Clinical characteristics, diagnosis, and impact on employment in patients with obstructive hypertrophic cardiomyopathy: results from a real-world survey in Canada

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Background

- Obstructive hypertrophic cardiomyopathy (HCM) is a cardiac disease characterized by cardiac hypertrophy and left ventricular outflow obstruction¹
- Patients with obstructive HCM may experience symptoms such as exercise intolerance, fatigue, chest pain, dyspnea, palpitations, and syncope²
- The aim of this study was to describe the clinical characteristics, diagnosis, treatment patterns, and employment status of patients with symptomatic obstructive HCM in Canada

Methods

- Data were collected between December 2022 and April 2023 as part of the Adelphi HCM Disease Specific Programme (DSP), a cross-sectional survey with elements of retrospective data collection from patient medical records
- Cardiologists were asked to complete an online patient-record form reporting data on patient clinical characteristics, diagnosis, treatment history, and employment status. Data were provided for up to 6 consecutive adult patients with symptomatic obstructive HCM
- The DSP methodology has been previously described,^{3,4} validated,⁵ and shown to be representative and consistent over time⁶
- Cardiologists were eligible for inclusion if they were involved in the treatment and management of patients with HCM
- Patients were eligible for inclusion if they were adults over the age of 18 years with obstructive HCM (cardiologist-confirmed diagnosis), and were symptomatic (minimum New York Heart Association [NYHA] class II) at the time of enrollment
- Analyses were descriptive and completed using Intelligence Reporter v7.5
 (UNICCOM Systems, Inc., Mission Hills, CA, US) and Stata 18 (StataCorp
 [2023]. Stata Statistical Software: Release 18. College Station, TX,
 StataCorp LLC)

Results

- Overall, 41 cardiologists provided data for 151 patients with symptomatic obstructive HCM. Patient demographics and clinical characteristics for these patients are presented in **Table 1**
- A fifth of patients (20.4%) experienced a delay in diagnosis of obstructive HCM, owing to having another condition diagnosed first, and no further tests were conducted to detect HCM at that stage. When HCM was subsequently diagnosed for these patients, 61.1% were at NYHA class II, 33.3% at NYHA class III, and 5.6% at NYHA class IV (Figure 1)

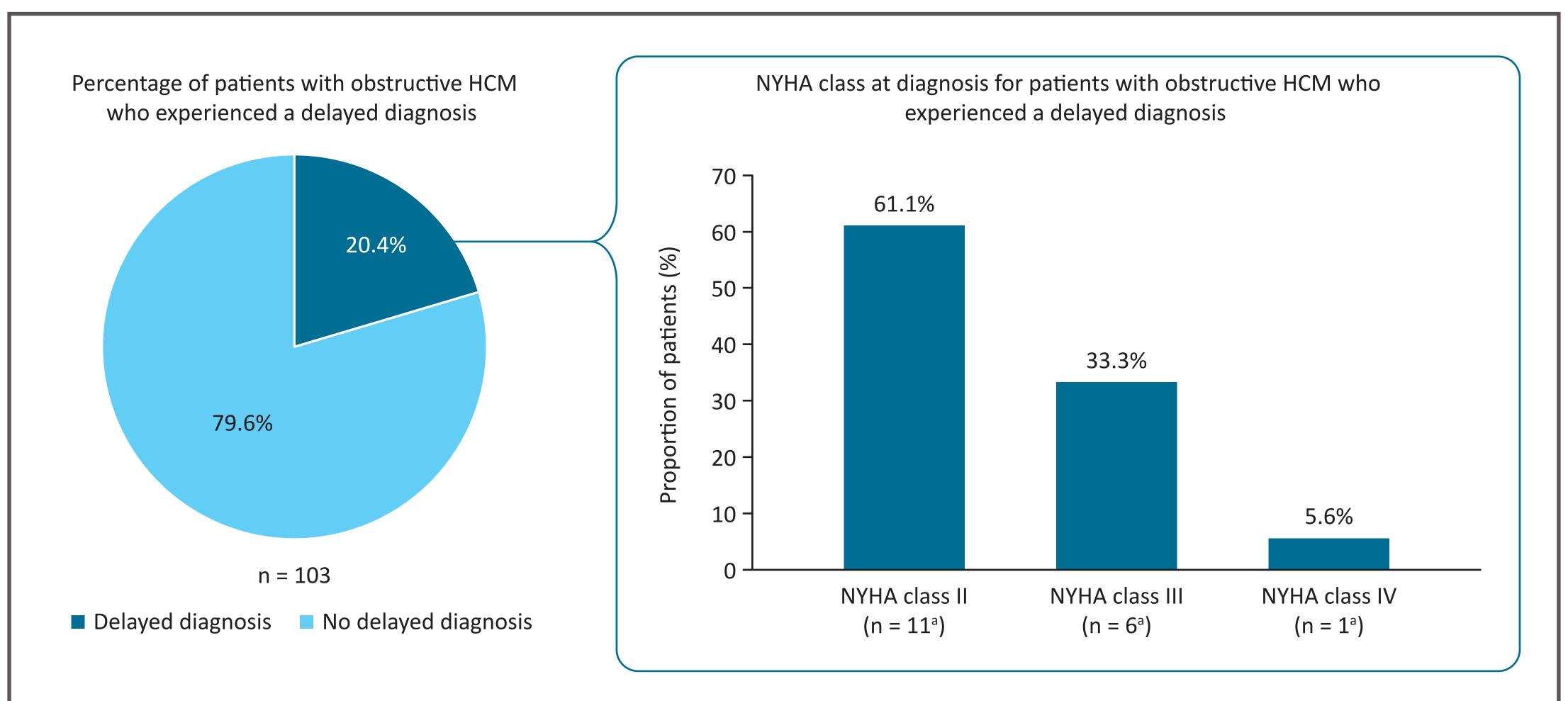
Table 1. Patient demographics and clinical characteristics

	Patients with symptomatic obstructive HCM (N = 151)
Age, mean (SD), years	55.5 (15.35)
Sex, n (%)	
Male	103 (68.2)
Female	47 (31.1)
Intersex	1 (0.7)
BMI, mean (SD)	27.0 (6.44)
Current NYHA class, n (%)	
Class II	125 (82.8)
Class III	24 (15.9)
Class IV	2 (1.3)
Time since diagnosis, shown by current NYHA class, n; mean (SD), years	
NYHA class II	115; 2.2 (2.7)
NYHA class III	22; 3.1 (4.2)

^aNo data were available for NYHA class IV.

BMI, body mass index; HCM, hypertrophic cardiomyopathy; NYHA, New York Heart Association; SD, standard deviation..

Figure 1. NYHA class at diagnosis for patients who experienced a delayed diagnosis

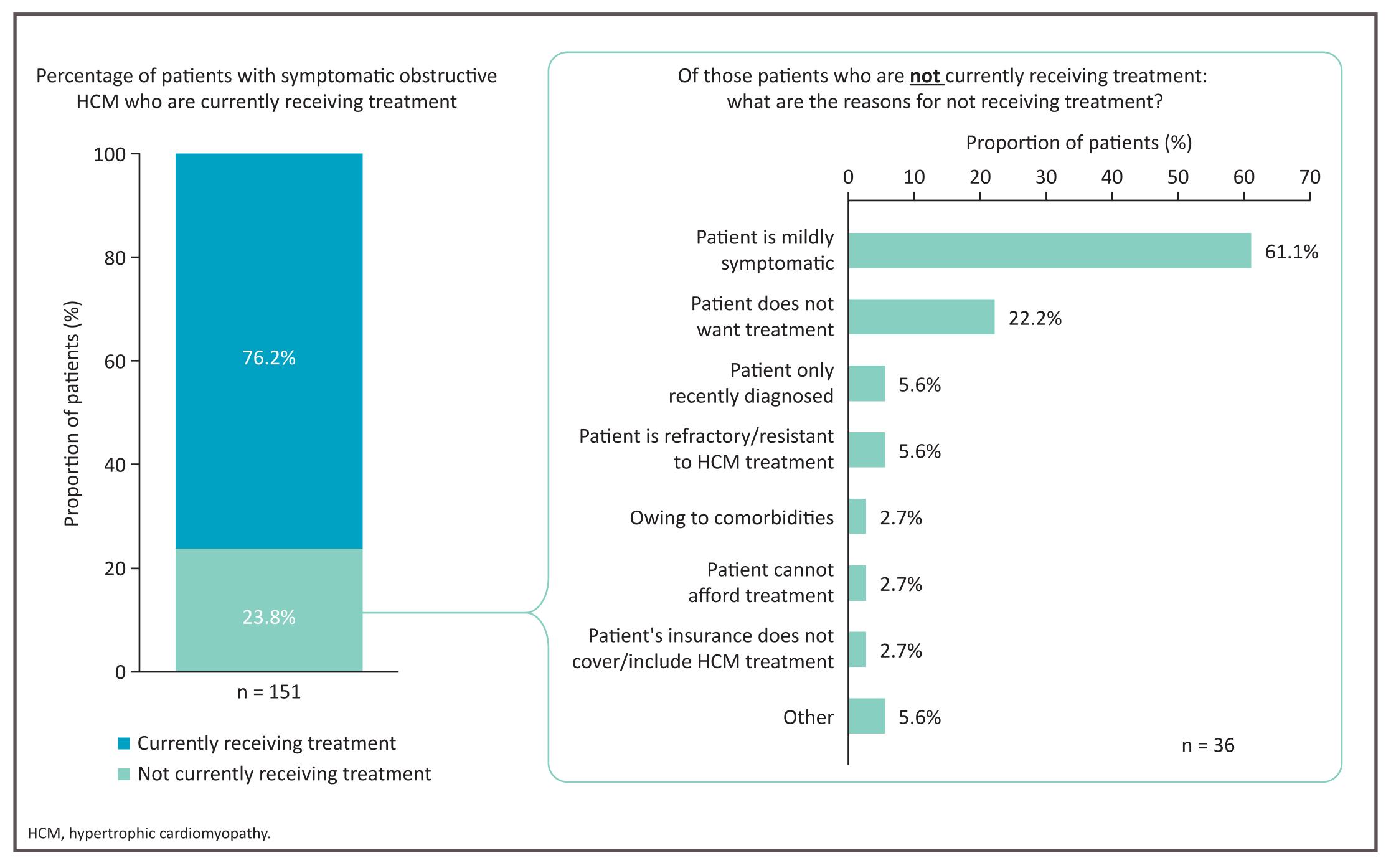


Delayed diagnosis was physician-stated: when the physician stated that the patient had experienced a delay in diagnosis of HCM, due to having another condition diagnosed first, and no further tests were conducted to detect HCM at that stage.

^aLow sample size.

HCM, hypertrophic cardiomyopathy; NYHA, New York Heart Association.

Figure 2. Treatment status and reasons for not receiving treatment



- Almost a quarter of patients (23.8%) were not currently receiving treatment for obstructive HCM and 14.6% had never received treatment. The most frequent reasons for not receiving treatment were the patient being mildly symptomatic (61.1%) or refusing treatment (22.2%) (**Figure 2**)
- Overall, 76.2% of patients were currently receiving pharmacological treatment for obstructive HCM. Of those patients currently receiving pharmacological treatment, 81.4% were receiving beta-blockers and 16.3% were receiving calcium-channel blockers, alone or in combination with other treatments. No mavacamten treatment use was reported. 11.3% of patients had undergone septal reduction therapy
- Overall, the most prevalent symptoms experienced by patients, as reported by cardiologists, were dyspnea when active (90.7%), fatigue (22.5%), and palpitations (21.2%). For those patients receiving treatment, these were dyspnea when active (93.9%), fatigue (27.0%), and palpitations (24.3%)
- Overall, 38.9% of all patients with obstructive HCM were not in full-time employment, and of these, 63.2% were retired. Of the total patients who were not in full-time employment, 8.9% were not working due to their obstructive HCM
- Of the patients receiving treatment, 34.8% were not in full-time employment, and of these, 70.0% were retired. Of the total patients who were receiving treatment and not in full-time employment, 7.5% were not working due to obstructive HCM

Limitations

- The patient sample may not reflect the general consulting HCM population because patients who consult more frequently were more likely to be included
- Participants in the DSP do not constitute a true random sample because participation was influenced by cardiologists' willingness to complete the survey
- The cross-sectional design of the DSP cannot be used to inform causal relationships; however, identification of associations is possible

Conclusions

- Obstructive HCM is associated with substantial clinical and societal impacts. This study suggests that a substantial proportion of patients may experience a delayed diagnosis for obstructive HCM
- Despite current treatment, considerable symptom burden remains.
 Some physicians reported impacts on the patients' ability to continue working due to their obstructive HCM
- Of patients not currently receiving treatment, patients being only mildly symptomatic was the most frequently reported reason for not receiving treatment
- This highlights the need for timely diagnosis as well as new treatment options and further research to address the unresolved disease burden

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Acknowledgments

- This study was supported by Bristol Myers Squibb.
- Bristol Myers Squibb did not influence the original methodology of the DSP. The analysis described here used data from the Adelphi Real World HCM DSP. The DSP is a wholly owned Adelphi Real World product. Bristol Myers Squibb is one of multiple subscribers to the DSP.
- All authors contributed to and approved the presentation; writing support was provided by Adelphi Real World and editorial assistance was provided by Elaine Tucker MSc of Oxford PharmaGenesis, Oxford, UK, and funded by Bristol Myers Squibb.

Disclosures

 Mollie Lowe, James Jackson, Laura LeBrocq, and Sophie Barlow are employees of Adelphi Real World. Yue Zhong, Marta Contente, Harshila Patel, and Taryn Krause are employees of Bristol Myers Squibb and may own stock options in Bristol Myers Squibb.