

# Productivity impacts and the need for carer support in obstructive HCM: A patient and carer survey

Neil Reynolds,<sup>1</sup> Yue Zhong,<sup>2</sup> Michael Hurst,<sup>3</sup> Vijayalaxmi Mudaliar,<sup>1</sup> Laura Mirams<sup>1</sup>

<sup>1</sup>Adelphi Real World, Bollington, UK; <sup>2</sup>Bristol Myers Squibb, Lawrenceville, USA; <sup>3</sup>Bristol Myers Squibb, Uxbridge, UK

## Introduction

- Obstructive hypertrophic cardiomyopathy (HCM) is a chronic, progressive myocardial disorder characterized by restriction or blockage to the blood flow from the left ventricle to the aorta, and affects 50-70% of HCM patients.<sup>1,2</sup>
- Obstructive HCM imposes a significant symptomatic burden that impairs patients' quality of life,<sup>3,4</sup> and symptomatic (non-specific) treatments (such as  $\beta$ -blockers, calcium channel blockers, and disopyramide) often lack efficacy and tolerability.<sup>5</sup>
- Recent cross-sectional research found that patients with HCM in Europe experienced issues regarding employment, and significant psychological burden.<sup>4</sup>
- There is a lack of evidence regarding the impact of obstructive HCM on productivity, and the need for carer support in this patient population.

## Objective

- This study aimed to explore the broad societal impacts of obstructive HCM on employment/career, as well as the need for support from informal carers (such as family/friends), and the impacts on those carers themselves.

## Methods

- Patients ( $\geq 18$  years) diagnosed with symptomatic obstructive HCM (New York Heart Association [NYHA] class II-IV) in Canada were recruited via the patient's treating physician to complete a single online cross-sectional survey.
- Patients were not included if they were currently participating in a clinical trial, had undergone septal reduction therapy (SRT) in the preceding 6 months, or had ever received treatment with mavacamten.
- Participating patients were able to nominate people who were their informal caregivers to also fill out the survey.
  - Informal carers were defined as individuals who provide voluntary support for the patient's everyday needs but are not professional caregivers/are not employed as the patient's carer.
- The study was hypothesis generating and as such, all analysis were descriptive.

Table 1. Patient characteristics

	Overall cohort (n=29)
Patient age, years	n=29
Mean (SD)	63.8 (15.1)
Time since diagnosis of obstructive HCM, years	n=21
Mean (SD)	9.8 (9.6)
Patient gender, n (%)	n=29
Female sex	15 (52%)
Patient race, n (%)	n=29
White	21 (72%)
Patient NYHA class (physician confirmed), n (%)	n=29
NYHA class II	24 (83%)
Patient employment status, n (%)	n=29
Retired	14 (48%)
Working full time	7 (24%)
Working part time	3 (10%)
Unemployed	2 (7%)
Student; On long term sick leave; Voluntary work; Home-duties/Homemaker/Stay at home parent; Prefer not to say	1 (3%)
Current obstructive HCM top 10 symptoms experienced, n (%)	n=29
Shortness of breath when active	17 (59%)
Fatigue/weakness	13 (45%)
Palpitations	11 (38%)
Chest pain; Dizziness	7 (24%)
Swelling of legs/ankles/feet; Nocturia	6 (21%)
Inability to sleep	5 (17%)
Weight gain; Anxiety/depression caused by my concerns regarding my condition	4 (14%)
Obstructive HCM treatments currently received, n (%)	n=20
Beta blocker	16 (80%)
Calcium channel blocker	6 (30%)
Anti-arrhythmics	2 (10%)
Septal myectomy; Other; None; Don't know/unsure	1 (5%)

Abbreviations: HCM: hypertrophic cardiomyopathy; NYHA: New York Heart Association SD: standard deviation

Note: The separator ';' used to reflect multiple different responses which had the same quantity.

## Results

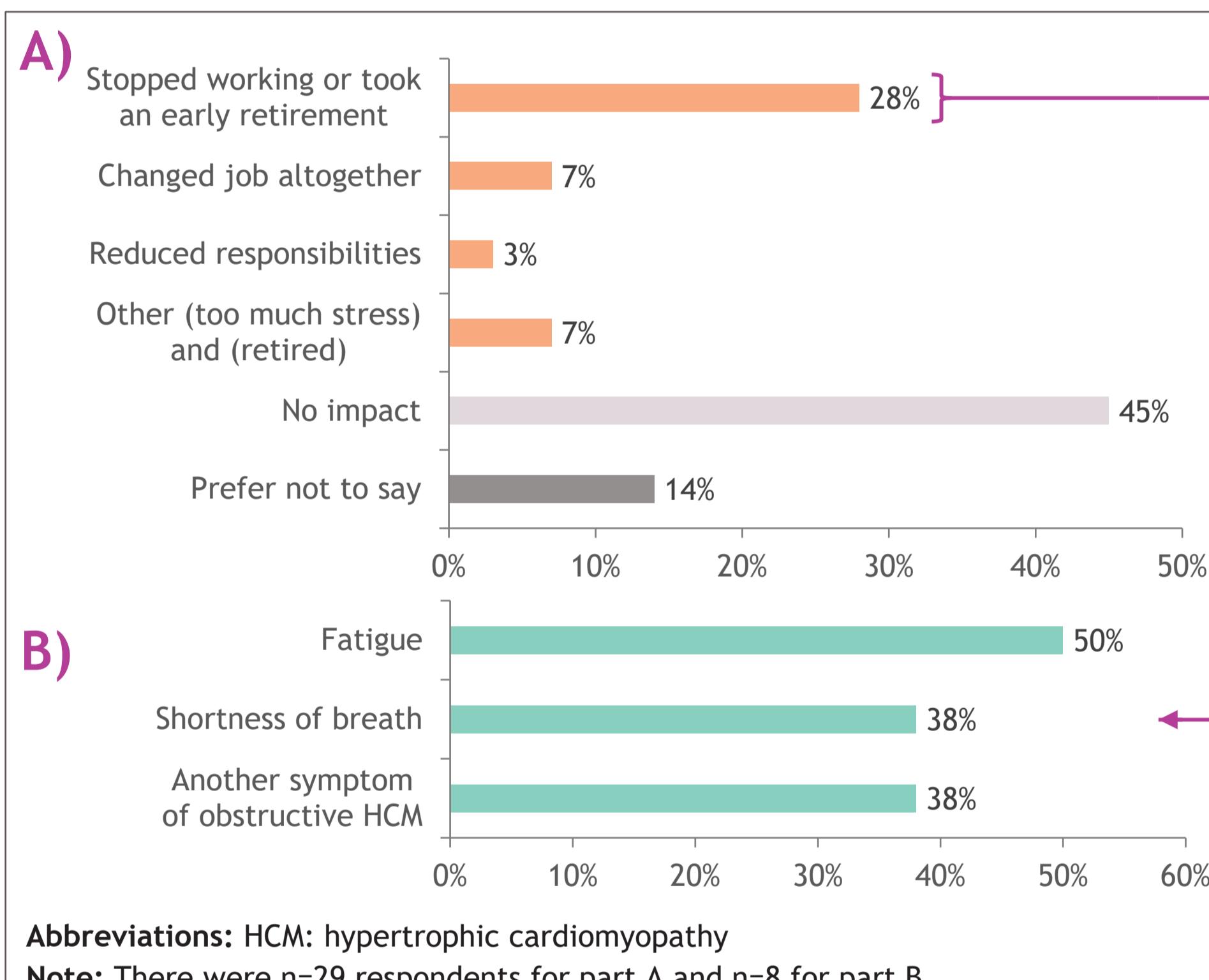
### Patient characteristics

- Among the 29 patients surveyed (52% female, 72% White, mean (SD) age = 63.8 (15.1) years), most were assessed as New York Heart Association class II (83%) (Table 1).
- Symptoms were heterogeneous, with the most commonly reported including shortness of breath when active (59%), fatigue/weakness (45%), and palpitations (38%) (Table 1).
- The majority of patients (80%) were currently in receipt of beta-blockers (Table 1).
- Overall, 34% (n=10) of patients were in employment (Table 1).

### Impact of disease on employment, quality of life and caregiver support

- Among the 29 patients surveyed, 28% reported stopping working/taking an early retirement since developing symptoms, and 10% had either changed jobs or reduced their work responsibilities (Figure 1).
- The eight patients who stopped working or retired early, offered fatigue (50%), shortness of breath (38%), and other obstructive HCM symptoms (38%) as reasons for their curtailment of employment (Figure 1).

Figure 1. A) Impact on patients' career/employment since starting to experience symptoms of obstructive HCM; B) Symptoms due to which patients stopped working/took an early retirement



Abbreviations: HCM: hypertrophic cardiomyopathy

Note: There were n=29 respondents for part A and n=8 for part B

- Of the 10 patients in current employment (encompassing part-time and full-time), three anticipated that the disease would have a future impact on their employment/career (Table 2).

Table 2. Patient reported impact of obstructive HCM symptoms on employment/career and need for caregiver support

	Overall cohort (n=29)
Modification to life due to obstructive HCM symptoms, n (%)	n=29
Yes	13 (45%)
Patient anticipated future impact on employment/career, n (%)	n=10
I may need to stop working or take an early retirement	1 (10%)
I may need to change to part-time/reduced working hours	1 (10%)
Other (may need to stop completely)	1 (10%)
Required carer support with their day-to-day activities, n (%)	n=29
Yes	13 (45%)
Who provides/has provided support with day-to-day activities, n (%)	n=13
A family member (or family members) or a friend (or friends)	12 (92%)
A paid professional carer <sup>a</sup>	2 (15%)
Current support from an informal caregiver, n (%)	n=13
Yes	11 (85%)
Level of support received at survey completion vs diagnosed, n (%)	n=11
I require a lot less support now	0 (0%)
I require somewhat less support now	1 (9%)
I require about the same level of support now	6 (55%)
I require somewhat more support now	3 (27%)
I require a lot more support now	1 (9%)
Hours a week receiving support, hours	n=10 <sup>b</sup>
Median (IQR)	8.0 (1.8-94.5)

Abbreviations: HCM: hypertrophic cardiomyopathy; IQR: interquartile range; SD: standard deviation

<sup>a</sup> Two patients received care from a professional carer (as reported in the patient data), however no data was collected from these professional carers. The caregiver sample only included primary informal carers to the patients, however the patient survey included questions regarding any support received from professional carers.

<sup>b</sup> One patient who currently had caregiver support opted not to provide a response and as such the denominator for this question was n=10.

• Due to their obstructive HCM symptoms, 13 patients (45%) had made a lifestyle modification (Table 2).

• Owing to obstructive HCM, 13 patients (45%) had required carer support at some point post diagnosis, with 12 (92%) of these receiving support from family or friends (Table 2).

• Among the 11 patients receiving carer support, the median [interquartile range (IQR)] number of support hours per week was 8 [IQR: 1.8 - 94.5] (n=10), and 4 of these 11 patients reported an increase in support required since their diagnosis (Table 2).

### Informal carer characteristics and survey results

• Among informal carers surveyed (n=10, 70% female, mean age = 61.3 years), 8 carers lived with the person with obstructive HCM (Table 3).

• There were three carers currently in employment (Table 3).

• Four out of the 10 carers reported an impact of caring on their own employment/career (Table 3).

• Five out of 10 reported a negative impact of caring (Table 3).

Table 3. Informal carer characteristics and impact of caregiving on employment/career

	Carer cohort (n=10)
Carer age: mean (SD), years	61.3 (12.8)
Carer gender: n (%), Female sex	7 (70%)
Carer race: White, n (%)	7 (70%)
Carer employment status, n (%)	
Retired	6 (60%)
Working full-time	1 (10%)
Working part-time	2 (20%)
Unemployed	1 (10%)
Carer living status, n (%)	
I live in the same house	8 (80%)
I live in a separate house, in the same neighbourhood; I live in a separate house, in a different neighbourhood	1 (10%)
Impact on carer's employment/career due to caregiving, n (%)	
Reduced responsibilities; Unable to travel for work; Could not work in the career/industry I want; Needed flexible working hours; Difficulty concentrating at work <sup>a</sup>	1 (10%)
Other	3 (30%)
Level of impact on caregiver's day-to-day life due to caregiving, n (%)	
1 = No impact on my day-to-day life	1 (10%)
2	5 (50%)
3	3 (30%)
4	1 (10%)
5 = Extremely high impact on my day-to-day life	0 (0%)
Impact of caregiving, n (%)	
It has a positive impact on my life	4 (44%)
It has a negative impact on my life	5 (56%)

Abbreviations: SD: standard deviation

Note: Separator ';' used to reflect multiple responses which had the same quantity.

<sup>a</sup> Multiple-choice question where n=1 carer chose each option

<sup>b</sup> Base is all who indicated some degree of impact

### Strengths and limitations

• The study results improve understanding of the broad societal impacts of obstructive HCM, and despite the limited sample of carers, the results provide valuable insights into caregiving burden, given the lack of existing literature.

• Due to the online nature of the survey, the sample is biased towards computer literature participants, and the findings may reflect the views of the specific sample rather than the broader obstructive HCM population.

• Due to recruitment via physicians, the sample may also be biased towards patients treated at specialist centres.

## Conclusion

• Obstructive HCM is associated with impacts on employment/career, and everyday life, with just under a third of patients stopping work or taking an early retirement since developing symptoms, and just under half having made a lifestyle modification due to their symptoms.

• Obstructive HCM is also associated with a substantial need for carer support, with just under half of patients having required carer support at some point after being diagnosed.

• Obstructive HCM is also associated with an impact on employment/career and everyday life for informal carers, with half of the carers surveyed reporting a negative impact of caring on their life.

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