhat dismissed by the information leaflets he was offered instead. Written informational materials could be extremely useful in aiding patient understanding however, Dominic felt as though they were offered as a way of avoiding having a human interaction. Henry also expressed feeling a lack of human connection with his cardiologist and described him as being detached and uncaring.



"I just wasn't happy with how blasé he was about it and he just didn't seem to have a really nice human touch about him. He was very matter of fact and even then, he didn't really seem to care. I was probably just one of a number for him." (Henry, 1047-1053)

Henry's final statement showed how systemic pressures placed on cardiologists sometimes led to unintended consequences for patient care that could be harmful to patients' sense of self. Henry felt that his emotional needs weren't met by his cardiologist because he was just one of many patients they saw. Henry expressed feeling invalidated as a result of this not aligning with his own lived experience: that the experience was a uniquely traumatic event for him. Similarly, Kate expressed a similar feeling of being on a conveyor belt of patients and when prompted to reflect on the reasons for this, she likened the diagnosis process to that of a sausage factory, suggesting that compassion fatigue and the automated processes needed to treat such an overwhelmed service contributed to a robotic demeanour from clinicians.

"There's a level at which you can say its compassion fatigue, that's not a real answer. That's just trotting out another word. Yes, there is that. It's a big system, there's pressure of numbers, there's a sausage factory element to it" (Kate, 1079-1088)



Objectifying, technically driven encounters repositioned patients as bodies to be managed and narrowed room for individual voice and choice and shifted decision-making toward procedure rather than collaboration. The accumulative effect of unconscious messaging and mechanical care, nudged patient's sense of self into more of a passive role, where decisions and actions were felt as happening to rather than *with* the person.

7.3.2 Loss of Agency & Social Recognition

Following the initial *disruption and objectification* of identity, patients' accounts then moved into a new phase of the process arc, characterised by a growing *loss of agency and social recognition*. As the diagnostic journey unfolded, many described becoming passive within clinical encounters, feeling as though decisions were made around them rather than with them, and that their autonomy over a body that already felt unfamiliar was further eroded. This loss of agency was closely related to how others perceived them: clinicians appeared to focus on the malfunctioning heart or "case" rather than the person, while family or friends sometimes struggled to recognise the seriousness of an often-invisible condition. Together, the subthemes ***passive patient*** and ***invisibility*** show how disrupted embodiment was reinforced by encounters in which patients felt unseen, interchangeable, or disbelieved, leaving them isolated and describing CM as an external force that attacked both their body and their sense of self.

7.3.2.1 Passive Patient (Subtheme)

A prominent subtheme theme of passivity emerged as patients recounted their experiences of receiving clinical care during their CM diagnoses. Many described a profound sense of surrender, particularly when receiving life-saving emergency care, leaving them feeling like mere components within the clinical process.



"Within ten minutes I was in a bed in the resus bay, wired up like a crash test dummy." (Carl, 352-354)

Carl described his internal experience of becoming a passive object of clinical assessment rather than a complex, autonomous human. Similarly, Alex's experience reinforced this sense of enforced passivity.

“They wired me up and then they told me to sit down and don’t move and they said, ‘you’re not going home’. That was that.” (Alex, 54-57)



Alex interpreted this as an abrupt command, which, when combined with the finality of the phrase, “you’re not going home,” led Alex to believe he had no choice but to obey. The quote emphasised how the patient's role can at times shift from active participant to passive observer. This experience can no doubt compound the unsettling sense of confinement whereby patients feel trapped in a body that is no longer serving them.



“I went, ‘I can’t feel my arms, I now can’t breathe.’ It felt like I could only breathe into the top part of my lungs and then I lost my vocals, I couldn’t shout, I couldn’t throw my voice, so I was mouthing for help and then I got an oxygen mask put on” (Charlotte, 218-223)

Charlotte’s account of physical incapacitation highlighted the intense distress associated with a perceived loss of control over her body. Her description spoke to her profound sense of loss: loss of functionality, of control, and even of her voice, which was ultimately silenced by the placement of an oxygen mask over her face. Although providing her body with oxygen, this intervention temporarily deprived her of speech, symbolically excluding the ‘self’ from the clinical encounter. Alex similarly expressed this theme of passivity, describing the expectation he felt clinicians placed on him to remain in bed, immobile, whilst taking prescribed medication he had very little understanding of.

“Most the time they just wanted me in bed and shovelling all these drugs down me to slow everything down.” (Alex, 573-575)



In Kate's reflection, she also expressed frustration at the expected passive behaviour she felt she must display when discussing consent with her clinician.



“You arrived and be consented and it’s like, I can’t be consented, it’s an active process.” (Kate, 87-89)

By characterising consent as being an “active process,” Kate highlighted how she felt her agency was denied during this clinical interaction. Rather than experiencing a mutual engagement that respected her

choices and valued her consent, Kate felt clinicians undervalued her voice and agency by presenting consent as a passive expectation rather than an active choice.

Patients reported complex emotional landscapes as they navigated the paradox of receiving essential physical care while simultaneously feeling distant from their own bodies and identities. Dominic's reflections illustrated moments of surrender and powerlessness that were commonly featured within the patients' narratives.

"You're just moving along thinking, they're looking after me, I will be alright and you will, you know, chances are most of us are and we will be and at the end of it the answers will come" (Dominic, 392-396)



Dominic's words suggested a childlike trust in the health care system, shared by many patients. However, he also hinted at an unsettling detachment between his sense of self and the body under his clinician's care. Kate similarly expressed gratitude for the care she received, yet her choice of phrase, *"handled me"*, acknowledged her passivity within the process.



"They handled me very nicely" (Kate, 148)

Furthermore, Charlotte's account underscored a desire to be included in discussions regarding her health, revealing the emotional toll of being excluded as an active participant in her care. Unlike sentiments shared by Dominic and Kate, Charlotte expressed a yearning for connection and could not reconcile a positive clinical care experience without the recognition and inclusion of her personhood.

"There was a lot of discussion behind the nets or the blinds...you hear them talking about you...I did say to them, 'look, it's pretty rude'...just making me part of it I think would have been nice." (Charlotte, 579-589)



These accounts outlined how patients' roles were reshaped from active agents into passive bodies being managed, moved and "handled" within clinical systems, even when care was experienced as kind or life-saving. This erosion of agency did not occur in isolation but was intertwined with how patients felt seen or

unseen by others. The next subtheme, **invisibility**, considers how this passivity was compounded when patients' symptoms, needs and identities were overlooked or minimised, further undermining their sense of social recognition.

7.3.2.2 Invisibility (Subtheme)

Within this phase of the process arc, many patients also described a quieter but equally destabilising experience: feeling invisible. While the subtheme, **passive patient** captured how patients' agency within clinical encounters was reduced, the subtheme of **invisibility** reflected how patients felt their needs, their illness or their personhood were unseen or unrecognised. The apparent mismatch between looking "well" and living with a serious cardiac condition meant that their CM was easily overlooked in hospital settings, minimised by others, and at times difficult even for patients themselves to fully acknowledge. Invisibility operated on several levels – in clinicians' interactions at the bedside, in how family, employers and wider society responded to an often hidden illness, and in patients' own internal struggles to reconcile an unchanged outward appearance with a disrupted inner experience. The following extracts illustrate how this sense of being overlooked or disbelieved further eroded patients' social recognition and sense of self.



"He probably sees people a lot worse, I get that, but for me it was the worst thing in the world..."
(Henry, 1054-1059)

Henry expressed frustration: feeling that his unique personal experience was not considered, despite experiencing a life-altering diagnosis. Even the mundane detail of Phoebe being moved to a different department was described in a way that suggests feeling unseen, unheard or forgotten about.

*"I was moved to E.M.A.U...where I lingered...for about 3 or 4 days....For a whole day I had sat under
someone else's name" (Phoebe, 159-165)*



Phoebe portrayed the feeling of being lost in the system, a nameless entity within a sea of patients. Alex described a similar experience of feeling nameless and forgotten when he called to arrange a follow-up appointment after an admission to hospital.



"After five weeks I chased them up and they didn't even know who I was" (Alex, 77-79)

This felt sense of invisibility extended beyond clinical interactions to other social interactions. Patients described feeling as though their friends, families and other people they met were unable to see their true 'selves' following diagnosis.

"People look at you and just think you're alright and you can look perfectly fine, but actually on the inside, you know, your circulation could be low, you could feel dizzy, you could feel a little bit lightheaded, you could just feel lethargic, and people just think you're lazy unfortunately." (Charlotte, 775-781)



Charlotte discussed the social stigma associated with an invisible illness. Her outwardly healthy appearance led to judgment and disbelief, adding another layer of emotional burden to the already challenging experience of CM diagnosis. Carl echoed this sentiment, highlighting the disconnect between the patient's inner experience and the external perception of their health.



"A lot of friends understand on a very superficial level, but then they're like, 'yes, but you look alright. Yes, you look fine'" (Carl, 1747-1749)

"The lady there said, 'I wouldn't have known if I'd just looked at your heart now'" (Jessica, 152-154)



Moreover, Jessica's statement highlighted the invisible nature of the disease itself. CM is a condition that cannot be seen by the naked eye, making it difficult for patients to comprehend and for others to truly 'see'.

These quotes collectively illuminated the multifaceted nature of "invisibility" in the context of cardiomyopathy diagnosis. While the physical symptoms of the condition could have been hidden, the emotional and psychological impact of this invisibility was significant, impacting the patient's experience within the health care system, their social interactions, and their internal understanding of their illness. Recognising and addressing this invisibility is essential for providing comprehensive care and support to individuals navigating the complexities of a cardiomyopathy diagnosis moving forwards. As the diagnostic journey progressed, participants began to respond to this disruption, loss of agency and

invisibility by actively trying to make sense of what had happened to them and to renegotiate who they were now, a shift explored in the next phase of the process arc, *meaning making and identity renegotiation*.

7.3.3 Meaning Making & Identity Renegotiation

As the process arc moved beyond the initial disruption of diagnosis and the loss of agency and social recognition, patients' accounts began to show a more active phase of *meaning-making and identity renegotiation*. Instead of only describing what was done to them, patients started to grapple with what their diagnosis meant for how they understood health, illness and themselves. For some, this involved revisiting long-held assumptions about what heart failure or cardiac illness should look and feel like; for others, it meant experimenting with different ways of talking about their heart, body and CM in an attempt to regain a sense of footing. The subthemes **Challenging Prior Beliefs** and **Separate Entities** illustrate how patients tried to piece together new explanations and language that could accommodate both the disruption of CM and an emerging, renegotiated sense of self.

7.3.3.1 Challenging Prior Beliefs (Subtheme)

A key part of this meaning-making phase involved patients having to revisit and, in many cases, unpick long-held beliefs about health, illness and the heart. Their accounts showed how cultural narratives, media portrayals and personal experiences had shaped expectations about what heart failure should look and feel like, leaving many initially unable to reconcile a serious diagnosis with an outwardly well-looking body.



“Heart failure is a really hard word to take on board because you only have one heart. You have two lungs, you have two kidneys, you can get by with one if you really needed to...obviously, the heart is the centre of the body, without the heart you don’t function” (Charlotte, 955-964)

Charlotte's statement reflected a deeply ingrained belief that heart failure implies that the heart will imminently and completely cease. This belief was challenged by her own experience, as she continued to

function despite her HF diagnosis. This example highlights the disconnect between societal understanding of a clinical label and the reality of living with a diagnosis of CM and heart failure.

Similarly, patients' prior beliefs about how illness manifests were also challenged. Dominic's reference to watching a defibrillator being used in "ER programmes" and Alex and Carl's assumption that shortness of breath and dizziness must have been due to unfitness and age reveals a reliance on media portrayals that often depict dramatic and acute presentations of cardiac illness, leaving patients unprepared for the more subtle symptoms of cardiomyopathy.

"Our main source of information's the TV and if you've ever seen an ER programme of some sort there's someone walking around with a pair of pads shouting 'clear', you know, and probably that's the only image I had that I could relate to" (Dominic, 838-843)



"I thought I'm out of breath and that, but I thought I was just unfit or something" (Alex, 334-336)

"She said, 'well, you're not supposed to go dizzy.' I went, 'oh, come on, I'm 55. Everybody who's 55 goes bloody dizzy now and again" (Carl, 256-259).



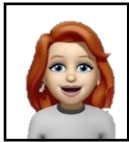
Carl also expressed a pre-existing belief about aging, suggesting that symptoms like dizziness or a general decline in health were simply normal aspects of growing older and didn't need to be taken seriously. Additionally, his comparison of his own condition to that of his grandmother's friend, who appeared visibly unwell and required supplemental oxygen due to a cardiac illness, highlights his difficulty in reconciling his experience with the perceived seriousness of the diagnosis. Carl's preconceived notions about cardiac illness were challenged, as he neither felt ill nor needed supplemental oxygen.



"I remember a friend of my nan who had heart failure, and she never went anywhere without a bottle of oxygen and a facemask." (Carl, 580-583)

In fact, multiple patients expressed their struggle to comprehend a diagnosis of CM as it seemed incongruous with their previous understanding of health and illness. Patients held an array of previously

held beliefs about how illness manifests – that they would feel pain, that they would be symptomatic and that they would feel unwell, that did not reflect the reality of their experience.



“[I didn’t see myself as particularly ill] ...as I wasn’t in any pain” (Dominic, 829-832)



“I wasn’t poorly at all, and I didn’t feel unwell in hospital.” (Jessica, 528-230)



“To this day I can’t work out why it happened to me 100% because I wasn’t ill” (Phoebe, 301-303)

Similarly, Kate also highlighted the impact of prior experiences on her understanding of cardiac illness.

Kate’s reference to how her only other encounters with cardiac illness had led to a steep decline in health and sudden death speaks to the influence of personal experiences, and the potential for these narratives to shape health expectations and fears.



“[speaking about her son] He’s encountered two significant adults in his life who have died of heart issues, dropped. Without knowing anything about cardiomyopathy, we know heart -boom – gone” (Kate, 323-329)

Alex firmly believed that illnesses could be cured and that clinicians could *fix* them. However, his perception of illness as something that either prompted curative treatment, or death was challenged when he received a diagnosis of CM.



“There was no talk of cures or anything like that... Well, what is it? Can you fix it?” (Alex, 412-414)

Personal beliefs and values were challenged by their CM diagnoses and needed to be reconsidered. Carl reported frustration at no longer being able to enact his idea of chivalry due to physical limitations, while Charlotte similarly felt that her body’s physical decline following the birth of her child reflected poorly on her identity as a mother and as a woman.



“We had to move a load of stuff around in this conference room, I was like, ‘alright guys, I can’t really do that’ and then you feel a proper plonker because there’s ladies moving chairs around and you’re just stood watching” (Carl, 1801-1805)

"It makes me feel like I've failed as a mum or as a woman because I gave birth and my body couldn't do it, if that makes sense." (Charlotte, 983-986)



Patients accounted moments that challenged their prior beliefs about illness, ageing and what heart failure looked like and saw these as central to how their identities began to shift in response to CM. As these familiar explanations started to feel less secure, many patients turned to new ways of talking about their bodies, hearts and CM itself, a move that is explored in the next subtheme, **Separate Entities**.

7.3.3.2 Separate Entities (Subtheme)

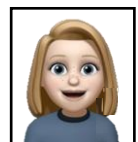
As previously held beliefs were unsettled, patients began to talk about their bodies, hearts and CM in ways that positioned them as partially separate from the self. This subtheme captured how participants used distancing language and metaphors to describe their bodies as unreliable or their hearts as a threatening outside entity, suggesting an emerging attempt to live with CM by renegotiating where the illness ended and the 'self' began. One example of this was from data provided by Charlotte.



"I'm laying down, there's water coming out of everywhere...at one point my body just completely failed." (Charlotte, 805-807)

Charlotte began her narrative by referring to her body as "my body" but this initial sense of ownership over her body was quickly challenged as symptoms begin to emerge. Charlotte assigned the perceived failure to be that of her body, and not of herself. Fear and lack of trust in her body created a perceived disconnect, and distancing language emerged, exemplified by Charlotte's later statement.

"You suddenly have to learn to trust something that's a ticking timebomb inside you."
(Charlotte, 966-968)



The heart - a vital organ within the body, was no longer an integral part of the self, but rather an external entity, a "ticking timebomb" to be feared and distrusted. This separation was further solidified by the patients' language. Charlotte referred to the heart as "it" and even personified it, suggesting it needed to "fight back", further emphasising the division between the self and her heart. She also referred to her body and 'self' using the plural pronoun, "we" instead of the singular pronoun, "I" in relation to carrying

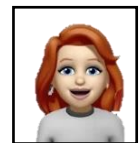
herself up the hill. She further highlighted this separation of body and 'self' using distancing language, referring to 'the legs' instead of taking ownership of them ('my legs').



"I'd like to think that [the heart] it's a muscle and it can fight back." (Charlotte, 1287-1288). "I was like, 'we're getting there. We're getting there. The legs are not moving very well, but we're getting to the top.'" (Charlotte, 1312-1315)

Jessica similarly referred to herself as being a separate entity to her body although she did retain ownership by using the determiner 'my'.

"It was me and it was my body" (Jessica, 132-133)



Patients also used language inferring that CM itself was also a separate entity to both the body and the self which would directly attack the body and indirectly affect the self. Henry described palpitations as something that acted independently upon the body, implying that the body was no longer subject to his control but instead under the influence of CM. This sense of helplessness is echoed in his second statement below.



"My body's trying to relax and they [palpitations] come on." (Henry, 1326-1327)... "You don't know what's happening in your body. You think you're healthy." (Henry, 1219-1221)

The experience of illness further reinforced this separation by altering the body's functionality. CM, through the body, became a barrier to the self's desires, as seen by Henry's inability to jog due to chest pain. This separation was also reflected in Phoebe's experience, where her ability to breathe was directly dependent on her position.

"I tried to jog, and I got some really weird shooting pains in my chest." (Henry, 95-97)



"If I sit down and I don't do anything then I'm not in pain and I can breathe." (Phoebe, 743-745)

Henry described the interaction and dynamics between CM, the body and the self when he described how it felt to try and run following his diagnosis of CM. He described how the self was wanting to run, the body was trying to work with him to accomplish this goal, but CM was preventing his heart from being able to meet the body's needs at that time.

“I’m trying to run and my body’s trying to work harder, and it can’t pump it around quick enough”

(Henry, 954-957)



The quotes highlighted key elements of evolving identity for those facing a CM diagnosis: the gradual shift from a sense of embodied ownership to a more distanced perspective, where the body becomes a separate entity. An entity confined to the parameters set by CM. This separation, while often challenging and unsettling, may allow individuals to cope with the realities of their illness, enabling them to focus on managing their condition without being consumed by its impact on their self-concept. The concept of "separation of body, self, and illness" is a powerful tool for understanding the complex lived experience of individuals navigating a new diagnosis of CM.

Across this process arc, the superordinate theme **evolving identity** captured how patients moved from the initial disruption and objectification of diagnosis, through a phase marked by loss of agency and social recognition, towards more active meaning-making and identity renegotiation. Systemic norms, clinical practices and others’ responses intersected with patients’ own beliefs, fears and embodied experiences, leaving them to continually rework who they were in relation to a body and heart that no longer felt entirely trustworthy. Rather than a single pivotal moment, identity shift brought on by CM was experienced as a series of moments accumulating into a period of significant adjustment. Patients repeatedly had to rethink who they were, how their bodies worked, and how to carry on with everyday life with a new renegotiated sense of self, one that allowed for CM, and clinical input to exist alongside them.

7.4 Seeking Certainty (Superordinate Theme)

Alongside shifts in identity, patients expressed a strong desire for certainty amidst a period of significant change: certainty regarding their diagnosis, prognosis and place within the healthcare system. This superordinate theme brings together six interwoven subthemes. Patients spoke about feeling abandoned or “slipping through the net” when follow-up was delayed or absent (**Abandonment**), and about implicit messages that signalled who did and did not “qualify” for support (**Unconscious messaging**). These experiences were compounded by confusing terminology and frightening labels (**Language barrier**) and by

cautious, sometimes vague reassurance that made it hard to know how serious their situation was (**Trust**). In response, some described adopting a detective-like stance, scrutinising conversations, records and online sources for clues (**Patient detective**), all while wondering whether they counted as “worthy” of time, resources and clear answers in a stretched NHS (**‘Worthy’ patient**). The excerpts below highlight experiences during their cardiomyopathy (CM) diagnosis process that contributed to feelings of uncertainty. This superordinate theme underscores the challenges patients faced in navigating a complex and often ambiguous healthcare landscape during their CM diagnosis journey.

7.4.1 Abandonment (*Subtheme*)

CM diagnosis was found to be challenging, not only in managing the diagnosis itself but also in addressing the psychological and emotional turmoil it brings. While CM can have serious physical implications, patients also reported a felt sense of abandonment during their diagnostic journey, which only heightened their desire for clarity and support. The data revealed that this sense of abandonment manifested in various ways, usually stemming from perceived neglect by the health care system. Delayed follow-up appointments, limited clinician accessibility, and a scarcity of information resources all contributed to patients' feelings of isolation.



“I just found not being followed up till four months after was a bit of a piss take from the cardiologists”
(Charlotte, 623-626)

Charlotte’s frustration with a four-month delay in follow-up care demonstrates these issues. The lack of timely communication and attention contributed to feelings of isolation and uncertainty, which led to feelings of anger and injustice rather than empowerment and trust through her diagnostic journey.

Beyond practical limitations, some patients also reported feeling dismissed or unheard during consultations, leaving them with unanswered questions and great anxiety. For instance, Henry’s account of his clinician abruptly exiting the room without adequate explanation illustrated this disconnect. Similarly, Dominic’s experience of being discharged following an ICD implantation and minimal guidance highlighted how patients perceived there to be an absence of empathetic and personalised care.

“He went to the left and he just was going on there for longer than usual and then he left the room.”

(Henry, 147-149)

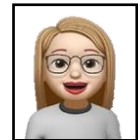


“But literally they gave me my ICD, the following day they said, ‘you’re okay to leave, see you in three months’ time.” (Dominic, 397-400)

Additionally, patients underscored the critical role that access to information and support networks played in reducing feelings of abandonment. Kate’s struggle to navigate the health system due to physical limitations highlights the need for accessible and tailored support. Henry’s suggestion of connecting patients with online communities and resources speaks to the value of peer-to-peer support and shared knowledge in alleviating isolation and information scarcity.

“It’s like hadn’t I got any port of call...I can go to A&E. It’s quite hard to get a GP appointment. It’s physically quite hard for me to get there, I have to think about wheelchair palavers and blah, blah,

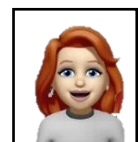
blah.” (Kate, 1244-1248)



“There’s plenty of people out there to learn off of, to speak to and instead of being sent off to go sit in your car and look at google you should be encouraged to speak to these people or to learn off these websites and it would make you feel a million times better instead of googling” (Henry, 1092-1099)

The need for certainty, a fundamental human desire, seemed to become even more acute during the CM diagnostic process. However, the experience of abandonment obstructed this pursuit, fuelling patients’ anxiety and fear. Jessica's statement demonstrated the desperation and helplessness that she felt during diagnosis.

“I felt like I’d slipped through the net and no one was really helping me... It was when I was left alone really and gone home that I felt like I don’t know what to do now and I’ve got all these questions and no one’s really getting in touch.” (Jessica, 724-730)



Without accessible information and support, patients faced greater uncertainty about their diagnosis, which could hinder their ability to engage in proactive coping strategies and make informed decisions about their health.

The subtheme of abandonment in patients' narratives highlighted the need to address both the medical

and emotional support offered during CM diagnosis in future research. Key measures could include improving communication, ensuring timely follow-up, providing accessible information, and fostering a sense of community through peer support, which might help to reduce feelings of abandonment and empower patients to navigate the uncertainty of their CM diagnosis journey with greater confidence. Against this backdrop of feeling abandoned or “left to get on with it”, patients became acutely sensitive to the implicit messages they received about how seriously their condition was viewed and how much support they were entitled to, a focus explored in the next subtheme, ***Unconscious messaging***.

7.4.2 Unconscious messaging (Subtheme)

Unconscious messaging within the NHS significantly influenced patients’ experiences of diagnosis and their understanding of their condition. These implicit, perhaps unintended, messages from health care professionals often led to confusion and mistrust during a time of great uncertainty. These sometimes-conflicting messages could undermine patients’ understanding of their illness, delay necessary support, and impact their engagement with health services. For example, Henry’s recollection of a clinician warning him about CM and exercise left him questioning the risks of physical activity, despite mainstream NHS messaging promoting exercise as beneficial for health and longevity. This contradiction placed Henry in a difficult position, undermining his trust in general health advice, leaving him feeling ‘othered’ from the general public, and causing anxiety about his routine activities.



“That’s one thing he told me as well at the very beginning, its what kills marathon runners. I’ll never forget that. I thought straightaway I do a lot of running, I do a lot of gym, is this going to be something that can kill me?” (Henry, 601-606)

Similarly, Kate’s experience highlighted how ambiguous messaging could create uncertainty about the severity of her symptoms. She was instructed by her GP to go urgently to A&E due to severe palpitations, yet faced a prolonged wait there, leaving her unclear as to the actual urgency or seriousness of her symptoms. This experience underscored a gap between health care guidance and real-world actions, leading patients to feel disregarded and question the relevance of the advice they were given.

"I was having loads of palpitations. I went to the GP and they was saying, 'how long?' I was saying, 'it's been going on for days. It's really pounding.' They said, 'go to A&E.' ...We sat around in A&E for centuries, like you do" (Kate, 612-619)



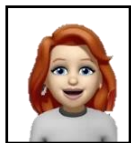
Kate further described her CM diagnosis journey as marked by "insidious neglect," noting that while high-tech devices like loop recorders are available, more basic needs are sometimes overlooked which amplified a sense of uncertainty, vulnerability and mistrust.



"Yes, I now have a diagnosis, but I think it's on this bed of insidious neglect. I know, like, this loop recorder is amazing tech...NHS sometimes they spend masses of money on things and we're missing the small things. "(Kate, 565-572)

Furthermore, Henry was informed that he did not "qualify" for a heart failure nurse and Jessica told her condition disqualified her from accessing cardiac rehabilitation.

"They're like, 'you don't qualify for a heart failure nurse'". (Henry, 2028-2029)



"The cardiac rehab... and being told, like, 'we don't cover takotsubo' it's just a bit random because you do feel like, oh I'm on my own now." (Jessica, 1013-1016)

Such comments suggested an implicit hierarchy within care access, which patients could have perceived to mean they were deemed less deserving or not ill enough to receive support from certain services. This could deepen the psychological impact of the diagnosis, leaving patients feeling undervalued and alone in navigating their diagnosis. These instances of unconscious messaging, whether through ambiguous advice or limited access to care, amplified patients' feelings of abandonment, anxiety and uncertainty, reducing their ability to engage confidently in managing their CM. Addressing these messaging gaps through clearer communication and improved service accessibility was therefore important for fostering a more supportive, patient-centred approach that aligned with patients' needs throughout their CM diagnosis journey.

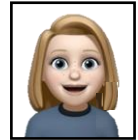
7.4.3 Language barrier (Subtheme)

Patients described encountering language barriers, comprehension difficulties or misunderstandings when communicating with health professionals during diagnosis. These barriers deepened patients' sense

of uncertainty, fuelling anxiety and complicating their ability to make informed decisions about their health.

One pervasive issue was the use of clinical labels, particularly the word *"failure"* in the clinical label, "heart failure," which Charlotte felt to be inaccurate or too negative.

"'Failure' just makes you feel like your body's given up." (Charlotte, 973-975)



Language with such negative connotations could provoke emotional responses that inhibited understanding and left patients feeling defeated rather than informed. This term underscored how word choice could influence a patient's emotional connection to their health condition, hindering their path to acceptance and comprehension. This insight was shared by consultant cardiologists in chapter 5.2.1 who echoed similar concerns regarding the term, 'heart failure'.

Patients reported confusion with clinical terminology and jargon they were unfamiliar with, which impeded their understanding of their diagnosis and treatment options. Kate, for instance, found herself unable to understand explanations that involved technical details like the presence or absence of calcium, leaving her uncertain about the meaning of her own medical records. Similarly, Alex expressed difficulty interpreting information from a clinical letter, noting that without foundational medical knowledge, he felt unqualified to interpret these terms on his own. For patients like Alex and Kate, this challenge indicated a critical need for translation of technical language into accessible explanations to facilitate patient understanding and empowerment.



"I don't really understand the terms. There's something about, oh there wasn't calcium and...I don't know. I don't know what that means." (Kate, 664-668)

"I know I'm not a doctor and I think well I'm not sure how to interpret some of the things it says on there" (Alex, 438-441)



Further complicating this issue was the inconsistency in diagnosis delivery methods. Kate, who was informed of her diagnosis over the phone, struggled to retain or spell the term "hypertrophic

cardiomyopathy” and was uncertain of its correct pronunciation and spelling, reflecting how remote communication could be inadequate for conveying complex health information.



“We think you have hypertrophic cardiomyopathy. There was...I wrote it down and I thought it was hypo and, no, it’s hyper.” (Kate, 491-495)

This reinforced the importance of face-to-face consultations in allowing patients to ask questions and clarify misunderstandings, reducing the risk of misinterpretation or feelings of uncertainty.

Additionally, patients reported multiple instances of ambiguity in the terminology used by clinicians, which contributed to confusion about the severity or specificity of their diagnosis. Dominic, for example, described the use of terms like “chronic cardiomyopathy” as vague, and expressed frustration over the lack of a clear diagnostic picture.

“I think chronic cardiomyopathy, well what does that mean? How bad...I don’t know maybe on a scale of one to ten or something...it’s difficult to get a picture.” (Dominic, 312-319)



Patients encountered instances where clinicians were equally unfamiliar with CM terminology, as Charlotte recalled having to explain her diagnosis to a doctor who was unfamiliar with cardiomyopathy entirely.



“The doctor didn’t know what cardiomyopathy was. I had to explain to him” (Charlotte, 1779-1778)

Such experiences could severely damage trust, as patients expected clinical professionals to possess comprehensive knowledge of the condition. This erosion of confidence created an additional burden for patients, who had to navigate an already uncertain diagnosis without the reassurance that their healthcare team fully understood or was prepared to support them.

The sense of vagueness and lack of clarity was further reflected in Dominic’s comment that the information he received “*was all vague*”, making it difficult for him to understand his prognosis and treatment options. Lacking clarity during diagnosis carried the potential for miscommunication and to heighten patients' uncertainty or undermine their engagement with care recommendations.

“It was all vague. I don’t know but for me, it was too vague” (Dominic, 324-327)



By adopting clear, unified and accessible language, clinicians could improve patients' understanding of their diagnoses, reduce anxiety, and facilitate trust between patients and the health services in charge of their care. When terminology felt frightening or opaque, patients' ability to trust what they were being told was further strained, raising questions about how far they could rely on clinicians' accounts of their condition, which is taken up in the subtheme, **Trust**.

7.4.4 Trust (Subtheme)

The subtheme of trust played a crucial role in patients' pursuit of certainty during a CM diagnosis, as newly diagnosed patients sought accurate, straightforward information to help them understand their condition and their future health. This subtheme highlighted how a lack of transparency and ambiguity could erode confidence in the health care system, leaving patients uncertain and anxious.

One key barrier to trust was the perception that clinicians were reluctant to offer detailed information about patients' prognosis. Alex, for example, expressed frustration that clinicians offered reassuring but vague statements like "you're going to be alright" rather than conveying a comprehensive picture of his future health.



"They probably don't want to tell you the worst things, but I'd rather know a bit more than them saying, 'oh, you're going to be alright' and I'm thinking...I don't know." (Alex, 170-174)

This lack of directness created an unsettling ambiguity, leaving Alex uncertain about the true severity of his diagnosis and the realistic challenges he faced. Alex's comment suggested a disconnect between the potentially supportive intentions of clinicians attempting to provide reassurance, and patients' need for factual clarity.

Dominic's perspective further emphasised the impact of clinicians' cautious communication style on patient trust. He likened doctors to politicians who avoided making definitive statements, as they could not always guarantee outcomes.

"Doctors have to be politicians anyway, don't they, because they can't...you know, unless they can absolutely, 100% guarantee what it is, what you've got and what they're going to do, they need to clearly err on the side of caution." (Dominic, 272-277)



This cautious approach, while understandable from a clinical and ethical standpoint, heightened patients' insecurity when they felt information was being withheld, even if unintentionally. By leading with cautious optimism, clinicians may unintentionally have conveyed clinical uncertainty, deepening patients' anxiety about their prognosis and diminishing their trust in their clinicians.



"They said, 'it's safer to say you've got cardiomyopathy than not.' So, I'm like, well is it that or is it something else?" (Charlotte, 158-161)

As a further example, this phrasing, while attempting to err on the side of caution, inadvertently conveyed doubt, making it unclear to Charlotte whether she indeed had cardiomyopathy or another condition. Such ambiguity could create lasting distrust, as patients may question whether they were receiving the most accurate diagnosis.

Patients also articulated a need for honesty and depth during consultations, as seen in Alex's description of a consultation where he anticipated a more in-depth discussion but instead felt that the doctor "pussyfooted around" the available options.

"When I talked to the doctor, I thought he was going to tell me an answer, but...he, sort of, sugar-coated it...it's not what I want. I want to know a bit more in-depth about it. He just pussyfooted around" (Alex, 226-242)



These accounts underscored how precise and transparent communication was critical in fostering trust, especially in the emotionally charged context of a CM diagnosis. Patients suggested they were likely to feel more supported and confident when clinicians provided clear, unfiltered information, even when such transparency might be difficult to hear. Acknowledging patients' desire for full disclosure and engaging in open dialogue could strengthen the clinician-patient relationship, enabling patients to approach their diagnosis with a sense of control and assurance. This approach not only enhanced trust but also empowered patients, allowing them to make informed, proactive decisions about their health. As confidence in clear, direct information faltered, many described shifting into a more investigative stance, looking for clues in conversations, letters and online spaces, a move captured in the next subtheme, **Patient detective**.

7.4.5 Patient detective (*Subtheme*)

When patients found themselves caught between clinical ambiguity and a desire for concrete answers, they adopted detective-like roles as they worked to decode their health status. This active search for certainty was evident as patients observed, inferred and investigated every detail of their clinical interactions in order to gain insight into their unfolding diagnostic picture.

Dominic's investigative mindset was prompted by feelings of uncertainty after clinicians did not follow through with planned medication. He explained how he inferred that the prolonged lack of a prescription indicated a greater complexity than was initially communicated to him.



"They said you'd just be on tablets ... Then as it drags on you think, well if they're going to give me tablets, I'd be having them by now" (Dominic, 266-270)

This inference, combined with the involvement of multiple specialists, led Dominic to suspect that his care team may also have been unclear about his condition. This ongoing uncertainty drove him to search for more clues.

"The fact that they were throwing different specialties at me I surmised that they didn't know."

(Dominic, 281-283).



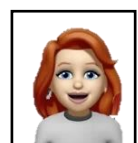
Henry and Jessica's experience also reflected a similar effort to obtain certainty through interpretation of indirect cues and comments. For Henry, a clinician remarking that he needed to 'go speak to the doctor' and promptly leaving the room during an echocardiogram, raised immediate concern.



"He said, 'I've got to go speak to the doctor.' I thought, oh that doesn't sound good" (Henry, 150-152)

Jessica's account of "putting two and two together" also revealed her attempt to fill the informational void, as she collected fragments of overheard comments and used them to construct a more coherent understanding of her diagnosis.

"I put two and two together and all the little bits that you hear, but no one had really said until that point" (Jessica, 254-257)



This drive toward clarity demonstrated how, in the absence of direct answers, patients instinctively sought to interpret even small details within their environment, hoping for a sense of direction and resolution.

Charlotte and Phoebe's behaviours illustrated the efforts patients made to find clarity, including reviewing their medical records or paying close attention to diagnostic procedures. Charlotte described closely examining her heart monitor and looking through her clinical notes whilst in hospital, noticing phrases like "possible cardiomyopathy" and then using online resources to develop a deeper understanding of what her symptoms might indicate.



"I was looking at my heart [monitor] and my heart notes and the ECG's and, you know, they put on there, 'possible cardiomyopathy' and all of that, so obviously you start looking into things. You've got a lot of time, so you do start googling" (Charlotte, 396-402)

Phoebe noticed subtle differences between how her echocardiogram was conducted and that of another patient on her ward, leading her to infer that her condition might have required extra attention.

"I watched them do one [a scan] opposite and suddenly when I'm having it, I'm being told to move this way, to move that way, to breathe in and...then he's taking lots of pictures" (Phoebe, 293-297)



Both examples highlighted how, when feeling left in the dark, patients engaged directly with all available evidence, in search of clues that might alleviate the discomfort of their diagnostic uncertainty.

For many patients, like Henry, the search for certainty extended into online spaces. He described turning to social media and online communities, utilising hashtags like '#cardiomyopathy' to find information and peer support. This resourcefulness represented a modern extension of the search for clarity, where patients, eager for knowledge that their clinicians might not be able to provide in full, took their inquiries online. The certainty they sought was then found in shared experiences and in detailed information that offered more context or reassurance than clinical interactions alone.

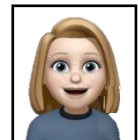


"I like to try and talk about it or find out. I reached out, it sounds silly but there's a hashtag cardiomyopathy, or dilated cardiomyopathy, so I was searching that to try and find information on it." (Henry, 809-814)

Furthermore, Charlotte's concerns about medication changes and Carl's interpretation of his cardiologist's compassionate gesture reflect how nonverbal cues also feed into this search for certainty. Charlotte described feeling uneasy when she was prescribed multiple medications within a short timeframe. Without what she considered to be an adequate explanation from her clinical team, Charlotte began to wonder whether this raised concerns about the gravity of her condition.

"I'm a bit confused, three different drugs within the space of four months was a little bit concerning."

(Charlotte, 552-554)



Similarly, Carl described sensing that his cardiologist's unusually comforting behaviour and body language signalled he might be delivered bad news.



"He [cardiologist] literally sat next to me and put his arm round me and gave me a hug. Then you start asking questions, don't you?" (Carl, 483-486)

These experiences highlighted how even indirect elements of care could contribute to, or undermine, patients' sense of certainty, prompting them to analyse their treatment environment. The patients' accounts illustrated the broader theme of seeking certainty in a diagnosis process that was often marked by ambiguity and delayed clarity. Lacking direct answers, patients could become active agents in their own health investigations, engaging with every observable detail to construct a clearer picture of their condition. This need for certainty underlined the importance of transparent, comprehensive communication in healthcare settings, which not only supported patients' psychological well-being but also facilitated trust between patient and clinician. Even as patients worked hard to piece together their own picture, they were left wondering whether they were seen as deserving of the time and resources needed for certainty, an unease that sits at the heart of the final subtheme, **'Worthy' patient**.

7.4.6 'Worthy' patient (Subtheme)

This sub-theme highlighted how patients' self-worth was perceived to be affected by their experiences of diagnosis. Patients were found to question their 'worthiness' when seeking certainty during diagnosis, revealing the emotional burden placed on those who felt they had to prove themselves deserving of attention, NHS resources and medical validation, especially in the face of ambiguous symptoms and an

often-strained health care system. Patients' worth was perceived to be undervalued during diagnosis, or contingent on specific characteristics, such as symptom severity or lifestyle factors. This sub-theme was labelled as such due to data provided by Kate, who likened the consultation experience to that of a job interview, suggesting her worthiness was being judged or assessed throughout her interactions with her clinical team.

"You're, kind of, like, going for a job interview as being a worthy patient" (Kate, 1126-1128)



Charlotte recalled feelings of distress that came from not feeling believed or taken seriously during her diagnosis. She expressed how this lack of validation impacted her sense of worth too.



"[not being believed] can make us feel like we're just...I don't know, just another passer-by again or we're not worthy or any medical attention or it's not true, it's all in our heads." (Charlotte, 1740-1744)

Her words highlighted the internalised impact of external doubt, suggesting that disbelief from medical professionals could make patients feel unworthy, or even irrational, in seeking care. This perception compounded the difficulty of seeking certainty, as the very legitimacy of their experience felt questioned, leaving them grasping for validation.

Similarly, Kate's account reflected an internalised sense of how one must perform as a "worthy" patient, balancing assertiveness with an avoidance of appearing "needy" in order to get the most out of her clinical interactions.

"...to go and present as an acceptable patient. There is this sense of, to be deserving, but not needy."

(Kate, 1037-1040)



For Kate, seeking certainty involved not only addressing her symptoms directly but also presenting herself in a way that aligned with her perceived expectations of the clinicians in charge of her care. This pressure to be both compliant and deserving, yet not overly demanding, underscored a pressure felt by some patients to actively manage how they were viewed by clinicians in an attempt to be deemed deserving of attention and valuable NHS resources.

The sense of worthiness, for Kate, was further complicated by anxieties surrounding weight-based healthcare "rationing". Kate was fearful that certain characteristics of her personhood, such as her

weight, could influence the value assigned to her as a patient, thereby affecting the level of certainty and quality of care she was afforded.



“I’m not immediately in a very serious state, it’s a milder end of cardiomyopathy, but because of my size I’m going, oh am I going to face NHS covert weight rationing and it’s also feeling like, so would I be denied surgery or kept waiting” (Kate, 290-296)

Kate described the additional emotional toll some patients faced when feeling stigmatised or judged by medical professionals, leading to worries about how their health care might be affected by ‘covert weight rationing’, suggesting she believed intentional withholding or delaying of treatment based purely on factors such as weight could occur.

The role of resource allocation also played into this theme, as shown in Phoebe’s reaction to a fellow patient who was hospitalised due to drug misuse. Phoebe’s sense of worthiness was shaken when she saw this individual prioritised for a bed over her, despite her belief that her situation was more deserving.

“I said you know what’s not bloody fair I said, having to sit here I said because my heart is no longer working properly and you’re sitting in that bed because you take bloody drugs I said... I had to wait 4 days to get a bed on this ward and you bloody got one so shut up!” (Phoebe, 956—963)



Her anger reflected a moral judgment intertwined with a need for fairness, as she felt that her own “worthy” behaviour (in contrast to someone who had ‘caused’ their heart issues) should have warranted greater priority. This experience intensified the emotional burden of seeking certainty when worthiness appeared to be evaluated against a backdrop of perceived blame and responsibility.

Charlotte’s encounter with perceived medication rationing further reinforced this sense of personal unworthiness. When a nurse commented that her heart medication was generally reserved for patients with a more severe condition, Charlotte described feeling undeserving of the treatment despite it being previously prescribed to her.



“They [nurse] said, ‘oh, you shouldn’t be on it unless your EF’s below 30’ because a lot of people are really trying to get it that are lower than mine and they’re not able to get it unless they reach the NICE quota.” (Charlotte, 489-493)

The comment from her nurse subtly signalled to Charlotte that her condition might not meet the thresholds deemed “worthy” of certain resources, exacerbating her uncertainty and reinforcing a sense that the worthiness of her care was contingent on specific metrics rather than her own experiences of illness.

Phoebe similarly illustrated a struggle with worthiness when she recalled the limited interactions she received during ward rounds. She expressed a deep sense of unimportance when the cardiologist did not engage with her directly.

“The cardiologist pops around, doesn’t even acknowledge me with his minions running behind”

(Phoebe, 520-522) “...I know they’re busy but I just, they don’t look at you.” – (Phoebe, 892-893)



For Phoebe, the brevity and impersonality of these encounters intensified her feelings of worthlessness as a patient and she felt as though her need for information and clarity was secondary to the routine of the ward round. Her experience echoed a recurring frustration among the patients interviewed who, whilst seeking certainty, felt dismissed or deprioritised due to the busy schedules of health care professionals.

Alex’s comparison with cancer patient pathways shed light on another dimension of perceived worthiness within healthcare prioritisation. By comparing the swifter diagnostic pathway provided to cancer patients, Alex described feeling implicitly that cardiomyopathy, and by extension he himself, might be less worthy of prompt attention. This experience reflected an underlying hierarchy within healthcare, which patients could interpret as a further unconscious message about the relative importance of their own health.



“The doctor who’s doing it [an echocardiogram], he knows what you’ve got there and then, so why can’t they condense it all a bit and get it done quicker? It’s like cancer they have you in and done pretty quick.” (Alex, 555-559)

In conclusion, the sub-theme of the ‘worthy patient’ highlighted the emotional toll on patients who sensed that they had to prove they were deserving of care in order to gain the clarity they sought during diagnosis. These experiences underscored how worthiness was shaped by a variety of factors, including patient-

clinician interactions, perceived medical rationing and perceived stigma based on personal characteristics or health behaviours. As a result, patients' search for certainty became doubly challenging: not only were they seeking answers about their condition, but they were also navigating an implicit hierarchy that appeared to assign greater value and priority to certain patients or conditions over others. This theme highlighted the importance of a health care system that recognised and validated each patient's experience as inherently worthy of care, regardless of illness type, severity or perceived culpability.

7.5 Chapter Summary

Newly diagnosed cardiomyopathy patients' insights into their diagnosis journey within NHS services in England were represented by three superordinate themes: *Processing loss*, *Evolving identity* and *Seeking certainty*. These themes and their constituent subthemes are mapped in Figure 17.

Processing loss captured how patients psychologically worked through loss in response to their diagnosis, often in a way that resembled other forms of grief. This sense of loss centred on losing parts of themselves, their taken-for-granted identities and elements of their pre-diagnosis lifestyle. Seven non-linear stages of loss were identified, illustrating the emotional complexity involved in receiving and adjusting to a CM diagnosis over time.

Evolving identity highlighted how patients' sense of self shifted as they moved through the diagnosis journey. This theme was organised as a process arc that traced identity change from an initial phase of disruption and objectification, through a period marked by loss of agency and social recognition, and into a more active phase of meaning-making and identity renegotiation. Patients described feeling reduced to malfunctioning hearts or "cases", becoming passive or invisible within clinical and social contexts, and later grappling with how to reconcile pre-existing beliefs about illness and ageing with the emerging reality of

living in a body shaped by CM. Many spoke about a perceived separation between body, self and illness as they tried to incorporate CM and ongoing healthcare input into a renegotiated sense of who they were.

Seeking certainty illuminated patients' felt uncertainty and their sustained efforts to obtain clear information and guidance throughout the diagnosis process. Across six interlinked subthemes, patients described feeling abandoned or as though they had "slipped through the net", attending closely to unconscious messaging about who did and did not "qualify" for services, and struggling with the language used to describe their condition. Difficulties with jargon, frightening labels and cautious or vague reassurance affected the development of trust in their clinical teams. In response, some patients adopted a "patient detective" stance, drawing inferences from verbal and non-verbal cues, written information and online resources in an attempt to construct their own understanding of CM. At the same time, they reflected on whether they were seen as "worthy" of time, resources and clarity, describing pressures to appear engaged but not "needy" in order to secure the care they felt they required. Together, these three superordinate themes showed that CM diagnosis was not a single clinical event but an ongoing psychological, relational and ethical task that unfolded within the constraints and possibilities of contemporary NHS care.

The findings from patient interviews suggested several implications for practice and research. Clinically, it is important to recognise the complexity of the diagnostic journey, including patients' experiences of processing loss, evolving identity and seeking certainty, and the many small moments that accumulate to shape these processes over time. When these developments are viewed as expected features of CM diagnosis rather than as individual pathology, care is more likely to be compassionate and psychologically informed. This might involve shaping diagnostic conversations to acknowledge grief, routinely checking how patients are making sense of their diagnosis and treatment, and widening access to peer support and clinical psychology input along the pathway. At a service and research level, patients' accounts also pointed towards the value of co-designed information resources, tools that support communication about identity disruption and diagnostic uncertainty, and evaluations of pathway changes that seek to reduce abandonment, invisibility and

perceptions of being an “unworthy” patient. Applications of these findings to practice and future research, including more operational detail, are elaborated in Chapters 8 and 10.

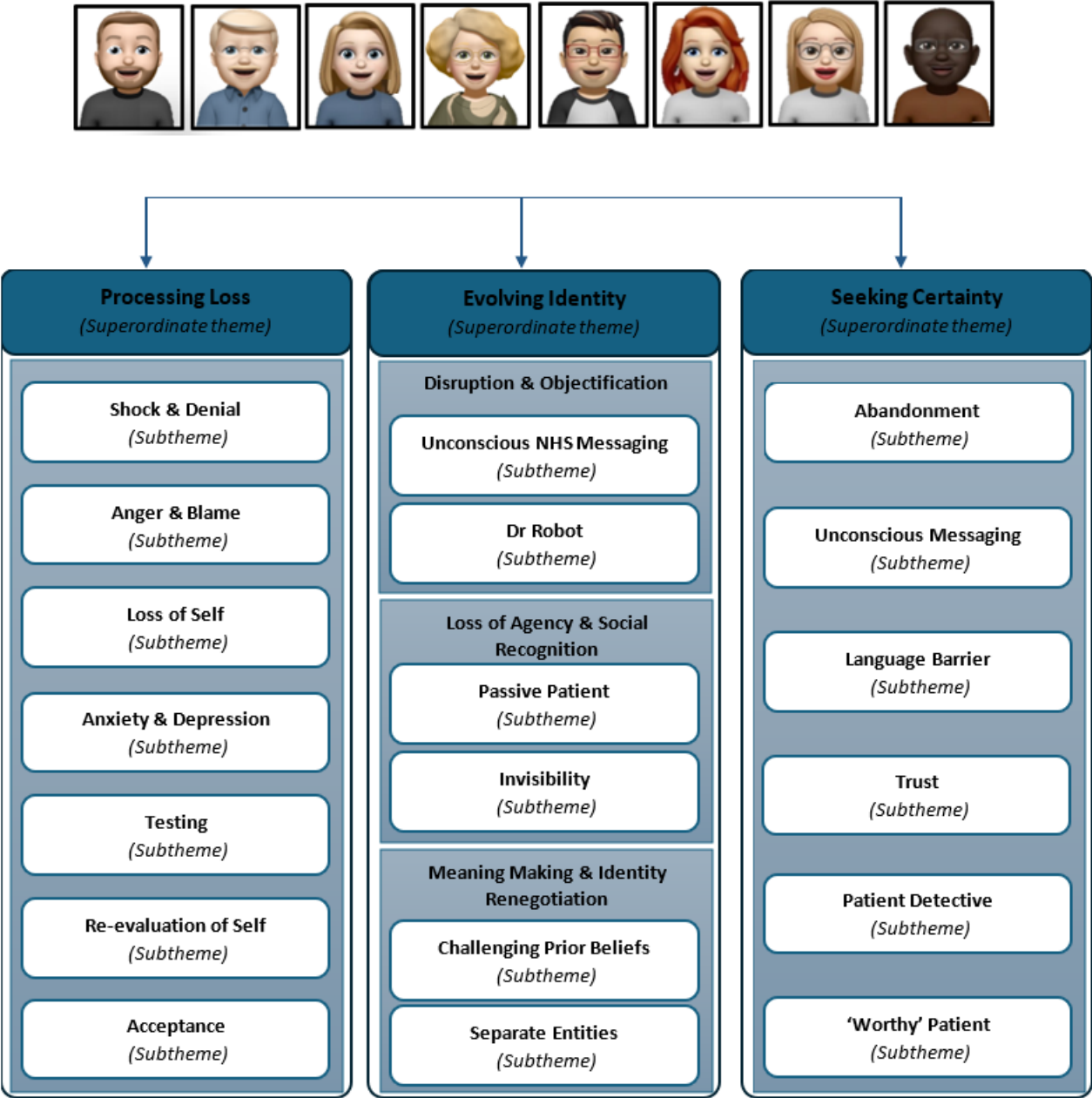


FIGURE 17. INTERVIEWS WITH PATIENTS: SUMMARY OF FINDINGS.

8. Discussion: Interviews with Patients

8.1 Chapter Introduction

Having presented the findings from patient perspectives in Chapter 7, the thesis now moves to a critical discussion of these results. This chapter discusses interpretations of the findings in the context of existing literature and relevant theoretical frameworks. Three superordinate themes emerged from the analysis of patient interview data using Interpretative Phenomenological Analysis (IPA). The first theme, **Processing Loss**, reflected a shared sense of loss among newly diagnosed cardiomyopathy patients, which they processed emotionally through seven distinct but non-linear phases. The second theme, **Evolving Identity**, highlighted small everyday moments and experiences that acted as drivers of identity change throughout the cardiomyopathy (CM) diagnosis journey. The third theme, **Seeking Certainty**, explored how aspects of the diagnostic process contributed to a sense of uncertainty and how patients responded in attempts to regain clarity. This chapter will examine these themes and sub-themes in detail, discussing how they relate to, and enhance, the existing body of research.

8.2 Processing Loss (Superordinate Theme)

The findings from Chapter 7.2 revealed that newly diagnosed cardiomyopathy (CM) patients experienced a sense of loss, processed through a non-linear series of emotional stages: shock and denial, anger and blame, loss of self, anxiety and depression, testing, re-evaluation of self, and acceptance. These stages framed loss as a state patients moved in and out of, rather than something they worked through in a fixed order. These findings also broadly aligned with existing literature on the emotional journey of chronic illness patients (Gunning and Taladay-Carter, 2024), including those with conditions like diabetes (Bateman, 2018), chronic pain (Pratt, 2018), and post-limb amputation (Mir *et al.*, 2023). Data from the cardiomyopathy patients within this study suggested that loss was closely tied to living with ongoing embodied uncertainty and risk, particularly when patients moved from high monitoring and containment in hospitals back into everyday life: *“Coming out of hospital and being taken home I’d lost my safety net a little bit. I’d had this safety blanket around me for a month being in hospital”* (Dominic, 503–506). Although the five-stage grief

model by Kübler-Ross and Kessler (1969), originally formulated for terminal illness, is often referenced to understand the impact of a chronic diagnosis, it was not intended to be a rigid progression. The current study also found that patients fluctuated between stages, supporting the view that stage-like accounts can be non-linear in chronic illness, with clear movement between stages shown when patients reflect on their emotional journey from a new perspective after some time: *“It didn’t really register... I didn’t really get it. I really didn’t see how poorly I was”* (Jessica, 306–315).

With Kübler-Ross and Kessler (1969) original works being criticised for using more rigid definitions of ‘stages’ of grief and loss (Daniel, 2025), over time, adaptations and more flexible alternatives to the five-stage model have emerged to reflect diverse patient experiences, as shown in studies like Bateman (2018), Pratt (2018), and Mir *et al.* (2023). This study contributes to that body of work by examining specific experiences of cardiomyopathy (CM) patients. Table 9 illustrates where CM patients’ accounts echo existing loss models, and where the accounts of CM patients may differ. The comparison shown in the table suggests that within CM accounts, the management of uncertainty and attempts to re-establish a sense of control forms part of the CM loss model, especially through the ‘testing’ phase, which will be discussed further.

TABLE 9. COMPARISON OF EMOTIONAL STAGES ACROSS MODELS OF LOSS.

Kübler-Ross (1969)	Pratt (2018)	Current Model
Terminal Illness	Chronic Pain	Cardiomyopathy
Denial	Denial	Shock & Denial
Anger	Pleading, bargaining, desperation	Anger & Blame
Bargaining	-	Loss of Self
Depression	Anxiety and Depression	Anxiety & Depression
Acceptance	Loss of Self and Confusion	Testing
-	Re-evaluation of life, roles	Re-evaluation of Self
-	-	Acceptance

As shown, shared stages like shock, denial, anger, and acceptance were not exclusive to CM patients but may be commonly experienced with any illness-related grief. Similar patterns have also been reported by young adults following a cancer diagnosis (Shahmari *et al.*, 2023) and among adults with multiple sclerosis (Moore, Yeske and Parikh, 2023). More widely, these phases have also been found relevant in studies on experiences of organisational change (Castillo, Fernandez and Sallan, 2018) and addiction (Chambers and Wallingford, 2017) suggesting they may be foundational to processing any perceived loss, not just physical illness-related loss. However, certain stages of emotional adjustment within chronic illness literature, such as “loss of self” and “re-evaluation of self,” appear specific to chronic illness (Richman, 2022). In CM, this identity shift was moved forwards by the discordance between looking ‘well’ and feeling newly vulnerable, which made the loss harder to explain to others and was challenging to reconcile internally. Patients described how quickly they could become known through the condition rather than as themselves, for example, “*My aunt introduced me to everyone as... ‘the one with the dodgy heart’*” (Carl, 1770–1771). These stages prompted patients to reassess their roles, responsibilities, and contributions to society, and have been similarly documented in coronary heart disease patients as they transition through an evolving self-identity from what Astin, Horrocks and Closs (2014) labelled as the ‘unfamiliar self’ to the ‘shifting self’. Kirk and Hinton (2019) also found that newly diagnosed multiple sclerosis patients’ self-concept changed as their emotional responses altered and patients described themselves in new ways (both positive and negative), for example, being more irritable, angry, mature or compassionate following diagnosis, demonstrating a similar re-evaluation of self. Patients in this study described similar shifts through changes in work roles, independence, and how they felt others perceived them, alongside a sense of felt helplessness: “*All my choices have been taken away from me... Who’s going to fix me?*” (Henry, 893–898).

The Dual Process Model (DPM) of grief, developed by Schut (1999), also aided in understanding chronic illness-related grief, such as when processing the loss of health. This model identified two main types of stressors: *loss-oriented* (direct impact of the illness, including physical limitations and body image) and *restoration-oriented* (adapting daily activities or career plans to manage illness) (Stroebe and Schut, 2010; Fiore, 2021). In the current data, ‘shock’, ‘anger’, and ‘anxiety’ often reflected loss-oriented processing,

whereas ‘testing’ and ‘re-evaluation’ reflected restoration-oriented efforts to re-enter life with a revised sense of safety. The DPM, like this study, considers grief to be non-linear and dynamic, where patients alternate between processing loss and adapting to future challenges.

The ‘testing’ stage observed in CM patients adds further nuance, as patients carefully explored their physical limits to establish a ‘safe zone’ from which to rebuild their lives. It was not simply a way to get back to ‘normal’, but a way of checking what the body could now tolerate without triggering fear or additional symptoms. This stage, while not commonly labelled as such, aligned with findings from other chronic illness diagnosis studies where patients gradually reintegrate into daily activities (Kitagaki *et al.*, 2025; Ore and Foli, 2020). For instance, Henry described testing social boundaries by drinking non-alcoholic beer as a way of re-engaging socially without feeling he was taking a risk: *“That feeling of a crisp, cold beer in the sun is still there, but I’m just not getting drunk”* (Henry, 697–700). This captured how patients started to integrate a changed sense of self into their everyday life, while accounting for their new limitations. However, it is worth noting that, if ‘testing’ remains high-frequency for an extended period of time and does not gradually relax, it may increase the risk of hypervigilance or avoidance-based coping, depending on whether it builds confidence or keeps symptoms (and the threat they represent) at the forefront of patients’ minds.

A unique aspect of this testing phase in cardiac patients may be its role in making invisible threats more tangible. Through self-monitoring technologies like heart rate monitors, patients gained insights into heart rate or blood pressure variability, which promoted self-management and provided reassurance which patients found encouraging, particularly when beginning to reintegrate into daily life. For example, Henry described using a monitor to keep within a perceived ‘safe’ range: *“I make sure my heart rate is staying below 150bpm”* (Henry, 567–574). However, for some patients, frequent monitoring might also intensify hypervigilance and anxiety (La Marca *et al.*, 2026), particularly when readings fluctuate or symptoms are ambiguous (Burnett and Austin, 2025). Unlike other conditions such as cancers, where self-monitoring is less accessible, indicators such as heart rate and oxygen levels are easily tracked through mobile devices. Other studies suggested that patients’ anxiety decreased when they felt adequately informed (Kugbey,

Meyer-Weitz and Oppong Asante, 2019) and that cardiac patients in particular benefited from feeling as though they understood their body (Burnett and Austin, 2025). Therefore, promoting self-monitoring during the testing phase might help alleviate anxiety by providing actionable health information for CM patients. Similar results were observed by Fritschi *et al.* (2022) with diabetes patients, where wearable glucose monitors facilitated experiential learning, increased motivation, and encouraged behavioural adaptation. These findings and associated research suggested that while the testing phase may be common across chronic illnesses, the specific impact of the testing stage may vary by condition.

The stages identified in this study could improve clinicians' understanding of cardiomyopathy patients' experiences during diagnosis, enhancing communication and supporting shared decision-making. Shared decision-making was viewed to be vital, particularly with the NHS agenda promoting self-management and patient-centred care (Deeny, Thorlby and Steventon, 2018). Treffers and Putora (2020) noted that oncology patients' emotional states heavily influenced their engagement with clinical decisions. Understanding the emotional stages of cardiomyopathy patients could help clinicians better time discussions about shared decision-making, ensuring patients have the emotional capacity to participate meaningfully. This was reflected directly in Kate's account of early decision points: *"I've got a lifechanging heart condition, I'm actually not in a great place for making [decisions]"* (Kate, 210–212). This understanding may also guide care provision, such as determining the timing of interventions. For instance, insights from these findings could improve the timing of cardiac rehabilitation programs based on patients' emotional readiness. Kaushal *et al.* (2022) identified factors influencing engagement with cardiac rehabilitation, including motivation, peer connections, and a commitment to forming new habits. Such factors might be more accessible when patients are in 'testing' or 're-evaluation of self' stages, rather than in acute emotional distress. Further research could examine whether an optimal emotional state exists for healthcare engagement, providing a framework for considering emotional readiness in clinical care.

8.3 Evolving Identity (Superordinate Theme)

Patients experienced a disconnect between their physical symptoms and their intellectual or conceptual understanding of the 'self' once symptoms of cardiomyopathy (CM) began to manifest. This disconnect was perceived to be exacerbated by clinicians, who, in focusing on diagnosing and treating CM, prioritised the physical body over patients' sense of self. Patients often viewed CM as an external entity attacking the body and, by extension, the self. Reconciliation was achieved when patients adjusted to, or accepted, a redefined self-concept that included both CM and ongoing clinical intervention, as illustrated in Figure 16 (Chapter 7.3).

The concept of 'self' lacks a standardised definition across clinical and psychological literature, with varied interpretations across disciplines (Morin, 2017). For this study, 'self-concept' is defined following Hards *et al.* (2024) definition as encompassing all known information about oneself, including evaluations, abilities, and representations of the past self, present self, and imagined future self.

Patients' changing identity following diagnosis has been widely researched in relation to multiple sclerosis (Kirk and Hinton, 2019), diabetes (Walker and Litchman, 2021), cancer (Buote *et al.*, 2020) and congenital heart disease (Van Bulck *et al.*, 2018). However, the process by which identity change is experienced by newly diagnosed CM patients is vastly under-researched. Most studies focus on the concept of an 'illness identity' – a term coined by Charmaz (1987) which refers to the integration of illness into one's self-concept. She identified four states within this framework: engulfment (where the illness dominates identity), rejection (denial or avoidance of the illness), acceptance (recognising the illness as part of one's identity without becoming overwhelmed), and enrichment (viewing the illness as a source of personal growth). Acceptance and enrichment were deemed adaptive, promoting a balanced self-concept and improved self-management, while engulfment and rejection often resulted in poorer outcomes. This research underscored the need to understand how cardiac patients, such as those with CM, integrated their illness with their existing self-concept. The data suggested that small everyday moments and experiences within the CM diagnosis journey led to small subtle shifts in identity. What had previously felt like a stable, coherent sense

of self was disrupted through moments of reduced agency and social misrecognition, and identity was gradually reshaped through ongoing meaning-making. Six subthemes contributed to this superordinate theme and were grouped under three narrative headings that reflected the main experiences and drivers of identity change described by CM patients: *Disruption and Objectification*, *Loss of Agency and Social Recognition*, and *Meaning Making and Identity Renegotiation*.

Researcher's Reflection:

As in the findings chapter (Chapter 7.3), six subthemes were arranged using an illustrative 'process arc', which could be read as suggesting a stepwise progression from disruption/objectification, through diminished agency and social identity, towards meaning making and a renegotiated sense of self. However, participants did not describe identity change in this linear way, and not all experiences were shared by everyone. Instead, they pointed to small, often everyday moments that built up over time and interacted to push identity change forward. The process arc is therefore intended as an analytic organising tool rather than a fixed linear pathway, recognising that participants moved back and forth, skipped elements, and shifted between moments in non-linear ways.

8.3.1 Disruption and Objectification

This narrative heading captured the earliest shifts within the process arc of *Evolving Identity*. Patients described encounters with health services as unsettling a previously assumed unity between body and self, often introducing a sense of depersonalisation and objectification. In these moments, attention moved away from individual personhood and became increasingly focused on the body as a clinical 'problem'. This shift did not simply influence how symptoms were understood but also affected how patients understood themselves within the diagnostic pathway.

Two related subthemes sat within this heading: ***Unconscious NHS Messaging*** (small but consequential cues embedded in language, routines, and institutional priorities that subtly repositioned the self) and ***Dr Robot*** (experiences of technically competent yet emotionally mechanical encounters that intensified body–self separation). The first explored how implicit messages within healthcare systems shaped patients' meaning making, while the second considered how these dynamics were felt within face-to-face

clinical encounters. Neither subtheme suggested identity disruption occurred due to overtly negative experiences of care but instead highlighted the everyday features of healthcare delivery that gradually shifted how patients viewed themselves. In terms of the narrative process arc, this early shift appeared to lay the foundations for the reduced agency and social misrecognition discussed later in this theme.

8.3.1.1 Unconscious NHS Messaging (Subtheme)

This subtheme highlighted how implicit communication, healthcare prioritisation, and institutional frameworks influenced patients' perceptions of their health, their engagement with health services, and ultimately, their self-concept. While these messages were rarely deemed to be intentional, they nonetheless emerged through verbal and non-verbal interactions with NHS staff, service priorities, and public health initiatives. This subtheme therefore discussed how such messaging inadvertently shaped patients' interpretations of their symptoms and their perceived value within the healthcare system.

Patients described unconscious messaging embedded in routine clinical conversation. For example, Henry recalled being told that “*normal people*” have an ejection fraction “*55% or higher*” and that his was “*45%*” (Henry, 178–180). Although likely intended as a straightforward comparison to provide a gauge from which Henry could understand the severity of his heart's functioning, the phrase “*normal people*” subtly suggested that Henry was now outside of the category of normal, unsettling his previously held self-concept at the same time as information was being delivered.

Similar messaging appeared even earlier in the pathway, outside of specialist cardiology services. The paramedics' statement, “*nothing's wrong,*” (Alex, 29–33) was likely intended as reassurance after ruling out a heart attack. Reassurance at the scene has been recognised as an important part of paramedic work, particularly in emergency situations where emotions run high (Simola, 2024). It may also have reflected the clinicians' own relief at being able to rule out a high-risk presentation that required rapid assessment and action. However, from Alex's perspective, the phrase minimised the seriousness of his symptoms, despite later being diagnosed with CM. While “*no heart attack*” was clinically good news, the wording implied there was no cause for concern at all, which risked invalidating his lived experience of

real cardiac symptoms. The authority of medical interpretation appeared to override his personal experience, subtly repositioning Alex as someone whose symptoms were less meaningful than he initially believed.

This example illustrated how reassurance, if phrased too broadly, could inadvertently signal that symptoms were not legitimate or worthy of further attention. Patients relied on health professionals for guidance and interpretation and may have read statements like this as a cue that their problem was minor compared with more clearly recognised emergencies such as heart attacks. Wider qualitative evidence suggests that experiences of being dismissed or minimised by clinicians can be harmful and can affect trust, help-seeking, and a patient's sense of being taken seriously within healthcare (Bontempo, Bontempo and Duberstein, 2025). In this way, seemingly small wording choices had effects beyond the moment itself, influencing how patients evaluated the seriousness of their own symptoms and, by extension, themselves.

Unconscious messaging was not always felt through words. Phoebe described watching monitors "*beeping*" with "*lights flashing red*" and thinking, "*no one is coming*" (Phoebe, 831–835). Regardless of whether staff were appropriately monitoring the situation, the lack of visible response was interpreted as inaction and risk, leaving Phoebe questioning what would happen if she was the one in trouble. Patients were reading cues from a system they did not yet understand, and early feelings of uncertainty were amplified through what was perceived to be a lack of response to felt danger.

The NHS's prioritisation of certain health conditions through initiatives (usually in general practice) such as "ABC" checks -atrial fibrillation, high blood pressure, and high cholesterol (University College London partners, 2022; NHS England, 2019) demonstrated how institutional frameworks created implicit hierarchies of illness (Raleigh, Jefferies and Wellings, 2022). Programmes like the Quality Outcomes Framework (QOF) incentivised clinicians to focus on specific, measurable outcomes, often at the expense of less quantifiable or non-incentivised conditions (Ahmed *et al.*, 2021). Symptoms and conditions that sat outside of these targets may have received less attention, reinforcing the sense that

some problems were treated as more legitimate and urgent than others. This is not to suggest that QOF directly shaped individual interactions within this study but rather that it provided important background context for how patients interpreted what clinicians said and did during the diagnostic pathway. For patients like Alex, this prioritisation may have fed into feelings of invalidation, particularly when comments were perceived as dismissive. When a condition did not align with high-priority targets, patients may have felt that their symptoms were undervalued, which could have delayed help-seeking, reduced trust or created false reassurance regarding risk.

Unconscious messaging may have also undermined the NHS's commitment to patient-centred care. Ahmed *et al.* (2021) highlighted how incentivised targets shifted focus toward completing measurable actions rather than exploring the individual needs and context of each patient. In practice, this reduced the scope of the consultation and limited space for psychosocial dimensions of care, potentially weakening engagement and trust with health services over time.

Charlotte's reaction to the slogan, "*Fight for every heartbeat*" (Charlotte, 1000-1006) illustrated the unintended consequences of public health-style messaging. Although likely intended to inspire resilience, Charlotte interpreted it as implying that her heartbeat, and her life, were only secure if she kept 'fighting'. For someone living with CM, this kind of framing may have intensified feelings of vulnerability and reinforced the fear that her sense of safety was fragile and conditional.

Research by Carbone-Moane and Guise (2021) similarly illustrated how public health campaigns that emphasised individual responsibility had unintended emotional consequences. Slogans such as, "*Stay home, protect our NHS, save lives*" (Ferry *et al.*, 2021, p. 2) and "*you can play your part to protect the NHS and save lives*" (Department of Health and Social Care, 2020) aimed to mobilise collective action during the COVID-19 pandemic. However, these messages might also have invoked shame and stigma amongst people who relied on NHS services, particularly when illnesses were perceived to be linked to lifestyle factors (e.g., smoking, alcohol use, or obesity). Such messaging risked increasing feelings of being a

burden and self-blame, which moved away from a sense of partnership and support with NHS services (Cowan, 2021).

Overall, the subtheme of ‘unconscious NHS messaging’ highlighted how everyday language, service prioritisation, and public health messaging may have subtly nudged patients’ meaning-making, sense of symptom legitimacy and sense of self-worth during diagnosis, contributing to the early destabilisation of identity described within this subtheme. Importantly, it was not the messages themselves but how they were interpreted and the meaning that was assigned that appeared most impactful to newly diagnosed CM patients.

8.3.1.2 Dr Robot (Subtheme)

While the previous subtheme explored how systemic messaging shaped meaning-making, this subtheme examined how objectification was experienced within interpersonal encounters during diagnosis.

Patients described interactions in which their individual personhood appeared to be overlooked in favour of treating their body or physical condition. This objectification was experienced as contributing to a sense of dualism, separating patients’ identities into two distinct parts: the body and the self.

Interactions with healthcare professionals, combined with pre-existing assumptions about the medical model of care, appeared to reinforce this perceived separation. Over time, this extended beyond momentary dissatisfaction with communication. For some patients, repeated experiences of being approached primarily as a diagnosis seemed to influence how they began to understand or relate to themselves, actively contributing to identity disruption.

Some patients frequently characterised clinicians as detached or mechanical in their approach to care. Kate described clinicians as *“looking at bodies as objects rather than people”* (Kate, 1106–1107), capturing how she felt her identity was reduced to just her physical body, absent of any individuality. She further suggested that *“[Doctors] are frightened of patients having feelings and they want to, oh god just shut this one down and get them out”* (Kate, 1052–1058), implying that emotional expression itself was perceived as inconvenient by clinicians. Similarly, Henry reflected that his care focused solely on the

condition and did not treat him “*as a whole person*” (Henry, 2126–2127). These accounts suggest that technical competence alone was not sufficient and that a unified sense of self was not possible without clinicians recognising patients’ individuality and enacting compassion or empathy. In other words, the absence of relational engagement appeared to intensify the perceived division between body and self.

Dehumanisation in healthcare has been defined as a failure to honour individuals’ dignity and worth (Brown *et al.*, 2018) and has frequently been linked to systemic pressures including understaffing, limited time, and resource constraints (Busch *et al.*, 2019). Kate likened her diagnostic journey to being processed through “*a sausage factory*” (Kate, 1079–1088), acknowledging service pressures and the need for efficiency, while still experiencing the process as depersonalising. Henry similarly described feeling “*probably just one of a number*” (Henry, 1047–1053), highlighting the discordance between the routine nature of the clinical process and the uniquely traumatic nature of his own diagnosis experience. Systemic pressures may therefore help to explain incidents of detached or robotic care (Basile *et al.*, 2021). However, findings from this study highlight the impact of such care on identity destabilisation within this population.

Subtle forms of depersonalisation may also be found in clinical language and practice norms. Dawson (2021) highlighted administrative labels such as “medically optimised” or “bed-blockers” (Dawson, 2021, p. 224) as examples of language that can reduce patients to only their clinical status or resource consumption. Within this study, depersonalised care was also evident in how information was delivered. Dominic reflected that he would have preferred a personal conversation over generic written material, stating, “*Right let me tell you about the device, not just a pamphlet*” (Dominic, 936–938). Although written information can support understanding if personalised or used in conjunction with clinical discussion (Bhattad and Pacifico, 2022), here it was experienced as a substitute for human interaction and collaborative engagement, which contributed to the perception of depersonalised care.

Importantly, participating patients did not frame clinicians as intentionally uncaring. Patients acknowledged compassion fatigue and acknowledged overwhelming demands may be at play. Wider

research suggests that healthcare professionals may unconsciously engage in forms of emotional distancing as a coping strategy to manage emotional strain (Kim, Kim and Byun, 2020). A lack of confidence in navigating psychosocial dimensions of care may also contribute to impersonal delivery (Jones *et al.*, 2024). Regardless of intent, the interpersonal consequences of robotic care were significant. Repeated experiences of mechanical interaction appeared to shape patients' evolving self-concept during diagnosis, reinforcing the body–self disruption as described in this theme.

Addressing these dynamics therefore requires attention beyond individual clinicians' behaviour. Wider organisational and systemic pressures may reduce opportunities for relational care and contribute to experiences of depersonalised or task-focused interactions (Basile *et al.*, 2021). However, research also indicates that reflective practice and empathy-focused training can improve patient experience (Ellis-Hill, Pound and Galvin, 2022). Even seemingly small environmental changes, such as redesigning hospital gowns to preserve dignity, have demonstrated measurable reductions in perceived dehumanisation (Morton *et al.*, 2020; Punchihewa, 2023) during in-patient hospital stays. These findings suggest that while systemic reform is complex, small-scale relational changes in environment and communication could make a significant difference in patients' perceptions of care.

The “Dr Robot” subtheme therefore illustrated how perceived mechanical or robotic care during CM diagnosis was psychologically consequential. Interpersonal encounters became pivotal moments where patients' sense of embodied unity was either preserved or further fragmented. In the context of an already destabilising diagnosis, robotic care and reduced engagement appeared to add to identity disruption, reinforcing the separation between body and self that characterised this stage of their diagnostic journey.

8.3.2 Loss of Agency and Social Recognition

Following on from the disruption and objectification described in Section 8.3.1, patients' accounts captured how internally felt changes to identity were reinforced through interactions with other people. They described a growing loss of individual agency within healthcare encounters, often feeling that

decisions were being made *around* them rather than *with* them. At the same time, they described their needs as being less recognised or understood by others, both clinically and socially. Within services, patients felt interchangeable or spoken about rather than spoken with. Outside of health services, cardiomyopathy (CM) was sometimes minimised or misunderstood because symptoms were often invisible. The subthemes, ***Passive Patient*** and ***Invisibility*** therefore show how earlier identity disruption became sustained through reduced agency and reduced recognition, and how this fed into the meaning-making and identity renegotiation discussed next in Section 8.3.3.

8.3.2.1 Passive Patient (Subtheme)

This subtheme explored feelings of passivity experienced by patients during their CM diagnostic journey, where they often felt required to surrender control to the clinical process. Within this context, agency appeared to involve having voice, choice, bodily autonomy, and meaningful participation in decisions. Patients described passivity as involving physical confinement, reduced autonomy, limited choice, and detachment from clinicians who seemed to treat their bodies rather than acknowledge their individual personhood. This dynamic contributed to a growing perceived separation between body and self, intensifying feelings of disconnection and helplessness, particularly within in-patient or emergency services.

Carl illustrated this sense of passivity when he likened himself to a “*crash test dummy*” (Carl, 352–354). This analogy captured both his loss of control and his perception of being treated as an object subjected to procedures, rather than an active participant in care. Similarly, Alex’s experience of being told, “*you’re not going home*” (Alex, 54–57), reflected the directive nature of some clinical interactions. Although such decisions were clinically necessary, the way they were communicated reinforced feelings of confinement and reduced agency.

These accounts align with broader healthcare research suggesting that loss of control, autonomy, and choice are commonly experienced during hospitalisation in contexts such as enforced isolation due to infection (Ponce-Ruiz *et al.*, 2022), during the COVID-19 pandemic (Cazeau, 2020), and in intensive care

units (Zengin, Ören and Üstündag, 2020). Environmental (ward noise, temperature and busyness), social (isolation and communication difficulties), and physical stressors (pain and discomfort) have all been shown to contribute to patients' sense of passivity during hospital stays (Zengin, Ören and Üstündag, 2020). Research also suggests that patients with prior hospital experience might feel better prepared for such constraints, whereas those without previous stays might experience the sudden loss of control as particularly distressing (Kellezi *et al.*, 2020).

Such experiences of passivity were seemingly at odds with the NHS' focus on delivering patient-centred care. Although quality-of-care frameworks emphasise effectiveness, safety, accessibility, and equity (Castro and Wang, 2023), the meaning of patient-centredness may differ between clinicians and patients. Clinicians may prioritise physiological stabilisation and disease management, whereas patients are often more concerned with preserving autonomy, identity, and participation in meaningful aspects of daily life (Sathanapally *et al.*, 2020). Ingvarsson *et al.* (2024) captured this difference well in their observation that patients can feel like they are *"being the main character but not always involved in one's own care"* (p.1).

Communication appeared to contribute greatly to how passivity was experienced. Blackburn, Ousey and Goodwin (2019) found that clear information-sharing in emergency departments enabled patients to participate more actively, even within time-pressured environments. In contrast, unclear or limited communication was associated with frustration and exclusion. Kate described consent discussions that felt procedural rather than collaborative (Kate, 87–89), a sense of reinforcing passive compliance rather than active choice. Charlotte also expressed frustration at overhearing conversations held about her rather than with her (Charlotte, 579–589), which she felt diminished her sense of participation.

Patients also highlighted the mitigating role of compassionate care. Kate's description of being *"handled nicely"* (Kate, 148) suggested that although physical constraint was sometimes unavoidable, its emotional impact was shaped by the quality of interpersonal interaction. Respectful and attentive communication appeared to soften the experience of reduced control.

These narratives illustrate how reduced agency was experienced not only through physical constraints but also through communicative and relational dynamics. Feeling positioned as a recipient rather than a participant of care reinforced earlier body–self disruption and contributed to diminished recognition within healthcare. For some patients, the erosion of their ability to participate appeared closely intertwined with experiences of being unseen or overlooked, which is developed further in the following subtheme of *Invisibility*.

8.3.2.2 Invisibility (Subtheme)

Cardiomyopathy (CM) patients frequently reported feeling isolated and invisible throughout their diagnostic journey, both within healthcare systems and in their social lives. Many described being overlooked or excluded during clinical interactions, such as when doctors talked over them or failed to make eye contact. These experiences left patients feeling unseen as individuals. A recurring theme was the sense of being nameless and forgotten within the system. For instance, Phoebe described being mislabelled during her hospital stay (Phoebe, 159–165), reflecting her sense of being reduced to a faceless entity in a sea of patients. Alex expressed similar frustration when follow-up staff failed to recognise him or acknowledge his case (Alex, 77–79), further compounding his feelings of invisibility.

These experiences resonate with the findings of Eriksson-Liebon, Roos and Hellström (2021), who found that patients receiving emergency care often felt neglected and overlooked when they struggled to gain staff attention or felt their concerns were not being listened to. In their study, participants attributed these experiences to factors such as heavy workloads and long waiting times, which left patients feeling that clinicians were too busy to engage. As in the current study, many patients accepted these circumstances despite feeling abandoned or anxious, often hesitating to seek help for fear of being perceived as a burden (Eriksson-Liebon, Roos and Hellström, 2021).

Invisibility was not only experienced through administrative oversights and limited interactions, but also through a perceived failure to recognise the personal significance of diagnosis. Henry reflected on feeling that the life-altering impact of his condition had not been fully acknowledged, stating: “*He probably sees*

people a lot worse, I get that, but for me, it was the worst thing in the world..." (Henry, 1054–1059). His account highlighted how patients could feel that their experiences were minimised when clinicians focused primarily on clinical severity rather than personal impact.

These findings echo earlier work by Lang (2012), which emphasised the importance of communication behaviours such as responsive eye contact, rapport-building, and 'comfort talk' in helping patients feel recognised and valued. Similarly, research exploring patients' perspectives on ideal clinician behaviours found that patients consistently valued clinicians who demonstrated respect, empathy, attentiveness, and a willingness to take time during consultations (Bendapudi *et al.*, 2006). Despite significant advances in healthcare since this time, the fundamental need to feel acknowledged and understood as an individual appears largely unchanged. The sense of invisibility described by CM patients therefore highlights the importance of balancing clinical efficiency with compassionate, individualised care to ensure patients feel recognised and respected throughout the diagnostic process.

Social invisibility was also a common experience for CM patients, who felt a disconnect between their outwardly healthy appearance and their internal health struggles. This disconnect led to misconceptions and judgement, resulting in a lack of understanding and empathy from friends, family, and wider social circles. Charlotte described how her invisible symptoms, such as lethargy and dizziness, were dismissed by others. She explained that when she was unable to participate socially, *"...people just think you're lazy unfortunately"* (Charlotte, 775-781).

Charlotte's account highlighted the stigma associated with invisible illnesses due to preconceptions and beliefs around illness and disability. Her outwardly healthy appearance often led to disbelief and judgement, adding emotional strain to the already challenging experience of living with CM. Carl echoed his frustration, describing the understanding he received from friends as *"very superficial"* (Carl, 1747-1749).

Invisible illnesses are not unique to CM: It is estimated that around 70-80% of disabled people in the UK lived with an invisible illness (Kelly and Mutebi, 2023). Research has shown that living with an invisible

condition was linked to poor psychosocial outcomes due to interpersonal challenges: feeling judged, disbelieved, or forced to choose between feeling burdensome when asking for help and isolating oneself to avoid asking for help (Auriemma *et al.*, 2023).

Kaushansky *et al.* (2017) found that young people with chronic illnesses often withheld disclosure to peers due to fears of rejection, pity, or being seen as different. Similarly, Hamilton, Hulme and Harrison (2023) reported that university students with chronic illnesses faced perceptions that their conditions were not valid disabilities due to their invisible nature. As a result, these students often struggled to access disability support compared to those with visible disabilities or acute illnesses such as a broken bone.

Parker *et al.* (2021) highlighted the dilemma faced by individuals with invisible chronic illnesses: they must choose between disclosing their condition to become 'visible' and legitimise their experiences and needs, potentially exposing themselves to judgement, or remaining invisible, isolated, and unsupported. Further research suggested that people may be less likely to offer support to those without a visibly apparent illness and that even close contacts can underestimate or lose sight of the ongoing impact of a chronic condition in the absence of visible reminders (Copeland and Bogart, 2026). The largely invisible nature of symptoms may therefore contribute to others underestimating the ongoing impact of illness, particularly during periods when individuals appear outwardly well (Turpin *et al.*, 2018). This may help to explain the feelings of invisibility reported by CM participants in the current study, who frequently described their condition as being overlooked or insufficiently recognised by both healthcare professionals and those within their wider social networks. The lack of recognition undermines patients' self-concept, leaving them feeling invalidated and isolated.

Addressing these challenges requires not only increased awareness but also improved support systems that acknowledges and validates the lived experiences of individuals with hidden conditions, fostering a sense of identity that integrates their illness rather than marginalises it. For CM patients, the experience

of not being fully recognised appeared to prompt efforts to reassert credibility, which was a process explored in the final narrative heading of *meaning-making and identity renegotiation*.

8.3.3 Meaning Making and Identity Renegotiation

Following the loss of agency and social recognition described in Section 8.3.2, patients' accounts also highlighted the internal work involved in making sense of cardiomyopathy (CM) in the later stages of the process arc. Here, participants described their attempts to reconcile previously held beliefs about health, ageing, gender roles, and bodily reliability with the realities of CM. Meaning-making appeared to involve revising previously held beliefs around how illness *should* look and feel, and what that now meant for their identity.

Two interrelated subthemes captured this process. The subtheme, **Challenging Prior Beliefs** highlighted how a diagnosis of CM disrupted patients' implicit understanding of health and life roles, prompting them to re-think what mattered and how they understood themselves. The subtheme, **Separate Entities** focused on the language patients used to describe their body and illness, often framing CM as something unpredictable that felt separate from them, and at times in conflict with them. Together, these subthemes suggested that identity renegotiation followed on from the effects of reduced social recognition, but also from the steady internal work of trying to make CM fit into an evolving sense of self.

8.3.3.1 Challenging prior beliefs (Subtheme)

Patients described identity change as being driven by moments that challenged and destabilised previously held beliefs about health, personal values, and life roles. For some, this began with the language and meaning attached to the term 'heart failure' itself. Charlotte described heart failure as "*a really hard word to take on board*" because "*you only have one heart... without the heart you don't function*" (Charlotte, 955–964) and Kate's assumptions around the term, "*Without knowing anything about cardiomyopathy, we know heart -boom – gone*" (Kate, 323-329). Their accounts showed how the label carried immediate existential weight and highlighted previously engrained belief about threats to the heart being a threat to their very functioning and even their lives, setting up a sense of unsafety before

they had fully understood what the diagnosis meant, its day-to-day impact, or their prognosis. Similarly, Alex described his response to receiving a diagnosis; *“Well, what is it? Can you fix it?”* (Alex, 412–414). This captured how CM may have challenged his previously held binary model of illness (viewing illness as being only either fixable or fatal) and forced him to consider a new option of living with chronic illness, and what that meant for him.

Patients also described how CM sometimes unsettled assumptions about how illness *should* present. Prevalence figures from Kosmala and Marwick (2020) estimated that 25%–35% of heart failure patients had ‘Stage B’ heart failure (also known as asymptomatic left diastolic dysfunction which is heart failure without any obvious symptoms). Often, this later developed into symptomatic heart failure and was characterised by decreased elasticity in the heart muscle fibres and is often associated with ageing and comorbidities (Wan, Vogel and Chen, 2014). This challenged the everyday belief that serious cardiac illness would be obvious, painful, or visibly disabling, but could also have fed into the common assumption that cardiac conditions are mainly an ‘older person’s problem’ (Nedkoff and Weber, 2022). Dominic reflected this mismatch simply: *“I didn’t see myself as particularly ill... as I wasn’t in any pain”* (Dominic, 829–832). This showed how pre-existing beliefs about serious illness being painful, or symptomatic, made the reality of patients’ own CM diagnoses harder to reconcile.

These findings aligned with wider research showing that symptoms prior to cardiac diagnosis are often vague and non-specific, contributing to shock and delayed interpretation (Palmer, Bowles and Morphet, 2023). Cleland *et al.* (2021) similarly found that common symptoms such as breathlessness and ankle swelling were often only investigated on a cardiac pathway once severe enough to require hospitalisation. This may reflect broader assumptions about what constitutes serious illness and when symptoms warrant further investigation. Patients’ difficulty grasping the diagnosis was not simply a consequence of misunderstanding, but also of reconciling previously held conceptions of illness (what it is ‘supposed’ to look and feel like) with the reality of living with a condition that may be subtle, intermittent, or even entirely asymptomatic (Ciarambino *et al.*, 2021).

Patients also described how these beliefs were often grounded in previous exposure to cardiac illness within their social culture, for example, often patients only prior exposure to cardiac illness was on TV or films, where drama and immediate threat was the predominant theme. Dominic's reference to ER programmes, *"a pair of pads shouting 'clear'... probably that's the only image I had"* (Dominic, 838–843), captured how media portrayals can narrow expectations of what a cardiac event should look like. Carl's comparison to a friend of his nan who *"never went anywhere without a bottle of oxygen"* (Carl, 580–583) showed a similar embedded image or understanding of heart failure being visibly disabling. When their own presentation did not match these images, the diagnosis became harder to reconcile, and bodily trust became harder to regain.

Alongside beliefs about symptoms and visibility, patients also described how CM challenged assumptions about ageing, capability, and gender roles. Alex's, *"I thought I was just unfit"* (Alex, 334–336) and Carl's, *"I'm 55... everybody who's 55 goes bloody dizzy"* (Carl, 256–259) showed how symptoms were initially fit into pre-existing mental models of ageing, fitness, or stress, rather than interpreted as serious illness. These early interpretations helped preserve a sense of normality but became harder to maintain once the CM diagnosis disrupted their existing mental model. As a result, patients had to revise what bodily signals *meant* and what their body could be relied on to do, which then fed into how safe they felt, how capable they felt, and how they understood themselves in relation to others and their social roles. This kind of role-based revision has been found in other long-term cardiac and neurological conditions, where people moved from an 'unfamiliar' to a 'shifting' sense of self as they adjusted to new physical limitations and increased understanding of their condition (Astin, Horrocks and Closs, 2014; Kirk and Hinton, 2019).

Some accounts showed the CM diagnosis had a clear impact on identity, self-worth, and gendered expectations. Carl described feeling exposed when he could not enact his usual sense of chivalry: *"you feel a proper plonker because there's ladies moving chairs around and you're just stood watching"* (Carl, 1801–1805). Charlotte similarly linked her physical decline to feeling she had failed in meeting a

gendered expectation of herself: *“It makes me feel like I’ve failed as a mum or as a woman”* (Charlotte, 983–986). These moments suggested that challenging prior beliefs was about more than understanding a diagnosis; it also involved renegotiating values, roles, and self-worth in response to a body that now felt less predictable or familiar.

Overall, these accounts suggest that CM diagnosis challenged patients’ prior beliefs in two linked ways: it disrupted expectations about what serious illness looks and feels like (often because symptoms were subtle, intermittent, or interpreted retrospectively), and it destabilised role-based assumptions about capability, ageing, gender and identity. As familiar explanations started to feel less concrete, patients turned toward new ways of talking and thinking about the body and illness, which is further discussed in the next subtheme, ***Separate Entities***.

8.3.3.2 Separate Entities (Subtheme)

This subtheme examined how individuals diagnosed with CM described a perceived separation between their sense of self, their body, and CM (Figure 16, Chapter 7.3). This separation was reflected in the language patients used, with the body or heart described as external, unpredictable, and at times threatening to the ‘self’. CM was frequently personified as a *“ticking timebomb”* (Charlotte, 966–968) or an independent force acting upon the body, contributing to feelings of mistrust and loss of control. Patients often used distancing language, for example Henry referred to his heart as *“it”* (Henry, 954–957) or Charlotte referred to her legs as *“the legs”* and at times described moments of cooperation between her body and herself using plural pronouns such as *“we”* (Charlotte, 1312–1315). Together, these linguistic patterns suggested a psychological divide that was experienced as unsettling but, in some instances, protective, allowing patients to manage CM without fully internalising its implications for self-identity.

Charlotte described bodily collapse as letting her down or breaking her trust: *“at one point my body just completely failed”* (Charlotte, 805–807). Later, she described having to *“learn to trust”* her body not to fail again (Charlotte, 966). Henry’s phrasing also captured a separation between body, self and CM: *“I’m*

trying to run and my body's trying to work harder, and it can't pump it around quick enough" (Henry, 954–957). That framing implied that the self was wanting, the body was trying, and the heart (and the effect of CM) was failing to meet demand. In other moments, the split was described more explicitly but still with ownership intact: *"It was me and it was my body"* (Jessica, 132–133). Henry similarly captured how bodily reliability had shifted: *"You don't know what's happening in your body. You think you're healthy"* (Henry, 1219–1221). These examples suggested that CM disrupted embodied trust and pushed patients into renegotiating where the illness ended and the self began.

Historical and philosophical perspectives may provide additional context for this perceived separation. Cartesian dualism, introduced by René Descartes in the 17th century, conceptualised the body and self as distinct entities: the physical body (*"res extensa"*) and the mind or soul (*"res cogitans"*) (Leder, 1984; Shahar and Lerman, 2013; Miles, 2024). In contrast, Merleau-Ponty (1962) proposed a more integrated conceptualisation in which body and 'self' functioned in unity, with the body enacting the intentions of the self. Illness, however, was seen to disrupt this unity, compelling individuals to become more acutely aware of bodily sensations and to act as intermediaries between their body's needs and the clinical system that treats their illness (Miles, 2024). Within the current study, patients' descriptions matched this disruption, as the body was no longer experienced as trustworthy or reliable, but as a separate entity requiring monitoring and negotiation.

The use of metaphor (such as a "timebomb" or "crash test dummy" as previously mentioned) played an important role in how patients articulated this altered relationship between body and self. Language appeared to help patients communicate their subjective bodily experiences. Metaphors provide access to lived experience, help to facilitate reflection and promote meaning-making, particularly within narratives around illness (Aloni *et al.*, 2023). Disease is frequently described as an external invader or opponent, using terms such as 'the intruder' (Piburn, 1999) or a 'scary enemy' (Aloni *et al.*, 2023). War metaphors, such as describing cancer cells as "invaders" or chemotherapy as "chemical warfare", can convey urgency and mobilise support but may also lead to hopelessness if the struggle sounds

unwinnable (Sontag and Broun, 1978; Hauser and Schwarz, 2020). Conversely, more constructive metaphors, such as framing illness as a “challenge” or a “value,” have been associated with improved psychological and clinical outcomes. For example, breast cancer patients who adopted more adaptive metaphors reported lower depression and anxiety and higher quality of life compared to those who conceptualised illness as an ‘enemy’ or ‘punishment’ (Degner *et al.*, 2003). Similar findings have been reported in multiple sclerosis, where more positive personifications were associated with better outcomes than predominantly negative descriptions (Aloni *et al.*, 2023).

Within the context of CM, these linguistic and philosophical patterns illustrated how patients negotiated the relationship between body, illness, and self. Externalising or personifying CM appeared to provide a way of managing unpredictability while preserving aspects of their pre-illness identity. At the same time, separation signalled a disruption in embodied unity, requiring individuals to renegotiate how their illness was integrated into their self-concept. The metaphorical imagery of separate entities (a perceived split between body and self) formed a key insight into the broader process of meaning-making and identity renegotiation described during the CM diagnosis journey.

8.4 Seeking Certainty (*Subtheme*)

Patients described a strong need for certainty during a period of rapid and significant change, where the stakes felt high and the information available often felt incomplete, inconsistent, or difficult to interpret. Across patient accounts, uncertainty was not experienced as a single moment (such as, when a diagnostic label was communicated), but as an ongoing undercurrent felt throughout the diagnostic journey. Patients described trying to make sense of what was happening, what would happen next, and what their diagnosis meant in terms of their risk, lifestyle, and future planning. Patients’ search for certainty appeared to function as both a coping strategy and a way of restoring some sense of control, particularly when the diagnostic process felt unpredictable or fragmented.

Within this theme, six subthemes captured the different ways uncertainty presented itself, was interpreted, and was managed during CM diagnosis. **Abandonment** described how gaps in follow-up care, delays, and

fragmented care left patients feeling unsupported at key moments. **Unconscious Messaging** reflected how conflicting or poorly contextualised comments, alongside inconsistent experiences of urgency, shaped perceptions of risk and safety. **Language Barrier** explored how jargon, unfamiliar terminology, and the emotional weight of clinical labels could hinder understanding and heighten anxiety. **Trust** examined how uncertainty was intensified when communication felt evasive or when professional competence was questioned. **Patient Detective** captured how patients responded by monitoring verbal and non-verbal cues and interpreting small changes in care as meaningful signals. Finally, **Worthy Patient** described the internal negotiation patients undertook when seeking information or support whilst balancing a desire for clarity with concerns about being perceived as demanding or undeserving of limited NHS resources.

The diagnosis of chronic and serious illnesses has often been associated with uncertainty (Clarke *et al.*, 2022) and a natural fear of the unknown (Simons and Falahee, 2022). Throughout the diagnosis journey, cardiomyopathy (CM) patients often continued to experience uncertainty, particularly around what the condition meant for prognosis, risk, and day-to-day life. The findings of this study aligned with previous qualitative research exploring the experiences of cardiac patients during and after diagnosis (Hess and Donnenwirth, 2022; Jönsson *et al.*, 2021). These results also supported quantitative research, such as studies using Mishel's Uncertainty in Illness Scale (Mishel, 1981), which demonstrated significant correlations between the presence of illness-related uncertainty and adverse outcomes such as depression, poor health-related quality of life, and difficulties with self-management of their condition (Chen *et al.*, 2018; Xia, Yu and Wu, 2022).

Together, these subthemes suggested that uncertainty during CM diagnosis was not solely due to a level of diagnostic ambiguity, but was shaped by how information was communicated, how care was organised, and how patients interpreted their own entitlement to support. Understanding these processes was important for identifying where uncertainty might be unavoidable, and how it could be reduced through clearer communication, better continuity of care, and more transparent explanations of what was known, what was not yet known, and what would happen next.

8.4.1 Abandonment (*Subtheme*)

CM patients frequently described a profound sense of abandonment by healthcare services, which was evident within their accounts of both inpatient and outpatient care. This feeling was often associated with critical moments in the diagnostic journey, such as undergoing an echocardiogram where CM was initially detected, immediately following a diagnostic consultation, or after an emergency hospital admission. Henry's account captured a moment of abrupt disconnection during an echocardiogram, "*... then he left the room*" (Henry, 147–149), leaving Henry alone and uninformed while awaiting the clinician's return. Delayed follow-up care, limited transparency regarding the diagnostic process, and a lack of clear information or resources about CM frequently compounded this perceived abandonment. For example, Charlotte described how she was informed of her CM diagnosis but wasn't given any additional resources or information and then waited four months for a follow-up appointment. She described this gap in care as "*a bit of a piss take*" (Charlotte, 623–626).

These findings aligned with broader research such as Brown *et al.* (2020), who highlighted how patients with chronic illnesses often experienced significant delays in receiving definitive diagnostic labels, with some waiting several years. In certain cases, treatment was initiated based on presumed rather than confirmed diagnoses, further extending uncertainty and distress throughout the diagnostic process. Similarly, Dilbaz and Çifçili (2024) identified that systemic delays, such as prolonged waits for pathology results, unnecessarily extended diagnoses and follow-up care of cancer patients, supporting the notion that delays contributed to heightened feelings of uncertainty and abandonment.

The growing availability of digital health information added another dimension to this issue. Simpson and Amin (2025) noted that patients now have increasing access to test results or clinic letters confirming a diagnosis through digital portals before attending an in-person consultation. While many patients favoured immediate access to such information, even when it pertained to life-altering diagnoses (Steitz *et al.*, 2023), this practice might amplify feelings of abandonment. In such cases, patients were left with an awareness of their diagnosis but without a prognosis or treatment plan, exacerbating uncertainty and

emotional distress (Leonard *et al.*, 2022). Despite being face-to-face with a clinician, Henry's experience explicitly framed this as being "*sent off... to look at google*" rather than being directed toward credible support services or resources, arguing that guidance towards peer and charity resources would have made him "*feel a million times better*" (Henry, 1092–1099).

Additionally, CM patients reported frustration with the perceived lack of co-ordination among outpatient health services. They described feeling burdened by the need to attend multiple, seemingly unconnected services that lacked sufficient communication and integration. Kate described the absence of a clear route back into support, alongside the practical barriers of accessing care; "*It's like hadn't I got any port of call...I can go to A&E. It's quite hard to get a GP appointment...it's physically quite hard for me to get there*" (Kate, 1244–1248). This feeling was consistent with findings from research such as Nordfonn *et al.* (2019) who also found that newly diagnosed heart failure patients often felt abandoned due to poor co-ordination between health services, which left them either feeling helpless or compelled to assume the role of care co-ordinators themselves to mitigate the impact of fragmented care.

Upon discharge from inpatient care, CM patients frequently reported feeling abandoned and without the 'safety blanket' of immediate clinical care. Patients described a loss of the security provided by having clinicians readily available to monitor and respond to changes in their health. This aligns with research highlighting a sense of being 'out of sight, out of mind' following hospital discharge, often due to inadequate follow-up care and insufficient self-management education or resources (Finstad *et al.*, 2021). Dominic described the abruptness of being discharged soon after receiving both a CM diagnosis and an ICD (implantable cardioverter-defibrillator) and being told, "*you're okay to leave, see you in three months' time*" (Dominic, 397–400). He reported leaving without adequate education about the device, the diagnosis, or what these changes might mean for his quality of life. Barisone *et al.* (2022) conducted a meta-synthesis of qualitative studies exploring patients' experiences following ICD implantation and found similar patterns. Patients often felt unsupported after discharge and expressed a need for better information and follow-up care from healthcare professionals. For example, they wanted guidance on

living with an ICD and adopting precautions in daily life, rather than only technical information about surgical aftercare. Insufficient information left many participants feeling uncertain and unprepared for life with an ICD. The study also emphasised the emotional challenges of living with an implanted device, suggesting that family and peer support could help patients accept their condition and adjust post-implantation. Without such support, patients frequently reported a sense of abandonment and ongoing uncertainty, despite being grateful for the care they had received during hospitalisation (Barisone *et al.*, 2022). Whilst it is unclear how many of the studied population were diagnosed with CM, this research also did not provide contextual information such as whether the devices were fitted as an urgent treatment following a significant cardiac event (as was the case for Dominic) or whether they were routine or preventative procedures. Despite this, the data clearly demonstrated a sense of abandonment and a need for more clarity and certainty following discharge. Jessica did not have a device implanted, however was diagnosed with CM as an inpatient and similarly described her post-discharge experience as feeling she had *“slipped through the net...left alone...I’ve got all these questions”* (Jessica, 724–730).

Abandonment was experienced as a constant undercurrent to diagnosis through gaps in clinical contact, gaps in information, and gaps in clarity surrounding the diagnostic process or how to self-manage and co-ordinate care. These findings highlighted the importance of comprehensive post-diagnostic support to address both practical and emotional needs, reducing the risk of patients feeling neglected or uninformed following diagnosis and treatment.

8.4.2 Unconscious Messaging (Subtheme)

Patients often reported receiving conflicting or unclear messages from health care professionals, adding to confusion and mistrust during an already uncertain time. For example, Henry was told that his condition was *“what kills marathon runners”* (Henry, 602–603), leaving him uncertain about continuing his active lifestyle. He described how that line immediately re-framed his routine fitness behaviour as dangerous; *“I’ll never forget that... I do a lot of running, I do a lot of gym, is this going to be something that can kill me?”* (Henry, 603–606). This message conflicted with broader health advice promoting regular exercise for

cardiac health and longevity (Moyad *et al.*, 2025), undoubtedly adding to Henry's uncertainty around how to lead a healthy lifestyle. Research suggested that clinicians' lack of confidence and knowledge in advising CM patients about exercise has contributed to sedentary behaviours among this population, which posed greater health risks than the condition itself (Gati and Sharma, 2022).

Exercise had long been discouraged in individuals with arrhythmogenic right ventricular cardiomyopathy (ARVC) due to its association with life-threatening arrhythmias and increased disease progression (Wang *et al.*, 2018). However, recent studies suggest that low to moderate exercise, up to 150 minutes per week, may safely maintain physical fitness without significantly increasing risk (Prior and La Gerche, 2020). Similarly, hypertrophic cardiomyopathy (HCM) had been linked to high rates of exercise-induced sudden cardiac events in young adults (Lee *et al.*, 2025), leading to equal caution in advising exercise for HCM patients. Such data may have contributed to a generalised perception that all CM diagnoses carry severe exercise-related risks, increasing uncertainty and hesitancy around physical activity for both patients and clinicians. Importantly, Henry was not explicitly advised to avoid exercise. It could be inferred that the consultant's remark was an attempt to emphasise the seriousness of CM or make the condition relatable by linking it to high-profile sports cases. However, the unintended effect of such comments on patient understanding and sense of safety should not be overlooked. Henry interpreted the message as a warning, exacerbating his uncertainty and created anxiety around his routine physical activities. Avoiding the use of blanket soundbites and instead using careful, context-specific communication and clear, evidence-based guidance on physical activity therefore appeared essential to mitigating these effects.

Other examples of unclear messaging were not necessarily about what patients were told, but about the mismatch between the advice given and what happened next. Kate described being urged by her GP to attend her local Accident and Emergency department (A&E) because her palpitations had been going on "for days" and were "really pounding," only then to have "sat around in A&E for centuries" (Kate, 612–619). The mismatch in that series of events was clearly stated: urgent instruction implied imminent risk, yet long waiting in A&E implied the opposite. Even if the wait was driven by unavoidable capacity pressures rather

than a lack of clinical need, Kate's account showed how unconscious messaging sometimes left patients without a stable sense of how seriously to take their symptoms, particularly when messaging between services did not appear to be consistent.

Researcher's Reflection:

Kate explained her experience beyond this single episode, describing her diagnosis as being built on *"this bed of insidious neglect,"* and outlining the contrast between having *"amazing tech"* and *"missing the small things"* (Kate, 565–572). This quote captured how she experienced the NHS as both impressive in its use of technological advancement but also as deficient at the human level of care. This provided insight into a difficulty she experienced within NHS services: if the system can be relied upon to offer sophisticated monitoring and treatment, why does basic reassurance, follow-up, and clarity feel so inconsistent? That mismatch may have become part of the uncertainty she carried. Over time, this inconsistency (both across and within services) seemed to erode her confidence in whether the system was reliably able to meet *all* of her needs throughout diagnosis.

Several accounts also pointed to implicit hierarchies in service access, where the wording of exclusion criteria was personally impactful. Henry recalled being told, *"you don't qualify for a heart failure nurse"* (Henry, 2028–2029). Jessica described being told cardiac rehabilitation *"don't cover takotsubo"* and described the emotional impact of this exclusion, *"you do feel like, oh I'm on my own now"* (Jessica, 1013–1016). Both of these quotes highlighted what denial of access communicated to patients at a key moment within their diagnosis journey. *"Don't qualify"* and *"don't cover"* were phrases that sounded corporate, administrative or impersonal in nature, but in context they were perceived as 'you don't count' or 'this isn't serious enough', while other patients were offered access to those same services. This was particularly impactful during a time where patients were already trying to understand their own level of risk, and the legitimacy of new symptoms.

This may have helped to explain why some patients compared their CM diagnosis pathway to cancer diagnoses, raising concerns about prioritisation and their perceived value within the system. While other conditions such as cancer were perceived to have clearer routes to psychological care and social support, CM patients interpreted their experience of delays, fragmented follow-up care, and exclusion from services as a form of illness hierarchy. This aligned with evidence that perceived discrepancies in care

standards and illness legitimacy led to poorer psychological and physical health outcomes in those positioned as ‘low priority’ (Brandt *et al.*, 2022). Similar results have been observed in people with conditions that were less visible or harder to categorise (Jeske, James and Joyce, 2024). At a policy level, strategies such as the ‘major conditions strategy’ (Department of Health and Social Care, 2023) may also unintentionally reinforce public perceptions of illness hierarchy, because policy attention people can often be viewed as a signal of relative importance.

CM patients demonstrated how unconscious messaging within health services often left them reading between the lines in search of clarity and certainty about the seriousness of their condition, the services they were able to access, and the ability of services to consistently meet their needs. The next subtheme, **Language Barriers**, discusses how medical jargon and clinical language further contributed to uncertainty during diagnosis.

8.4.3 Language Barrier (Subtheme)

Patients reported that complex terminology and the use of medical jargon heightened anxiety and created confusion. Kate exemplified this when she looked at her clinic letter and stated, *“I don’t really understand the terms... I don’t know what that means”* (Kate, 664–668), and Alex similarly described feeling unable to interpret clinical letters without specialist knowledge; *“I know I’m not a doctor... I’m not sure how to interpret some of the things it says on there”* (Alex, 438–441). As previously discussed, particularly in the context of shared decision-making (Chapter 6.3), language use could become a barrier to patient comprehension and ultimately delay patients’ ability to emotionally process and engage fully with their care during diagnosis. Wider research has likened the impact of complex clinical language and jargon to accessing care in a foreign language (Links *et al.*, 2019), suggesting patients in both scenarios encounter misinterpretation, confusion, and heightened anxiety.

Patients reported how clinical labels, such as ‘heart failure’, incited feelings of defeat rather than empowerment. Charlotte described the emotional impact of the label; *“‘Failure’ just makes you feel like your body’s given up”* (Charlotte, 973–975). Recent guidelines created to increase adherence to medical

advice in patients with cardiovascular disease suggested that when it came to patient perceptions, *“Helplessness impairs adherence, perceived control improves adherence”* (Pedretti et al., 2023, p. 157), highlighting the way language and meaning making shaped adherence and longer-term health outcomes. Furthermore, research has indicated that even well-intentioned efforts by clinicians to reassure patients may inadvertently contribute to heightened health anxiety (Tyrer, 2020), suggesting that the language used in medical consultations could feed a cycle of anxiety that is challenging for clinicians to navigate.

Rimmer (2014) explained how language contributed to patient misunderstanding, as clinical language meant one thing to the lay public but had a different meaning when used in a medical context. Dominic reported having limited understanding of his diagnosis of *“chronic cardiomyopathy”* and expressed frustration with not having a clear sense of what this meant; *“How bad... I don’t know... on a scale of one to ten... it’s difficult to get a picture”* (Dominic, 312–319). Rimmer (2014) specifically referred to the word ‘chronic’ in his research, explaining that although it usually referred to ‘prolonged or recurrent illness’ in medical contexts, it was often understood by lay public to mean, ‘more severe’.

Language barriers were also shaped by *how* diagnostic information was delivered. Kate described being told over the phone, *“We think you have hypertrophic cardiomyopathy”* and then she struggled to comprehend the word itself; *“I wrote it down and I thought it was hypo... no, it’s hyper”* (Kate, 491–495). This reinforced how remote delivery further reduced opportunities for checking understanding, correcting misconceptions, or clarifying terminology.

Pitt and Hendrickson (2020) coined the term ‘jargon-oblivion’ to describe the disparity between medical professionals’ self-assessed ability to explain terms in plain language and the level of understanding reported by patients. Patients’ accounts in this study provided a clear example of this gap in practice, suggesting that although information was technically available, it was not always meaningfully accessible. Pitt and Hendrickson (2020) classified seven reasons jargon was used by medical professionals, with the aim of supporting training that discouraged inaccessible terminology during patient interactions. This implied that inaccessible language was often used out of habit rather than with intent, and that drawing

attention to the function of jargon might have disrupted its routine use and encouraged more direct language, whether speech was directed at patients or colleagues.

Studies have found that interventions to improve health literacy among patients reduced anxiety, improved mood, and increased wellbeing amongst chronically ill populations (Magallón-Botaya *et al.*, 2023).

Findings echoed in this study also suggested that increased understanding during clinical interactions could lead to greater feelings of empowerment and control, reducing uncertainty. Dominic's summary of the information he received as "*all vague... too vague*" (Dominic, 324–327) illustrated how unclear language could leave patients without the clarity needed to orient themselves to risk, prognosis, or self-management.

Whilst jargon and complex clinical language were viewed as barriers to understanding during patients' diagnostic journey, lack of familiarity with key clinical labels such as 'cardiomyopathy' amongst physicians also contributed to uncertainty, as the competence of the clinician was called into question. Charlotte described having to explain the diagnosis to her primary care doctor: "*The doctor didn't know what cardiomyopathy was. I had to explain to him*" (Charlotte, 1779–1778). Such experiences could severely damage trust, as patients expected all health professionals to hold knowledge of the condition and its terminology. Patients appeared to value clinical expertise but also valued that expertise being shared in accessible ways which allowed them to be brought into the medical world rather than excluded from it. Concerns about professional preparedness echoed research showing NHS general practitioners lacked sufficient knowledge and confidence in treating cardiac conditions such as heart failure (Hossain *et al.*, 2022; Lam *et al.*, 2023), suggesting systemic inequalities in clinical education and familiarity may have shaped both the language clinicians used and the language they felt able to translate during diagnosis.

8.4.4 Trust (*Subtheme*)

Trust in clinicians and in health services appeared to shape how willing patients were to sit with uncertainty, and how they went about seeking clarity during CM diagnosis. Trust in health services has been shaped over time by wider social shifts such as the movement away from paternalistic models of

care (Linzer *et al.*, 2021). More recently, trust has been impacted by perceived resource rationing, service inequality and COVID-19 pandemic-related uncertainty (Richmond *et al.*, 2024). In this study, trust was something patients actively tested and negotiated through what clinicians said, what they did not say, and how consistently they acted across services and different clinical encounters.

A key issue was the tension between reassurance and honesty within clinical encounters. Several accounts suggested that reassurance, especially when it sounded generic or vague, did not reliably reduce uncertainty and instead worsened it. Alex captured this clearly when he reflected that clinicians “*probably don’t want to tell you the worst things*”, but that he would “*rather know a bit more*” than be told “*you’re going to be alright*” (Alex, 170–174). His reaction illustrated how vague reassurance could be read as avoidance rather than care. This tension was also reflected in wider research into clinical communication, where clinician’s attempts to manage distress was often interpreted by patients as them withholding information, or minimising their distress (Akyirem *et al.*, 2022). It also mapped onto research suggesting that perceived confidence in clinicians was associated with lower anxiety and uncertainty amongst patients (Merenstein, Shuemaker and Phillips, 2023; Thomas, Cohen and Mecca, 2024), but that confidence depended partly on whether explanations felt transparent and usable rather than merely comforting.

Dominic’s “*politicians*” analogy developed this further by suggesting the problem lay not only in what is being said but also in the style of the communication. Trust was eroded by communication that felt calculated, careful, and strategically non-committal. His phrasing suggested he understood why clinicians “*erred on the side of caution*” (Dominic, 272–277) but he also experienced that caution as a barrier to trust when he needed clarity. Wider research has found that trust is strengthened when clinicians’ and patients’ expectations and goals are aligned, and when patients feel the clinician’s motivations are clearly anchored in their wellbeing (Thomas, Cohen and Mecca, 2024). In cardiomyopathy (CM) diagnoses, where patients are often asked to make lifestyle changes quickly, a shared understanding of, and alignment with,

patients' goals and values mattered because such recommendations carried consequences for identity, work, and family planning, not just symptom management.

Importantly, uncertainty itself seemed to be tolerated better by patients when it was named clearly, but eroded trust when uncertainty was attempted to be obscured by hedging language. Charlotte's account of being told, "*it's safer to say you've got cardiomyopathy than not*" showed how a cautious stance, intended to reduce risk, could still be heard as indirect diagnostic uncertainty which caused alarm and frustration; "*is it that or is it something else?*" (Charlotte, 158–161), and destabilising trust in the diagnostic label. This echoed research suggesting that patients can interpret hedged clinical language as deliberate information withholding rather than a necessary expression of medical uncertainty (Faiq, 2018). Piquette's (2023) discussion of 'fuzzy' language in critical care planning offered a useful parallel, where clinicians managed ethical risk through ambiguity, patients experienced the same ambiguity as evasiveness, which negatively affected trust in the patient-clinician relationship.

Alex's description that clinicians had "*sugar-coated*" information and "*pussyfooted around*" options (Alex, 226–242) highlighted how he interpreted communication that did not meet his expectations. He appeared to expect more direct statements about prognosis and treatment options, but when these were not provided, he interpreted the clinician's language as deliberate masking, withholding, or avoidance. In other high-stakes contexts, transparent discussion of options and uncertainties has been linked to reduced anxiety and greater patient-clinician trust (Hillen *et al.*, 2014). This more direct and transparent approach to communicating uncertainty has also supported patients (or their families) to become more confident partners in managing their condition even when uncertainty persists (Hinton and Armstrong, 2020). Patient accounts from this study suggested a similar preference in that they did not necessarily expect certainty, but they did expect clinicians to distinguish clearly between what was known, what was suspected, and what remained uncertain.

On the other hand, Le *et al.* (2022) highlighted that honesty could be costly and required careful judgement about what a patient needed in that moment. Delivery style also has been found to shape how honesty is

received, and how bluntness could erode trust when it feels careless (Fritz, 2020). This tension seemed particularly relevant in CM diagnosis, where clinicians were perceived to be balancing patients' need for emotional containment with ethical transparency. Given that the current data were retrospective accounts, it was also possible that patients' preferences and priorities shifted over time, meaning that some responses may have felt attuned and appropriate in the moment, but were later reinterpreted (alongside subsequent experiences) as being too vague or insufficient.

The nature of the clinical encounter or consultation may also be relevant as it would be harder to establish trust quickly in brief, one-off diagnostic encounters, where patients did not yet have a relational foundation established with clinicians. Consistent with research on continuity effects, longer-term relationships can generate a 'halo effect' that makes missteps more tolerable, whereas early interactions can be fragile and disproportionately impactful (Hoffstädt *et al.*, 2020).

The findings suggested that trust in clinicians during CM diagnosis was shaped by what information was shared, and how. Communication that felt transparent, clear, and appropriately specific to the patient was perceived more positively and tended to strengthen trust, whereas cautious language was often experienced as evasive, undermining trust and increasing uncertainty. Where uncertainty was acknowledged explicitly and explained clearly, patients described feeling better able to stay engaged even without definitive answers. Trust therefore functioned as a relational anchor that helped patients tolerate uncertainty across the CM diagnosis journey. When that anchor felt unstable or when trust eroded, some patients appeared to shift into a more investigative stance, listening for cues, revisiting letters, and seeking information elsewhere in an attempt to regain clarity, which will be explored in the next subtheme.

8.4.5 Patient Detective (*Subtheme*)

A diagnosis of cardiomyopathy often prompted significant feelings of uncertainty among adult patients, which led them to adopt more active, detective-like roles within their diagnostic journey. Rather than remaining passive recipients of information and care, patients described closely observing, inferring, and piecing together meaning from their clinical encounters in an effort to make sense of their condition and

predict their future care. As illustrated in Chapter 7.4.5, this pattern was evident across participants. For example, Dominic described how delays in initiating treatment led him to question and anticipate the clinicians next steps, explaining that “*as it drags on you think... well if they’re going to give me tablets, I’d be having them by now*” (Dominic, 266–270), and later inferring that “*they didn’t know*” what had caused his symptoms due to the involvement of multiple specialists (Dominic, 281–283). Similarly, Jessica described “*putting two and two together*” from fragments of overheard information (Jessica, 254–257). These accounts highlighted how, in the absence of direct explanations, patients actively constructed their own understanding of their condition.

This process aligns with existing research suggesting that patients closely observe clinical interactions and infer meaning from both verbal and non-verbal cues, which can significantly influence emotional responses and perceptions of health (Danaher *et al.*, 2023; Rehman and Sohail, 2023). However, research exploring this phenomenon directly, particularly within the context of cardiomyopathy diagnosis, remains limited. As previously discussed in Chapter 7.3, non-verbal communication has been recognised across disciplines as a central component of social interaction (Chitac, Knowles and Dhaliwal, 2024). It has also been widely acknowledged that clinicians routinely interpret patients' non-verbal cues, including facial expressions, body posture, and other behavioural indicators, to infer subjective experiences such as pain (Herr *et al.*, 2024) and distress (Abdulghafor, Turaev and Ali, 2022). The present findings extend this understanding by demonstrating that patients engage in a reciprocal process, drawing on clinicians’ behaviours and contextual cues to infer information that has not been explicitly communicated.

In line with this, Priolo and Tartaglia (2023) described how waiting for diagnostic certainty can generate an overwhelming need for answers, with patients becoming increasingly focused on identifying the cause of their symptoms. The current findings build on this by illustrating how this need manifests behaviourally, with patients treating elements of their care environment as sources of diagnostic evidence. For instance, Henry interpreted a clinician leaving mid-procedure to “*go speak to the doctor*” as a signal of concern, stating “*that doesn’t sound good*” (Henry, 150–152). Similarly, Charlotte described noticing the phrase

“possible cardiomyopathy” in her notes and subsequently turning to online resources to understand its implications (Charlotte, 396–402). These findings suggest that, in the absence of clear and timely communication, patients may rely on indirect indicators such as delays, language, and fragmented information to construct or infer meaning about their condition.

The scrutiny of clinicians’ behaviours appeared to play a crucial role in shaping patients’ perceptions of their health status. Research has increasingly highlighted the psychological impact of the clinical environment, including the potential effects of language that is overheard but not directly addressed to patients. Katz *et al.* (2022), for example, described a case in which a patient overheard staff discussing her prognosis in clinical terms that had not been communicated to her directly, leading to significant distress and physiological consequences. A similar process was evident in the current findings, where Charlotte’s exposure to the term *“possible cardiomyopathy”* prompted anxiety and independent information-seeking in the absence of a clear clinician-led explanation. This suggests that meaning making is not confined to formal communication, but occurs across the wider clinical environment, including moments where patients are not the intended audience.

In addition to verbal and environmental cues, CM patients also drew heavily on non-verbal aspects of care. Ohrling *et al.* (2024) discussed how clinicians and caregivers interpret patients’ bodily cues during palliative care consultations, highlighting the importance of attunement to non-verbal communication. However, the present findings suggest that this interpretive process is bidirectional. Patients appeared highly attuned to clinicians’ non-verbal behaviours, particularly within high-stakes contexts such as diagnostic discussions, where such cues may carry heightened meaning (Ohrling *et al.*, 2024; Sengupta *et al.*, 2022). Ravi and Vethabothagam (2021) further suggested that clinicians’ awareness of their own non-verbal communication is essential to avoid unintended interpretations. This was reflected in Carl’s account, where a gesture intended as comfort (his cardiologist placing an arm around him) was instead interpreted as an indicator of bad news (Carl, 483–486). While physical touch has been described as an important component of empathetic care, metaphorically likened to a ‘waltz’ governed by unspoken

norms (Kelly *et al.*, 2018), Carl's experience suggests that, within contexts of uncertainty, such gestures may be reinterpreted through a lens of threat. This challenges assumptions that empathetic non-verbal behaviours are universally experienced as reassuring, as suggested by Kraft-Todd *et al.* (2017), and instead highlights the contextual sensitivity of such interactions.

The act of 'detective work' seemed to serve an important psychological function: by actively seeking information and constructing meaning from this, patients were able to regain a sense of agency within an otherwise uncertain and often disempowering process. This extended beyond clinical interactions, with patients such as Henry turning to online platforms and social media communities to gather information and connect with others (Henry, 809–814). However, this interpretive process came with an associated cost. Inferences made in the absence of clear communication were not always accurate and could contribute to increased anxiety or confusion. For example, Charlotte described feeling concerned by multiple medication changes, interpreting this as a sign of worsening illness despite limited explanation (Charlotte, 552–554). Attempts to resolve uncertainty could therefore paradoxically amplify it, particularly when patients were left to interpret complex or fragmented information independently.

When communication was perceived to be ambiguous, incomplete, or difficult to interpret, patients engaged in considerable interpretive effort, scrutinising both verbal and non-verbal cues in order to construct a coherent understanding of their condition. While this process functioned as an adaptive coping strategy, it also introduced the potential for misinterpretation and increased distress. These findings underscore the importance of clear, transparent, and timely communication within clinical practice, not only to support understanding but also to reduce the burden placed on patients to 'work out' their diagnosis. This raises important questions about how far patients felt able (or entitled) to seek clarity, and whether the need to adopt a detective role reflected not only uncertainty, but also a deeper concern about their legitimacy within the healthcare system. This unease sits at the centre of the final subtheme, 'Worthy' patient.

8.4.6 Worthy Patient (*Subtheme*)

Cardiomyopathy (CM) patients internalised their medical experiences, including the validation they felt from health professionals and the resources allocated, as reflections of their own worthiness and deservingness of care. As illustrated in Chapter 7.4.6, patients expressed a fear of being perceived as unworthy or considered less of a priority than others. This reported internalised pressure to perform and be viewed through a favourable lens contributed to a diminished sense of self-worth and heightened uncertainty throughout the diagnostic process.

The findings suggested that patients perceived their worthiness of care as contingent on factors such as symptom severity, lifestyle choices, and implicit biases within the healthcare system. As reflected in patients' accounts, Kate described consultations as *“going for a job interview as being a worthy patient”* (Kate, 1126–1128), while Charlotte explained that not being believed could leave individuals feeling *“not worthy of any medical attention... [as if] it's all in our heads”* (Charlotte, 1740–1744). These accounts illustrated how perceptions of worthiness were not abstract but actively shaped how patients understood their position within the healthcare system and how they engaged with care. This aligned with wider research that explored how certain patient groups may be perceived as ‘less worthy’ of clinical attention: Higashi *et al.* (2019) identified categories of patients such as frequent attenders, individuals perceived as drug-seeking, non-adherent parents, and persistently defiant patients as more likely to be deprioritised. The current findings extended this by demonstrating how such perceived judgements were not only anticipated by patients but also influenced how they presented themselves within clinical interactions in order to avoid being viewed negatively.

Kate's comparison of medical consultations to job interviews illustrated the performative nature of patienthood, where individuals appeared to feel required to demonstrate their worthiness in order to secure care, positioning patients as subject to evaluation and clinicians as those who implicitly judged them. In this way, patients were not only seeking answers about their condition but were also attempting to manage how they were perceived within the clinical encounter. Since the time this data was collected,

such dynamics may have been further intensified within the context of the COVID-19 pandemic, where public messaging around protecting NHS resources contributed to increased feelings of being a burden (Sloan *et al.*, 2022).

Alongside this performative pressure, patients described how experiences of not being believed contributed to an internalised sense of unworthiness. Charlotte's account that not being believed could make individuals feel "*not worthy of any medical attention*" (Charlotte, 1740–1744) underscored how external doubt became internalised, leading patients to question the legitimacy of their own embodied experiences. This reflected literature on implicit medical bias and symptom legitimacy, where certain groups, particularly women, were less likely to have their symptoms validated and were subsequently less likely to receive adequate treatment (Hintz, 2023). Similarly, individuals living with chronic illness may have developed a reluctance to seek care due to prior experiences of dismissal (Ashe *et al.*, 2017). This fear may also have related to being perceived as exaggerating symptoms for secondary gain, such as attention or disability benefits, particularly as public perceptions of disabled people on benefits have been increasingly shaped by negative media portrayals (Healy, 2025). The current findings extended this literature by illustrating how such experiences may not only have affected help-seeking behaviour but also shaped patients' internal sense of legitimacy when navigating diagnostic uncertainty. Within this context, patients were not only seeking clarity about their condition but also questioning whether their need for care was justified.

Patients also described actively managing how they presented themselves within clinical interactions in order to maintain a position of perceived worthiness. Kate articulated the need to balance being "*deserving, but not needy*" (Kate, 1037–1040), highlighting the tension between assertiveness and compliance. This reflected wider research suggesting that patients must navigate implicit social rules in order to optimise access to care (Shaw and Lamdin, 2017). Shaw and Lamdin (2017) described how such negotiations were often invisible within clinical documentation, despite requiring significant emotional and cognitive effort from patients. The current findings built on this by highlighting the psychological cost

of this invisible labour, as patients described carefully regulating their behaviour in an attempt to avoid being dismissed or deprioritised, further contributing to the burden of the diagnostic process.

Beyond interpersonal interactions, broader systemic and structural factors also appeared to shape patients' perceptions of worthiness. As financial and political pressures on the NHS increased, public awareness of the need to conserve resources became more pronounced (Freedman and Wolf, 2023). Within this context, Kate's concern regarding "*covert weight rationing*" and whether she might be "*denied surgery or kept waiting*" (Kate, 290–296) highlighted how patients perceived personal characteristics as influencing their access to care. Research on weight stigma in healthcare (Ryan *et al.*, 2023b; Pearl and Sheynblyum, 2025) suggested that individuals with higher body weight frequently experienced bias that could affect clinical decision-making, including the use of treatment thresholds and eligibility criteria (McLaughlin *et al.*, 2023). Together, this body of work suggested that stigma operated both interpersonally and structurally, shaping access to care in ways that were perceptible to patients. The current findings extended this by demonstrating how such perceptions could amplify diagnostic uncertainty, introducing an additional layer of concern regarding how personal characteristics might influence treatment decisions.

Charlotte's perceived experience of medication rationing further illustrated how worthiness may be implicitly communicated through clinical decision-making. When she was told she "*Shouldn't be on it unless [her] EF's below 30*" and that others were "*really trying to get it*" (Charlotte, 489–493), this signalled that her condition may not meet thresholds deemed worthy of certain resources. When treatments were framed as being reserved for more severe cases, patients may have internalised the message that their suffering was less legitimate or less deserving. This aligned with research exploring the ethics of ration-based access thresholds (Sandman and Liliemark, 2019; Gaurke *et al.*, 2021) and the psychological impact of exclusion from treatment eligibility (Curnow *et al.*, 2021; Olasoji, Maude and McCauley, 2017). While such thresholds may have been clinically justified, the current findings suggested that their psychological impact may have been insufficiently acknowledged within routine clinical practice.

Similarly, Alex's comparison of cardiomyopathy diagnosis to cancer pathways, questioning why care could not be "*condense[d]... and get it done quicker*" as it was "*with cancer*" (Alex, 555–559), highlighted how patients perceived an implicit hierarchy of illness within the healthcare system. His observation reflected broader perceptions that cancer pathways were prioritised and expedited over other conditions (Wright, 2022), despite evidence suggesting that delays have also affected cancer care in recent years (Price and Lawler, 2025). Regardless of the empirical accuracy of this comparison, the perception of a hierarchy appeared psychologically meaningful, contributing to feelings of neglect and reinforcing uncertainty among patients with less visible or less-publicised conditions. This suggested that perceived prioritisation, rather than objective differences in care pathways, may have played a key role in shaping patients' experiences of worthiness.

Interestingly, perceptions of worthiness were not only shaped by interactions with clinicians but also through comparisons between patients. Phoebe's frustration that she had to wait "*four days to get a bed*" while another patient "*got one*" despite perceived self-inflicted illness (Phoebe, 956–963) illustrated how moral judgements influenced perceptions of deservingness. Her reaction reflected a belief that her condition was more legitimate than that of another patient whose illness was perceived to be self-inflicted. This aligned with literature on morality in healthcare (Ryan *et al.*, 2023b; Joslyn and Haider-Markel, 2019), which suggested that patients engaging in behaviours perceived as risky or self-inflicted may be viewed as less deserving of care. The current findings demonstrated how such moral comparisons could actively shape patients' own sense of worth and sense of fairness within the healthcare system, further destabilising their experience of diagnostic certainty.

These findings suggested that 'worthiness' functioned not only as a perceived judgement, but as a socially negotiated and internally regulated construct within the diagnostic process. Patients appeared to engage in ongoing efforts to position themselves as deserving of care, while simultaneously interpreting cues from clinicians, systems, and other patients to assess their relative standing. This placed an additional

psychological burden on patients, as the pursuit of diagnostic certainty became intertwined with concerns about legitimacy and entitlement to care.

These findings highlighted the importance of healthcare practices that actively promoted patient validation and equitable care. Clinicians should be supported to recognise the psychological impact of diagnostic uncertainty and to minimise unintended signals that may be interpreted as judgements of worth. This includes fostering open and transparent communication, addressing implicit biases, and providing clear explanations of clinical decisions. While resource allocation and triage systems are necessary within constrained healthcare systems, efforts should be made to communicate these decisions in ways that do not imply a hierarchy of patient worth. Enhanced patient advocacy and validation may help mitigate the distress associated with perceived unworthiness during the diagnostic process.

8.5 Chapter Summary

The analysis of patient interviews identified three superordinate themes: ***Processing Loss***, ***Evolving Identity***, and ***Seeking Certainty***. These themes were interpreted in relation to existing literature and explored through an interpretative phenomenological lens to understand how participating newly diagnosed adult cardiomyopathy (CM) patients made sense of their diagnostic experience.

Processing Loss demonstrated that CM diagnosis was experienced as a form of ongoing loss, not just in a single moment but as an experience extending across the diagnostic pathway. Patients moved between emotional states in a non-linear way, shaped by uncertainty, perceived risk, and negotiating clinical contact and everyday life. The findings extended existing models of illness-related grief by identifying a distinct *testing* phase, in which patients actively explored physical and social limits to re-establish a sense of safety and control. Loss in CM was therefore not only related to change, such as adjusting to an uncertain and unpredictable body, but also encompassed patients' efforts to reorient themselves in response to that change.

Evolving Identity highlighted how CM diagnosis disrupted previously stable assumptions about patients' sense of self, prompting gradual and often subtle nudges towards identity renegotiation. Identity change

was not experienced as a singular event, but as the cumulative effect of small, everyday interactions within healthcare systems and social contexts. Patients described a growing felt separation between body and self, shaped by objectifying clinical encounters, reduced agency, and social misrecognition. Identity was renegotiated through ongoing meaning-making, as patients revised beliefs about their health, capability, and social roles. These findings indicate that identity change was actively shaped by relational and systemic experiences across the CM diagnosis process.

Seeking Certainty showed how uncertainty functioned as a central and persistent feature of CM diagnosis. Patients actively sought clarity regarding risk, prognosis, and next steps, but often encountered fragmented care, inconsistent messaging, and barriers to understanding. In response, patients adopted active roles in managing uncertainty, including monitoring cues, interpreting interactions, and negotiating their entitlement to care. Uncertainty was therefore not only a product of diagnostic uncertainty, but also of how information was communicated, how care was organised and accessed, and how patients positioned themselves within the healthcare system.

Taken together, these findings suggested that CM diagnosis was experienced not as a single clinical event, but as an extended and psychologically complex process shaped by ongoing interactions between patients, clinicians, and healthcare systems. Across themes, patients were not only adjusting to a diagnosis but were actively working to restore a sense of safety, coherence, identity, and legitimacy in the context of uncertainty.

Loss, identity shifts, and the search for certainty operated as closely intertwined processes rather than as distinct experiences. Periods of uncertainty destabilised identity. Such identity disruption then shaped how patients interpreted clinical information and engaged with care, creating a self-reinforcing cycle. At the same time, patients' efforts to regain certainty were shaped by concerns about how they were perceived, including whether they were seen as credible, or appropriately deserving without being needy within a system with limited resources. This introduced an additional layer of psychological work, as patients navigated not only their condition, but their perceived position within healthcare.

These findings extend existing literature by demonstrating that diagnostic experiences are not solely shaped by clinical factors, but by relational and systemic dynamics that influence how information is interpreted, how identity is renegotiated, and how legitimacy is understood. CM diagnosis can therefore be understood as a process in which patients were not only seeking answers about their condition but also negotiating their place within the healthcare system and reconstructing a coherent sense of self that incorporated CM and ongoing clinical involvement.

Chapter 9 will build on these findings by bringing patient and cardiologist accounts together to explore where perspectives on uncertainty, communication, inclusion, and decision-making converge and diverge. Chapter 10 will then use these insights to identify opportunities for developing more consistent, collaborative, and psychologically attuned approaches to diagnostic care.

9. Integrating Perspectives

Following the presentation of separate datasets for cardiologists (in chapters 5 and 6) and patients (in chapters 7 and 8) chapter 9 will now move to phase 3 - integrating these perspectives to explore points of convergence and divergence between patients and cardiologist populations studied. This chapter discusses the findings in relation to existing literature and theoretical frameworks, highlighting implications for clinical practice, training, and service delivery.

9.1 Chapter Introduction

The research aimed to improve our understanding of the cardiomyopathy diagnosis process through the exploration of consultant cardiologists', and newly diagnosed adult patients lived experiences. The multiperspective design allowed for a comprehensive examination of both perspectives in isolation which provided valuable insight into the systemic, interpersonal and intrapersonal challenges and processes that must be navigated by the main actors during the journey through diagnosis. However, it is only through a considered integration of these findings that our understanding can be further enriched, and a more nuanced understanding of the entire CM diagnosis process can be achieved. Broad themes found to be relevant across both datasets were considered. Whilst some viewpoints across populations regarding these broader topics aligned, others differed. Eight broad themes were labelled as either 'convergent' or 'divergent'. This chapter will discuss these eight broad themes as outlined in Figure 18 below.

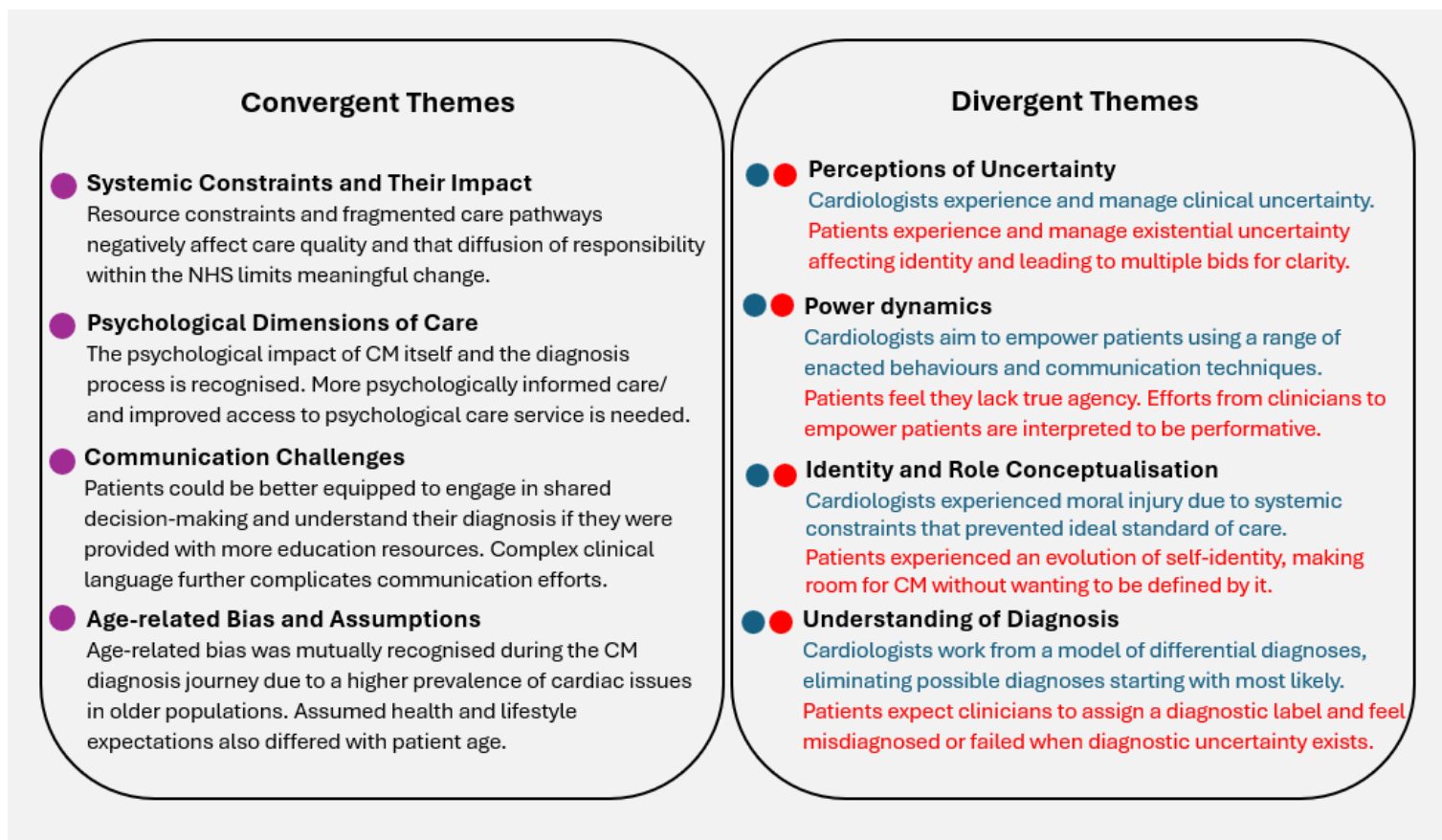


FIGURE 18. CONVERGENT AND DIVERGENT THEMES IDENTIFIED THROUGH THE INTEGRATION OF CARDIOLOGIST AND PATIENT PERSPECTIVES.

9.2. Methodological Underpinnings and Framework for Integration

As discussed in an interview with Professor Michael Larkin (Williams, 2023) the application and understanding of IPA has developed significantly since its inception, with part of that evolution focussing on its application to multiperspective research designs. Larkin, Shaw and Flowers (2019) outlined how the core principles of IPA can be maintained through a rigorous analytical procedure when comparing multiple perspectives experiencing the same phenomenon. However, critiques fear that IPA's ideographic focus and analytical depth may be lost in multiperspective designs as they move away from individual experience of a phenomenon within a given context (Dennison, 2019). However, Larkin, Shaw and Flowers (2019) argue that just as individual voices are maintained when moving from individual transcript analysis to multiple transcripts analysis, so too can individual voices be preserved and considered when moving from a single

perspective to a multiperspective analysis. Love, Vetere and Davis (2020) criticised the use of IPA when exploring multiple perspectives of a single experience collected at a single point in time (e.g., focus groups). However, this study differs in that the focus is not of the experience itself but the interpretation of the experience that contributes to a greater understanding of the essence of the broader phenomenon. The current study aims to explore the wider phenomenon of CM diagnosis by drawing on varied perspectives captured at different points in time. Although interpretations based on a single experience or time point can offer valuable insights, they may be more open to challenge when used to understand the essence of an entire phenomena, whereas a multiperspective approach can provide a more comprehensive understanding of the phenomenon itself (Larkin, Shaw and Flowers, 2019). McNally and Gray-Brunton (2021) argued that when exploring phenomena that are relational such as processes involving both a clinician and a patient, then the meaning or essence of the phenomena is often not in the subjective but in the intersubjectivity i.e., in the space between both perspectives. Eatough and Smith (2017) further acknowledge that contemporary IPA can and should engage with systems thinking when analysing experiences that are shaped by complex social structures. They argue that this does not compromise IPA's phenomenological commitment but rather enriches it by contextualising individual experiences within the systems that shape them.

An additional perspective can also add another layer of hermeneutic enquiry, adding another 'part' from which to understand the experience of the phenomenon as a 'whole' (Smith, Flowers and Larkin, 2009). Central to successful multiperspective IPA is the researcher's engagement with iterative reflexivity throughout the integration process (Engward and Goldspink, 2020). I believe this can be achieved through multiperspective analysis by revisiting individual datasets to gain a deeper understanding of their contribution to either divergent or convergent themes, whilst simultaneously holding an awareness of the researcher's own biases, and the wider context within which data was collected and analysed.

Multiperspective research provides additional opportunities to give voice to underrepresented or opposing viewpoints, further deepening the phenomenological insights gained and increasing rigour (Goldspink and Engward, 2019). This being a PhD research project meant iterative reflexivity was expanded even further by

the role of the supervisory team, which acted as an additional layer of interpretation and guard against bias.

This process is shown relative to the current study in Figure 19 below.

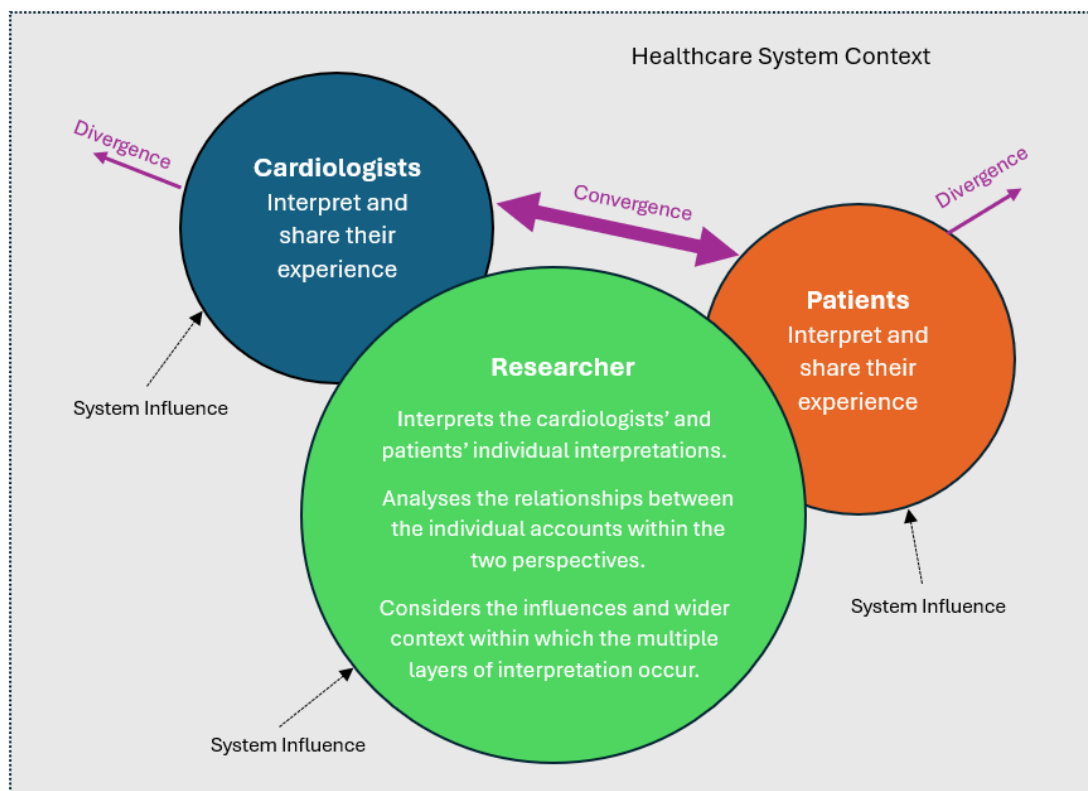


FIGURE 19. VISUAL REPRESENTATION OF DOUBLE HERMENEUTIC INTEGRATION.

9.3. Method of Integration

As detailed in chapter 4, each study was analysed individually following rigorous IPA procedures (Smith, Flowers and Larkin, 2009). Once super-ordinate themes had been established for each study, the process of comparative phenomenological analysis began. Comparisons were made between the findings of the two studies, and points of shared meaning (convergence) and contrasting interpretations (divergence) were highlighted. While relevant to both populations, specific viewpoints relating to these broader themes were not always aligned. Viewpoints between individual participants within the same dataset also occasionally differed, in which case the general consensus was used to determine overall convergence or divergence, and further nuance was discussed therein. Broadly speaking, four points of convergence and four points of

divergence were identified and included in the discussion below. This comparative process follows Larkin, Shaw and Flowers (2019) recommendations for IPA studies involving multiple perspectives, maintaining a commitment to both phenomenological detail and interpretative analysis.

9.4. Convergent and Divergent Themes: Summarising Integrated Findings

9.4.1. Convergent Theme: Systemic Constraints and Their Impact

Fragmented care pathways, inconsistent knowledge of CM, resource constraints, and unclear professional accountability were highlighted as significant systemic barriers to care during the CM diagnosis journey. These interrelated barriers were found to affect both patients and cardiologists in equal measure, undermining their high personal and professional expectations of health care. These systemic barriers contributed to a broader siloed working culture within the NHS that hinders efforts to improve and reform services. In the absence of coordinated support, patients are frequently left to navigate their own care, and charitable organisations are relied upon to fill gaps in service provision.

9.4.1.1 Fragmented Care Pathways

A lack of co-ordination between health services was a prominent concern, disrupting continuity of care and shifting the burden of service co-ordination onto patients. Many patients described feeling disempowered, abandoned, and unsupported during their CM diagnosis journey, at a time when clarity and consistency were expected, and needed most from health services. The level of fragmentation reflects broader systemic barriers within the NHS, suggesting that an overreliance on patients to make sense of disconnected pathways without sufficient guidance may be an issue that extends beyond cardiomyopathy care. A study from Healthwatch England (2023) found frustration was universally experienced by patients who were left to self-navigate health services following primary care referrals to secondary care services, with some patients forgoing follow-up care completely as a result. Checkland *et al.* (2020) also explored the use of the metaphor 'care pathway' within NHS policy, finding it to set up expectations of fluidity from a predetermined track from service A to service B - an ease of movement

between services which did not accurately reflect the reality of care offered within the NHS, leading to patient dissatisfaction.

From a clinical perspective, cardiologists noted that fragmented referral and follow-up procedures impeded continuity of care, particularly when transitioning care from tertiary centres back to primary care for ongoing CM management. The absence of robust follow-up protocols immediately following diagnosis led to inconsistencies in care provision, with some patients receiving proactive monitoring while others were left without any clear plan following diagnosis. Such inconsistencies were also found across different tertiary cardiac centres, with follow-up appointments being offered at different time intervals depending on the capacity of individual services. The highlighted inconsistencies reflected a broader service-level issue rather than individual service failures. Recent structural reforms in the management of chronic health conditions within the NHS, such as the proposal to shift acute health care to specialist hubs in order to reduce GP burden (Parr, 2024), risk compounding this fragmentation. Although such hubs may offer efficient acute care pathways, they potentially introduce yet another service layer for patients to navigate, particularly affecting those with multiple comorbidities (requiring input from multiple services) or those with lower health literacy that must navigate new changes to service provision (Chan, Wright and Majeed, 2024). These developments signal a move away from holistic primary care models, where GPs act as consistent single points of contact for all acute and long-term care being managed in the community, towards an increasingly compartmentalised system that values efficiency over holistic care. Such revisions would therefore contribute to the silo working culture already at play within NHS services. This could also present challenges for patients with chronic illnesses who experience acute episodes as part of their broader condition, and risks delaying diagnosis as early signs of chronic illness could go undetected. These changes demonstrate how systemic issues in care co-ordination extend beyond cardiomyopathy care, reinforcing the CM-specific constraints identified in this study. It further reveals the complexity of reforming systemic problems and how the wider impact of any systemic changes to health care structures must be properly considered.

9.4.1.2 Lack of Knowledge

A consistent theme across participant accounts was the variability in CM-related knowledge across healthcare settings, which contributed to diagnostic delay, service inefficiency, and increased uncertainty for patients. While cardiologists in tertiary centres were generally perceived to possess specialist expertise in CM, non-specialist settings, particularly primary care services, were rarely considered to have adequate knowledge of CM, the appropriate diagnostic pathways, or of relevant resources and local support services available to CM patients. Several patients reported being initially misdiagnosed or placed on generic heart failure pathways, which, while well-established, often failed to capture the distinct pathophysiology and diagnostic indicators of CM subtypes (Elliott *et al.*, 2014). Findings suggest that without improved channels for sharing knowledge and research dissemination across health services, initial indicators of CM will continue to be missed in non-specialist services. As highlighted by a participant in this study, *“We don’t know about all the diagnoses that we don’t know about, you know” (Dr Nichols, 377-379).*

Although some participants described a complete absence of awareness of CM, more commonly the issues pointed to a lack of confidence or clarity surrounding when and how to suspect CM in the absence of overt red flags. Primary care physicians were identified as key players in the CM diagnosis journey but were also seen to be least knowledgeable about CM indicators, lacking access to, or familiarity with, CM-specific diagnostic guidelines and referral pathways. These knowledge gaps often resulted in delayed referrals to cardiology, misattribution of symptoms to anxiety or lifestyle factors, or inappropriate investigations that led to patient frustration and prolonged uncertainty (Kwok *et al.*, 2022; Wong *et al.*, 2021). Similar experiences of symptom misattribution, diagnostic delay, and ongoing uncertainty have also been reported across other chronic illness populations (Sloan *et al.*, 2025). Participants suggested that additional decision-support systems may help improve early recognition of CM within primary care settings. Further research is needed however to determine its feasibility for use across the NHS, the cost of such a roll out, and to understand whether GPs value its use in their practice.

Even where specialist cardiologists held substantial expertise, their ability to influence diagnostic behaviours beyond secondary or tertiary care settings was constrained by systemic barriers: Time pressures, siloed working practices, and fragmented communication channels limited opportunities for cross-disciplinary knowledge-sharing. These findings collectively highlight the broader challenge of ensuring that conditions with more complex presentations such as CM are recognised early and escalated appropriately within overstretched health services. Without system-level strategies to disseminate specialist knowledge through shared guidelines, decision support tools, technology, or structured referral protocols, patients with CM are likely to remain at risk of delayed or inaccurate diagnoses.

9.4.1.3 Resource Limitations

Resource limitations within the NHS were identified as a significant barrier to the delivery of timely, high-quality cardiomyopathy care. Prolonged waits for specialist consultations and delays in accessing diagnostic tests such as echocardiograms and MRIs were commonly experienced, often resulting in heightened uncertainty and emotional distress for patients and frustration for cardiologists. These delays were widely interpreted as avoidable, stemming from systemic under-resourcing across health services, but particularly in secondary and primary care settings. Tertiary care settings such as specialist heart hospitals were perceived to be more appropriately resourced, however the potential for bias should be noted here as all participating cardiologists were employed by tertiary care services at the time of interview.

The impact of resource constraints was not limited to initial diagnosis: staffing shortages, financial pressures, and inconsistent access to advanced diagnostic tools across healthcare settings were found to impede both the speed and accuracy of diagnostic processes and the ongoing management of CM post-diagnosis. A particularly concerning consequence was the perceived variability in service provision across geographical regions, and how widely accepted this was. Furthermore, tertiary cardiac centres being located only within major cities meant that systemic inequality in resource distribution affected

patients and clinicians in more rural areas more so than those in highly populated areas. This reinforced the so-called ‘postcode lottery’ effect, whereby the quality of care could be significantly influenced by a patient’s location within England (House of Commons Public Accounts Committee, 2023; Thomas, Quilter-Pinner and Verma, 2020).

The widespread recognition of resource scarcity within the NHS appeared to influence perceptions of how services or conditions were valued and prioritised differently by NHS England. Specialist services were viewed to have preferential investment over less well-resourced services, adding to the more favourable view of tertiary care services. Comparisons drawn between cardiac care and other specialist services, such as cancer care, highlighted consistent disparities in resource allocations, with cancer services perceived to benefit from greater funding and support compared to CM services. Such contrasts led some to conclude that greater societal and institutional value was placed on cancer patients than on those living with cardiomyopathy. Limited access to resources, follow-up appointments and specialist support contributed to a sense of inequity in care, further compounding the emotional toll of the CM diagnosis process.

9.4.1.4 Diffusion of Responsibility

A key finding was the diffusion of responsibility across different levels of healthcare, which contributed to fragmentation of care pathways. The absence of clear accountability led to confusion regarding who was responsible for overseeing and coordinating care particularly when moving between services, resulting in delays, missed communications, and a reliance on individuals to navigate the system themselves. In practice, this often meant that processes for referrals, communicating test results, and frequency of follow-up appointments were inconsistent, with little continuity across services.

This fragmentation was seen to both contribute to (and be reinforced by) a wider culture of silo working, where care responsibilities are shifted between primary, secondary, and tertiary settings without clear transitions or ownership. Structural barriers such as unclear referral pathways and inconsistent inter-service communication further hindered continuity care coordination. The lack of integration between

services not only disrupted patient experiences, contributing to uncertainty, but also undermined efforts to deliver ideal standards of care.

The culture of silo working within NHS services was found to be perpetuated by systemic pressures to compete for resources. Echoing wider research, models for funding were seen to be strictly data-driven and reliant on performance metrics which only exacerbated these challenges (Olney, 2021). Incentive structures within the NHS were seen to reinforce service-level priorities, encouraging competition between silos rather than collaboration across services. As a result, services often focus on meeting internal targets rather than working collectively across organisational boundaries to optimise care quality and improve patient outcomes (Pedersen, Sudzina and Rosati, 2024). This echoes similar systemic issues of silo working found in the management of government policy (Scott and Gong, 2021) and in the expansion of research and innovation (Gidlow *et al.*, 2024), pointing to a wider societal or cultural influence that may be too deeply engrained to change.

9.4.1.5 Role of Charitable Organisations in Filling NHS Gaps

Charitable organisations were recognised as playing a significant role in the CM diagnosis journey and were seen to plug vital gaps in service left by the NHS. Participants valued charitable organisations for providing peer support, educational resources and emotional guidance for patients during and post-diagnosis. These supplementary services were perceived to be essential to ensuring high quality patient care that NHS services were unable or unwilling to prioritise. Some cardiologists suggested that more formal integration of charitable resources into diagnostic and treatment pathways could enhance patient education and reduce misinformation, particularly in cases where consultation time was limited. Cardiologists did not however, offer any practical methods of integration nor did they discuss the financial and ethical implications of doing so. Further research is needed to explore the feasibility and effectiveness of such integration.

9.4.1.6 Implications for Diagnosis and Ongoing CM Management

Findings highlighted the significant implications that systemic constraints had on the diagnosis and long-term management of CM. Bureaucratic barriers and rationing of NHS resources led to significant difficulties in accessing and being able to provide consistent, effective and timely care. Patients reported feeling uncertain and unsupported due to inconsistent follow-up care and unclear care pathways. Cardiologists felt forced compromise the standard of care they provide and expressed concern that systemic limitations led to suboptimal patient outcomes.

Since the date of data collection, NHS England has introduced integrated care boards (ICBs) to address these agreed systemic constraints (Lalani *et al.*, 2025). The integrated care boards act to meet the needs of patients on a local level, integrating services from the voluntary sector, local council services and healthcare services to improve care quality and gained legal and statutory powers in England from July 2022 (Naylor *et al.*, 2024). Albeit a positive step in addressing some of the systemic barriers to care identified in this study, the fairest way to allocate funds to each ICB continues to be debated (Jones, 2024). Whilst many health cost calculations use population age as an over-arching predictor of estimated healthcare needs (Gongora Salazar, 2024), other prediction models suggest that the population that requires most healthcare funding are those who are considered 'near to death' (NTD), meaning they are within the last 12 months of life, regardless of their age (Moore, Bennett and Normand, 2017). Jones (2024) observed that without accurate formulas for predicting each populations' care needs, ICBs will end up taking on the responsibility for managing the care of the local population but will continue to do so without the funds needed to enact any meaningful change. Furthermore, it could be argued that given the economical and political pressures health systems are continuing to face, ICBs are being tasked with increasing responsibilities and pressures to perform well in order to obtain resources which perpetuates the silo working culture that formed part of the barriers to care in the first place. There is growing concern that ICBs may not live up to their full potential because the underlying silo working culture has not changed (Naylor *et al.*, 2024). Naylor *et al.* (2024) suggested that ICBs need to "*think, plan and act in 'system-focused' ways*" (Naylor *et al.*, 2024, p. 4) in order to be successful. The role of ICBs

continues to develop and further research will be needed to ensure their continued success (Lalani *et al.*, 2025).

The highlighted systemic constraints found in this study underscores the urgent need for healthcare reforms that address fragmented care pathways, resource limitations, and the diffusion of responsibility within the NHS. The shared recognition of these barriers underscores the necessity for ICBs to be developed further to ensure inter-service communication, resource allocation, and the integration and role of charitable organisations in supporting patient care. Addressing these systemic issues would not only improve patient experiences but also alleviate some of the pressures faced by clinicians, enabling them to deliver more effective and compassionate care on a local level, irrespective of wider national pressures.

9.4.2. Divergent Theme: Perceptions of Uncertainty

A key finding was the contrasting ways in which uncertainty was experienced and managed during the CM diagnosis journey. Findings suggested that uncertainty is a recognised part of clinical decision-making, particularly in complex conditions like CM, and affects both patients and cardiologists alike. However, its manifestation and impact differed depending on the participant's position or role within the diagnosis journey. For clinicians, uncertainty was largely conceptualised as an unavoidable part of their job and viewed as a challenge to be managed through professional judgement, clinical guidance, and professional experience. For those receiving care, however, diagnostic uncertainty was experienced more existentially, contributing to deep questions about their self-worth, their future and their previously engrained beliefs about the world. For patients, diagnostic uncertainty was reported to be an emotionally distressing experience compounded by systemic and interpersonal barriers such as inconsistent information, communication difficulties, and a lack of continuity in care.

Clinical efforts to adhere to official guidelines such as those from the European Society of Cardiology (ESC) (McDonagh *et al.*, 2023; Arbelo *et al.*, 2023) and the National Institute for Health and Care Excellence (2025), were often challenged by real-world constraints, as previously discussed. While these

frameworks provide a structured diagnostic pathway, cardiologists described the difficulties faced when implementing them in full due to limited resources, time pressures, and inconsistencies in care infrastructure. Additionally, existing protocols were perceived to lack the nuance required to account for the variable presentations of CM. For example, reliance on Brain Natriuretic Peptide (BNP) testing, while standard in heart failure diagnostics, was seen as less clinically useful for CM-specific cases (Doherty, Doherty and Gardner, 2024). As a result, cardiologists navigated clinical uncertainty by relying on their individual expertise and knowledge, assessing each case individually, rather than strict adherence to guideline-driven pathways. This flexible, individualised approach was viewed by cardiologists to be a more person-centred way of navigating diagnostic uncertainty, particularly when communicating any level of clinical uncertainty with patients. Balancing transparency about medical unknowns with the need to maintain patient's confidence and trust in them, was described as a challenging yet essential part of the consultation process. While some cardiologists believed that acknowledging uncertainty encouraged rapport, openness and trust, others felt that projecting confidence and focusing on what was known, was important and led to a decrease in anxiety for patients. These varied approaches and communication styles were well-intentioned, but the lack of a consistent approach across services sometimes introduced confusion for patients who may be seen by multiple clinicians, all taking slightly different approaches to managing clinical uncertainty throughout the diagnosis journey.

From the patient perspective, uncertainty was experienced as deeply personal and often led to psychological distress. The diagnosis of CM often disrupted their sense of identity and self-confidence, particularly when it came with unclear or non-standardised follow-up care. Uncertainty, in all of its forms, often prompted patients to take on investigative roles in search for clarity and a sense of control in an otherwise uncontrollable and uncertain reality. Patients described closely monitoring verbal and non-verbal cues from clinicians, researching their symptoms online, and deriving meaning from even simple administrative details such as the urgency of appointments. While these behaviours attempted to restore a sense of control, they sometimes led to misinterpretation and further anxiety. Sometimes, they felt so uncomfortable with diagnostic uncertainty that they interpreted clinicians to deliberately be withholding

information about their diagnosis, which often needlessly created mistrust within the patient-clinician relationship.

A key theme in patient narratives was a profound sense of abandonment following diagnosis. Many described feeling unsupported after receiving their initial diagnosis, with limited guidance on next steps. Delays in follow-up care, unclear communication, and inconsistencies in medical advice reinforced this perception of systemic neglect. Patients reported struggling to find a point of contact for their ongoing care and expressed frustration over being passed between different services without clear direction. These experiences contributed to feelings of confusion and emotional distress, highlighting a gap in pre- and post-diagnostic support. Beyond the logistic challenges of medical uncertainty, patients described the impact on their identity and psychological wellbeing. Many struggled with the transition from being 'healthy' to living with a chronic condition, particularly given the invisible nature of CM. Some reported feelings of disbelief, grief, and existential questioning about their future. Others internalised uncertainty as a reflection of their worthiness of care, expressing concerns that their symptoms were not taken seriously or that they did not 'deserve' the same level of attention as patients with more visible or well-known illnesses. This psychological burden was further compounded by societal messaging about being a 'burden' on NHS resources, leading some to hesitate in advocating for their own care needs and preferences.

These findings highlight a fundamental disconnect between how uncertainty is experienced and managed by cardiologists and patients. What cardiologists view as adaptive flexibility and reassurance may, in practice, be perceived as inconsistency or abandonment by patients. Without a more standardised approach to post-diagnostic communication and follow-up support, well-meaning attempts to humanise care may inadvertently heighten patient distress. Bridging this divide requires more transparent communication, structured post-diagnostic support, and a greater emphasis on validating patient concerns and the impact of existential uncertainty, while acknowledging the practical complexities of medical uncertainty.

The complexity of managing uncertainty in clinical settings has gained increasing recognition in the field of health research. Historically, healthcare professionals have tended to avoid discussions about medical uncertainty, viewing it as a marker of ignorance, failure, or professional inadequacy (Simpkin and Schwartzstein, 2016). However, more recent work has emphasised the critical role of communication in navigating uncertainty in ways that preserve trust within the clinician–patient relationship (Santhosh, Chou and Connor, 2019). Simpkin and Armstrong (2019) highlight the various strategies used to communicate uncertainty in clinical practice, outlining the strengths and limitations of each approach. Their findings lend support to the non-standardised communication practices reported in this study, where clinicians adapted their approach according to context and personal judgement. Santhosh, Chou and Connor (2019) propose a structured four-step framework for communicating uncertainty during diagnostic consultations. This included (1) openly acknowledging the uncertainty, (2) inviting patients to share how this uncertainty affects them personally, (3) responding with empathy, and (4) clearly outlining next steps, including a rationale for these steps and a clearly determined timeframe or follow-up date. This approach reflects a psychologically informed model of care, as it recognises the emotional impact of uncertainty, provides space for patient expression, and promotes empathetic and validating clinician responses. Other similar frameworks have been developed such as the RAPS framework that seeks to (1) recognise uncertainty within the diagnostic process, (2) acknowledge the impact of uncertainty, (3) partner with the patient to encourage an alliance from which to make shared decisions, and (4) seek support such as peer support for both clinician and patient (Patel *et al.*, 2024). The RAPS approach works to protect patients from feeling adrift or abandoned within the health system and encourages cognitive restructuring of uncertainty to be approached as an opportunity for growth, learning and connection. However, neither framework explicitly references any involvement from psychologists, suggesting scope for further development involving psychological expertise. Additionally, putting these approaches into practice may be difficult due to the limited time available in routine appointments, especially within already overstretched healthcare systems.

Improving how diagnostic uncertainty is approached and communicated may therefore require revisions to the education and training of future healthcare professionals, ensuring they are equipped to deliver care that is more psychologically informed than current standards (Dekker *et al.*, 2023). However, such changes must also account for systemic barriers, including limited consultation times and inconsistent access to follow-up care. Additionally, patient experiences of existential uncertainty during the diagnostic process could be more effectively supported through timely referral to clinical or health psychologists. These professionals may assist directly by helping patients develop strategies to tolerate uncertainty, or indirectly by supporting clinicians through shared psychological formulations. Yet despite growing recognition of the need (Durcan, 2020; Ronaldson *et al.*, 2025), financial and structural constraints within the NHS continue to limit the integration of psychologists into physical healthcare services.

9.4.3. Convergent Theme: Psychological Dimensions of Care

9.4.3.1 Shared Recognition of Emotional Impact

The profound psychological consequences of a CM diagnosis were mutually recognised and should be acknowledged as one of the clearest points of convergence between patient and cardiologist accounts. Both groups reflected on the emotional challenges and identity shifts that often accompany the diagnostic journey, as patients are forced to come to terms with uncertainty, changing roles, physical limitations, and the long-term reality of living with a chronic cardiac condition. Despite occupying different positions within this process, both perspectives emphasised the need for greater access to psychological support, not only for patients themselves, but also through closer collaboration with clinical psychologists or designated psychology services to help inform and enhance care provision within cardiology settings.

The intensity of the emotional journey that followed diagnosis was clearly evident in both accounts. Shock, denial, and grief were commonly described as initial responses, followed by more fluctuating states of anxiety, low mood, anger, and efforts to adapt. This was found to be a non-linear process of psychological adjustment that was often invisible to others but deeply felt by those going through it and

aligned with other models of processing a loss (Kübler-Ross and Kessler, 1969; Pratt, 2018). Many patients struggled with the transition from seeing themselves as 'healthy' to living under the label of a cardiac patient, identifying a loss of former identity. Some expressed existential concerns around prognosis or future symptom management. Others reflected on their self-worth, often comparing themselves to others, describing a sense of becoming 'less than' they once were, or feeling like a burden to their families, and to the NHS.

Cardiologists, too, spoke of the emotional toll, particularly in younger patients, those requiring device therapy, or individuals with little prior experience of illness. Several raised concerns about the link between psychological wellbeing and cardiac health, aligning with the growing field of behavioural cardiology (Astin, Lucock and Jennings, 2019). This body of research shows that emotional distress can directly influence symptom severity, adherence to treatment, and long-term physical health outcomes (Jilani *et al.*, 2021; Thompson and Pedersen, 2023). While there was broad recognition of the need for psychological care, many cardiologists admitted feeling ill-equipped to address these issues themselves, citing a lack of formal training in mental health, and limited access to psychological support services within their teams.

9.4.3.2 Barriers to Addressing Psychological Needs

Despite a shared understanding of the emotional toll associated with a CM diagnosis, there was a clear sense of frustration across both patient and clinician accounts when reflecting on how psychological needs are currently addressed. Many patients spoke of being left to manage the emotional impact alone, often without any clear guidance or follow-up after diagnosis. Some turned to online communities or charitable organisations to fill this gap, while others quietly withdrew, feeling their emotional wellbeing had been overlooked. Participants described feeling unsure of where to turn or found themselves repeatedly passed between services without ever receiving meaningful support.

Cardiologists acknowledged the limits of their role in responding to emotional distress and highlighted a lack of training, limited consultation time, and an absence of integrated psychological pathways as key

barriers to providing more holistic care. Some admitted they simply didn't know where to refer patients for psychological support or felt constrained by the rigid boundaries of their clinical knowledge and role, demonstrating they too, felt left alone to manage their patients' emotional distress.

These challenges were underpinned by wider systemic issues. As previously noted, fewer than 24% of UK cardiac rehabilitation services have access to a dedicated psychologist (Doherty and Harrison, 2018), and even where services did exist, they were often stretched beyond capacity. Both groups pointed to the disconnect between what patients needed and what was realistically available. Those referred into general mental health services often felt misunderstood or out of place, while others received no support at all. This mismatch between psychological need and service provision continued to reinforce the sense that emotional wellbeing, although widely recognised as important (National Institute for Health and Care Excellence, 2025), remained an after-thought, peripheral or secondary in practice.

9.4.3.3 Call for Integrated Psychological Support

Across both patient and clinician accounts, there was a shared and consistent message: psychological support should no longer be treated as an optional add-on to cardiac care. Instead, it should be embedded as a core component of the diagnostic and treatment pathway. Cardiologists advocated for routine psychological screening to sit alongside standard physical health checks, such as blood pressure or heart rate monitoring. They also suggested revisions should be made to clinical training to ensure all health professionals are trained in basic psychological principles, bringing awareness to the emotional impact of the care they provide and facilitating more emotionally attuned care as standard during every consultation or clinical interaction.

These proposals closely align with recent research calling for better integration of psychological expertise into cardiac services (Gaffey *et al.*, 2022). Gaffey *et al.* (2022) advocated for a tiered model of care, where all healthcare staff are equipped with foundational skills, but with psychologists embedded within multidisciplinary teams to support more complex cases, service development, and staff training.

Further research should look at the feasibility and effectiveness of integrating psychologically informed care in this way, amongst cardiomyopathy care services.

Patients also emphasised the value of emotional support from the earliest stages of diagnosis. For many, it was not that intensive therapy was needed, but that consistent, compassionate engagement with cardiologists and other healthcare professionals was lacking. They valued having a space to talk about how their diagnosis was affecting them emotionally, and the reassurance that appropriate psychological care was accessible if needed. The lack of such support left many feeling isolated or overlooked, adding to the emotional weight of their condition. These findings lend support to other research calling for more structured frameworks for providing psychologically informed care, as previously mentioned (Durcan, 2020; Dekker *et al.*, 2023).

Both perspectives demonstrated a clear consensus that psychological wellbeing is not a peripheral part of cardiac care but is central to the CM diagnosis experience. The fact that patients and cardiologists independently reached this same conclusion reinforces the importance and urgency of the need for change. These findings move beyond what is already known about cardiac patients' psychological needs, offering a more nuanced insight into the specific psychological needs of both key players within the CM diagnostic journey. They highlight critical moments where CM patients may be most in need of support, identify patient groups most likely to be affected emotionally, and reveal a clear willingness (eagerness even) among cardiologists to see more psychological support being offered to those in their care. As Gaffey *et al.* (2022) argue, meaningful integration of psychological care into cardiac pathways is both clinically necessary and long overdue.

9.4.4. Divergent Theme: Power Dynamics

An inherent imbalance of power between cardiologists and patients was highlighted throughout this study. Whilst both perspectives acknowledged the existence of the imbalance, particularly within cardiologist–patient communication, they each appeared to lack insight into the other's perspective and lived experience. Increasing patient autonomy and patients' overall involvement in their care was a goal shared

by both cardiologists and patients, however, the strategies described by cardiologists to support this often had the opposite effect, leaving patients inadvertently feeling less empowered. Within the constraints of time-limited consultations, policy-driven protocols, and rigid healthcare hierarchies, even well-intentioned attempts to promote collaboration risked reinforcing the message that clinicians held the power and could decide whether to share it.

Clinicians recognised that NHS hierarchies shaped how policy decisions were made and that a similar hierarchical structure were at play within their consultations with patients. While many expressed a commitment to patient-centred care, they also acknowledged that their perceived expertise, particularly in tertiary settings, tended to be prioritised over patients' voices. Cardiologists described a complex dynamic in which they felt expected to lead decisions, especially when patients appeared overwhelmed by information or the stakes felt particularly high. The result was often a skewed interaction, even when intending to be more collaborative.

9.4.4.1 Cardiologist Hierarchy

Cardiologists described the methods used to increase transparency within consultations, using strategies like the 'teach-back' method (Denysyuk, Pires and Garcia, 2024), or dictating clinical notes in front of patients. However, these attempts still positioned them as gatekeepers of knowledge. They also acknowledged at times, choosing not to share certain prognostic possibilities or risk information with patients, even though patients in this study reported wanting more openness and clarity. This pointed to a clear disconnect between what patients hoped for and what clinicians believed they needed. On the other hand, when cardiologists did try to be open and acknowledge the uncertainty surrounding prognosis and risk, some patients interpreted this as the clinician being vague, avoiding the question, or simply trying to ease their concerns without giving a clear answer. This highlighted the difficult position cardiologists faced when deciding how best to communicate with patients that patients struggled to fully appreciate. Patients sometimes placed unrealistic expectations on cardiologists as they were perceived

to be the 'experts' in the room, reinforcing the power dynamic some were simultaneously fighting against.

The idea of shared decision-making was consistently supported in principle, but its feasibility was questioned. Differences in clinical knowledge, emotional impact, and legal and personal responsibility made it difficult to truly level the playing field. Even when genuine efforts were made to manage patient's involvement in consultations, the cumulative effect of systemic constraints and clinical hierarchies meant that the power still largely rested with the cardiologist. This pointed to a shared acknowledgment of an implicit hierarchy that was mostly accepted by both parties. Patient narratives suggest an appreciation of the clinician's expertise but called for their own expertise and unique knowledgebase to be valued within shared decision-making too, even if only some of the time. Patients felt their insights into their own lived experience, values-system, and personal expectations of health should be explicitly sought in order to guide care. If consultations were a dance, patients aspired to a dance where both partners would lead at different points, seamlessly knowing each other's strengths, each taking turns to share their relative expertise (clinical knowledge and individual lived experience) depending on the focus of the consultation. Findings suggested that currently, the consultation dance was led almost entirely by cardiologists, with patients sometimes struggling to keep up. Occasional, well-meaning attempts by clinicians to allow patients to lead often resulted in clumsy steps and moments where both partners fall completely out of sync. This finding is supported by other literature that discuss the importance of active listening during consultations (Epstein and Beach, 2023), define the role of respect in health contexts (Entwistle, Cribb and Mitchell, 2024) and explore how best to demonstrate respect during consultations (Bridges *et al.*, 2021). Ultimately, the wider field of research are aligned with the findings from this study - that patients want their role to be that of a respected partner with their unique contributions acknowledged, rather than being a passive follower to be entirely led.

9.4.4.2 Patient Experiences of Disempowerment

Many patients reported feeling like passive recipients of care, particularly during inpatient or emergency hospital stays or when faced with quick diagnostic decisions. The sense of being ‘processed’ in a system was commonly described, with emotive analogies such as a ‘sausage factory’ or being treated like a ‘crash test dummy’ was used to capture how depersonalising these experiences felt. Patient’s emotional needs were often set aside in favour of increasing efficiency, leading to patients’ feelings of invisibility. The perception of mechanical or robotic care (described as “Dr Robot” by some) demonstrated how easily the prioritisation of systemic pressures can come at the cost of human connection. Patients didn’t doubt the clinical competence of their care teams, but many felt emotionally disconnected from the healthcare staff, from their new diagnosis, and from their own body at times. Some went further, describing feeling trapped and held against their will - within their body, in the hospital or in the wider diagnostic experience affecting their sense of identity and their emotional adjustment. This experience was not one that cardiologists shared an appreciation for and was noticeably not discussed in any detail in their accounts, particularly in relation to inpatient experiences of CM diagnosis. Ashdown and Jones (2024), documented one of the author’s own experiences as a health professional turned patient through autoethnography. She documented how her personal experience of being a patient had evolved her understanding, seeing for the first time how small, subtle changes in practice had the ability to shape patients’ healthcare experiences from being frightening and disempowering, to feeling cared for and truly understood. This reinforces the call for more formalised communication training found in the current study but mostly highlights the need for patient experience to be considered in a meaningful way. We cannot educate clinicians by simulating the first-hand lived experience as was captured by Ashdown and Jones (2024) or the patients in this study described, but we can consider the expertise and insights that can be gained from patient’s first-hand experience. This showcases the importance of research focusing on lived experience as insights gained from individual accounts may not be generalisable but can be used to inform future care provision in a meaningful way, as was the case for the author of Ashdown and

Jones (2024) who described her clinical practice as forever changed following her experience as a patient.

9.4.4.3 Towards a More Equitable Model of Care

This theme was difficult to categorise but was ultimately found to be divergent as patients and cardiologists were fundamentally on different pages when it came to efforts to overcome power imbalance within the CM diagnosis process, and the impact of these efforts. What this theme ultimately exposes are the disconnect between system ideals and patient realities. Despite policies promoting patient-centred care (Abou-Saleh, 2023), many of the everyday practices described here suggest a model that still privileges medical authority and expediency over true person-centred care. Even clinicians themselves described aspects of their role as a ‘performance’, signalling how these constraints impact clinical professionals as well as patients.

Although improved communication skills may be beneficial, addressing the power imbalance in a meaningful way requires systemic reform to remove barriers to understanding each other’s perspectives and aligning expectations. This includes greater investment in training and time allocated for developing psychologically informed models of care. Key steps towards more equitable not just patient-centred, but human-centred care would be to allow more space and time during diagnosis for inclusive decision-making, acknowledging the emotional and existential weight of diagnosis and in-patient treatment, and embedding psychological support as routine in practice.

9.4.5. Convergent Theme: Barriers to Communication and Understanding

9.4.5.1 Perceptions of Clinical Language

Current clinical terminology associated with CM, such as ‘cardiomyopathy’ and ‘heart failure’, were seen to be overly complex and open to misinterpretation, unnecessarily contributing to patient distress during diagnosis. This adds to the growing number of studies highlighting the negative effects of unclear medical language and jargon on patient empowerment, health service satisfaction, autonomy, and psychological wellbeing (Marsh, 2019; Wahrenbrock *et al.*, 2025). It also supports findings that overly complex medical

language may be associated with increased health anxiety, particularly in patients from lower socio-economic backgrounds (Barbek, Makowski and von dem Knesebeck, 2022), those with lower health literacy (Fang and Mushtaque, 2024), and those living with complex invisible illnesses that are not easily explained, such as a cardiac or neurological condition (Tyrer, 2020).

There was shared concern that the term ‘heart failure’ was misleading and caused unnecessary distress. Rather than reflecting a spectrum of severity, the term ‘failure’ was often interpreted to mean a complete and imminent organ failure. Marsh (2019) similarly found that the use of emotive language such as the term ‘failure’ within a maternity context, negatively affected women’s pain tolerance and psychological wellbeing. Maternity care has led by example and routinely replaces emotive clinical language such as ‘contractions’ with more positively associated language like ‘surges’ or ‘waves’ due to the documented psychological and physiological benefits (Cutajar *et al.*, 2020). Some attempts have been made to refine or replace such terminology in cardiac care, replacing ‘heart failure’ with terms like ‘heart insufficiency’, but this has not been fully adopted, with cardiologists in this study suggesting that the original clinical terms are already too entrenched in clinical structure and policy now. Similarly, the term ‘chronic’ was perceived by some patients to be distressing, as they interpreted it as an indicator of severity, rather than duration, of illness, which further impacted their emotional response and understanding of their CM diagnosis.

While clinicians noted the alienating potential of medical jargon, patients described feeling overwhelmed by unfamiliar terms and pressured to keep up with explanations delivered in time-limited consultations. This shared recognition points to a need for essential clinical information to be delivered in a way that is accurate, accessible and accommodating of patients’ individual needs. As discussed in chapter 6.3, health systems must move beyond a tokenistic involvement of ‘expert patients’ or ‘constrained compliance’ (Vinson, 2016) and engage with meaningful co-production of health information resources that meet the specific needs of different patient groups (Chen, Croft and Currie, 2025).

9.4.5.2 Barriers to Information Provision

Systemic barriers were seen to reduce the time allowed to communicate/receive a diagnosis of CM, limiting not just the time patients spent in direct consultation with their cardiologists, but also reducing the number of opportunities for them to ask questions, learn about CM then process and adjust prior to planning treatment. Cardiologists expressed their frustration at not having enough time or opportunities to address individual patient concerns more fully and acknowledged that patients are at times left to make decisions about a diagnosis they are not entirely informed about. The findings suggest that complex conditions such as CM, require a series of opportunities for patients to meet with health professionals, if not the same cardiologist, to discuss and understand their diagnosis prior to consenting to any treatment. This may be impossible under certain circumstances, however. Cardiologists highlighted the role that MDT working played within the diagnosis journey, suggesting that, at least in tertiary cardiac centres, patients are put in contact with a heart failure nurse who may have more time to spend addressing concerns. However, it was clear that even in the small proportion of patients that have access to such provision, more could be done to educate patients.

Patients similarly found information provision during diagnosis to be insufficient. Several individuals reported receiving no written material or structured explanation about CM at the point of diagnosis, leaving them to search for answers independently. While some turned to reputable sources, others found misinformation online, which occasionally led to heightened anxiety and confusion. With the modern ability for anyone to post 'health information' on social media and publish via other online sources, the public's ability to critically evaluate information shared online, particularly their ability to discern rumour from truth is a growing concern (Oh and Lee, 2019). After all, anyone may be susceptible to misinformation if they are not aware of their own susceptibility and do not regularly engage in reflection about the online content they consume (Salovich and Rapp, 2021). Older people (Vivion *et al.*, 2025), those who speak English as an additional language (Mansour *et al.*, 2024), and those with lower health literacy skills (Fang and Mushtaque, 2024) have been found to be particularly vulnerable to believing misinformation from online sources. Misinformation not only leaves patients ill-informed, but

can contribute to lower compliance to medical recommendations, poorer engagement with health professionals and increase the risk of engaging in behaviours that adversely affects their health (Smith *et al.*, 2020; Vally, 2021). CM affects populations of all ages, races, and socio-economic backgrounds meaning more should be done to develop accessible and accurate information for newly diagnosed CM patients, particularly where access to health professionals is limited. On the other hand, a meta-analysis found that patients engaging with their own online research felt better able to contribute to shared decision-making, had improved communication skills and reported an improved relationship with their health care team (Tan and Goonawardene, 2017). A growing number of researchers are calling for a collaborative approach whereby physicians guide patients to reputable sources of information, if not able to provide information resources directly (Swire-Thompson and Lazer, 2020). Instead of feeling threatened by patients doing their own research, cardiologists in this study suggested they would like to empower their patients to learn as much as possible about CM in order to aid shared decision-making and achieving true informed consent, with some suggesting more formalised integration with charitable services who provide reputable information such as, '*CardiomyopathyUK*'.

Such formalised charitable integration has been seen in other models of care, for example, cancer care services where 'MacMillan' have funded a significant number of specialist nurses to relieve systemic pressures within the NHS, in addition to peer support, counselling services and information resources to better meet the needs of cancer patients (Kerr, Donovan and McSorley, 2021). A common comparison was made between the information and support offered in cardiomyopathy care versus cancer care services, with cancer services being perceived to offer more comprehensive education and emotional support following diagnosis. Some cardiologists and many patients called for a similar model of integrating third sector service provision into the diagnosis pathway in order to alleviate systemic pressures and better meet the needs of cardiac patients. These suggestions reflect a shared belief that communication and education should extend beyond the initial diagnosis to become a continuous part of care. Future research should focus on the feasibility of formal integration of services, or perhaps even

improved signposting from clinicians to reputable third sector information resources and services relating to CM.

9.4.5.3 Implications for Practice

The convergence of perspectives on communication difficulties underlines a pressing need for systemic improvements in how information is conveyed during CM diagnosis. While clinicians are aware of the limitations posed by existing terminology and time constraints, patients continue to report confusion and distress when trying to understand and manage their condition.

Addressing these challenges will require more than minor adjustments. A multifaceted response is needed, involving clearer language, longer consultations where possible, and the integration of educational tools and psychosocial support into standard care. Improving how information is shared has the potential to reduce uncertainty and increase engagement and may also support more confident decision-making. These reforms would ultimately help both patients and clinicians to navigate CM diagnosis in a more collaborative and equitable way.

9.4.6. Divergent Theme: Identity and Role Conceptualisation

Intrapersonal challenges affected both patients and cardiologists throughout the CM diagnosis journey. Although they were experienced in different ways, both groups negotiated changes to their identity and role expectations. With a perceived burden of responsibility weighing more on cardiologists, while an evolving self-concept weighed more heavily on patients. Interestingly, neither party were overt in their acknowledgment of the other's struggle in this way, suggesting a subconscious emotional processing that is not usually recognised or articulated.

9.4.6.1 The Role of a Cardiologist: Expectation Versus Reality

Cardiologists endured a disconnect between the kind of care they aspired to offer, and the realities dictated by an overstretched NHS. Limited consultation time, understaffing, and resource constraints often undermined their attempts to provide ideal care standards, contributing to a gradual erosion of their clinical identity, and leading them to question the effectiveness of the care they provide. Direct

contact with patients was observed to be less about holistic, patient-centred care and more about efficiently meeting urgent clinical needs and stratifying risk. The emotional labour required to reconcile these conflicting pressures was profound. Maintaining a compassionate stance while simultaneously shielding themselves from burnout required constant psychological negotiation. This finding mirrors growing research into the high rates of burnout amongst NHS staff linked to systemic pressures, particularly since the Covid-19 pandemic (Crossland *et al.*, 2021).

Emotional distancing and focusing on factors they could achieve (such as the efficiency of their own clinic) was posed as possible strategies for coping. However, with it came guilt, particularly when patients misinterpreted this as disinterest or they felt unable to meet the individual needs of their patients. This moral tension contributed to moral injury, which is being increasingly recognised within healthcare research and describes the emotional toll clinicians feel when they are unable to provide their ideal standard of care due to systemic constraints (Xue *et al.*, 2022). This finding lends support to other research calling for strategic frameworks of support to be in place for those affected by moral injury and emotional labour, such as the need for regular staff debriefing, ethics committee involvement and dedicated psychological support for NHS staff (Reis and Lesandrini, 2025). Initiatives such as in-house psychology services for NHS staff (Appelbom *et al.*, 2021) and dedicated ‘wellbeing champions’ were set up in NHS trusts throughout the country in response to a growing number of NHS colleagues needing to access emotional support via their workplace following the Covid-19 pandemic. However, as of 2024, the ongoing funding for these services is not certain (British Psychological Society, 2025). Future research should highlight the psychological needs of NHS staff, assess the utilisation of the support services offered thus far, and tailor support for those who need it most. However, the psychological wellbeing of front-line clinical staff will continue to decline unless the systemic barriers inflicting moral distress are meaningfully reformed.

9.4.6.2 Evolving Patient Identity

For patients, CM diagnosis represented a deconstruction, and eventual reconstruction, of their identity over time. Their sense of self was forever changed by their diagnosis, leaving them to reconsider their values, priorities, fears and their ability to trust in their own body. The psychological adjustment was often non-linear, marked by fluctuating levels of denial, fear, loss, and, for some, eventual acceptance that mirror other models of processing loss (Kübler-Ross and Kessler, 1969; Pratt, 2018). A phase seemingly unique to CM was what was labelled as ‘testing’ – a phase whereby patients adjusted to their newfound construction of self and tentatively took steps to test the boundaries set by their illness, using trial and error to find a happy balance between their valued activities and the confines of their physical health. Many found themselves revisiting foundational beliefs about what it means to be healthy, capable, or in control entirely.

The evolving patient identity was especially present in younger patients or those with previously active lifestyles, who found it difficult to integrate a ‘chronic illness identity’ into their existing self-concept. The invisible nature of CM further compounded these challenges. Without visible signs of illness, patients frequently encountered disbelief or minimisation from others, leaving them not only physically constrained also socially and emotionally invalidated. This finding extends beyond CM and supports similar findings from populations with other invisible illnesses (Hamilton, Hulme and Harrison, 2023). Moreover, this lack of recognition reinforced a disconnect between how they felt internally and how others perceived them.

Language used to describe CM often revealed a fragmented relationship with the body. Patients spoke of CM as an ‘enemy’ or force acting against them. Patients sometimes considered CM to be something external, unpredictable, and uncontrollable during diagnosis. Patients such distancing language, as though their body was no longer belonging to them. For some, this split made it easier to cope day-to-day. For others, it bred mistrust in their own body’s signals and deepened feelings of alienation.

9.4.6.3 Parallel Struggles

Although both groups contended with significant identity-based challenges, these experiences unfolded in isolation from one another. A similar method of emotional distancing was used by both groups when recalling the profound distress associated with CM diagnosis. Neither cardiologists nor patients spoke explicitly about intentionally using emotional distancing as a coping strategy, but each were identified and interpreted through the analysis of their language-use during interview, suggesting a sub-conscious emotional experience that neither group may be aware of within themselves, let alone, considered within one another, limiting opportunities for mutual connection and empathy that could support the clinician-patient relationship.

The experiences of patients and cardiologists are interwoven. Addressing one without the other risks perpetuating the very disconnect that contributes to distress. Improving care, then, requires systemic change that supports both parties: giving clinicians the space and resources to practice in alignment with their professional values, and giving patients the time, validation, and psychologically informed care needed to reconstruct their sense of self.

9.4.7. Convergent Theme: Age-Related Biases and Assumptions

The presence of age-related biases during CM diagnosis was acknowledged and was found to skew both interpretations of initial symptoms, and the assumptions made about patients' health expectations. Cardiologist recognised the implicit age-bias as a 'true bias', referring to the increased likelihood of symptoms to be due to cardiac illness in older people, compared to younger people (Veenis *et al.*, 2020). However, they also recognised how these implicit biases may lead to assumptions being made about patients' health expectations and lead to sub-optimum care. Patients similarly recognised the challenges associated with navigating a new diagnosis within services that are affected by such implicit biases.

9.4.7.1 Mutual Recognition of Age Bias

Cardiologists recognised that their diagnostic and treatment decision-making could be influenced by implicit age-related biases. As the majority of cardiac patients are over 65 (Veenis *et al.*, 2020), younger

patients presenting with overlapping symptoms could be overlooked, as their symptoms may not fit traditional clinical expectations. Conversely, older adults were sometimes diagnosed later due to symptoms being attributed to 'normal ageing' rather than a potential cardiomyopathy aligning with findings from wider research highlighting how the comorbidities in some elderly patients can delay diagnosis of cardiac issues as all symptoms are attributed to natural decline in health over time (Lazzeroni *et al.*, 2022). Cardiologists acknowledged that while age is a key factor in differential diagnosis, its influence sometimes led to delays or inconsistencies in care. Patients also perceived age-based assumptions influencing their diagnostic journeys. Younger patients reported feeling dismissed when presenting with breathlessness or fatigue, as these symptoms were often attributed to stress, anxiety, or asthma rather than potential CM, aligning with other similar literature (Kirkpatrick *et al.*, 2018; Hull, Godbout and Boulet, 2020). Many felt they had to persistently advocate for themselves to receive appropriate investigations. Conversely, older patients felt their symptoms were frequently normalised as part of the ageing process, leading to delays in referral or treatment.

9.4.7.2 Impact of Age Bias

Both patients and cardiologists identified the significant impact of age bias on diagnosis timing and treatment decisions. Delays in recognising CM in younger adults often meant that their condition progressed further before appropriate interventions were initiated. For older adults, assumptions about frailty sometimes resulted in them being offered fewer intensive treatments, or had assumptions made about their expectations of longevity. This echoed the findings of other research (São José *et al.*, 2019) demonstrating how pervasive the issue is in current health systems. Cardiologists acknowledged that these biases could lead to inequitable care, with some groups facing unnecessary delays or being offered suboptimal treatment options based purely on their age rather than their overall health status. Age-related biases also shaped patient-clinician interactions and trust in the healthcare system. Younger patients such as Charlotte, who felt dismissed or unheard, were more reluctant to seek medical attention, fearing they would not be taken seriously. Older patients who perceived ageist attitudes within their care team, reported feeling disempowered and were less confident in their treatment plans.

Cardiologists acknowledged that age-based assumptions could unintentionally create barriers to effective communication, as patients might withhold concerns or hesitate to challenge clinical decisions if they sensed their age was influencing the discussion. The recognition of these biases highlights the prevalence and impact of agism spanning beyond CM and highlight the importance of developing more personalised and age-inclusive approaches to patient care.

Both patients and cardiologists recognised the presence of age-related biases within CM diagnosis and treatment, acknowledging their impact on clinical decision-making, patient experiences, and healthcare outcomes. Addressing these biases requires increased awareness among clinicians, ensuring that symptoms are assessed based on individual presentation rather than assumptions linked to age. More structured diagnostic protocols, improved education on age-related disparities, and fostering open communication between patients and clinicians can help mitigate the effects of implicit bias and promote more equitable care across all age groups.

9.4.8. Divergent Theme: Understandings of Diagnosis

The diagnosis CM is clinically complex due to its diverse presentation, overlapping symptomatology with other conditions, and variable disease progression (Heidenreich *et al.*, 2022; Arbelo *et al.*, 2023). Despite the development of increasingly specific diagnostic guidelines (Arbelo *et al.*, 2023), this study identified a persistent mismatch in how diagnosis is conceptualised by clinicians and patients.

A core point of divergence centred on the nature of diagnosis itself. For clinicians, diagnosis was seen as a process of exclusion: ruling out of alternative explanations through investigative reasoning, clinical judgement, and ongoing interpretation of emerging data. In contrast, patients more often viewed diagnosis as a definitive, linear process from symptom onset to diagnostic label. This difference in orientation routinely led to misaligned expectations and miscommunication.

9.4.8.1 Diagnostic Reasoning and the Limits of Certainty

One of the more pressing barriers to timely diagnosis was the variability in specialist knowledge across primary and secondary care. Symptoms of CM were frequently attributed to more common conditions

such as anxiety, asthma, or simple deconditioning. These misattributions led to diagnostic delay and mirrored broader findings suggesting that misdiagnosis of CM and heart failure is a prevalent issue, even within secondary care (Wong *et al.*, 2021). The issue therefore extends beyond individual clinical errors and may instead reflect a broader systemic difficulty in recognising less common cardiac presentations, particularly among patients who do not fit conventional profiles of cardiac disease.

This diagnostic uncertainty, while a normalised part of cardiological reasoning, often appeared invisible to patients. Where clinicians viewed uncertainty as an inherent part of the differential diagnosis, patients interpreted that same uncertainty as a lack of competence, withholding or poor-quality care. This points to a fundamental misalignment in the understanding of what diagnosis entails and invites further exploration surrounding how best to mitigate this within the patient-clinician relationship.

9.4.8.2 The Psychological Weight of Uncertainty

For many patients, the diagnostic journey was not experienced as a process but as a series of contradictions. Multiple, conflicting explanations for symptoms, ranging from stress to asthma, were not understood as necessary steps in clinical reasoning but as evidence of being passed around, mismanaged or misdiagnosed. The use of vague or cautious medical language only heightened this perception. Phrases like “*not severe enough*”, “*borderline*”, or “*idiopathic*” frequently led to confusion, anxiety, and mistrust, particularly when not accompanied by a clear plan for follow-up or review.

Importantly, this wasn’t simply a matter of unmet expectations. It spoke to deeper issues of safety, validation, and agency that patients required during the CM diagnosis process. Patients wanted to feel heard and believed. When the process failed to offer these forms of recognition, emotional distress often intensified and, in some cases, led to decreased engagement with health services.

9.4.8.3 Bridging the Gap

Perceptions of delayed diagnoses, fractured clinician-patient relationships, and declining trust in the health system were all shaped, in part, by this fundamental mismatch in expectations and understanding of diagnosis. The psychological burden of diagnostic uncertainty was great but addressing this issue may

require more open conversations about the nature of diagnosis itself, and an understanding of each other's perception. Normalising uncertainty, offering patients realistic expectations, and explicitly outlining the investigative process may help buffer the emotional impact. In doing so, services may be better placed to support both earlier recognition of CM and offer more emotionally attuned care.

9.5. Chapter Summary

This chapter offered a comprehensive overview of the integrated perspective, outlining the key areas of divergence and convergence between cardiologists and patients during the CM diagnosis process. Although not intended to be generalised to wider populations, findings highlighted in this chapter may be used to springboard future research into the CM diagnosis process and the complex relationship between cardiologists and patients during diagnosis. Findings also may be used to inform future care provision, improving health care structures and improving the CM diagnostic experience for both clinicians and patients alike. Implications of the research, research appraisal and reflections on learning are provided in the final chapter, Chapter 10.

10. Thesis Conclusion

Drawing together the insights provided by this research as outlined in previous chapters, Chapter 10 concludes the thesis by responding to the original research question, summarising the research's contributions to knowledge and outlining any practical implications for cardiomyopathy care and key areas of development for consideration in future research.

10.1. Research Aim

This thesis set out to explore lived experiences of the cardiomyopathy (CM) diagnosis journey from the perspectives of its two central actors: newly diagnosed adult patients and consultant cardiologists. The research was carried out in three qualitative phases with phase one exploring the views and experiences of cardiologists, and phase two investigating the lived experiences of adult patients recently diagnosed with a CM. Qualitative data was collected during interviews with each population, transcribed verbatim and analysed through detailed interpretative phenomenological analyses. In phase three, a final integrative discussion brought together these distinct viewpoints to examine areas of convergence and divergence in how each group conceptualised and navigated the CM diagnostic process. The overarching aim of the study was therefore addressed through the following research question:

What are patients' and cardiologists' lived experiences of the cardiomyopathy diagnosis journey?

10.2. Key Findings

Synthesising findings across both datasets revealed multiple points of convergence and divergence that have been discussed in more detail throughout chapter 9. However, in brief, both patients and cardiologists described the CM diagnosis as an emotionally significant life experience, but their accounts frequently differed in terms of how this event was understood, communicated, and managed in practice. Systemic constraints acting as a significant barrier to care was a dominant theme found throughout the research. Fragmented care pathways, inconsistent follow-up protocols, limited time, resource constraints, and unclear professional accountability were experienced as major barriers by both patients and cardiologists. These issues reflected a wider siloed working culture within the NHS, contributing to disrupted continuity of

care and leaving patients to navigate complex service landscapes themselves, contributing to patients' feelings of systemic abandonment. Charitable organisations were frequently viewed to step in to provide emotional support, education, and guidance services, when eventually found, filling the gaps in care left by constrained NHS services. Many participants felt that NHS service provision should be developed to include these services or reformed to formally integrate reputable third sector services within the CM diagnostic care pathway.

Inconsistent CM knowledge across healthcare settings further compounded diagnostic challenges. While cardiologists from tertiary cardiac centres were seen to possess relevant expertise, primary care services were seen to lack familiarity with CM-specific symptoms, guidelines, and referral pathways. Cardiologists attributed delays, misdiagnoses, and misplaced referrals to be directly related to unfamiliarity in primary and even secondary care services. Cardiologists recognised their limited ability to influence diagnostic behaviours beyond their specialist settings due to time pressures, communication barriers, and system fragmentation, which fuelled feelings of frustration and inadequacy.

Resource limitations, including staffing shortages, lengthy waiting times, and inequitable access to diagnostic tools were a shared frustration. Clinicians and patients noted that service provision varied significantly depending on geography, with patients in rural areas more likely to encounter diagnostic delays. Resource constraints not only affected timing of diagnosis but also the quality and consistency of follow-up care.

A diffusion of responsibility across service levels added further complexity. The absence of clear accountability created confusion about who was responsible for overseeing patients' CM care during diagnosis, particularly during transitions between services. This contributed to missed opportunities for communication and inconsistent care planning. Both perspectives described a culture of siloed working, reinforced by funding models and performance targets that favoured internal service goals over collaborative person-centred care.

A shared theme was the recognition of psychological distress associated with the diagnosis of CM. Patients described a non-linear emotional adjustment process involving shock, denial, grief, anxiety, and identity disruption. Cardiologists also acknowledged the psychological burden faced by their patients, particularly younger individuals or those newly adapting to chronic illness. Despite this awareness, psychological needs were often unmet due to a lack of training, time, and integrated pathways to enable psychologically informed models of care. Cardiologists themselves reported feeling emotionally burdened by their inability to offer the level of care they believed their patients deserved.

Barriers to communication and understanding were also consistently reported. The use of complex clinical language and jargon, particularly terms like “*heart failure*” and “*chronic*” were seen to unnecessarily confuse and distress newly diagnosed patients, especially among patients with low health literacy. Patients often received very limited or no written information at diagnosis and turned to the internet for answers, where misinformation could pose further risks. While both groups recognised these barriers, efforts to improve communication and education were hindered by limited consultation time and the lack of standardised accessible resources and varying levels of competence in clinician-patient communication.

A shared awareness of age-related biases also emerged. Younger patients described their symptoms being dismissed as anxiety or lifestyle-related, while older adults reported that their symptoms were normalised as part of ageing. Cardiologists acknowledged that such assumptions could lead to diagnostic delays and suboptimal treatment planning, potentially reinforcing inequities in care. Cardiologists simultaneously acknowledged it as a “*true bias*” however, demonstrating their need to hold both their formal training surrounding differential diagnosis in one hand, whilst acknowledging the individual’s unique circumstances, health expectations and presentation with the other.

A significant theme was the different experiences and interpretations of diagnostic uncertainty. While cardiologists saw uncertainty as an expected part of medical decision-making, made through professional judgment and evolving evidence, patients experienced it as deeply unsettling and emotionally distressing.

Patients described being left with unanswered questions, inconsistent information, and unclear follow-up, which often led to mistrust or disengagement from services.

Power dynamics within the diagnostic process were also experienced differently. Cardiologists acknowledged the structural hierarchies within NHS services and described efforts to support shared decision-making. However, patients often felt disempowered or passive within consultations. Efforts to promote autonomy were sometimes perceived as tokenistic or poorly timed, with patients unsure how or when they were permitted to lead discussions. Despite genuine efforts and intentions, the dominant position of the clinician remained largely unchallenged, and patients' contributions were perceived to not always be valued equally.

A further divergence arose in how diagnosis itself was conceptualised. Cardiologists described diagnosis as a dynamic, iterative process of exclusion and clinical reasoning, whereas patients often expected a clear and immediate answer. When this was not provided, some patients interpreted it as incompetence or a dismissal of their experience. The misalignment between these perspectives contributed to patient frustration and perceptions of misdiagnoses being made.

Both groups reported intrapersonal identity shifts, but these were experienced in role-specific ways. Patients described profound changes in self-identity following diagnosis, including feelings of grief, disbelief, and separation from their previous conceptualisation of the 'self'. Many struggled with the invisible nature of CM and described feeling invalidated by others. Cardiologists, meanwhile, expressed feelings of moral injury when systemic constraints prevented them from delivering optimal care. The emotional labour of their role led some to adopt coping mechanisms such as emotional distancing, which was often misinterpreted by patients as uncaring or robotic behaviour.

Together, these findings offer a nuanced understanding of the systemic, psychological, and interpersonal challenges involved in the diagnosis of CM. The data highlight both areas of shared understanding and points of misalignment that shape the CM diagnostic journey for patients and cardiologists alike.

10.3. Original Contribution to Knowledge

This research contributes to the literature by providing one of the first UK-based qualitative explorations of cardiomyopathy (CM) diagnosis from multiple perspectives. In contrast to much of the existing cardiology literature which has tended to focus on clinical outcomes or adherence to diagnostic guidelines, this study centres on lived experience and meaning making throughout the CM diagnosis journey. It therefore offers a foundation for understanding how CM diagnosis is experienced in practice, and how this may shape future service development for the benefit of both clinicians and patients.

In terms of patient participants, a further contribution lies in the inclusion of multiple cardiomyopathy phenotypes. This differs from much of the existing research, which often focuses on heart failure more generally, or on a single CM phenotype. By including a range of diagnostic experiences, this study captures both shared and distinct aspects of the diagnostic process across the CM population.

The study also contributes to theoretical understanding by examining how key concepts within healthcare, such as diagnostic uncertainty, shared decision-making, and the emotional demands associated with diagnosis, are experienced and managed in practice. Rather than considering these concepts in isolation, the findings highlight how they intersect within real-world clinical encounters, shaping both patient and clinician experience. In addition, the identification of a 'testing' phase within the broader process of processing loss extends existing models of adjustment to loss associated with chronic illness diagnosis. This phase reflects how participants actively and repeatedly tested their physical, emotional, and social limits following diagnosis, suggesting that adjustment is not only a process of acceptance, but also one of ongoing negotiation and experimentation in response to perceived loss.

Methodologically, the research extends the application of interpretative phenomenological analysis through the use of dual datasets, allowing for both within-group and across-group analysis. In addition, the use of a quantitative participant identification tool provided a structured approach to sampling within a qualitative design, supporting transparency and consistency in participant selection.

10.4. Limitations of the Research

While this study offers new insights, several limitations must be acknowledged. Firstly, I understand that the qualitative nature and relatively small, purposive sample size limited the generalisability of the findings. Participants were diverse in age, background, and clinical experience, and the studies were conducted within an NHS context and may not reflect diagnostic processes or healthcare dynamics in private health systems. In fact, cardiologists and patients were only recruited from services within NHS-England, further limiting its perceived scope. However, the aim of this study was not generalisation, but to provide in-depth insight. Insight is not conclusive or generalisable in the statistical sense but does provide a valuable snapshot of individuals lived experiences, that can help to inform future care provision and serves only as an exploratory exercise and foundational basis from which to springboard further research.

Secondly, patient participants were recruited post-diagnosis and asked to retrospectively reflect on their experiences. Although rich and in-depth analyses was conducted, this may introduce memory bias, particularly for those with longer diagnostic journeys (as patients were recruited up to six months following diagnosis). Similarly, cardiologists' accounts may reflect idealised or socially desirable perspectives on practice, given their status and their previous affiliation or experience with academic research.

Additionally, the sampling strategy evolved from a purely purposive approach to a hybrid model incorporating elements of self-selection (volunteer sampling) at the point of recruitment. This shift limited the extent to which the sample could be strategically shaped and may have introduced self-selection bias whereby participants with particular motivations, experiences, or levels of engagement with healthcare services were more likely to take part. Additionally, patient participants who were not computer literate or who did not have access to the internet may also be underrepresented due to the nature of the online participant identification tool. Consequently, the breadth and diversity of both the cardiologist and patient cohorts may not fully reflect the wider population of individuals involved in cardiomyopathy diagnosis within NHS England. In particular, individuals who were less engaged with healthcare services, those with more

complex or fragmented care pathways, or those who were experiencing greater socioeconomic or health-related barriers may be under-represented, with additional implications for the transferability of findings.

Recruitment challenges were a key contributing factor, particularly limited engagement from NHS Trust research and development departments, with only three of ten sites providing recruitment support. While this reflects a practical constraint, it also highlights the presence of a broader structural barrier to research access within NHS settings. Future research may benefit from exploring the factors influencing research engagement within these departments, particularly in relation to smaller-scale doctoral projects, to enhance the feasibility of achieving more diverse and representative samples.

Finally, my unique position as a lifelong cardiomyopathy patient, aspiring clinical psychologist and voluntary roles in offering patient advocacy and peer support services, have increased the potential for my interpretations to be somewhat biased by my own lived experience. However, as previously detailed, great lengths were taken to mitigate the risk of undue bias through reflective practice embedded throughout the data collection and analysis, analyses triangulation with my supervisory team, and through the creative use of co-produced timelines in order to confirm my understanding of patients' experience in real-time. I affirm that my positionality adds to the uniqueness of this research in that I have been explicit about the important role I, as the researcher, play within the IPA research process. It is understood however, that this transparent position may not be accepted by those with differing epistemological or ontological assumptions about the nature of knowledge, and the role of the researcher.

Despite these limitations, the themes identified speak to broader tensions in clinical care and health structures that resonate with, and expand on, other chronic illness experiences documented in wider literature.

10.5. Directions for Future Research

This research highlights several important areas for future study. In particular, further work is needed to explore the longer-term psychological and relational impact of cardiomyopathy (CM) diagnosis, especially in terms of how early communication shapes patients' understanding, sense of identity, and engagement

with health services over time. Given the findings of this study, it would be helpful to better understand how experiences of uncertainty, loss, and adjustment continue to develop beyond the initial diagnosis.

Future research should evaluate how changes to service provision work in practice. Building on the potential implications of the research in practice (outlined in section 10.6.1 below), future research could examine the impact of introducing more structured diagnostic pathways, including improved access to psychological support, more psychologically informed communication within routine care, and stronger links with third-sector organisations. Exploring how these approaches work in real-world settings would help to determine whether they support patients in managing uncertainty, adjusting to changes in identity, and engaging more effectively with health services.

Comparative research across healthcare systems may also offer useful insights into how structural differences shape both diagnostic interactions and patient experience. For example, comparing service provision across NHS Wales, NHS Scotland, and NHS England may help to identify how organisational factors influence the delivery and experience of diagnosis, particularly in relation to continuity of care and access to support.

Methodologically, longitudinal designs following patients from pre-diagnosis through to post-diagnosis would provide a more detailed picture of how understanding, emotional responses, identity, and engagement with health services evolve over time. This would help to address some of the limitations of cross-sectional research and better reflect the process-based nature of diagnosis identified within this study.

Additionally, the involvement of patient and public involvement (PPI) groups across both recruitment pathways was valuable in shaping research materials and ensuring accessibility for the target cohorts. However, recruitment was more successful via the charity pathway than through NHS Trusts, potentially reflecting closer alignment between the research topic and the priorities of third-sector organisations. This suggests that earlier and more sustained consultation with both PPI groups and service stakeholders during the design phase may help to better align research aims with organisational priorities. Such alignment may

foster greater investment, awareness, and support for recruitment, particularly within NHS contexts where engagement from research and development departments can be variable.

Finally, the use of digital and assistive tools within healthcare represents a promising area for future research. These tools may support clinician education, improve consistency in communication, and help patients better understand complex conditions such as CM. However, further work is needed to explore how these tools can be integrated in a way that supports, rather than replaces, the relational aspects of care.

10.6. Implications of the Research

This research has clear implications for both clinical practice and wider service design. Across both datasets, communication during the diagnostic process was frequently experienced as insufficiently attuned to patients' emotional and informational needs. Patients described difficulties in understanding their diagnosis, managing uncertainty, and navigating the relational and power dynamics inherent in clinical encounters. These findings suggest a need for more psychologically informed approaches to communication, with greater attention to language use, accessibility of information, and the relational context within which a diagnosis is delivered.

10.6.1 Implications for Clinical Practice

At a practical level, the findings support a shift away from viewing diagnosis as a single event, toward understanding it as a staged and ongoing process. The data suggest that a one-off consultation is often insufficient to support patients in processing complex and life-altering information, particularly in the context of uncertainty.

One potential response would be the implementation of a structured diagnostic protocol, designed to support both information delivery and emotional processing over time (Figures 20 and 21). For example, an initial diagnostic consultation could be extended (e.g., 30 minutes rather than the standard 10 minutes) to allow for a clear, plain-English explanation of the diagnosis, alongside explicit acknowledgement of uncertainty. Distinguishing between what is known, what is stable, and what remains uncertain may help patients better orient themselves within the diagnostic process. This extended timeframe may also allow

for initial questions, support early rapport-building, and create space to acknowledge and normalise the emotional impact of the diagnosis.

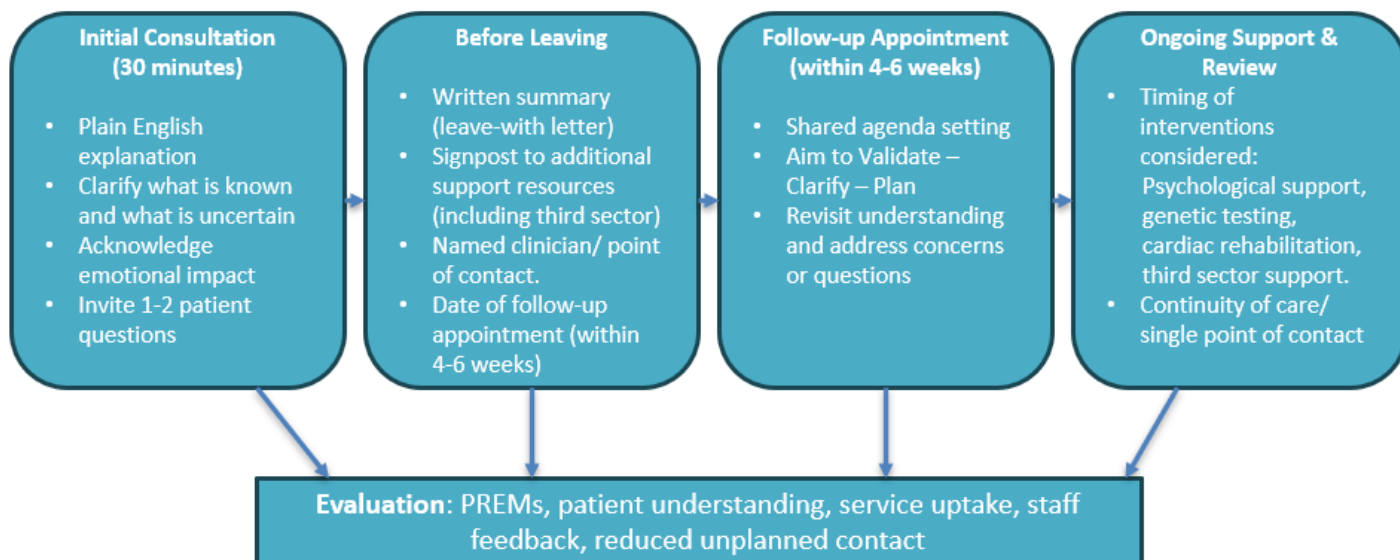


FIGURE 20. STAGED DIAGNOSTIC PROTOCOL

Importantly, the findings suggest that patients benefit from leaving consultations with something tangible. Providing a brief written summary of the diagnosis, including key information and next steps, may reduce reliance on memory at a time of emotional overwhelm. Cardiologists in this study described using visual aids to support understanding; incorporating simple diagrams or visual representations may further enhance comprehension. Inviting one or two patient-led questions within the consultation may also support engagement without overloading the interaction.

Rather than placing the burden on a single consultation, a follow-up appointment could be automatically scheduled within 4–6 weeks, with a named clinician to support continuity. This staged approach allows patients time to process the diagnosis and return with more informed questions, supporting more

meaningful engagement over time. Between appointments, offering a single point of contact may help reduce uncertainty and prevent escalation of distress.

The integration of third-sector organisations, such as cardiomyopathy-specific charities, also represents an important practical implication. These organisations can provide accessible information, peer support, and continuity beyond clinical settings, addressing gaps that clinicians may not have capacity to fill. Similarly, the timely offer of psychologically informed support, cardiac rehabilitation, and genetic services may improve engagement, particularly when introduced at appropriate points in the patient journey rather than at the point of initial diagnosis.

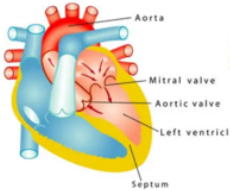
Information & Support Summary <i>NHS Trust/ Service Name</i>	
Discussed Today Your diagnosis: This means...	
Your Next Appointment	
Date:	Location:
Time:	Clinician:
Questions I Have	Contact Information Clinician: Service/department: Phone/ Email:
Community Support Resources  Cardiomyopathy^{UK} the heart muscle charity  Heartbeat Community + other third sector local support services	Notes

FIGURE 21. SUGGESTED PATIENT SUPPORT HANDOUT

These recommendations align with the themes identified within this study. Structuring diagnosis as an ongoing process may help to reduce uncertainty, support adjustment to changes in identity, and provide

some containment for the sense of loss described across accounts. Importantly, these changes do not necessarily require a complete restructuring of services, but rather a reorganisation of existing resources to better support patients over time.

From a service perspective, implementation could be evaluated through patient-reported experience measures (PREMs), staff feedback, and engagement indicators, such as uptake of support services or reduced unplanned contact. Improvements may be reflected in patients reporting a clearer understanding of their diagnosis and next steps, as well as increased engagement with available support pathways.

In addition, the findings highlight the importance of training in psychologically informed communication styles. While cardiologists demonstrated high levels of technical expertise, patients' accounts suggest that emotional attunement and communication style plays a significant role in shaping the diagnostic experience. Training or input from clinical psychologists may support clinicians in balancing clarity, honesty, and empathy, enhancing patient-centred care without requiring significant additional time. The integration of clinical psychologists within the multidisciplinary team may also support shared formulation, helping clinicians to better understand individual patient needs and respond to challenges such as disengagement, uncertainty, or disagreement within shared decision-making.

In addition to patient-focused benefits, these recommendations may also have implications for clinician wellbeing. A more structured and staged diagnostic protocol may support cardiologists in approaching complex diagnostic conversations with greater clarity and confidence, particularly when navigating uncertainty and managing patient expectations. The integration of psychologically informed communication frameworks, alongside access to multidisciplinary team input from clinical psychologists, may further support clinicians in responding to patient distress in a more contained and supported manner. This may be particularly relevant given the emotional labour associated with delivering life-altering diagnoses and managing ongoing uncertainty. Access to shared formulation, opportunities for reflective discussion, and clear pathways for signposting to third-sector support may help to reduce the individual burden placed on clinicians, potentially mitigating experiences of moral distress when perceived

standards of holistic care cannot be met within existing service constraints. In this way, these recommendations may not only enhance patient experience but also contribute to more sustainable and supported clinical practice.

Finally, it is important to acknowledge that these recommendations are based on qualitative findings and represent data-informed suggestions rather than tested interventions. Further work would be needed to evaluate their feasibility and impact in practice.

10.6.2 Theoretical Implications

The findings also have broader implications for theoretical understandings of diagnosis and healthcare interactions. Firstly, the study contributes to existing models of shared decision-making (Deeny, Thorlby and Steventon, 2018; Treffers and Putora, 2020), suggesting that these models may not fully account for the emotional and temporal complexity of diagnostic encounters. In practice, patients were often required to make sense of their diagnosis under conditions of uncertainty, distress, and limited understanding. This raises questions about the extent to which shared decision-making is achievable at the point of diagnosis and suggests that current models may benefit from greater consideration of timing, emotional readiness, and the progressive nature of understanding. This aligns with evidence that emotional state and relational context shape patients' capacity to engage meaningfully in decisions (Treffers and Putora, 2020).

Secondly, the findings extend existing work exploring diagnostic uncertainty in chronic illness (Santhosh, Chou and Connor, 2019) which has often conceptualised uncertainty as a deficit in information or predictability. Rather than being experienced solely as a lack of information, uncertainty was shown to be relational and dynamic, shaped by how clinicians communicated, what was left unsaid, and how patients interpreted both verbal and non-verbal cues. This aligns with research demonstrating that patients actively construct meaning from clinical interactions, drawing inferences from both explicit and implicit communication (Danaher *et al.*, 2023; Rehman and Sohail, 2023). This suggests that uncertainty is not simply an inherent feature of medical diagnosis, but something that is actively constructed and negotiated

within clinical interactions. As such, theoretical models of uncertainty may benefit from moving beyond individual accounts, toward more interactional and context-sensitive models of understanding.

Thirdly, the data offer insights relevant to the concept of moral injury within healthcare. Cardiologists' accounts highlighted tensions between providing optimal patient care and working within systemic constraints, including time pressures, fragmented care pathways, and limited resources. These findings align with broader literature highlighting how structural and organisational pressures can constrain professional autonomy and contribute to distress among clinicians (Brennan and Davidson, 2019; Care Quality Commission, 2018). Within the present study, such tensions were evident in clinicians' reflections on responsibility, uncertainty, and the limits of what could realistically be offered in practice. While moral injury is more commonly discussed in relation to acute or crisis-based settings, these findings suggest it may also have relevance within routine clinical practice, particularly in the context of diagnostic communication. Further understanding of moral injury may therefore be useful in understanding how these constraints are experienced and managed within diagnostic contexts, particularly where clinicians feel unable to deliver care that aligns with their professional values.

Finally, the study supports a reconceptualization of diagnosis itself. Rather than a distinct clinical event, diagnosis was understood as an ongoing, relational process, shaped by interactions over time, systemic factors, and individual patient meaning making. This builds on existing work in chronic illness research, where diagnosis is understood as a disruption to one's sense of self, requiring ongoing identity negotiation (Charmaz, 1987), and where experiences of uncertainty and adjustment unfold over time rather than at a single point (Mishel, 1981). The present findings extend this perspective by demonstrating how diagnosis is co-constructed through repeated interactions across the diagnostic pathway, influencing not only understanding of illness but also patients' sense of self and position within healthcare systems. This has implications for how diagnosis is conceptualised within both clinical practice and research, suggesting a need to move beyond event-based models toward more process-oriented understandings.

It is important to note that, in line with the explorative nature of this research, these theoretical contributions are grounded in qualitative data from a specific clinical context. As such, they should be understood as extensions or refinements of existing frameworks, rather than definitive revisions. Further research across different conditions and settings would be valuable in exploring the broader applicability of these ideas.

10.7. Reflecting on the PhD Process

The process of designing and conducting this research, from study development and consulting with service users to obtaining NHS ethical approval, collecting and analysing data, and producing a thesis to doctoral standards, has been both intellectually demanding and personally significant. Alongside these academic demands, a series of personal health challenges placed ongoing pressure on my time, capacity, and emotional resources. This required a constant balancing of personal resilience and academic expectations and shaped my experience of the research process in ways I had not anticipated.

Experiences of self-doubt and perceived inadequacy were present throughout the PhD journey, reflecting what has been widely described as imposter syndrome within doctoral training (Handforth, 2022). For me, these feelings were often linked to a strong sense of responsibility to represent participants' accounts accurately, alongside a desire to produce work that would be meaningful for the cardiomyopathy community. While this led to a careful approach to analysis, it also led at times to over-scrutiny of interpretations and hesitation in asserting analytic claims. Being aware of this helped me balance staying close to participants' accounts with the interpretative demands of qualitative research.

A key feature of this PhD was its extended duration. Beginning in September 2016 and concluding almost a decade later, this timeline brought both challenges and opportunities. The data were collected within a specific context, while the thesis was completed within a very different clinical, academic, and personal context. This required me to remain grounded in the original data while recognising that my understanding had developed over time. At the same time, the longer timeframe allowed space for deeper reflection, supporting more considered engagement with both the data and its wider implications. The extended

timeframe also means that the data, collected prior to the onset of the global COVID-19 pandemic in 2020, may now offer additional value beyond the original aims of the study. Specifically, the findings provide a pre-pandemic baseline against which future research may explore changes in diagnostic experiences, service delivery, and patient understanding in a post-pandemic context.

The duration of the PhD also overlapped with significant professional development. I began this research shortly after completing my undergraduate degree, with a theoretical understanding of psychology but limited clinical experience. Midway through the PhD, I began working as an Assistant Clinical Psychologist across several NHS services, including Clinical Health Psychology and Community Mental Health Teams. These roles expanded my understanding of the practical, emotional, and systemic aspects of healthcare, including medical models, multidisciplinary working, and patient–clinician relationships.

This shift in experience undoubtedly influenced how I interpreted the data. Ideas that were initially approached in a more theoretical way became grounded in clinical practice. For example, increased exposure to systemic pressures may have shaped how I understood clinicians' accounts of constraint and responsibility, while clinical experience of patient distress deepened my engagement with the emotional aspects of patient narratives. I reflected on these changes regularly in both clinical and academic supervision. However, this shift in perspective also brought some challenges. As my clinical knowledge developed, there was a risk that I might interpret earlier data through a more informed lens than I had at the time it was collected. To manage this, I returned regularly to the original transcripts during analysis and writing, aiming to stay close to participants' accounts while remaining aware of how my perspective had changed.

In addition to changes in interpretation, my academic skills, including critical analysis and writing, developed over the course of the PhD. While this is expected within doctoral training, the extended timeframe meant these changes were more noticeable. This was reflected in differences in writing style and analytical depth across earlier and later chapters. Recognising this, I undertook a process of revision to ensure greater consistency in academic voice and analytical rigour across the final thesis.

These reflections show that the PhD process was not fixed, but developed over time, shaped by personal circumstances, professional experience, and distance from data collection. Rather than viewing these factors only as limitations, they can be understood as part of the research process itself, influencing both the questions asked of the data and the interpretations developed. Aligned with Interpretative Phenomenological Analysis (Smith, Flowers and Larkin, 2009) I remained an active participant within the analytical process, even amidst an evolving personal and professional lens. Staying aware of these influences has been important in ensuring the analysis remained grounded in participants' accounts while being transparent about my role in shaping the research.

Another important area of reflection related to my personal relationship with cardiomyopathy and my positionality as a researcher. I have been open about this throughout the research process however, it required careful consideration in relation to how I positioned myself with different participant groups. Within qualitative research, and particularly within Interpretative Phenomenological Analysis (IPA), data are shaped through the interaction between researcher and participant. My position therefore sat between insider and outsider, requiring ongoing reflection. Following discussion with my academic supervisors, I chose to disclose my patient status to patient participants to support rapport and open discussion of difficult experiences. In contrast, I chose not to disclose this to participating cardiologists, to reduce the likelihood that clinicians would alter their language or avoid sensitive reflections when speaking to a researcher they perceived as a patient.

The influence of these decisions can be seen within the data. Patient accounts were often direct and emotionally open. For example, Alex stated, *"I was a bit suicidal then"* (Chapter 7), while Henry described, *"I have to block it out of my head"* (Chapter 7) and *"It's killed my life. All my choices have been taken away from me... Who's going to fix me?"* (Chapter 7). These accounts were notable for the level of openness with which difficult experiences were shared, often without being softened or heavily explained. Participants did not appear to manage or filter how their experiences were presented, which may suggest a sense of trust or psychological safety within the interview context.

Expressions of anger were also shared openly, such as Phoebe's comment: *"I told her to take her fucking book and get out of my room"* (Chapter 7). In some cases, participants used brief or compressed language to describe complex internal experiences, for example, *"Not that they probably would anyway, but it's just in my head"* (Chapter 7). Statements such as this were offered with minimal elaboration, which may indicate that participants felt able to speak freely without needing to fully explain or structure their accounts for my sake.

In contrast, cardiologist accounts were often candid and direct in a professional sense. For example, Dr Garcia stated that cardiomyopathy diagnosis *"most of the time isn't done very well"* (Chapter 5) and that *"people get the diagnosis wrong"* (Chapter 5), while Dr Cartwright described aspects of care as being *"done incredibly poorly"* (Chapter 5). Clinicians also spoke openly about uncertainty, such as Dr Nichols' reflection that *"we don't know about all the diagnoses that we don't know about"* (Chapter 5), and systemic pressures, including *"they don't have time. They're too busy"* (Chapter 5). These accounts suggest that participants were not adjusting their language for a perceived patient audience.

These patterns suggest that how I positioned myself as a researcher may have shaped both what participants shared and how they shared it. Within IPA, this reflects the idea that meaning is developed through interaction, rather than simply collected. However, these decisions may also have had limitations. While sharing my patient status may have supported openness, it may also have shaped how patients told their stories. Participants may have assumed shared understanding and therefore left some things unexplained or emphasised certain aspects of their experience. Similarly, while not disclosing my patient status to cardiologists may have supported more open discussion, it also meant that the data reflect professional perspectives rather than how clinicians communicate directly with patients.

In addition, my awareness of the clinician–patient dynamic may have influenced how I conducted interviews. At times, I may have been less likely to explore certain responses in more depth, particularly where there were perceived differences in expertise or status. This may have shaped the depth and direction of some discussions. Rather than viewing these factors only as sources of bias, they can be understood as

part of how the data were produced. Reflexivity within qualitative research does not aim to remove the researcher's influence, but to recognise and utilise it (Ugiagbe *et al.*, 2025). The choices made in this study were intended to support openness and depth across both participant groups, although in different ways. Being aware of these dynamics has been important in interpreting the findings and understanding how they were shaped.

10.8 Concluding Statement

This research set out to explore the lived experience of cardiomyopathy diagnosis from multiple perspectives. What emerged was a richer, more nuanced understanding of how diagnosis is shaped, not just by clinical expertise, but by a complex interplay of power, communication, and human connection within the context of a constrained health system.

By giving voice to those central to the diagnostic experience, this study invites new ways of thinking about what diagnosis entails, and what it truly means to comprehend a diagnosis of CM or other chronic health conditions. The work presented here lays the groundwork for reimagining CM diagnosis as a more humane, collaborative, and empowering process that more closely aligns with the perceived ideal standards and needs of all involved. Such progress, however, depends on our continued commitment to valuing and listening to the individuals at the heart of the CM diagnosis journey.

Appendices

Below is a table of appendices referred to within this thesis. All included appendices have been provided for the purposes of transparency regarding the processes used for data collection and analysis. All personal identifiable indicators within the data have been anonymised.

Appendix No.	Content	Referenced in page(s)
1	Ethical approval	47
2	Preparation interview topic guide	52
3	Summary of results from patient identification tool	52/ 58
4	Cardiologist recruitment email	53
5	Final interview topic guide – cardiologist interviews	56/ 57
6	Patient recruitment poster	61
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12	IPA table: example of emergent themes – multiple transcript level	72
13	IPA table: example of superordinate themes – multiple transcript level	73

Appendix 1 – Ethical Approval Letters

REC and HRA approval letters demonstrating the study has been granted full NHS ethical approval for all stages of study, as referenced in page 47.



Office for Research Ethics Committees Northern Ireland (ORECNI)

Customer Care & Performance Directorate
Unit 4, Lissue Industrial Estate West
Rathdown Walk
Moir Road
Lisburn
BT28 2RF
Tel: 028 95361400
www.orecni.hscni.net
HSC REC B

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

07 June 2017

Miss Jennifer Rees
PhD Student
Liverpool John Moores University
Tithebarn Building - 81 Tithebarn Street
Liverpool, L2 2ER

Dear Miss Rees

Study title: Cardiomyopathy: Exploring Patients' and Clinicians' Experiences of Diagnosis
REC reference: 17/NI/0099
IRAS project ID: 215198

Thank you for your letter dated 31 May 2017, received 06 June 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair of the Proportionate Review Sub-Committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Providing Support to Health and Social Care





Health Research Authority

Miss Jennifer Rees
PhD Student
Liverpool John Moores University
Tithebarn Building,
-81 Tithebarn Street
Liverpool,
L2 2ER

Email: hra.approval@nhs.net

16 June 2017

Dear Miss Rees

Letter of HRA Approval

Study title:	Cardiomyopathy: Exploring Patients' and Clinicians' Experiences of Diagnosis
IRAS project ID:	215198
REC reference:	17/NI/0099
Sponsor	Liverpool John Moores University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Appendix 2 – Preparation interview topic guide

Initial interview topic guide used in preparation interview as referenced in page 52.

Overall Research Question	Interview Question	Prompts
<i>Information checking prior to interview -</i>	<i>Can you tell me your full name and your job title?</i>	<i>Where do you work?</i>
What are clinician's experiences of diagnosing cardiomyopathy?	Tell me about your experience of diagnosing cardiomyopathy?	What makes it different to diagnosing other conditions?
		Do you diagnose it often or are patients already diagnosed when they get to you?
	What are the challenges/ benefits in diagnosing cardiomyopathy?	Can you think of a specific time when a CM diagnosis was a particularly challenging or upsetting experience?
		Can you tell me about a time when diagnosing CM was a positive or rewarding experiences?
	When giving a patient a new diagnosis of cardiomyopathy, how have you gone about this?	Is there a specific process you go through or does it change from patient to patient?
		Can you give an example of this?
		How does it feel personally, when it falls on you to deliver a diagnosis of cardiomyopathy?
	Final Question: Do you think the current health services available to patients sufficiently meet the needs of patients following a new diagnosis of cardiomyopathy?	Physical health services? Mental Health services? Family planning/ genetics services?
		If so, why? If not, can you explain in more detail what services are missing or in what way the current services don't meet patients' needs.
	Is there anything else that you would like to add that hasn't already been mentioned?	

Appendix 3 – Summary of results from participant identification tool

Summary of demographic information, HADS and KCCQ data collected by participant identification questionnaire as discussed in pages 52 and 58.

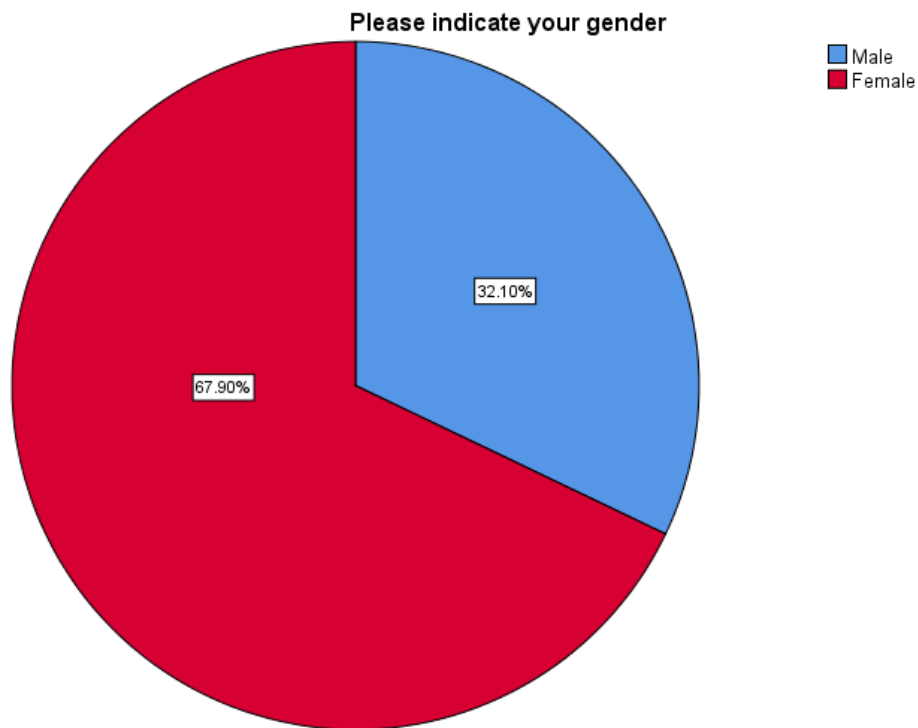


Chart 1. Proportion of male and female participants who completed the participant identification questionnaire online. (N=81).

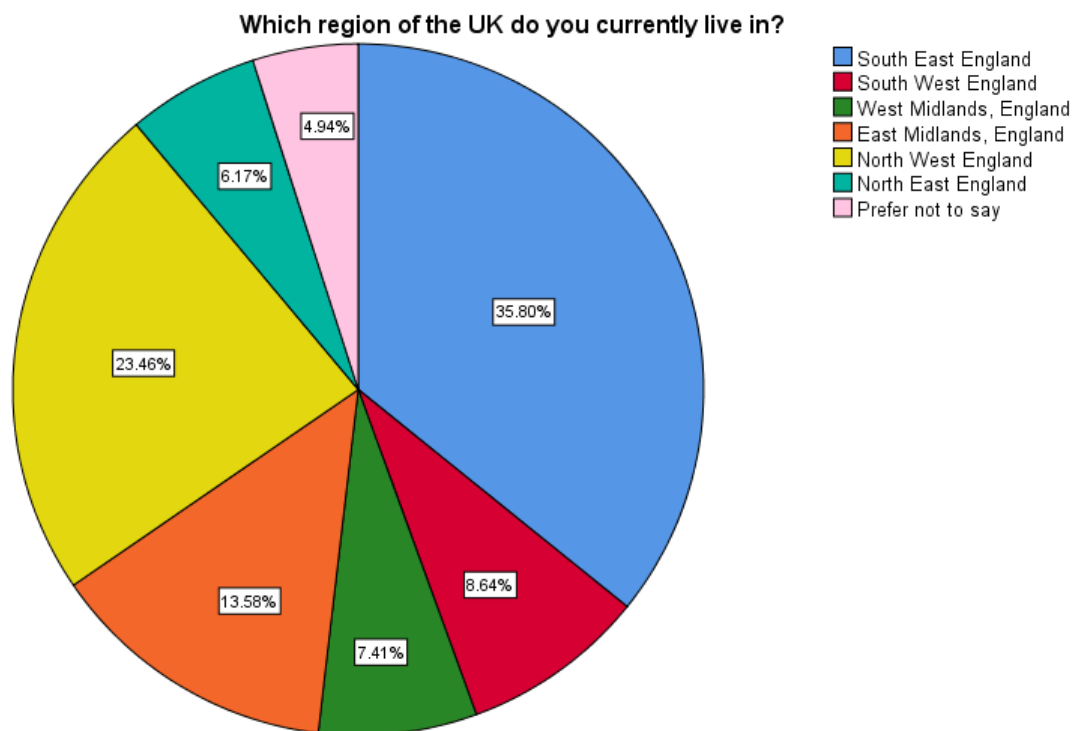


Chart 2. Proportion of participants from different geographical regions of England who completed the online patient identification questionnaire (N = 81).

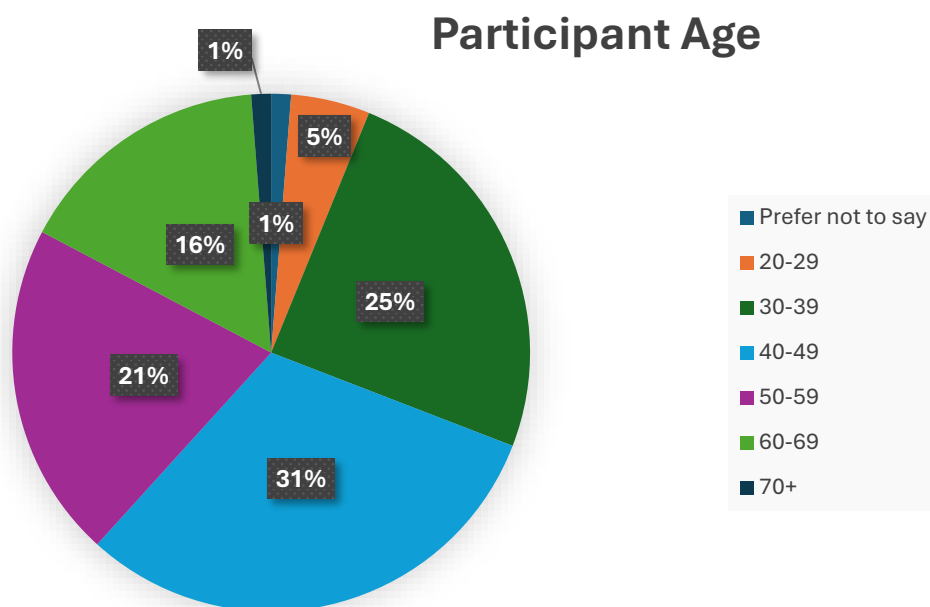


Chart 3. Proportion of participant age ranges among respondents to the online patient identification questionnaire (N = 81).

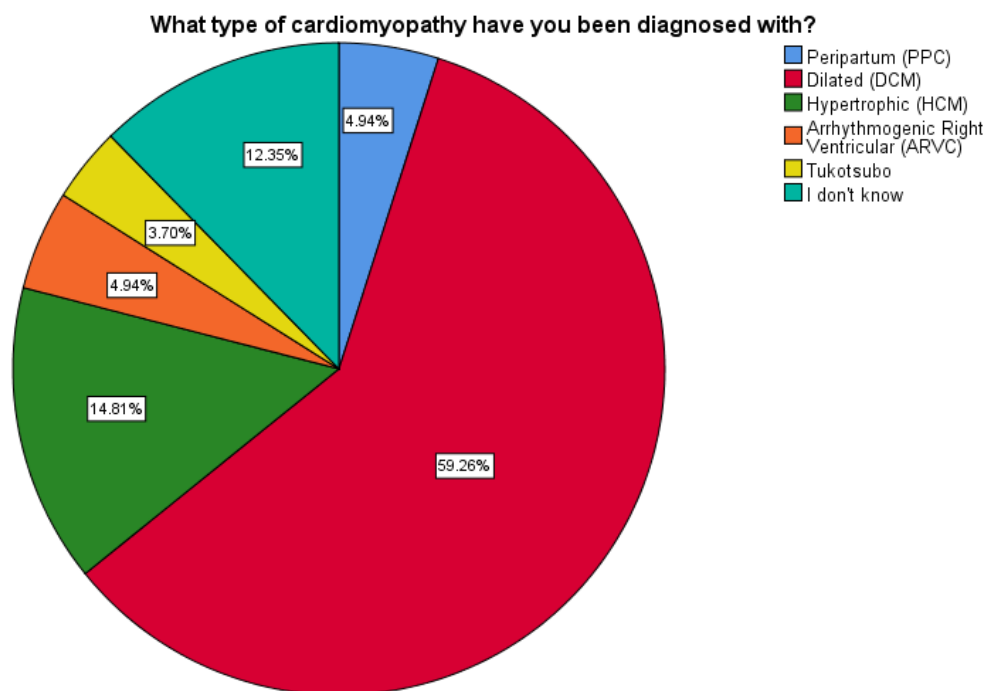


Chart 4. Proportion of different cardiomyopathy phenotypes represented among respondents to the online patient identification questionnaire (N = 81).

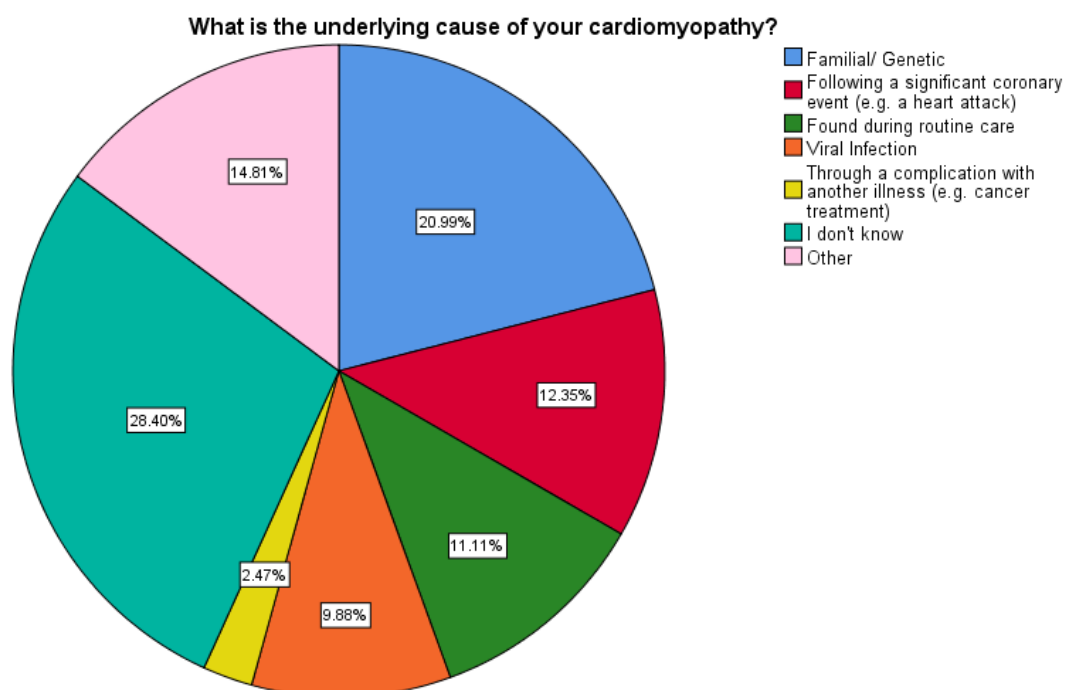


Chart 5. Proportion of different causal factors patients attributed to their cardiomyopathy diagnosis, based on responses to the online patient identification questionnaire (N = 81).

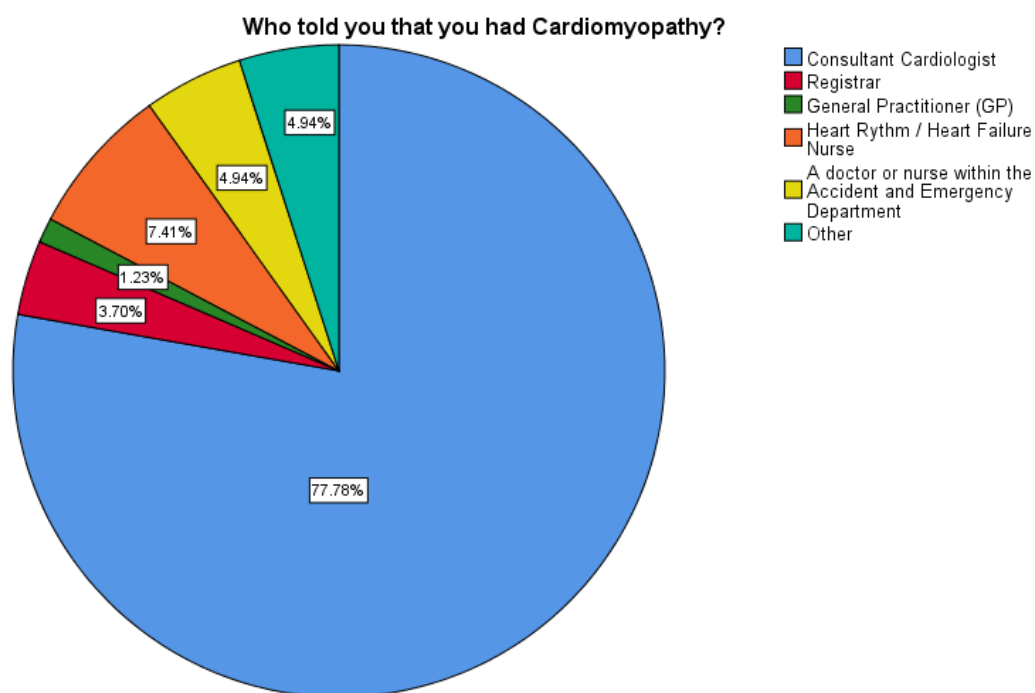


Chart 6. Proportion of different clinical roles identified by patients as having communicated their diagnosis, based on responses to the online patient identification questionnaire (N = 81).

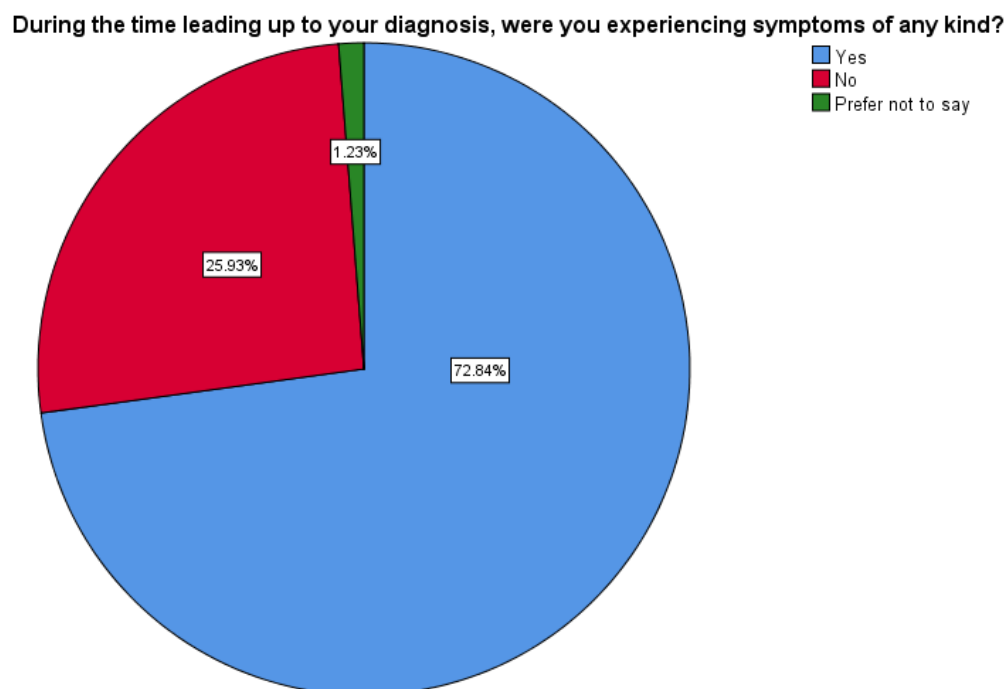


Chart 7. Proportion of participants who experienced cardiac symptoms prior to diagnosis, based on responses to the online patient identification questionnaire (N = 81).

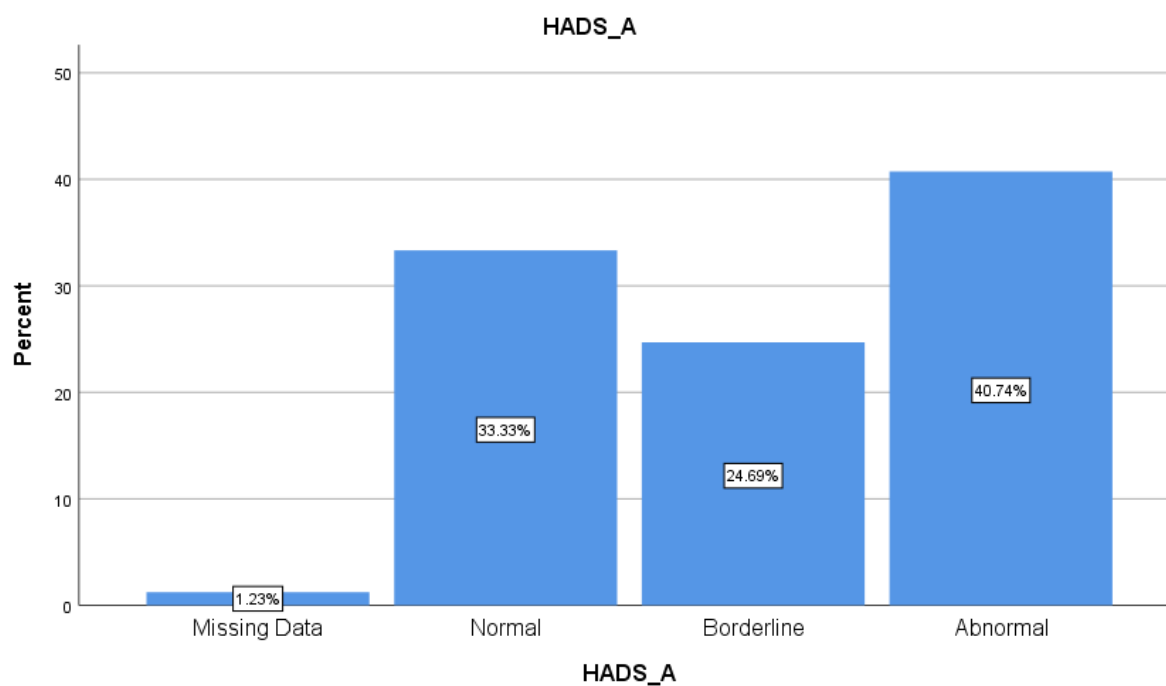


Chart 8. Proportion of participants who scored within the 'Normal', 'Borderline' or 'Abnormal' range for anxiety using responses to HADS-A (and those with whom scores could not be generated due to missing data), based on responses to the online patient identification questionnaire (N = 81).

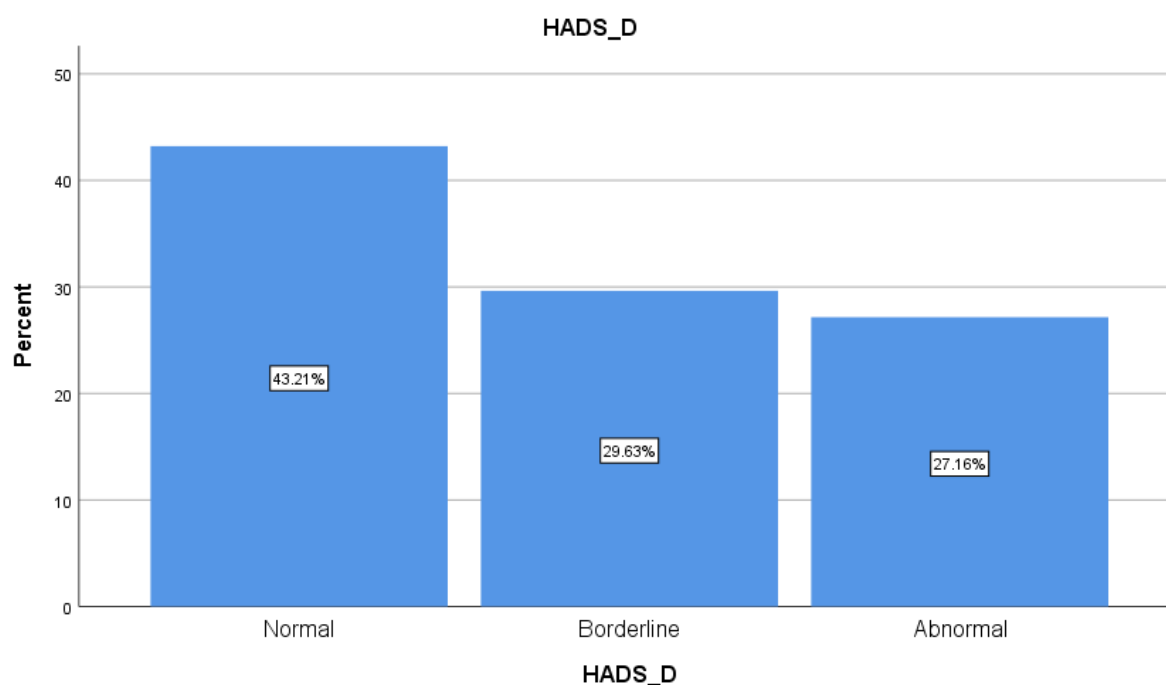


Chart 9. Proportion of participants who scored within the 'Normal', 'Borderline' or 'Abnormal' range for depression using responses to HADS-D (and those with whom scores could not be generated due to missing data), based on responses to the online patient identification questionnaire (N = 81).

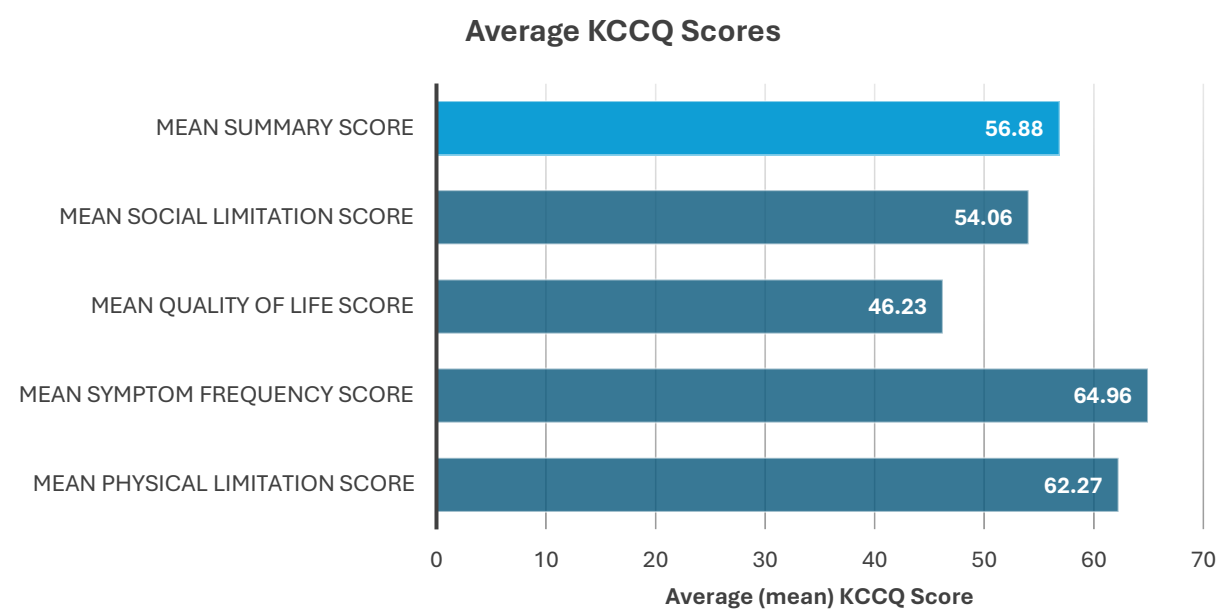
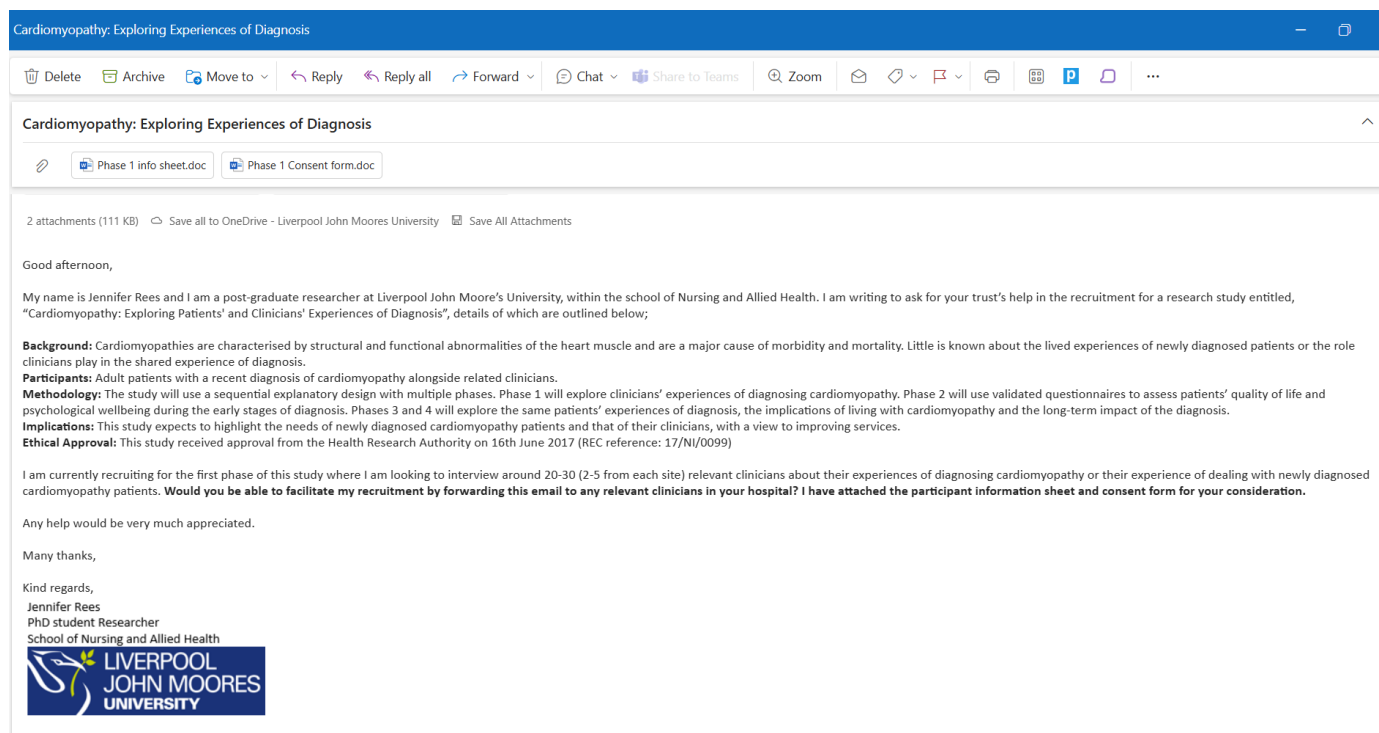


Chart 10. Mean KCCQ sub-section scores (out of 100) and Mean KCCQ Summary score (out of 100), based on responses to the online patient identification questionnaire (N = 81).

Cardiomyopathy: Exploring Lived Experiences of Diagnosis

Appendix 4 – Cardiologist recruitment email

Standardised recruitment email sent to participating NHS trusts (R&D teams or directly to consultant cardiologists' secretaries) to recruit cardiologists for interview, as referenced in page 53.



Appendix 5 – Final interview topic guide – cardiologist interviews

Revised interview topic guide used in interviews with cardiologists, as referenced in pages 56 and 57.

Phase 1	Version: 2.0	13 th September 2017
Overall Research Question	Interview Question	Prompts
Information checking prior to interview -	Can you tell me your job title where you work?	How long have you been working with cardiomyopathy patients?
What are clinicians' experiences of diagnosing cardiomyopathy?	Can you tell me about your first encounter with cardiomyopathy?	Where did you first learn about the condition? Do you undertake any on-going training in cardiomyopathy?
	Tell me about your general experiences of diagnosing cardiomyopathy?	What makes it different to diagnosing other conditions? Has there been a particularly complex/ challenging case that you can tell me about as an example? Can you take me through an example of how you would come to form a diagnosis of cardiomyopathy? Do you diagnose CM often or are patients already diagnosed when they get to you?
	What are the challenges/ benefits when diagnosing cardiomyopathy?	Can you think of a specific time when a CM diagnosis was a particularly challenging or upsetting experience? Can you tell me about a time when diagnosing CM was a positive or rewarding experience?
	How do you explain a diagnosis of cardiomyopathy to a newly diagnosed patient?	Is there a specific process you go through or does it change from patient to patient? Can you give an example of what you would say? How do you know patients have understood what you have told them? Have you had any training in relation to communicating with patients?
IRAS no: 215918		

Phase 1	Version: 2.0	13 th September 2017
How do you manage patient knowledge and expectations?	How do newly diagnosed patients find out information about CM? What information materials are available during the consultation?	
How do patients generally react to a diagnosis of cardiomyopathy?	Any differences between Age groups? Gender? Phenotype? Cause of diagnosis? What is it that patients generally want to discuss first?	
What services are available to newly diagnosed CM patients?	Are there any access criteria or are they available to everyone diagnosed with CM? How do patients access these services? Do they sufficiently meet the needs of newly diagnosed CM patients? Can you think of any way that current services could be improved?	
Final Question: is there anything else that you would like to add that hasn't already been mentioned?		

IRAS no: 215918

Appendix 6 – Patient recruitment poster

Patient recruitment poster displayed in outpatient waiting rooms within participating NHS trusts, and posted in online forums as discussed in page 61.

LIVERPOOL JOHN MOORES UNIVERSITY

Research Participants Needed

Cardiomyopathy: Exploring Clinicians' and Patients' Experiences of Diagnosis

Have you been diagnosed with any form of cardiomyopathy in the last 6 months?

Are you aged 18 or over?

Would you be willing to participate in a short online questionnaire?

Interested?

Simply follow the web-link below:

<https://ljmu.onlinesurveys.ac.uk/cardiomyopathy-diagnosis>

Alternatively, please contact:

Name: Jennifer Rees, PhD Researcher
Email: J.L.Rees@2016.ljmu.ac.uk
Tel: 0151 231 5849

This study aims to explore the diagnosis process in cardiomyopathy by speaking to clinicians and patients like you. This phase of the study involves completing a short questionnaire online about your experiences and feelings, as newly diagnosed cardiomyopathy patients.

This study has been developed to form a part of a PhD thesis, to be assessed by Liverpool John Moores University.


Scan me

Appendix 7 – Participant information documents

Patient information leaflet provided to potential participants, as referenced in page 64. This document was printed double sided then tri-folded into a booklet, therefore it is shown in two parts below.

Cardiomyopathy: Exploring Clinicians' and Patients' Experiences of Diagnosis



[https://ljmu.onlinesurveys.ac.uk/
cardiomyopathy-diagnosis12](https://ljmu.onlinesurveys.ac.uk/cardiomyopathy-diagnosis12)

Have you recently been
diagnosed with any form of
cardiomyopathy?

Are you aged 18+ years?

Would you be willing to complete a
short survey?

If so, we would love to hear from you.
Please read the information in this
leaflet to find out more.



To access the questionnaire,
either scan the QR box below
with your smartphone, or follow
the web-link



This study has received ethical
approval from
the Health Research Authority

Contact Us

Researcher: Miss Jennifer Rees,
PhD Researcher
Tel. 01512315849
Email. J.L.Rees@2016.ljmu.ac.uk

Academic Supervisor: Prof. Ian
Jones, Senior Cardiac Nurse
Tel. 01512314017
Email. I.D.Jones@ljmu.ac.uk

Participants Needed for a PhD Cardiomyopathy Study



"Hello, my name is Jennifer Rees
and I am a post-graduate
researcher from Liverpool John
Moore's University.

Being a cardiomyopathy patient
myself, I am keen to
explore how receiving a
diagnosis of cardiomyopathy in
adulthood may affect our
psychological well-being and
quality of life."



IRAS: 215198

Version 2.0

5th June 2017

Patient information leaflet side 1.

Cardiomyopathy: Exploring Lived Experiences of Diagnosis

What is the purpose of the study?

Understanding the experiences of patients is key when trying to improve services. This study aims to better understand what it is like to be diagnosed with cardiomyopathy, from the perspective of the patient. The information gained from this study will help to identify what patients' needs are during the diagnosis process. It is hoped that the results may also be used to develop and improve services for newly diagnosed patients.

What will happen to the data collected?

This study will make up the second phase of a larger 4-phase study, which will be submitted in the form of a PhD thesis for assessment at Liverpool John Moores University. Results may also be written up for the purposes of publication within related research journals. All data will be securely stored in line with the university and British Psychological Society's (BPS) research guidelines.

How long will it take?

The questionnaire should take around five minutes to complete.

What would participation involve?

Once you have decided to take part, you will be asked to tick some statements to show you agree to participate. You will also be asked some eligibility questions to ensure that you meet all of the criteria we are looking for.

Demographic Information: You will be asked to provide some information about yourself which will help us to identify trends in the results based on different age groups, genders or types of cardiomyopathy.

Scale-style Questions: Next, you will be presented with a series of 22 different statements such as; *"I feel tense or wound up"* and asked to indicate how well the statement represents your feeling over the past week. You will answer by selecting one of four possible answers on a scale. Finally, you'll be given the opportunity to participate further in the study, if you wish.



What if I don't have access to a computer?

You can still take part by contacting the lead researcher and requesting a printed copy of the questionnaire to be posted to you, along with a pre-paid return envelope.

Will my answers remain confidential & anonymous?

The answers you give will be pseudo-anonymized. This means that only the researcher will be able to identify individual responses. This ensures that, up until analysis takes place, you are able to withdraw your answers from the study, if you wish, by contacting the researcher. However, please note that you will not be able to withdraw your data once analysis has begun.

Are there any risks involved?

While there are no direct risks of physical harm, the personal nature of the questions asked, may cause some distress. If this happens and you wish to withdraw from the study, you may do this at any time, without giving a reason, simply by exiting the web browser. Alternatively, you may choose to not answer certain questions by simply leaving the question blank and moving onto the next question.

Do I have to take part?

No. It is entirely up to you to decide whether you would like to participate in the study. You may also change your mind and withdraw your answers from the study at any time, up until data analysis.

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Version 1.0

5th June 2017

Patient participant Information leaflet, side 2.

Study Phase: 1 Version 1.0 - 9th May 2017

LIVERPOOL JOHN MOORES UNIVERSITY

PARTICIPANT INFORMATION SHEET

Title of Project: Cardiomyopathy: Clinicians' and Patients' Experiences of Diagnosis

Name of Researcher and School/Faculty:
Miss Jennifer Rees, PhD student researcher - School of Nursing and Allied Health, Faculty of Education, Health and Community.

You are invited to participate in an interview as a part of a research study. Before you decide whether to participate, it is important that you understand why the research is being carried out, and what participation would involve. Please take time to read the following information. Ask us if there is anything that is not clear or if you would like more information. It is entirely up to you to decide whether you would like to take part or not.

You may only take part in this particular research study if you meet the following requirements:

- You are a registered Cardiologist working within the NHS.
- You are experienced in delivering cardiomyopathy diagnoses, to patients.

1. What is the purpose of the study?
Subasic (2013) highlights the clinical relevance of understanding the patients' lived experiences of cardiomyopathy, arguing that healthcare providers should consider more than just their medical understanding of cardiomyopathy, but also acknowledge the emotional impact on the patient, the implications for their lifestyle, and address concerns raised by immediate family members in order to provide truly holistic care. Unfortunately, little is known about the experiences of patients living with cardiomyopathy, less about their journey towards diagnosis and there is a complete absence of research that focus on the experiences of the clinicians who share this journey. This study aims to explore clinician's experiences of the diagnostic process within cardiomyopathy.

2. Do I have to take part?
No. It is up to you to decide whether to take part. If you do decide to take part, you will be asked to sign a consent form. You are still free to withdraw from the study at any time and without giving a reason. However, please note that you will not be able to withdraw your data from the study once transcription has occurred as the data will become anonymised and impossible to identify.

3. What would participation involve?
Once you have read the information sheet and decided to take part, the lead researcher will agree a mutually acceptable time and place whereby the interview can take place. Interviews may be carried out over the telephone where necessary. Upon arrival at the interview, you will be asked to sign a consent form stating your willingness to participate. If the interview is being carried out over the telephone, an electronic copy of the consent form will be emailed to you and you will be asked to sign and return this form electronically, prior to the start of the interview. With your permission, the interviews will be audio-recorded so

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that I can engage with you in conversation rather than focusing on note taking. For telephone interviews, this will mean that a speakerphone setting will be used in order to allow the interview to be audio-recorded. In both cases, you will be informed when the recording device is switched on and off. The interview should last between 30 minutes to one hour, although it is not limited to this timeframe. During the interview, you will be asked to participate in a conversation about your experiences of diagnosing cardiomyopathy. Topics covered may include:

- Your experiences of delivering a new cardiomyopathy diagnosis.
- Ways in which you explain cardiomyopathy to newly diagnosed patients.
- Challenges to the process of delivering a cardiomyopathy diagnosis.
- Facilitators to the process of delivering a cardiomyopathy diagnosis.
- Exploring the extent to which written information materials, meet the needs of your newly diagnosed patients.

At the end of the interview you will be thanked for your participation and provided with further contact information for the research team, should you have any further questions or concerns about the project.

4. Are there any risks / benefits involved?
There may be some travel involved as all participants will need to meet at an agreed location to conduct the interview, however, interviews will be arranged at your convenience and can take place over the phone or at your place of work.

While there are no direct risks of physical harm, the reflective nature of some of the topics discussed, may evoke some feelings of upset. If this happens and you wish to withdraw from the study, you may do this at any time, without giving a reason. Alternatively, you may choose not to answer certain questions, in which case we can move onto the next topic.

5. How will anonymity and confidentiality be upheld?
All data will be anonymised in order to protect participants and their patients. At the point of transcription, all identifying features of both the participant and any patients referred to during the interview, will be removed. This will ensure all data is anonymised prior to analysis and dissemination. The audio-recording of the interview will be destroyed after transcription has finished.

6. What will happen to the data collected?
This study will make up the first phase of a larger 4-phase study, which will be submitted in the form of a PhD thesis for assessment at Liverpool John Moores University. This study may also be written up for the purposes of publication and wider dissemination.

7. How will my data be stored?
All data relating to the study will be securely stored in line with LMMU and British Psychological Society's (BPS) guidelines. This ensures that all data is stored electronically on a password protected file on the LMMU network and where necessary, any hard copies of data such as consent forms will be stored in a locked cabinet within the researcher's office. After the study has ended, the data will be archived and kept on site at LMMU for a minimum

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of 5 years. Any audio-recordings of the interviews will be destroyed after transcription by electronically deleting all versions of the file from the recorder and any associated computer.

This study has received ethical approval from the Health Research Authority.

Contact Details of Researcher: Miss Jennifer Rees, PhD Researcher
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Email: j.j.rees@lmmu.ac.uk

Contact Details of Academic Supervisor: Prof. Ian Jones, Senior Cardiac Nurse and Academic
Tel: 01522314017
Email: i.jones@lmmu.ac.uk

If you have any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@lmmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

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Cardiologist participant information sheet.

Appendix 8 – Final interview topic guide – patient interviews

Interview topic guide used during interviews with patient participants as discussed in pages 66 and 68.

Phase 3

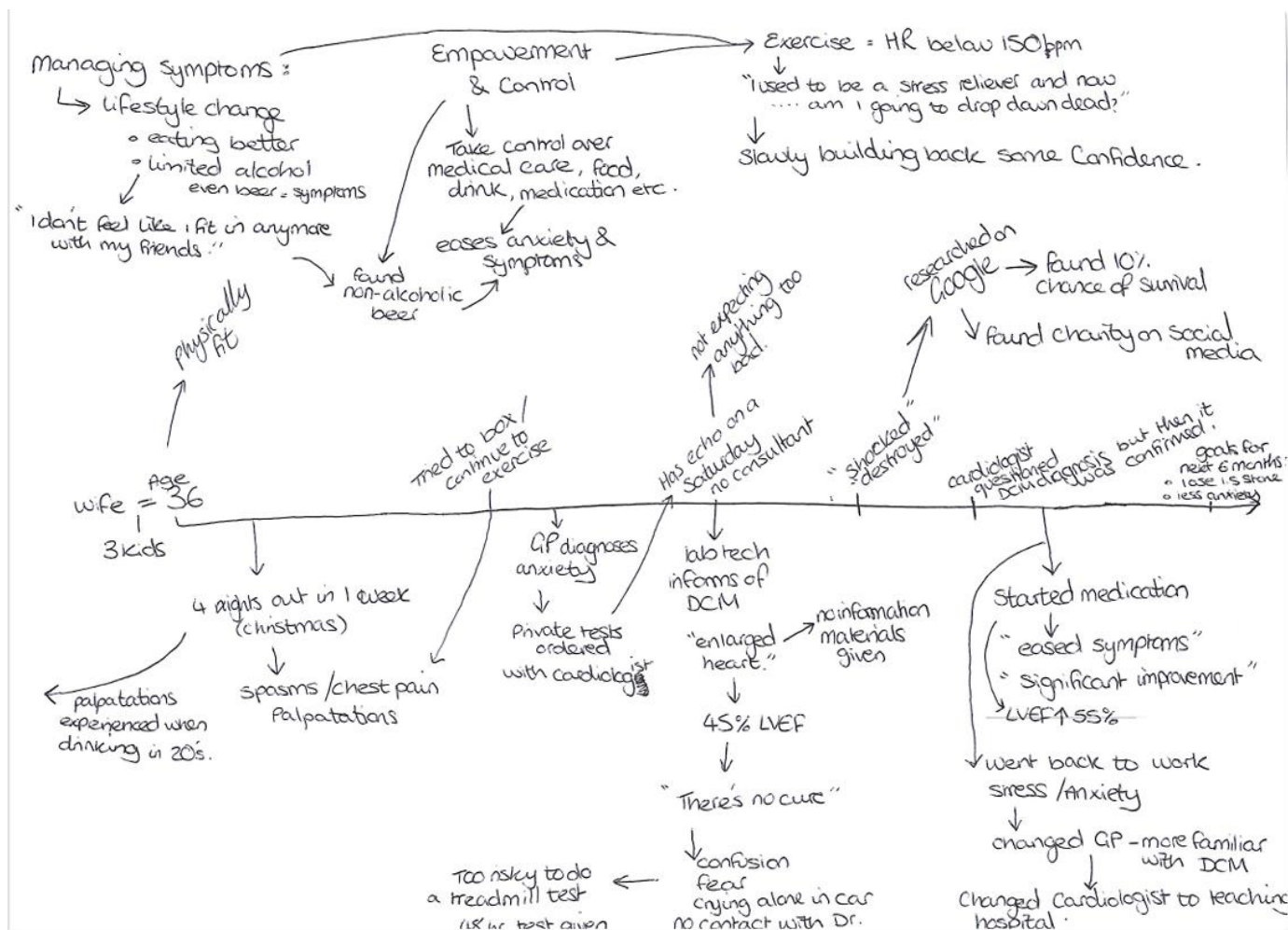
Version 1.0

9th May 2017

Overall Research Question	Interview Question	Prompts
<i>Fact-checking/ Overview</i>	<i>Can you tell me a bit about yourself?</i>	<i>How old are you? Do you work? Do you have a support network at home?</i>
What is the journey towards diagnosis like, from a patients' perspective?	Can you tell me about your diagnosis?	When?
		Where?
		By who?
		Write a timeline.
	How was cardiomyopathy explained to you?	Was this clear?
	What did you think about the level of services and understanding you received from your clinical team?	What services were offered?
		How did your clinical team help you through the adjustment period?
What impact, if at all, does a cardiomyopathy diagnosis have on the patient's life?	How did you feel when you learnt you had cardiomyopathy?	What were your immediate thoughts?
		How did you react?
	What does cardiomyopathy mean to you?	
	How much has the written information available to you, helped you?	How accurately do they represent your experiences of diagnosis?
		Are there services/information you think are missing?
What impact, if at all, does a cardiomyopathy diagnosis have on the patient's life?	Has cardiomyopathy had an impact on your daily life?	In what way?
		Career/Family/ Financial/ Other Health implications
		Impact on short-term and long-term plans.
	What are your expectations for the future?	For example, the next 6 months.
		In terms of Health, Family, Career, Other

Appendix 9 – Patient interview timeline

Example of timeline that was co-created by interviewer and patient participant during interview, as discussed in page 68.



Appendix 10 – Handwritten IPA examples – individual transcript level

Example of a completed handwritten analysis using IPA, at the individual transcript level, as described in page 71.

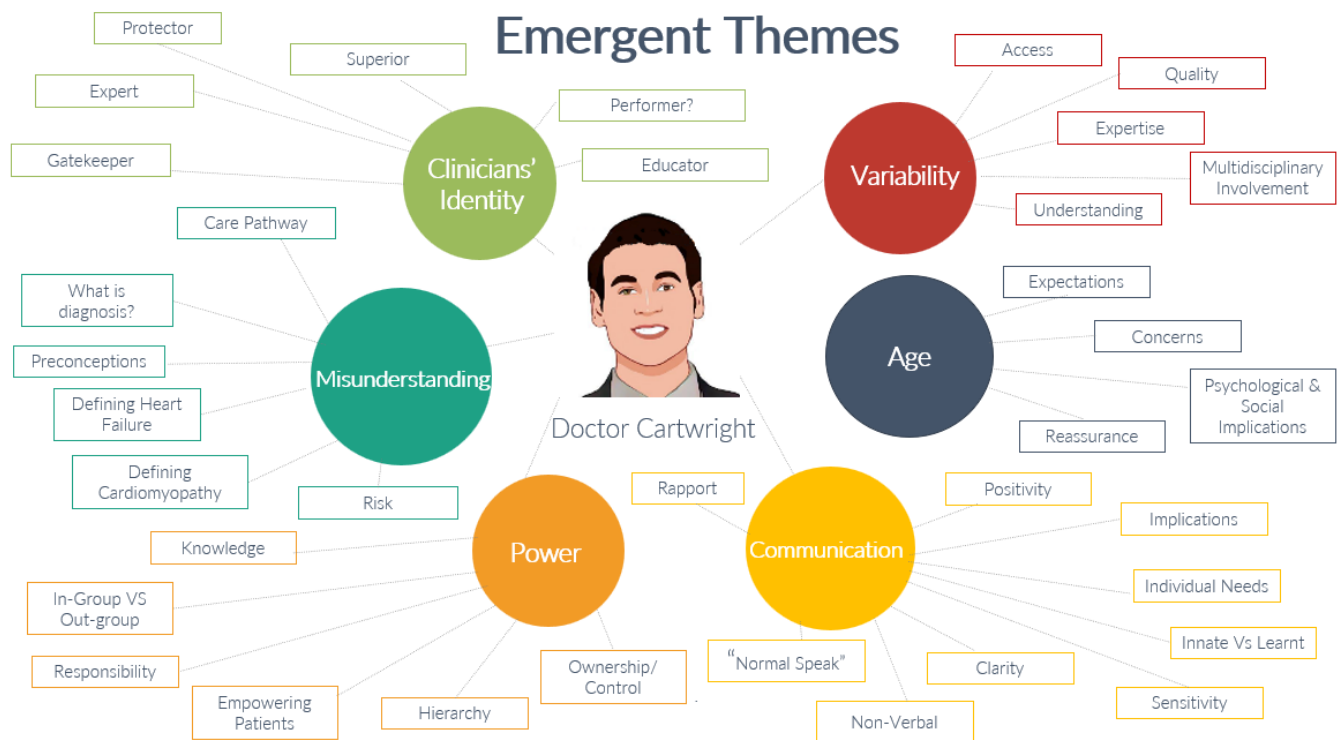
Line No.	Transcript	Coding			Theming	Personal Reflections
		Description & Content	Language Use	Interrogative	Emergent Themes	
574. 575. 576. 577. 578. 579. 580. 581. 582. 583. 584. 585. 586. 587. 588. 589. 590. 591.	R Probably if the patients focusing on them it's about their symptoms and making them feel better. I think that takes precedent and making them feel better. 'Can you fix this?' is probably the undertone to this or 'can you make it go away?' if you got a step further. That's not easy because you can't physically...it's done, you know, it's sort of a matter of getting used to this. Often, part of the conversation is you may be feeling these things now, but the longer you have a diagnosis the more easy it will be to deal with it. there's a sense of, once you get a bit of distance from ground zero it	patient expectations perhaps going against known perception of Dr's "ground zero" ↓ evolve imagery of an attack war.		Dr's make it better?	managing expectations from patients & from self ↓ clinical identity ↓ • fixer • warrior • fighter	May be my own perception ↓ I have said this to my son

Example. Handwritten annotation of transcript showing process of analysis at individual transcript level

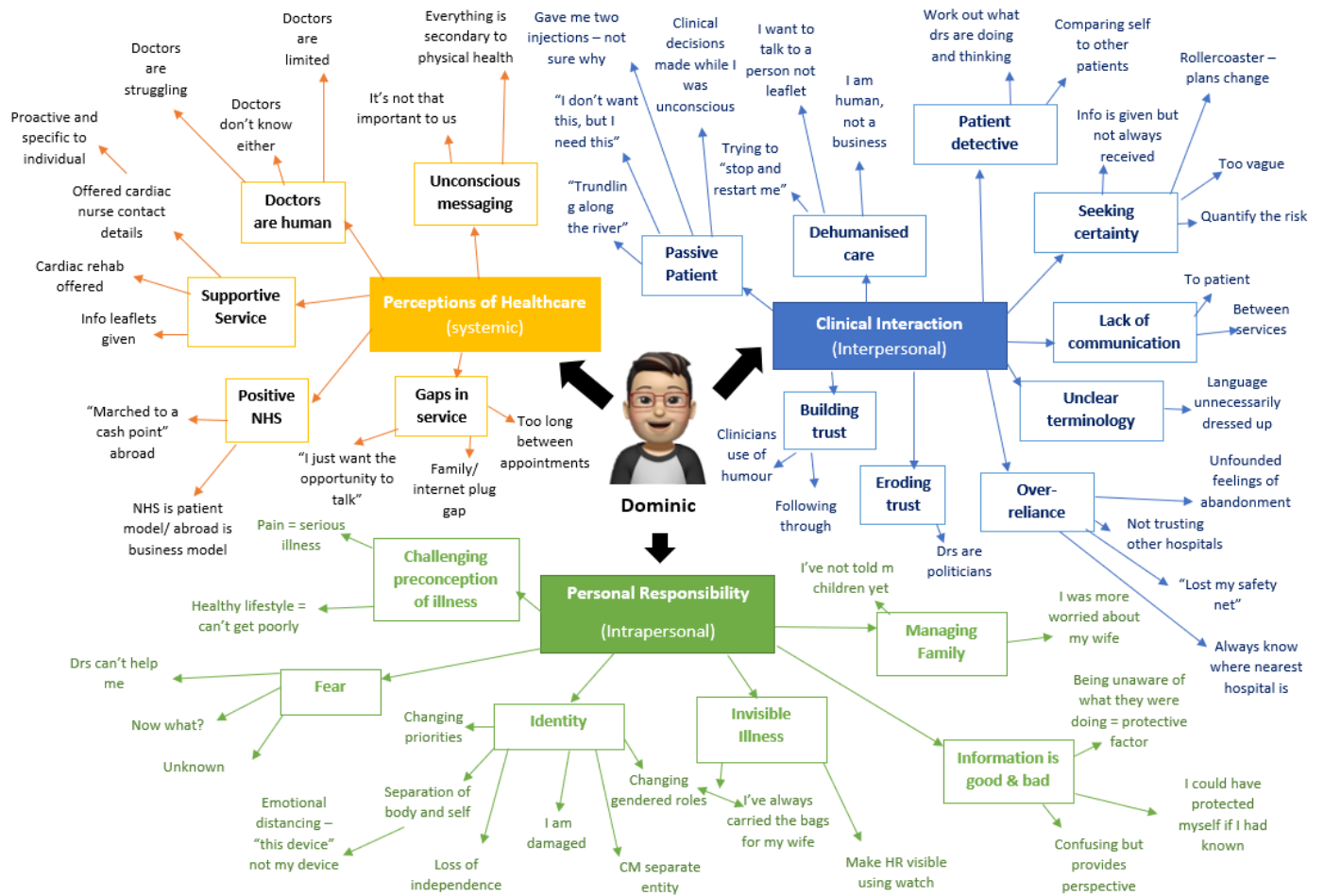
(initial coding and emerging themes) using a transcript from interviews with cardiologists.

Appendix 11 – Examples of mind map of emergent themes and codes – individual transcript level

Example of a mind map of emergent themes constructed to visually represent initial codes and emergent themes and to support IPA analysis when moving from individual transcript analysis to multiple transcript analysis, referred to in page 72.



Example 1. Mind map of initial codes and emergent themes identified in data from a cardiologist interview.



Example 2. Mind map of initial codes and emergent themes identified in data from a patient interview.

Appendix 12 - IPA table: example of emergent themes – multiple transcript level

Example of IPA analysis at multiple transcript level, using a Microsoft Word document to combine emergent themes and identify super-ordinate themes, as described in page 72.

Awareness	Quotation	Notes
Access	<i>"Sometimes they're told in hospital that they've got an echo that looks normal. I saw a guy two weeks ago who that happened to four months ago and the entire time he's been getting more and more wound up, fearing that he's going to die because he does his own reading, the internet says there's a risk of sudden cardiac death - "</i> (116-126)	Patient left without answers will seek out information for themselves. Importance of having access to correct information/ counselling throughout diagnosis?
	<i>"I've got loads of information behind you there that I give my patients."</i> (176-178)	Importance of access to information.
	<i>"you go to the national conferences, you see the same people from the same places at every meeting and this is where supposedly everyone's being updated about developments in this and developments in that and end treatments. The same people go and they're from the same 15 hospitals"</i> (254-263)	Access to education for clinicians not reaching the right people. Non-specialists should be able to access these conferences too. If they can but choose not to engage – why?
Regional Awareness	<i>"you go to the national conferences, you see the same people from the same places at every meeting and this is where supposedly everyone's being updated about developments in this and developments in that and end treatments. The same people go and they're from the same 15 hospitals"</i> (254-263)	Education for clinicians not currently reaching non-specialist centres. Why is this? Same 'experts' attending only widens the knowledge gap between regional and specialised services.
Clinical Labels	<i>"Despite interest it wasn't very well understood and when doctors don't understand something very well generally you can't explain things very well to patients."</i> (43-48)	CM – Did not know what it was so described it leading to use of descriptive term. Labelled with clinicians in mind.
	<i>"The term hypertrophic is not adequate. It's not a diagnosis. It's a descriptive term. It's daft. But, you have to spend a reasonable amount of time with a patient to be able to explain what thickening is, what hypertrophic cardiomyopathy is"</i> (141-149)	Misunderstanding and usefulness of current clinical label assigned to HCM.
	<i>"I would explain that the diagnosis is not really a diagnosis. It's a descriptive term, hypertrophic technically they've developed cardio/heart, myo/muscle, pathy/problem, technically a heart muscle problem. You often see that people go, oh, okay, I get it."</i> (302-310)	Breaking down the 'code' to make it understandable. Usefulness of current clinical language.

Example. Multi-transcript level analysis of cardiologists' interview data.

Appendix 13 – IPA table: example of superordinate themes – multiple transcript level

Example of table produced during analysis when working at the multiple transcript level referenced in page

73. Individual quotes all contributing to the same superordinate theme were listed, grouped into sub-themes, and reflected upon.

Evolving Identity		
Quote	Sub-theme	Notes
"He comes back in about five minutes later, so I still had all this jelly, and I was laying on the bed" (Henry, 159-161)	Passive Patient	Feeling vulnerable, just waits whilst laying in a vulnerable position, half dressed, with jelly on his chest, being scanned by a stranger using technology he doesn't fully understand.
"They wired me up and then they told me to sit down and don't move and they said, 'you're not going home'. That was that." (Alex, 54-57)	Passive Patient	Authoritarian clinician. They did this to Alex. He reported feeling like he had no choice.
"normal people it's pumping at 55% or higher and yours is at 45'" (Henry,178-180)	Unconscious NHS Messages	You are no longer normal – you are less than normal
"'Fight for every heartbeat' -I was like you've got to be bloody kidding me. It literally does feel like you're doing that, but to be told that as a slogan was a bit like, fight for it, what do you mean fight for it? I should just be allowed to have my heartbeat" (Charlotte, 1000-1006)	Unconscious NHS Messaging	Mismatch between messages intent and interpretation: Intent = to encourage resilience and refer to inner strength of patients Charlotte's perception = you have fundamentally changed and are no longer entitled to live without a fight.
"[Doctors] are frightened of patients having feelings and they want to, oh god just shut this one down and get them out." (Kate, 1052-1058)	Dr Robot	Kate felt dismissed when emotional. She interprets clinicians and unreceptive and even fearful of her emotions.
"I'm laying down, there's water coming out of everywhere...at one point my body just completely failed." (Charlotte, 805-807)	Separate Entities	There's the 'my body' and there's 'me' = separation
"My body's trying to relax and they come on (palpitations)" (Henry, 1326-1327)	Separate Entities	Self is separate to body. Palpitations associated with CM which is viewed as separate to body and self.
"We had an amazing week with the family, but I ate and drank, you know...I paid for it with my shortness of breath, tiredness." (Henry, 917-923)	Separate Entities	Symptoms= punishment or penalty that must be paid for enjoying life as before. CM affects body.

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