Patient Preference and Adherence

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Experiences, Values and Goals of People Living with Obstructive Hypertrophic Cardiomyopathy: Exploratory Patient Interviews

Simon Fifer[1], Annmarie Pendleton[2], Jodie Ingles[3], Jenni Godsell[1], Yue Zhong[4], Taryn Krause[5]

[1]Research and Innovation, Community and Patient Preference Research Pty Ltd, Sydney, NSW, Australia; [2]Bristol Myers Squibb, Melbourne, VIC, Australia; [3]Genomics and Inherited Disease Program, Garvan Institute of Medical Research, and UNSW Sydney, Sydney, NSW, Australia; [4]Bristol Myers Squibb, Global Health Economics and Outcomes Research, Princeton, NJ, USA; [5]Bristol Myers Squibb, Global Health Economics and Outcomes Research, London, UK

Correspondence: Simon Fifer, Research and Innovation, Community and Patient Preference Research Pty Ltd, Level 20, 25 Bligh Street, Sydney, NSW, 2000, Australia, Tel +61403862091, Email simon.fifer@cappre.com.au

Purpose: This qualitative study explored the experiences, values and goals of patients living with symptomatic obstructive hypertrophic cardiomyopathy (HCM).

Patients and Methods: A cohort of patients were recruited between March and August 2023 via the Australian Genetic Heart Disease Registry and Cardiomyopathy Association of Australia. Patients were eligible if aged 18 years or older, English speaking and diagnosed with obstructive HCM, with symptomatic status reflective of New York Heart Association class II and above. Patients first completed the Kansas City Cardiomyopathy Questionnaire (KCCQ-23) and then underwent a 60–75-minute semi-structured video interview. Interviews were analyzed using thematic analysis, which was facilitated by NVivo software.

Results: Ten patients participated in structured interviews (6 women and 4 men, mean age: 64.5 years). All were receiving pharmacologic therapy and 50% had undergone septal reduction therapy. Results showed that patients continue to experience notable impact from their obstructive HCM (KCCQ-23 summary score: 63.6; clinical summary score: 66.1). Patients frequently reported living with symptoms for years before diagnosis, often attributing limitations to poor fitness. Symptom burden was substantial, including dyspnea, fatigue, palpitations, chest pain, dizziness and syncope, with variability linked to exertion and environmental factors. Emotional responses ranged from resilience to anxiety, frustration, and fear of sudden death. Lifestyle adjustments were common: patients limited physical activity, modified daily routines, and reduced social engagement. Treatment goals prioritized efficacy and safety, with strong preference for therapies that alleviate symptoms and improve quality of life. Patients valued delaying surgery and favoured oral, once-daily regimens, while placing little importance on objective clinical measures (e.g. echocardiographic findings).

Conclusion: The study provides a unique window into lived experiences of patients with symptomatic obstructive HCM in Australia, demonstrating the impact extends far beyond symptoms. It highlights the need to consider individual patient priorities and treatment goals to provide a tailored, patient-centric approach.

Keywords: Australia, cardiomyopathy, hypertrophic, quality of life, symptom burden

Introduction

Hypertrophic cardiomyopathy (HCM) is characterized by unexplained left ventricular hypertrophy leading to symptoms including shortness of breath, chest pain, dizziness and, sometimes, ventricular arrhythmia and cardiac dysfunction.[1] Although HCM often develops in adolescence, it is usually diagnosed when patients are in their mid-40s.[2] In cascade testing, about 50% of cases are inherited as an autosomal dominant Mendelian genetic trait.[1] Obstructive HCM is associated with an increased risk of sudden cardiac death and long-term cardiac complications.[3,4]

The clinical management of obstructive HCM can be complex, primarily owing to the heterogeneous presentation.[1,5] Standard of care treatments are typically used to improve functional capacity and to reduce symptoms.[1] Treatment can range

https://doi.org/10.2147/PPA.S554609
Received: 28 July 2025
Accepted: 13 April 2026
Published: 14 May 2026

from lifestyle modification (eg, avoiding competitive sport), use of pharmacological agents (eg, beta-blockers, calcium channel blockers, diuretics) or surgical options (eg, septal myectomy or alcohol septal ablation of the myocardium) for those with significant outflow obstruction and insufficient response to pharmacological therapy.[5,6] At the time of this study (2023), no pharmacological treatments licensed in Australia for obstructive HCM were designed to address the underlying pathophysiology of the disease: cardiac myosin inhibitors were not available in Australia at the time the study was conducted.[1,6] Despite the available treatments at the time of the study, patients with HCM can experience cardiac symptoms that affect their quality of life.[7]

Exploring patient impacts and preferences is crucial with new therapies being introduced.[8–10] This study aims to explore, from the patients' perspectives, impacts of obstructive HCM on their lives, as well as treatment preferences and goals.

Materials and Methods

Patients

Interviews were conducted with Australian patients with a diagnosis of obstructive HCM and a symptomatic status reflective of New York Heart Association (NYHA) class II and above. Patients were identified through the Australian Genetic Heart Disease Registry (AGHDR) and Cardiomyopathy Association of Australia (CMAA), who sent study advertisements by email. This sampling method aimed to include a diverse population, with different backgrounds, experiences and perceptions of obstructive HCM. An unforeseen limitation of patient recruitment via these organizations may have been the potential for selection of patients who were more engaged in care and/or with more severe disease (see Discussion). Patients were recruited until no new relevant knowledge was obtained from new patients ("data saturation").[11]

Potential patients were screened anonymously using an electronic system. Patients were included if they were aged 18 years or over, had a diagnosis of obstructive HCM, self-reported current symptoms, were an Australian citizen or permanent resident, and were able to read and understand English. Eligibility was confirmed via email prior to the interview. Patients were blinded to the sponsor of the study until the end of the interview.

All patients provided written informed consent before the interview including publication of anonymized responses and direct quotations. Patients received AUD$125 as a gift card or electronic funds transfer to compensate them for their time and their contribution to the study.

The study was conducted in accordance with a pre-specified research protocol, International Conference on Harmonisation Good Clinical Practice (GCP), International Society for Pharmacoepidemiology (ISPE), Good Pharmacoepidemiology Practices (GPP), the laws and regulations of Australia, and the Research Society's Code of Professional Behaviour. Human Research Ethics Committee (HREC) approval was issued by Bellberry Limited (approval number 2022–08-874). The study complies with the Declaration of Helsinki.

Data Collection Methods

Patients firstly completed the Kansas City Cardiomyopathy Questionnaire (KCCQ-23),[12,13] a validated 23-item self-administered questionnaire measuring perception of health status, including heart failure symptoms, physical and social function, and quality of life within a 2-week recall period. Items are mapped to seven domains and two summary scores: symptom frequency; symptom burden; symptom stability; physical limitations; social limitations; quality of life; and self-efficacy (the participant's understanding of how to manage their disease); the clinical summary score (CSS), and the overall summary score (OSS). The scale ranges from 0 to 100, with 0 representing the most symptoms, most limitations and poor quality of life, and 100 indicating no symptoms, no limitations and excellent quality of life.

Semi-structured interviews (60–75 minutes) were conducted by those skilled in qualitative research after the KCCQ-23 was finished. Demographic data on the patient's age, family situation and working status were collected. Key comorbidity data were extracted from the interviews. Interviews were conducted via video conferencing, using a discussion guide (see Supplemental Methods for further information on the discussion guide). The discussion guide encouraged a smooth flow of conversation and allowed for spontaneous feedback on key topics, ensuring authentic and impartial opinions were evaluated. Patients were prompted with questions to ensure the research objectives were addressed in detail. Interviews were digitally recorded, anonymized and transcribed. (See Supplemental Methods for further information on data collection).

Data Analysis

Interview transcripts were analyzed using thematic analysis (both inductive and deductive).[14,15] The inductive process encouraged the analysis of themes directly from the transcripts. The deductive approach was developed to include themes that were directly in line with the study objectives.[15] Initially, transcripts were reviewed by a single researcher to gain an overview of participant perceptions. Codes were grouped to form broader categories and initial themes. Ongoing refinements were made based on further examination of the transcripts. NVivo™ v12 (Lumivero, Denver, CO, USA) was used to analyze the data. NVivo is an advanced thematic analysis software that assists researchers to identify common themes and evidence-based insights when examining the large amounts of text generated in qualitative interview transcripts. A comprehensive framework was developed that enabled meticulous and systematic analysis of the qualitative data and allowed the findings to be reviewed by two researchers for validity and reliability. The researchers collaborated to identify common themes, reviewing data allocated to each code, and evaluating and interpretating conclusions and study insights. A coding tree was developed that identified the following key themes for exploration: physical, emotional, social, work, financial and family impact of obstructive HCM on quality of life; and feedback on the treatment journey and perceptions of treatment (benefits and challenges).

Results

Patient Screening

Patients were screened between March 28, 2023, and August 3, 2023. Of 47 screened patients, 21 elected to stop the screening survey before completing all the questions, 3 were excluded owing to non-obstructive disease and 7 were excluded owing to not having any current obstructive HCM symptoms. A further 3 patients were excluded when they were found to be non-obstructive on follow-up questioning and 3 patients did not respond to follow-up. This left 10 patients eligible for interview (Figure 1). No repeat interviews were carried out. Interviews were conducted between April 6, 2023, and July 27, 2023. The decision was made to halt interviews after 10 were completed owing to data saturation (that is, no new information was identified in later interviews). Screening continued in the period July 27, 2023, to August 3, 2023, before the decision to close the study was made.

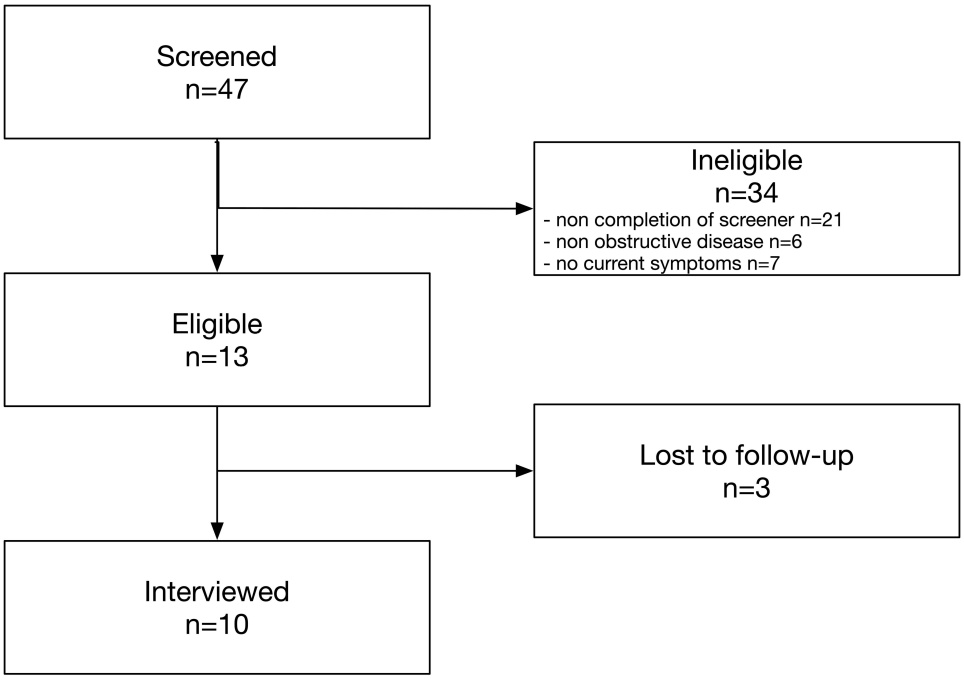

Figure 1 Participant flowchart.

https://doi.org/10.2147/PPA.S554609

Patients

Six women and 4 men participated, with a mean age of 64.5 years (range 42.0–81.0 years) and half lived in New South Wales (n = 5, 50%) (Table 1). There was a mix of patients from metropolitan and regional suburbs. Age at obstructive HCM diagnosis ranged from 17.0 to 77.0 years. Most were retired, semi-retired or had stopped working early (n = 8, 80%). All patients had received oral medications for their obstructive HCM, with some having also undergone septal myectomy (n = 3) or septal ablation (n = 2). The mean ± standard deviation (SD) KCCQ-23 OSS was 63.6 ± 9.7, and the mean ± SD KCCQ-23 CSS was 66.1 ± 12.6 (Table 2), indicating impaired health despite symptomatic treatment. Most patients lived with comorbidities, including glaucoma, pulmonary embolism, atrial fibrillation, hypercholesterolemia, hypothyroidism, gastric reflux, arthritis, asthma and diabetes.

Understanding of Obstructive HCM

Patients generally understood that obstructive HCM led to a "thickening" of the heart muscle, leading to narrowing of the left ventricle and restriction of blood flow; usually this information was from their specialist physician. Some reported receiving a pamphlet at the time of diagnosis describing the condition and its potential impacts; others obtained information from their own research. Generally, they felt they had received sufficient information about their condition but noted there were limited opportunities to ask questions during consultations, especially about the emotional component of obstructive HCM.

Table 1 Patient Characteristics (Self-Reported)

Characteristic	N=10
Sex, n (%)	
Female	6 (60)
Male	4 (40)
Age, mean ± SD (min, max)	64.5 ± 13.6 (42.0, 81.0)
Age at diagnosis of obstructive HCM, mean ± SD (min, max)	47.6 ± 19.0 (17.0, 77.0)
State, n (%)	
NSW	5 (50)
QLD	1 (10)
SA	1 (10)
VIC	3 (30)
Region, n (%)	
Metropolitan	4 (40)
Regional	5 (50)
Unknown	1 (10)
Employment status, n (%)	
Full-time	1 (10)
Part-time	1 (10)
Retired	3 (30)
Semi-retired	2 (20)
Stopped working early	3 (30)
Type of treatment received,[a] n (%)	
Current oral therapies	10 (100)
Prior septal ablation	2 (20)
Prior septal myectomy	3 (30)
Type of device received	
Pacemaker	2 (20)
Implantable cardioverter-defibrillator	2 (20)

Notes: [a]Numbers do not add to 100% as patients could receive more than one treatment type.
Abbreviations: HCM, hypertrophic cardiomyopathy; NSW, New South Wales; QLD, Queensland; SA, South Australia; SD, standard deviation; VIC, Victoria.

Table 2 Kansas City Cardiomyopathy Questionnaire (KCCQ-23) Scores

KCCQ-23 Domain	Mean	SD	Minimum	Maximum
Overall summary score	63.6	9.7	49.0	78.4
Clinical summary score	66.1	12.6	47.9	84.3
Symptom frequency	69.6	12.2	50.0	87.5
Symptom burden	72.5	7.9	58.3	83.3
Symptom stability	50.0	0.0	50.0	50.0
Physical limitation	61.2	18.6	37.5	87.5
Social limitation	60.4	13.1	43.8	81.2
Quality of life	61.7	9.8	50.0	75.0
Self-efficacy	62.5	27.6	25.0	100.0

Abbreviation: SD, standard deviation.

> "I think they did explain it and had a little model of the heart and showed me how, what the issues were for me. So yes, I guess from an intellectual perspective there was information provided which would cover the basic condition, yes. But there is a whole lot of emotional and other questions that arise around the treatment of that as well." (Participant 7)

Others reported not wanting to have too much information, in order to reduce the emotional burden associated with diagnosis.

Diagnosis

Several patients reported unknowingly living with the condition for some period of time before receiving their diagnosis. They reported having trouble with physical activities for some time but assumed this was due to their being physically unfit or feeling "lazy". For some, the diagnosis had been incidental, such as when a general practitioner noticed dyspnea during a routine consultation. Others reported symptoms which they assumed to be a heart attack, or "passing out" (including one instance of a participant having to be pulled out of a swimming pool after collapsing). These patients were taken to hospital for investigation.

Diagnosis was made based on a number of investigations, including echocardiograms, coronary angiograms, chest X-rays, electrocardiograms, blood tests, cardiac magnetic resonance imaging and cardiac exercise stress tests. In addition, some patients were referred for genetic testing and were encouraged to have their children tested. For most patients, the results had been negative or inconclusive. One participant voiced disappointment at their inconclusive result, as they believed determining what gene was responsible for the condition could impact the management of their condition.

For those who had conclusive genetic testing results, patients had conflicting feelings:

> "Mixed feelings, but predominantly pleased that they had it, in the sense that if I wanted to pursue something with it I could, I had that option mainly for the children and siblings. But yes, for me it was a positive thing overall. It was just then the dilemma of what do I do with this information." (Participant 9)

Experiences

Emotional Impact

Generally, patients were philosophical about their condition. Some had a very resilient mental approach, either not having time to worry about their condition, or taking the view that things could be worse.

> "I'm pretty fortunate, I handle that [the mental approach] with ease … well that is my life, and so be it. There is plenty worse … I'm still here." (Participant 4)

However, for others, the emotional impact was clear, expressing their frustration, disappointment, anxiety and grief at their situation.

> "Sometimes, like I said, I can't even walk, I might get up from watching TV and go the letter box … I'll feel a bit short of breath and got to stop. Other times I can run out there and have no effect at all. Mentally that's probably where, mostly where it's disappointed me, it's limiting my life, what I want to do." (Participant 10)

The uncertainty for the future was troubling for some.

> "What the progression is going to be, and the 'sudden death' factor is always there … you worry a little bit about how long you are going to be around." (Participant 3)

Others expressed feelings of embarrassment about their inability to be as active as their peers, or due to the physical scarring secondary to septal myectomy.

> "The anxiety that I get … if I'm pushing too hard and I'm trying to keep up with everybody, that pressure to keep up that I put on myself." (Participant 9)

Patients were generally aware of the strong genetic component of this condition, with some speaking of family members who were also affected, including those who had died suddenly. One participant had been told not to have children, which they perceived as "inappropriate" and "discouraging" feedback. The participant did have children and, with concerns that her children may also have the condition, she has ensured regular monitoring for her children and discouraged any strenuous exercise.

> "We take precautions just because there is [a] chance that they could have it. So, I don't like them doing any strenuous exercise already." (Participant 6)

For those with children, there were concerns about the ability to acquire life insurance and whether it would impact potential career opportunities. One patient elected not to have genetic testing for this reason.

> "It's a real burden for my boys and their sons … knowing that that is what the future may be, never being able to get insurance." (Participant 4)

Others were concerned about the need for genetic testing of their children. One participant spoke of his father dying from obstructive HCM, the emotional impact of which was not only the pain of losing his father, but also the anxiety of having inherited the same condition.

> "[Father] was complaining about … being lightheaded and everything, he was going to the doctor, and they put it down as angina. And then soon after his 60th birthday he went to the bathroom and dropped dead. How do I feel? I wish he didn't give it to me that's for sure." (Participant 8)

Symptoms

Patients reported a wide variety of symptoms associated with their obstructive HCM. Symptoms associated with greater disease severity included "palpitations", "rapid heartbeat" (tachycardia); "short of breath", "breathless" (dyspnea); "lightheaded" (dizziness); "thought that I was having a heart attack", "chest discomfort" (chest pain); "exhaustion", "get tired" (fatigue); and "fainting", "blacking out" (syncope). Others included arrhythmia, hypertension, physical weakness, vision disturbance, sweating and nausea. Some symptoms were very distressing for patients.

> "Well, I'm having palpitations and things that are waking me up at night, enough that I'm like, 'Oh my God, is this it? Like, am I about to die?'" (Participant 6)

The severity of symptoms experienced by the patients varied, and they believed these variations to be related to the type and level of exertion related to an activity. They reported a lack of sleep and higher temperatures as contributors to more severe symptoms. Their key approach to symptom reduction was rest.

> "If I have a really physical day, it wipes me out for the next day or sometimes 2 days … it just kind of knocks my body if I don't take a break." (Participant 4)

A few expressed a tentative approach to fitness for fear of the negative cardiac consequences.

Hospitalizations

Patients had generally not been hospitalized for extended periods to treat the clinical signs and symptoms of their obstructive HCM, except for those who had undergone septal reduction therapy, which required inpatient care for about a week. They had, however, visited emergency departments when experiencing severe symptoms (eg, palpitations), and had sometimes been admitted overnight for monitoring. Some underwent routine monitoring of troponin levels to rule out myocardial infarctions and other issues.

> "Well, they don't normally admit me, to be honest. They actually check me out and make sure I'm not having a heart attack, obviously, because they are just there to make sure you are not going to die immediately and then they send you off to see your normal specialist." (Participant 6)

Physical Impact

Patients expressed appreciation for having been able to remain independent in activities of daily living (eg, housework, shopping). One person hired a cleaner owing to difficulty completing household chores. Patients reported significant impacts on their fitness levels and were less able to engage in physical activities, hobbies and interests owing to their symptoms. The individuals experienced a decrease in energy, physical symptoms such as breathlessness and dizziness, the need for increased rest and recovery during and after physical activities, and the requirement to modify their typical activities. They also feared the consequences of subjecting their heart to heightened physical stress.

> "When I'm having … some heart issues, it's real. I just don't want to do anything." (Participant 8)

Impact on Lifestyle and Social Activities

Patients with obstructive HCM adjusted their lifestyle by limiting the number and duration of daily activities and avoiding some activities owing to concerns about the impact on their heart (eg, long-haul flights, standing for long periods, being in long queues).

> "There have been times when I've said, 'No I'm not going. I can't go' … and over the last couple of years it's lack of energy." (Participant 10)

They simplified tasks or performed activities sequentially.

> "There are still some of my friends that can go like bush walking up and down hills, I can't do that sort of thing. I can still play golf, but I need to use a cart because of my shortness of breath. I used to be able to go in the garden all day, whereas now it's all in a bit of a block. It's all a bit in slow motion. Like I'll go and do half an hour, and I'll think 'I have to go and rest'. So, that's the things that I've had to change and then get my head around that." (Participant 5)

Patients reported making healthy dietary choices, which often involved abstaining from alcohol in social settings. Patients reduced social activities owing to physical symptoms from obstructive HCM. In some cases, this led to complete withdrawal from social situations.

> "Well, I don't really go out anymore because I can't do things that they want to do …. Friends use to go water skiing and everything, I just can't. Like sometimes I go, just to like chill out there, but it's just like dangling a red flag to a bull. Like I'm going to go, like I'm going to try it and then I try and just separate myself from it so I don't do something that I shouldn't do." (Participant 8)

Logistical Factors

Patients faced logistical challenges in traveling for specialist visits, routine monitoring and surgical intervention. The travel burden was higher for regional patients traveling to centers with clinical expertise, typically in large metropolitan hospitals. Patients mentioned parking proximity to appointments and shopping as a concern.

> "I had to go to Sydney, that was a bit of a nightmare … I've got to go right through the city to go to [the] hospital and then parking is horrible. And [I am] not used to that much traffic and it was just a horrible day out. So I feel on a benefit:bother ratio, I thought I'd stay home." (Participant 1)

Financial Impacts

While several of those interviewed were already at retirement age upon diagnosis, those of working age reported substantial impacts on their work and finances because of their poor health associated with obstructive HCM.

> "And then when I do have my bad days … bad days turn into … weeks. And I can't go to work for like a week." (Participant 8)

For these patients, they considered themselves fortunate as their partners had sufficiently well-paid employment to manage the financial impacts of living with obstructive HCM.

> "I'd always planned on going back to work when the kids went to school. But I struggled every day just getting through life, so I didn't work … I'm just very blessed that he [spouse] can provide for us." (Participant 6)

Some had switched to more sedentary roles. Others mentioned the need to live more "frugally".

> "Obviously I've had to change to a different job. Like, I was on a disability pension for a fair while, but I was … it was doing my head in just not doing anything, because I'm a tradie [tradesman], like it was a very physical job that I had. I had a go at retail and it's like, it's pretty easy and I worked my way up to being an assistant manager which is a fairly sedentary job now, so it's easier for me but by no means is it the same pay that I used to get as a tradie." (Participant 8)

Having a supportive employer was perceived as vital in ensuring there are no negative implications when sick leave was taken.

Patients with obstructive HCM reported increased medical expenses including specialist fees and medication. While most patients did not have any paid support because of their condition, one participant mentioned that the added expense of requiring a cleaner for household chores had become too difficult to manage.

Impact on Family

Most patients reported being independent and autonomous but valued their family's financial support and help with household chores, transportation and activities of daily living.

> "Well, she's pretty much got another baby on for that day that I'm in bed because I get up, I'm all wobbly and everything. It's not even safe for me to go to the bathroom. To get up off the toilet, it's like a positional thing that I can pass out again. Yes, it's like looking after a 90-year-old or a 9-month-old rather [than a 44-year-old]." (Participant 8)

Patients reported family members have made sacrifices, such as attending medical appointments, slowing down physically when spending time with them or having to do things on their own. Others reported families deciding to move to be closer to specialist care.

> "We would go to church, and I'd faint. That's when she started to take me to the hospital to see a doctor and that's when it all started. So, a lot of decisions about what she was doing, taking me to Adelaide, trying to get doctors and things like that. I know she made a lot of sacrifices [for me]." (Participant 10)

Patients expressed worry about causing anxiety to family members and dying before their parents.

> "My mother is still alive, and I know if I die before she does … that would destroy her." (Participant 10)

Some said their illness affected their ability to be sexually intimate owing to fatigue, although others noted this was also because of their age. In a younger participant, there was mention of engaging in intimacy that was "easy on the body".

Treatment

Cardiologists were the key clinicians responsible for diagnosis and treatment of obstructive HCM. Other specialists (eg, respiratory physicians) were referred to for management of comorbidities such as bronchiectasis. Patients were satisfied

with the continuity of care for their obstructive HCM. They felt confident in their specialist's expertise and were well informed and included in decisions about their management and treatment. One participant expressed disappointment with the public healthcare system due to delays in obtaining appointments after changing cardiologists, feeling "lost in the system". She felt abandoned during a time when she was experiencing severe symptoms. She had also experienced problems with her medication supply, due to shortages, causing anxiety.

> "I always thought our public health system was amazing and that they were being very careful and monitoring me and everything, but now that I'm having problems, I feel like everyone has just turned their back and you know there is no support." (Participant 7)

Patients had 6- or 12-monthly reviews with their cardiologists, including physical examinations, echocardiograms, reviews of their implantable cardioverter-defibrillator (ICD) or pacemaker settings and treatment discussions. Following surgery, visits were more frequent (every 2 months). Few attended specialist cardiomyopathy clinics. A regional participant mentioned his cardiologist visiting his local clinical catchment area annually for those with cardiac issues and to check pacemakers.

Treatment Preferences

All patients had received oral medication treatment with or without pacemakers, ICD and septal reduction therapy. Patients reported using various oral therapies such as beta-blockers, calcium channel blockers, antiarrhythmics, anti-hypertensives, diuretics, nitrates and statins, either alone or in combination, for symptom management. Most preferred oral therapy over surgery. Many perceived invasive procedures, particularly septal myectomy, as a last resort.

> "Well, I'd prefer to take tablets rather than have surgery, if they both have the same outcome, I'd rather take a tablet … surgery is very invasive and … [with] the risks … the anesthetic, … being cut open, all that kind of thing, whereas a tablet you just swallow the tablet." (Participant 2)

Patients reported substantial benefits associated with treatment with respect to their symptoms, including tachycardia, arrhythmia, shortness of breath and headaches. They improved quality of life and increased participation in activities of daily living, including hobbies and interests. Patients also reported side effects, including bradycardia leading to dizziness and loss of consciousness, tachycardia, gastrointestinal upset, loss of libido and cognitive impairment. In some cases, this led to medication changes or discontinuation. Some had insufficient response to medication, and for others compliance was an issue.

Two patients had pacemakers implanted owing to ongoing symptoms, despite oral medication.

> "It was a dual pacemaker to slow up the left ventricle valve to try to keep it open. My understanding about a quarter per second longer and that allowed more blood flow out …. It worked for me, so I was fortunate that it was very helpful on that basis." (Participant 4)

They needed pacemaker software updates and replacement over time. One participant reported noticeable benefit, while the other experienced ongoing difficulties, exacerbated by the device's incorrect setup, causing up to 10 tachycardia episodes per day. Five patients had septal reduction therapy, either through alcohol septal ablation (n = 2) or septal myectomy (n = 3). Two patients had an ICD to prevent sudden cardiac death; both patients had undergone septal reduction therapy (alcohol septal ablation [n = 1] or septal myectomy [n = 1]). Many had spoken to their doctor about septal reduction therapy but others wanted to avoid invasive procedures, some were well controlled on oral medication and some were deemed unsuitable for septal reduction therapy. The procedure improved symptoms at first, but some experienced a gradual return of symptoms.

> "As the heart gets bigger and thicker and your symptoms get a bit worse, and I got to the stage where even with the septal ablation I was still getting out of breath even walking to the letterbox, almost having to take a second short breath every time I did fairly minor exertion." (Participant 3)

They were worried about the risks, such as death, and the uncertain success rates of surgery. Three patients underwent septal myectomy with mostly positive feedback on symptom burden and quality of life. For one, it meant that oral medication was ceased. Patients found the surgery to be invasive, requiring a week in the hospital and a lengthy postoperative recovery with frequent follow-up. One experienced a gradual return of symptoms following septal myectomy. Septal myectomy incurred high out-of-pocket costs.

Goals of Treatment

Treatment goals centered on maintaining or improving quality of life and achieving functional capacity and symptom reduction. The most common goals of treatments were to: address symptoms; allow participation in daily activities; allow participation in hobbies and interests; avoid side effects; and enable independence. Box 1 lists additional goals.

Goals less frequently cited by patients included: enabling them to spend time with family and friends (as they did not feel restricted in this area); having medical professionals who recommend the best treatment for them (as they were already satisfied with their management and trusted the cardiologists for optimal care); reducing the frequency of doctor visits (as the frequency of visits every 6–12 months was not perceived as a burden, but rather was seen as reassuring); being able to stop treatment (this was considered unrealistic); or being able to forget they have this condition (this was considered unrealistic).

Important Treatment Attributes

Patients focused on efficacy and safety in their discussion of important treatment attributes, and also cited delaying surgery, treatment type, cost, frequency and treatment interactions. Patients aimed to improve their quality of life by reducing the burden of disease, desiring increased energy and reduced dyspnea and fatigue. They were not concerned with objective measures of efficacy, such as imaging results, echocardiogram findings, left ventricular outflow tract gradients or NYHA classification. One participant expressed a desire to reduce septum thickness. One participant noted there was not always a correlation between objective measures and symptoms.

> "Well, the actual figure, the pressure gradient is the key. The two things that I think have been measured and I've been looking at was the septum thickness and the pressure gradient. They're the two things that get measured by the echocardiogram. But this is an example, as I was saying before, they can do an echocardiogram and they can say, 'Oh yes your septal thickness is fine, your pressure gradient is fine', but hey, I've still got symptoms." (Participant 3)

Patients wanted treatment for dyspnea, palpitations, fatigue, dizziness and chest pain. Improved symptoms were considered key to engaging in physical activities and exercise. While symptom improvement was considered most

Box 1 Key Treatment Goals

Treatment that:

- Reduces my symptoms
- Assists me to be able to participate in daily activities
- Assists me to pursue my hobbies and interests
- Does not have side effects
- Assists me in being independent/autonomous
- Assists me in engaging in my unpaid work/duties/responsibilities
- Delays the need for surgery
- Is easy for me to take/administer
- Assists in reducing my anxiety and/or depression that arises due to obstructive HCM
- Assists me in having an income or paid work
- Assists me in supporting my family in whatever they need
- Assists me in staying out of hospital
- Reduces disease progression
- Allows me to live a long life

Abbreviation: HCM, hypertrophic cardiomyopathy.

important, the time to improvement was not a priority, with a time frame of between 4 and 6 weeks being seen as acceptable. Patients acknowledged that treatment longevity is preferred but not guaranteed.

> "I guess you'd want it to be effective for a few years. I mean in an ideal world you'd want it to be effective for your life, but I'd still be happy to do it if it was only going to help me for a couple of years." (Participant 3)

Safety was raised as a central factor when considering important attributes of obstructive HCM treatment. Patients appeared to be willing to accept some minor side effects in exchange for benefits; however, they were wary of treatments that may contribute to a reduced quality of life. They wished to avoid nausea, stomach pain, ankle edema and any long-term impact on other organs (thyroid, kidneys, liver). They believed doctors were responsible for ensuring that treatments did not have negative interactions with current medications or conditions.

Although it was not brought up spontaneously, patients appreciated avoiding or delaying invasive procedures like septal ablation and myectomy. A small number of patients said they would consider surgery if recommended by their doctor and if associated with a higher success rate compared with medication.

Patients mostly followed their doctor's recommendations for treatment and were open to any suggested options. They favored less frequent treatment and specifically preferred once-daily oral medication over twice-daily. Patients favored oral medication over surgical interventions for obstructive HCM management owing to perceived safety and convenience. For some, implantable devices (ie, pacemakers, ICDs) were viewed as important tools for maintaining and monitoring heart rate.

Out-of-pocket costs were not prioritized over other treatment features. Current costs with obstructive HCM were largely considered reasonable, with several patients having private health insurance, receiving subsidies (ie, pensions), having superannuation or being financially secure. However, some patients did mention they were not particularly wealthy and needed to be careful with their finances to ensure they could pay for their medical needs. They also raised concerns regarding rising costs over time.

Discussion

To our knowledge, this is the first qualitative study exploring treatment preferences, goals and breadth of impact in those with obstructive HCM.

The symptom and impact burden of obstructive HCM is complex, variable and, to some extent, hidden by patients adjusting their lives to reduce the impact of the disease. This is recognized in the European Society of Cardiology (ESC) 2023 guidelines, which state

> Patients with cardiomyopathy may experience dyspnoea, chest pain, palpitation, and syncope and/or pre-syncope, although many individuals complain of few, if any, symptoms.

This study, through a structured questioning approach, the use of a validated patient-reported outcome instrument (KCCQ-23), and thematic analysis using NVivo which provided veracity to the research themes identified, demonstrated that obstructive HCM can impact many facets of a patient's life from emotional to physical, lifestyle, logistical, social, work, financial and family. The symptoms and impacts experienced by patients in our study align with the research of Zaiser et al in the USA.[7] Zaiser et al also highlighted the need for clinical assessments to consider not only symptoms but also their impact on the patient, as this is key to shared decision-making regarding treatment options, which is a key tenet of the ESC 2023[1] and American College of Cardiology (ACC)/American Heart Association (AHA) 2024 guidelines.[5] To do this effectively, it is important that clinicians understand the symptom and impact burden of HCM for each patient and their goals, to provide a framework for shared decision-making. Validated tools like the KCCQ[16] or Hypertrophic Cardiomyopathy Symptom Questionnaire,[1] may be useful in this context to allow for consistency of review over time. Or, if clinic time does not permit, clinicians could consider asking targeted questions to understand what the patient can no longer do to uncover hidden symptoms and assess the impact of HCM on patients' quality of life.

A number of patients expressed tentativeness and concerns regarding exercise for themselves/their children for fear of negative consequences. Recent evidence demonstrates that with appropriate assessment the benefits of exercise outweigh the risks in many patients, with this now embodied in both the recent ESC 2023 and AHA/ACC 2024 guidelines.[1,5] It is

therefore valuable for clinicians to assess/reassess a patient's risk and, where appropriate, provide patients with confidence to engage in suitable exercise to support improved cardiovascular health and quality of life, which has been shown in this study to be impacted by HCM.

It was also clear from the responses of patients in this study that they have varied information needs about their condition, with some reporting not wanting to have too much information in order to reduce the emotional burden associated with diagnosis. While in general patients felt they had received sufficient information about their condition, they also reported limited opportunities to ask questions during the consultations, including discussion of the emotional impact of HCM. It is important for clinicians to ask their patients what information they would find helpful not only during initial consultations but by continuing to ask this question in future consultations. Additionally, patients were reassured by frequent clinical follow-up (every 6–12 months).

One limitation of this study was that it may have included a more severe cohort of patients than a general consulting population, as indicated by a time since diagnosis of more than 15 years, and prior septal reduction surgery for half of the sample. This proportion is much higher than the typical population of patients with obstructive HCM who would typically undergo septal reduction, but probably reflects a participant cohort who had exhausted other standard of care options. This may be due to the study's opt-in nature or the database having long-term patients in its cohort. This skew in the sample patient population may not reflect the experiences/perspectives, or patient treatment preferences especially in newly diagnosed or younger patients. A further consideration is the registry source may represent patients who are more engaged in their care, or who have more severe disease. Access to the patients' NYHA scores was not available, limiting the ability to assess the severity of a participant's disease independently at the time of the study. While the study was small, and interviews performed by a single researcher to provide consistency, the patients were sourced from across Australia and qualitative study sample sizes were driven by the need to reach data saturation, which was achieved in this study. A recent review reported that studies reached saturation at small sample sizes (between 9 and 17 interviews, or 4–8 focus group discussions).[17]

Conclusions

This unique study provides direct insights into the wide breadth of impacts for those living with symptomatic obstructive HCM, beyond the substantial disease burden associated with symptoms. Understanding treatment preferences and treatment goals of patients is important for increasing patient centricity. This understanding can assist in bridging the divide between evidence-based medicine and patient-centric care.[18]

The patients enrolled in this small study had a general preference for oral daily medications compared to invasive procedures, primarily based on concerns about the risks of surgery. Many considered invasive procedures, particularly septal myectomy, only once other options had been exhausted. Not surprisingly, patients wanted their treatments to be safe and efficacious. While they were accepting of minor side effects, they wished to avoid adverse events such as nausea, stomach pain and ankle edema. Their expectations of efficacy were pragmatic – not expecting a clinical response for 4–6 weeks after treatment commencement, but they wished to improve their dyspnea, palpitations, fatigue, dizziness and chest pain.

Abbreviations

CSS, Clinical Summary Score; ESC, European Society of Cardiology; HCM, Hypertrophic cardiomyopathy; ICD, Implantable Cardioverter Defibrillator; KCCQ-23, Kansas City Cardiomyopathy Questionnaire; NYHA, New York Heart Association; OSS, Overall Summary Score; SD, Standard deviation.

Data Sharing Statement

Data not available due to privacy/ethical restrictions.

Acknowledgments

The authors thank Belinda Butcher BSc (Hons) MBiostat PhD CMPP AStat of WriteSource Medical Pty Ltd, Sydney, Australia, for providing medical writing support. Medical writing support was funded by Bristol Myers Squibb in

accordance with Good Publication Practice (GPP2022) guidelines.[19] JI is the recipient of a National Heart Foundation of Australia Future Leader Fellowship (#106732). Editorial support was provided by Oxford PharmaGenesis, Oxford, UK, funded by Bristol Myers Squibb.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This study was supported by Bristol Myers Squibb.

Disclosure

Simon Fifer and Jenni Godsell are employed by Community and Patient Preference Research (CaPPRe). Annmarie Pendleton and Yue Zhong are employees of Bristol Myers Squibb. Jodie Ingles is Head of the Ingles Laboratory at the Garvan Institute of Medical Research and the National Coordinator of the AGHDR. Taryn Krause is a former employee of Bristol Myers Squibb. Taryn Krause was affiliated to Bristol Myers Squibb, Global Health Economics and Outcomes Research, London, UK, at the time the study was conducted. The authors report no other conflicts of interest in this work.

This study was presented as a poster at the 73rd Annual Scientific Session & Expo of the American College of Cardiology (ACC.24), April 6–8, 2024, Atlanta, GA, USA.[20] The poster can be accessed at: https://www.postersessiononline.eu/173580348_eu/congresos/ACC2024/aula/-1244128ACC2024.pdf

References

1. Arbelo E, Protonotarios A, Gimeno JR, et al. ESC guidelines for the management of cardiomyopathies. *Eur Heart J*. 2023;44(37):3503–3626. doi:10.1093/eurheartj/ehad194
2. Canepa M, Fumagalli C, Tini G, et al. Temporal trend of age at diagnosis in hypertrophic cardiomyopathy: an analysis of the international sarcomeric human cardiomyopathy registry. *Circulation*. 2020;13(9):e007230. doi:10.1161/CIRCHEARTFAILURE.120.007230
3. Harris C, Croce B, Munkholm-Larsen S. Hypertrophic obstructive cardiomyopathy. *Ann Cardiothorac Surg*. 2017;6(4):429. doi:10.21037/acs.2017.07.06
4. Batzner A, Schafers H-J, Borisov KV, Seggewiss H. Hypertrophic obstructive cardiomyopathy. *Dtsch Arztebl Int*. 2019;116(4):47–53. doi:10.3238/arztebl.2019.0047
5. Ommen SR, Ho CY, Asif IM, et al. AHA/ACC/AMSSM/HRS/PACES/SCMR guideline for the management of hypertrophic cardiomyopathy: a report of the American heart association/American College of cardiology joint committee on clinical practice guidelines. *Circulation*. 2024;149(23):e1239–e1311. doi:10.1161/CIR.0000000000001250
6. The Cardiac Society of Australia and New Zealand. Diagnosis and management of hypertrophic cardiomyopathy - position statement. 2016. Available from: https://www.csanz.edu.au/Common/Uploaded%20files/Smart%20Suite/Smart%20Library/08e39ca0-febb-4d7e-adfa-0b9af2a70795/Diagnosis%20and%20Mangement%20-%20Hypertrophic-Cardiomyopathy%20.2016pdf. Accessed April 20, 2026.
7. Zaiser E, Sehnert AJ, Duenas A, Saberi S, Brookes E, Reaney M. Patient experiences with hypertrophic cardiomyopathy: a conceptual model of symptoms and impacts on quality of life. *J Patient Rep Outcomes*. 2020;4(1):102. doi:10.1186/s41687-020-00269-8
8. Desai MY, Owens A, Wolski K, et al. Mavacamten in patients with hypertrophic cardiomyopathy referred for septal reduction: week 56 results from the VALOR-HCM randomized clinical trial. *JAMA Cardiol*. 2023;8(10):968–977. doi:10.1001/jamacardio.2023.3342
9. Cremer PC, Geske JB, Owens A, et al. Myosin inhibition and left ventricular diastolic function in patients with obstructive hypertrophic cardiomyopathy referred for septal reduction therapy: insights from the VALOR-HCM study. *Circ Cardiovasc Imaging*. 2022;15(12):e014986. doi:10.1161/CIRCIMAGING.122.014986
10. Olivotto I, Oreziak A, Barriales-Villa R, et al. Mavacamten for treatment of symptomatic obstructive hypertrophic cardiomyopathy (EXPLORER-HCM): a randomised, double-blind, placebo-controlled, Phase 3 trial. *Lancet*. 2020;396(10253):759–769. doi:10.1016/S0140-6736(20)31792-X
11. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042
12. Nassif M, Fine JT, Dolan C, et al. Validation of the Kansas city cardiomyopathy questionnaire in symptomatic obstructive hypertrophic cardiomyopathy. *JACC Heart Fail*. 2022;10(8):531–539. doi:10.1016/j.jchf.2022.03.002
13. Spertus JA, Jones PG, Sandhu AT, Arnold SV. Interpreting the Kansas City cardiomyopathy questionnaire in clinical trials and clinical care. *J Am Coll Cardiol*. 2020;76(20):2379–2390. doi:10.1016/j.jacc.2020.09.542
14. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods*. 2017;16(1):1–13. doi:10.1177/1609406917733847
15. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa

16. Reza N, Day SM, Owens AT. Patient-reported outcomes in clinical studies of patients with hypertrophic cardiomyopathy. *Prog Cardiovasc Dis*. 2023;80:60–65. doi:10.1016/j.pcad.2023.08.007
17. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. *Soc Sci Med*. 2022;292:114523. doi:10.1016/j.socscimed.2021.114523
18. Engle RL, Mohr DC, Holmes SK, et al. Evidence-based practice and patient-centered care: doing both well. *Health Care Manage Rev*. 2021;46 (3):174–184. doi:10.1097/HMR.0000000000000254
19. DeTora LM, Toroser D, Sykes A, et al. Good publication practice (GPP) guidelines for company-sponsored biomedical research: 2022 Update. *Ann Intern Med*. 2022;175(9):1298–1304. doi:10.7326/M22-1460
20. Fifer S, Pendleton A, Godsell J, Zhong Y, Krause T. The experiences, values and goals of patients in australia living with obstructive hypertrophic cardiomyopathy: in-depth patient interviews. *J Ame College Cardiol*. 2024;83(13):444. doi:10.1016/s0735-1097(24)02434-3