

Living with a Violent Heart: The Lived Experiences of Patients with Hypertrophic Cardiomyopathy (HCM)

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Abstract

Background

Hypertrophic cardiomyopathy (HCM) is a chronic and complex condition that requires patients to adapt throughout their lives. Therefore, understanding the lived experiences of individuals with HCM is vital to developing holistic nursing care.

Objective

This qualitative study aimed to explore the lived experiences of patients with HCM.

Methods

Using a hermeneutic phenomenological approach, this study applied Van Manen's six-step method to explore the meanings that patients ascribed to their lived experiences. Twelve semi-structured interviews were conducted with 11 patients (six men and five women). The data analysis was performed using Van Manen's three thematic strategies: detailed, selective, and holistic.

Results

The identified themes were: (1) a long journey of diagnosis and stereotypical treatment; (2) disturbed corporeality and discomfort; (3) living with fear and anxiety; (4) adopting a new lifestyle; and (5) living with tension of revealing and concealing. These themes were synthesized into the overarching theme "living with a violent heart."

Conclusions

This study elucidates the lived experiences of individuals with Hypertrophic Cardiomyopathy (HCM), highlighting a trajectory marked by diagnostic delays and significant treatment challenges. The participants described profound fear, a sense of death, and pervasive anxiety stemming from the heart's unpredictable condition. In response, they actively adopt lifestyle adaptations to manage their conditions. These findings highlight the critical need for healthcare providers to transcend purely clinical care by delivering personalized and holistic support tailored to patients' lived experiences.

Introduction

Hypertrophic cardiomyopathy (HCM) is a prevalent cardiovascular disorder affecting individuals worldwide. Affecting approximately 1 in 500 individuals globally, HCM is the most common inherited

cardiovascular disease.^{1,2} This genetic disease causes left ventricular hypertrophy, tissue fibrosis, and diminished compliance, which can lead to severe complications such as sudden cardiac death.^{3,4} It may occur asymptotically or with mild symptoms for extended periods, with many patients leading their full lives with minimal or no evident clinical manifestations.⁵ However, this disease has the potential for severe, life-threatening complications, including serious symptoms such as shortness of breath, palpitation, and syncope, as well as an increased risk of atrial fibrillation, ventricular arrhythmias, heart failure, and sudden cardiac death.⁶ Sudden cardiac death can be the initial clinical manifestation, particularly in younger individuals.⁷

The burden of hypertrophic cardiomyopathy (HCM) extends beyond its clinical symptoms and profoundly impairs daily activities and quality of life. Serious symptoms such as dyspnea, fatigue, and chest pain directly restrict physical activity and disrupt performance in daily life, leading to significant functional limitations.⁸ Furthermore, these persistent physical challenges are strongly associated with psychological fragility, including elevated rates of anxiety and depression⁹, which subsequently diminish social functioning, work productivity, and overall well-being.¹⁰ Moreover, the unpredictable nature of the condition and persistent risk of severe complications, such as lethal arrhythmias, impose a substantial and ongoing psychological burden.¹¹ However, it can affect every aspect of daily life for those living with HCM.

While the etiology, clinical presentation, and management of hypertrophic cardiomyopathy (HCM) are well documented, studies have been dominated by a quantitative paradigm, largely overlooking the patient's subjective lifeworld. In a qualitative study, Borsari and colleagues identified anxiety, fear, and uncertainty as central themes, revealing the profound emotional impact of living with HCM.¹² Another qualitative interview study developed a conceptual framework outlining the primary symptoms of HCM, such as shortness of breath, palpitation, fatigue, dizziness, and chest pain, and their significant impact on patients, encompassing both physical limitations and emotional difficulties.¹³ Further research has illustrated that the diagnostic and treatment process for individuals with HCM is marked by significant challenges and a complex spectrum of emotional responses, from anxiety and denial to gratitude and acceptance.¹⁴

Understanding patients' lived experiences is increasingly recognized as a cornerstone of quality healthcare and a vital component of health humanities research.¹⁵ As emphasized by prominent nursing theorist Fitzpatrick, the meaning patients ascribe to their illness experiences is crucial for delivering truly effective and humanistic care.¹⁶ Hypertrophic Cardiomyopathy (HCM) is not merely a clinical diagnosis characterized by myocardial thickening; it is a condition that profoundly alters a person's life. While the pathophysiological aspects are well documented, the subjective, lived experience—what it feels like to inhabit a body with HCM, to navigate life under its shadow—remains largely concealed in the medical literature. Few studies have been conducted on the lived experiences of patients with HCM in Iran. Therefore, this study aimed to explore the lived experiences of patients with HCM.

Methods

Design, Sample, and Setting

This study adopted a hermeneutic phenomenological approach based on Van Manen's method to reveal participants' lived experiences and to identify the fundamental meanings of their stories. Through reflection and interpretation, this study attempts to grasp how individuals make sense of their experiences and connect them with the universal meanings of human life. Table 1 outlines van Manen's method and the researchers' tasks in this study.

Table 1. Steps of van Manen's Method and its usage in the current study

Insert Table 1 Here

Participants

The participants in this qualitative study were individuals diagnosed with HCM. Twelve in-depth semi-structured interviews (40–60 minutes each) were conducted with 11 participants (six men and five women). The inclusion criteria were: (1) age ≥ 18 years, (2) established HCM diagnosis based on clinical documentation, (3) ability to provide informed consent (oral and written), and (4) sufficient communicative competence to participate in an interview. The exclusion criteria included severe neurological conditions (such as stroke, neurodegenerative disease, or severe aphasia), severe psychiatric disorders (e.g., severe depression), or cognitive impairment (dementia, MoCA score < 26) that could compromise the interview process. Individuals with significant comorbidities such as ischemic heart disease, heart failure, or diabetes were also excluded, as these conditions could confound the study findings.

Table 2: Demographic characteristics of study participants with hypertrophic cardiomyopathy

Insert Table 2 here

Data collection

Individual semi-structured interviews were used to collect data, incorporating both open- and closed-ended questions to elicit in-depth narratives. participants were recruited from the cardiology clinics of Ardabil University of Medical Sciences between March 2023 and December 2024. All interviews were conducted by the first author (J.R.) in a private, quiet room at the university hospital or at the participants' preferred location. Each interview lasted between 40 and 60 minutes, with an average duration of 50 minutes. In addition to audio recordings, the researcher documented non-verbal signals—such as body gestures, facial expressions, and other forms of body language—that could not be captured by audio alone. Sample interview questions included:

- "Tell me what a typical day looks like for you."

- "Tell me a little about your illness—what's been your experience with it?"
- "How has your illness changed your life? What signs or symptoms do you deal with?"
- "What worries or feelings come up for you when you think about your illness?"
- "How are things with your family and other people in your life?"

All interviews were audio-recorded and transcribed verbatim into plain text for analysis immediately following each session. Data collection continued until theoretical saturation was achieved, meaning no new themes or insights emerged from subsequent interviews. Written informed consent was obtained from all participants prior to each interview, and they were assured of their right to withdraw at any time without consequence.

Data analysis

In this study, we approached data analysis as an iterative and cyclical process rather than as a linear one. We continuously managed and interpreted the data to uncover the underlying themes and patterns. Following Van Manen's phenomenological approach, the authors focused most intensely on reflecting on and interpreting the core themes within participants' experiences. The first author transcribed all the recorded interviews verbatim and independently conducted thematic analysis in collaboration with the corresponding author. Additionally, the authors transcribed other data, including life narratives, observations, personal reflections, and written materials, into text for analysis. Using Van Manen's thematic analysis method, meaning units and patterns within the textual data were systematically identified and interpreted. The three strategies described by Van Manen, holistic, selective, and line-by-line, were used to isolate meaning units ¹⁷.

Rigor

This study was conducted using principles of hermeneutic phenomenological rigor. The authors maintained reflexivity by maintaining a continuous journal of their pre-understanding of patients with HCM and how these were challenged by the data. Interviews were conducted in an in-depth and meticulous manner, inquiring about all aspects of patients' experiences. ¹⁸ In addition, the interpretive process was carefully recorded for an audit trail, including analysis memos and theme development activities. The authors adhered to a thick description to embed the findings within the specific contexts of the participants' lives. Member checking was a key rigour strategy during theme development to ensure that the findings accurately reflected the lived experiences of patients with HCM. The analysis entailed in-depth dialogue with the transcripts, carefully noticing language and metaphor as a means of constituting a coherent and persuasive interpretation of patients' life stories. Finally, the findings were compared with the literature to place the interpretive conclusions in the broader scholarly discussion. ¹⁹

Ethical considerations

Ethical approval was obtained from the Ethics Committee of the Research Deputy at Ardabil University of Medical Sciences. Prior to data collection, the participants were fully informed of the study's purpose,

and written and oral consent was obtained, which included permission to audio-record the interviews. The participants were assured that their involvement was voluntary and would not affect their medical care. All personal and demographic information was kept confidential, and the participants retained the right to withdraw from the study at any time.

Findings

The lived experiences of patients with HCM revealed five main themes: “Long journey of diagnosis and stereotypical treatment,” “Disturbed corporeality and discomfort,” “Living with fear and anxiety,” “Adopting new lifestyles,” and “Living with tension of revealing and concealing.” These individual themes were further synthesized into a comprehensive and overarching theme titled “Living with a Violent Heart,” which captures the entirety of the patients’ experiences.

Long journey of diagnosis and stereotypical treatment

In the initial stages of the interviews, most participants immediately began to speak about the challenges surrounding disease diagnosis and therapeutic management. They stated that the process of establishing a definitive diagnosis was difficult, often resulting in initial, erroneous, and stereotypical diagnoses in the majority of patients. The first participant stated: *“The first time I was hospitalized, they checked my heart for ischemic disease, but my heart muscle disease was not considered at all.”*

Another common stereotype reported by participants was the attribution of their symptoms to psychological problems by cardiologists before a definitive diagnosis was reached. Participant 2 stated, *“My heart rate was high and my physician believed that I was suffering from a mental or stressful problem. He treated me with Propranolol and Alprazolam for years. After 10 years and after visiting several specialist doctors, a cardiologist finally diagnosed my cardiomyopathy and prescribed appropriate drugs”.*

A frequently reported source of misdiagnosis arises when patients present with early manifestations of cardiomyopathy, such as recurrent palpitations. In these cases, the absence of overt structural abnormalities on the initial echocardiogram often leads clinicians to overlook the underlying pathology, which subsequently progresses to cardiac enlargement. Participant 3 emphasized: *“I was experiencing daily palpitations and chest discomfort and constantly complained about these symptoms to my doctor. In my scheduled visits he [cardiologist] used to run an EKG and an echocardiography, and finally just told me I had no problem. Years later, when my condition worsened, that same doctor informed me that my heart was enlarged.”*

Disrupted Corporeality and Discomfort

An important part of the participants’ narratives was profoundly centered on their body experiences; they meticulously detailed the manifestations of their illness, describing how specific symptoms—from palpitations to debilitating dysrhythmia—directly influenced their physical body and self-perception. The

first participant, a 62-year-old man, stated, *"When I place my hand on my chest, I can actually feel it rise and fall with the violent thrumming beneath. Sometimes, it feels like my heart will burst out of my chest."*

Participants' narratives revealed that they were constantly preoccupied with their disease, which changed their feelings and imaginations about their heart. Participant 5 stated, *"I constantly think about my heart and its irregular working. Sometimes, I can't get my mind off it for hours. I focus on its beating and become completely absorbed. Overall, my attitude toward my heart has disturbed. I feel someone has taken my heart out and replaced it with a bigger one."*

Living with fear and anxiety

Participants' experiences highlighted a persistent sense of fear and anxiety stemming from the unpredictable future of their heart conditions. Individuals living with HCM express anxiety about cardiac arrhythmias, especially those that can cause sudden episodes of syncope. Participants reported a constant fear of sudden death with heightened concern about the possibility of dying during sleep. The symptoms and complications associated with HCM further exacerbate anxiety, as these manifestations are often linked to life-threatening arrhythmic events and progressive heart dysfunction. Some patients described their heart condition as highly unpredictable, noting episodes where their heartbeat became irregular, paused, and then suddenly restarted —experiences that were both dangerous and deeply distressing. Participant number five, a 19-year-old man said,

"I was in the swimming pool, and my heart rate increased so much that I truly felt like I might pass out right there. It was like I was going to die. Even now, the arrhythmia causes me terrible distress, and I feel like my heart is bursting. I'm constantly expecting something bad to happen. The worst part is that the arrhythmia gives me absolutely no warning; it can hit at anytime and anywhere."

The participants' lived experiences revealed a deep intertwining of fear and anxiety in the presence of an implantable cardioverter defibrillator (ICD). Many have described a constant underlying anticipation that the device might activate unexpectedly during an arrhythmic episode, delivering a sudden shock. This ever-present expectation shaped their emotional landscapes, intensifying their vulnerability and psychological distress. The unpredictability of ICD activation was a profound source of anxiety, as the device's function has been occupying their everyday consciousness and significantly impacting their sense of safety and well-being.

Participant 1 expressed: *"The device in my chest that monitors my heart rate can activate at any moment, whether I'm asleep or awake. Because I never know when it will trigger, I'm constantly waiting for that shock. This persistent anticipation is incredibly frustrating."*

Adopting new lifestyles

Participants consistently reported significant changes in their habits and daily lives following disease progression, often shifting toward establishing new norms. Analysis of this portion of their narratives led to the main theme of 'Adopting New Lifestyles.' This theme refers to limitations and finding new norms.

Participant 6 said, *"My illness has completely taken away my mobility. I can't exercise or keep up with my work like I used to; I have to walk slowly just to avoid worsening my heart condition."* An analysis of the participants' narratives revealed that over time, they gradually developed and implemented a range of innovative coping strategies and self-management methods to effectively mitigate the daily symptoms of Hypertrophic Cardiomyopathy (HCM). Participant 4 highlighted this physical weakening, noting, *"My illness has completely taken away my mobility. I can't exercise or keep up with my work like I used to; I must walk slowly just to avoid from suffering palpitations."* Participant 6 stated, *"I've been living with this condition for a long time now, and I know how to manage it. If I feel dizzy, I don't wait for help so I put my legs up on the sofa, and that usually stabilizes my blood pressure somewhat. Also, if my palpitations worsen, I immediately take a dose of Sotalol."*

Participant 11 also stated, *"I have been living with this disease for several years now, and I have come to recognize my own limitations. I am a teacher, and when I stand for long periods, my heart palpitations increase. I try to sit while teaching to reduce the occurrence of palpitations."*

Living with tension of revealing and concealing

A significant part of the lived experiences of people with HCM is deciding whether and how to tell others about their heart condition. They described a complex emotional process of sharing their disease with relatives, friends, and colleagues. On one hand, revealing their diagnosis could bring comfort and support, as it allowed others to understand their needs and adjust their expectations with greater realism. This openness often fostered empathy and practical assistance, helping ease the burden of managing their illness. Participant 7 said, *'Sharing my diagnosis is a complicated choice, but it often helps people see what I'm going through. Once they know, they don't expect as much from me physically, and they're much more willing to support me when things get tough'*

At the same time, many felt vulnerable or distressed when it came to opening up about their illness. They worried that telling people might lead to them being judged or treated differently. Some also feared that sharing their diagnoses would only cause unnecessary worry for their loved ones, potentially straining their relationships or leaving them feeling more isolated. Participant 8 stated: *"The hardest part is dealing with the rumors at work. Some colleagues have been whispering that I'm disable. Seeing them talk behind my back and realizing they no longer trust my abilities is incredibly discouraging"*

Participant 9 said, *"After our son was born, my wife asked the doctor to test him because of my HCM. That was the moment I realized just how much she had been worrying that I might have passed the condition down to him."*

Discussions

This study explored the lived experiences of patients with HCM, revealing five main themes: long journey of diagnosis and stereotypical treatment, disrupted corporeality and discomfort, living with fear and anxiety, adopting new lifestyles, and living with the tension of revealing and concealing. These themes

collectively formed a comprehensive overarching theme entitled '**Living with a Violent Heart**,' which shows the phenomenon of suffering heart described by patients.

As presented in the first theme, the lived experiences of patients revealed that obtaining a definitive diagnosis was often a long journey accompanied by various events and challenges that affected their lives. This journey typically began with confusion, as the patients reported that they initially received only a general diagnosis such as 'heart disease' or psychological labels, which delayed them from receiving effective and appropriate treatment. In some participants, a delayed diagnosis resulted in more severe clinical outcomes. A prior study found that HCM is often misdiagnosed, noting that some patients fail to meet the standard diagnostic criteria despite the clinical presence of the disease.²⁰ Consequently, misdiagnosis can lead to unnecessary family screenings, which may cause anxiety and result in the inefficient use of healthcare resources. These findings highlight the importance of specialized cardiomyopathy centers in ensuring the accurate diagnosis and appropriate management of HCM ²¹. Misdiagnosis in HCM stems from a combination of the disease's clinical presentation, the difficulty in differentiating it from other cardiac conditions and phenocopies, the complexities of advanced imaging and genetic testing, and systemic barriers within healthcare.² Insufficient specialist knowledge often contributes to misdiagnosis, which can result in inappropriate treatment and medication. This reality was clearly reflected in the participants' experiences in this study. A study published by Zeitnick et al. reported that misdiagnosis commonly occurs in patients with cardiomyopathy, can delay the correct diagnosis, and can lead to negative consequences.¹⁴ The American College of Cardiology (ACC) and American Heart Association (AHA) guidelines also recommend referring patients with suspected HCM to a comprehensive center for specialized diagnosis and management.²² It is necessary for cardiologists and cardiac specialist nurses to benefit from continuing education courses and have special sensitivity to patients with cardiomyopathy. Another study conducted by Magnuson et al. on the lived experiences of cardiomyopathy showed that the diagnosis of cardiomyopathy is often delayed, and even incorrect diagnoses may be made. In addition, it was reported that patients were concerned about the lack of knowledge of healthcare specialists regarding hypertrophic cardiomyopathy, which is consistent with the findings of the present study.²³

The theme of disturbed corporeality and discomfort in patients with HCM demonstrates how altered heart function changes body perception and image. For instance, participants emphasized that suffering symptoms, such as cardiac dysrhythmias and palpitations, force them to immerse in and focus on heart function. In addition, the patients narrated that they used to check the pulse rate and rhythm from time to time anywhere. These additional actions distract their attention from the normal life world to engage in heart function. Indeed, symptoms are not simply symbols of the disease; they are deeply related to patients' mentality and sense of meaning in life. In a phenomenological study, Missel et al. explored the experience of illness symptoms and revealed that both acute and chronic illnesses alter body presence and change body perception from silent to intrusive, which can lead to existential disturbance and feelings of helplessness.²⁴

This study revealed that living with hypertrophic cardiomyopathy (HCM) often leads to significant fear and anxiety, mainly due to falling into arrhythmia cycles, suffering palpitations, and possible sudden cardiac death. The patients emphasized that the greatest source of fear was the risk of sudden cardiac death. A previous phenomenological study reported chronic fear and uncertainty among patients with HCM, which can increase the disease burden.²⁵ As observed in the current study, another notable cause of fear and anxiety was the presence of an implantable cardioverter defibrillator (ICD). Although the ICD can be lifesaving by delivering electric shocks to restore a normal heartbeat, the device itself can provoke fear and anxiety owing to the anticipation of sudden shocks to the heart. Abbasi et al. reported that living with an implantable cardioverter defibrillator can lead to fear because of device malfunction, death during shock, and pain due to shock.²⁶ Moreover, anxiety has been introduced as one of the main predictors of poor prognosis in patients with HCM and should be assessed and managed to improve outcomes in patients living with HCM.⁹

Adopting new lifestyles was another theme or finding that emerged from the lived experiences of patients with HCM, reflecting meaningful changes that patients had to adhere to after diagnosis and disease progression. Although patients with most chronic diseases need to be actively adjusted according to their conditions, those with HCM often experience more severe and life-threatening symptoms, such as throbbing palpitations, that prompt spontaneous behavioral changes. Health professionals and nurses should support patient-led changes such as avoiding intense activities, modifying exercise routines, and managing stress. Furthermore, they must educate patients on symptom management, adopt a healthy diet, maintain a healthy weight, avoid salty foods, limit sugar and saturated fats, and ensure adequate sleep.²⁷

An important aspect of the participants' communicative and social experiences involved their sensitivity toward disclosing—or not disclosing—their disease to others. In fact, they expressed ambivalent feelings about sharing their conditions with friends, colleagues, and relatives. Interestingly, patients with HCM viewed the disclosure of the disease as having both benefits and disadvantages. On one hand, it changed others' attitudes toward them, leading patients with HCM to be perceived as weak or disabled, akin to the stigma associated with chronic, debilitating diseases. On the other hand, disclosure leads to greater understanding and support from others. Consequently, the participants hesitated when deciding whether to inform others about their disease. Notably, while stigma typically arises in visible physical conditions that alter appearance, this study showed that in HCM, the progression of symptoms and hereditary nature eventually shape the sense of stigma in patients. A previous study conducted in the United States reported a feeling of stigma during cardiomyopathy care among Black cardiomyopathy patients.²⁸

Conclusions

This phenomenological study explored the lived experiences of patients with hypertrophic cardiomyopathy (HCM) and identified five main themes: long journey of diagnosis and stereotypical

treatment, disrupted corporeality and discomfort, living with fear and anxiety, adopting new lifestyles, and living with tension of revealing and concealing. The findings revealed that patients face a challenging progression from symptom onset to accurate diagnosis and treatment, highlighting the need for special cardiac clinics and centers to avoid overemphasizing ischemic diseases. Key issues include distressing palpitations, arrhythmias, fatigue, and altered body image, all of which require precise clinical attention and regular evaluation. Additionally, fear and anxiety pervade patients' lives due to the risk of sudden death, presence of implantable defibrillators, and chronic anxiety. Patients strive to adapt to their evolving chronic condition through self-care strategies such as lifestyle modifications, avoiding risky activities, patience, spiritual support, and life reorganization. Interactions with family, relatives, and significant others evoke dual experiences, ranging from support to misunderstanding, reproach, stigma, and family strain.

Abbreviations

HCM: Hypertrophic Cardiomyopathy

ICD: Implantable Cardioverter Defibrillator

ARUMS: Ardabil University of Medical Sciences

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Ethics Committee of the Research Deputy at Ardabil University of Medical Sciences (ARUMS) with ethical code of IR.ARUMS.REC.1401.254. In accordance with the Declaration of Helsinki, prior to data collection, all participants were fully informed about the study. Written consent was obtained regarding permission to audio-record the interviews and for the collective publication of data anonymously. The participants were assured that their involvement was voluntary and would not affect their medical care. All personal and demographic information was kept confidential, and the participants retained the right to withdraw from the study at any time.

Consent for publication

Participants received complete information about the study and gave written consent for their personal or clinical details to be published anonymously and collectively.

Availability of data and materials

All demographic data and main findings presented in this article were analyzed collectively. The raw data, which include personal life stories of participants, are stored confidentially by the first author.

Competing interests

The authors declare no competing interests.

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Author contributions

J.R. was responsible for the initial conceptualization of research proposal, data collection, and the first draft of the report. **M.S.** supervised the study and participated in conducting interviews, thematic analysis, and manuscript writing.

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Tables

Tables 1 and 2 are available in the supplementary files section

Supplementary Files

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