

# Perceptions of heart failure symptoms, disease severity, treatment decision-making, and side effects by patients and cardiologists: a multinational survey in a cardiology setting

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**Purpose:** Explore the extent to which heart failure (HF) symptoms and side effects of HF treatment experienced by patients are recognized by cardiologists, and concordance between patient–cardiologist perceptions of HF severity and patients’ contributions to treatment decision-making.

**Methods:** A multinational, cross-sectional survey of cardiologists and patients with HF was conducted. Patient-record forms (PRFs) were completed by cardiologists for consecutive consulting patients with HF, who completed a patient self-completion questionnaire (PSC). Responses from PRFs with an associated PSC were analyzed to compare patient- and cardiologist-reported occurrences of HF symptoms and treatment side effects, patient-perceived severity of HF and cardiologists’ perceived risk of death within 12 months, and patient input into treatment decisions. Concordance was calculated as the number of response agreements between PSCs and PRFs for total number of matched pairs. Over- or underreporting of symptoms and side effects by cardiologists relative to patient-reported occurrences were calculated.

**Results:** Overall, 2,454 patient–cardiologist pairs were identified. High levels of concordance between matched pairs were observed for the occurrence of reported HF symptoms (93%), side effects (77%–98%) and degree of patient input into treatment decisions (74%); for perceived HF severity, concordance was 54%. Most symptoms (except dyspnea when active and fatigue/weakness, experienced by >50% of patients) were underreported by cardiologists. Of patients reporting to have been informed by their cardiologist that their HF was mild, 28% were perceived by their cardiologist to have a moderate–high/very high risk of death within 12 months. Treatment choice was not discussed with almost a third of patients. When discussed, 94% of patients (n=1,540) reported the cardiologist made the final decision. Cardiologists more often under- than overreported the occurrence of side effects reported by patients.

**Conclusion:** Improved patient–cardiologist dialogue and shared decision-making is required for optimizing patient care and outcomes in HF.

**Keywords:** patient influence, disease awareness, treatment decision-making, patient-reported outcomes, disease-specific program, real world

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## Introduction

Results of previously published patient surveys indicate that individuals with heart failure (HF) have limited knowledge of the severity of their condition and its prognosis.<sup>1,2</sup> Almost half the participants in a survey of 52 patients <50 years old with HF thought that their disease was curable.<sup>2</sup> Effective two-way communication between

people with HF and health-care professionals (HCPs) is key to improving patients' knowledge and understanding of their heart condition and associated with improvements in both adherence to HF-management plans<sup>3,4</sup> and patient outcomes.<sup>5,6</sup> Communication between patients and HCPs is also needed to aid decisions on pharmacological treatment. It is important that patients are involved in these decisions so that they understand how to take their medication (dose, time of day) and the benefits of treatment, and are able to recognize possible side effects of pharmacotherapy.<sup>7</sup> Results of a qualitative, community-based interview study of individuals with HF indicated that patients did not feel involved in decision-making or encouraged to discuss treatment with their HCP.<sup>8</sup> With recent advances in care, it is now well recognized that shared patient–HCP decision-making is central to optimized HF management.<sup>9</sup>

There is a lack of international quantitative evidence on how patient perceptions of their HF and treatment correspond with those of their cardiologists. We thus used a large, real-world, multinational survey to investigate the extent to which HF symptoms and side effects of HF treatment experienced by patients were recognized by cardiologists. We also evaluated levels of concordance on perceptions of HF-disease severity by patients (which were based on information provided by their cardiologists) and cardiologists, in addition to patient contributions to treatment decision-making.

## Methods

### Study design

Data were collected from the Adelphi HF Disease Specific Programme (DSP),<sup>10</sup> a cross-sectional survey of cardiologists and their consulting patients with HF, conducted in 2016 in a real-world setting across ten countries (Argentina, Brazil, China, Colombia, France, Japan, Mexico, Russia, Saudi Arabia, and Turkey). The DSP comprises three main phases, details of which have been described previously: a preparatory phase involving development of survey materials and participant recruitment, a data-collection phase, and data analysis.<sup>10</sup>

### Preparatory phase

The DSP comprised a face-to-face cardiologist interview, a patient-record form (PRF), and a patient self-completion questionnaire (PSC). These questionnaires were developed in English and translated into the language of the relevant study country by native speakers from a local DSP agency. An independent UK-based translation agency subsequently verified the translated materials. The questionnaires were

developed empirically, and their pharmacometric properties were not systematically assessed.

### Participant recruitment

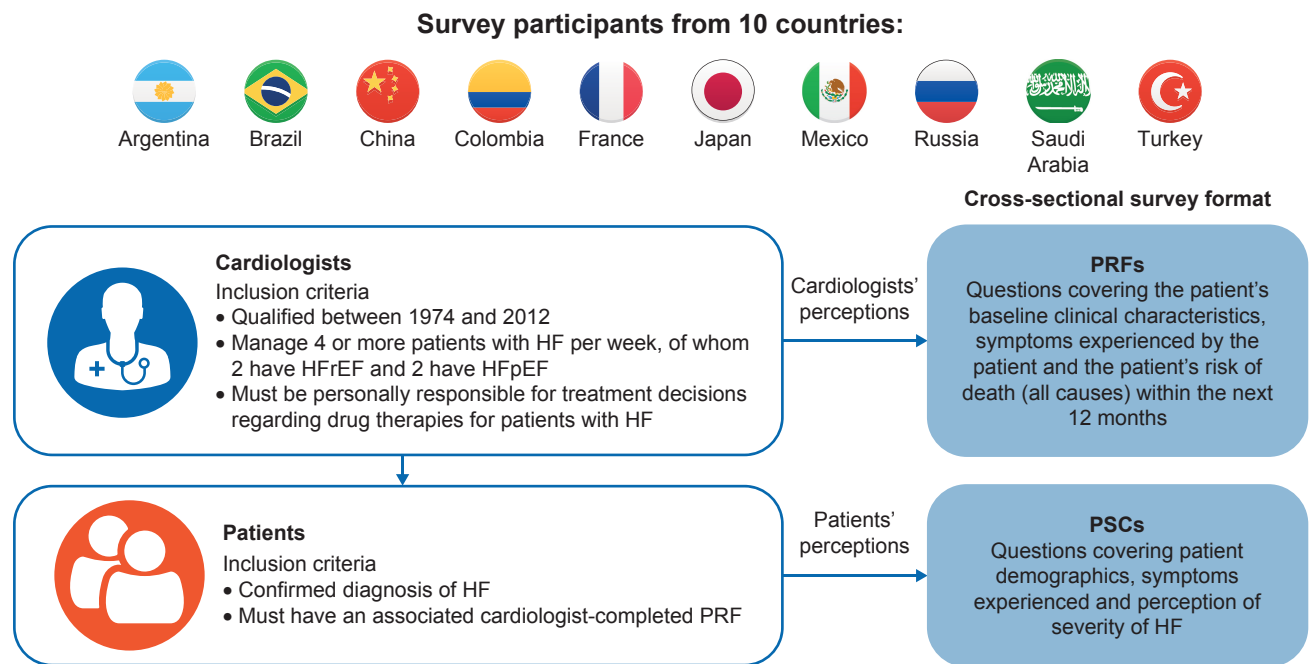
Cardiologists were identified from public lists of HCPs and invited to participate in the study, provided they had qualified as a cardiologist between 1974 and 2012, consulted with at least four patients with HF per week, and were personally responsible for drug-treatment decisions. To be eligible for inclusion, patients had to have a confirmed HF diagnosis and an associated cardiologist-completed PRF (Figure 1).

Cardiologists completed PRFs for consecutive consulting patients with HF (new or preexisting) using data from medical records. Patients with left ventricular ejection fraction (LVEF) <40% were classified as having HF with reduced ejection fraction (HFrEF), patients with LVEF 40%–49% were classified as having HF with midrange ejection fraction (HFmrEF), and those with LVEF ≥50% were classified as having HF with preserved ejection fraction (HFpEF). All patients were then invited to complete a PSC independently of their cardiologist immediately after their consultation. Patients gave informed consent to participate by ticking a box on the front page of the questionnaire to indicate that they had read the information provided and that they agreed to take part in the study.

### Data collection and analysis

Information gathered from PRFs and PSCs included patient demographics and clinical characteristics, HF symptoms, and treatment aspects (including common side effects and input into treatment decision-making). Responses were anonymized to ensure confidentiality and avoid potential biases. Cardiologists were not able to see or influence patient responses.

Only responses from PRFs with an associated PSC were analyzed. Patient-reported and cardiologist-reported occurrences of individual HF symptoms were compared and concordance calculated as the number of response agreements between the PSC and PRF for the total number of patient–cardiologist matched pairs. Underreporting and overreporting of symptom occurrence by cardiologists relative to patient-reported occurrence was calculated by taking the patient's perspective and evaluating how often a patient-reported symptom was not reported by their cardiologist in the PRF (underreported) and how often a cardiologist reported a symptom in the PRF that was not reported by the patient (overreported). Patient-perceived HF-disease severity (rated as mild, moderate, or severe) following information provided by their cardiologist was compared with the cardiologist's



**Figure 1** Disease Specific Programme methodology for identification of cardiologists and patients.

**Abbreviations:** HF, heart failure; HFpEF, HF with preserved ejection fraction; HFrEF, HF with reduced ejection fraction; PRF, patient-record form; PSC, patient self-completion questionnaire.

perceived risk of death within 12 months (rated as low, moderate, or high). Patients and cardiologists recorded the degree of patient input into treatment decisions and the side effects experienced because of the patient's current HF-treatment regimen. These data were compared, and concordance and cardiologist underreporting and overreporting were calculated as just described.

The questionnaires applied in this study follow guidelines outlined in the code of conduct published by the European Pharmaceutical Market Research Association.<sup>11</sup> This code states that ethical approval within this context is not necessary, because the goal of research is to improve understanding, rather than to test hypotheses. The research was conducted in accordance with the US Health Insurance Portability and Accountability Act 1996 and European equivalents.<sup>11,12</sup>

## Results

### Study population

A total of 4,903 PRFs were received from 563 cardiologists. Subsequently, 2,454 patients with HF completed a PSC, amounting to the total number of matched patient–cardiologist pairs (Table 1). The study population had a mean age of 66.7±11.9 years, with more males (58%) than females, and most patients (66%) were retired. Of patients with available information on HF functional class (n=2,442), 50% had

New York Heart Association (NYHA) class II, with similar proportions with NYHA classes I (24%) and III (22%), while 3% had NYHA class IV. The distribution of HF phenotypes across the studied population was HFpEF (43%), HFmrEF (32%), and HFrEF (26%; Table 1).

### HF symptoms

A high level of concordance between matched patient–cardiologist pairs was observed for the occurrence of reported HF symptoms (n=2,379): overall, 93% of matched pairs reported similar occurrences of any HF symptom. High concordance was also observed for the occurrence of individual HF symptoms (ranging from 80% for palpitations to 92% for persistent cough [Figure 2A]). For symptoms reported by >50% of patients (ie, shortness of breath when active and fatigue/weakness [Figure 2B]), cardiologists more commonly overreported than underreported their occurrence, whereas for symptoms reported by <50% of patients, cardiologists were more likely to underreport than overreport their occurrence (Figure 2B).

### HF severity

Overall concordance of patient-perceived and cardiologist-perceived severity of HF was 54% (n=2,260). Of 1,040 patients reporting to have been told by their cardiologist that their HF was mild, 28% were perceived by their cardiologist to have

**Table 1** Patient demographics and baseline clinical characteristics

	All patients (n=2,454)
Mean age, years (SD)	66.7 (11.9)
<b>Sex, n<sup>a</sup> (%)</b>	
Male	1,413 (58)
Female	1,039 (42)
Mean BMI, kg/m <sup>2</sup> (SD)	25.9 (4.6)
<b>Country, n (%)</b>	
Argentina	240 (10)
Brazil	182 (7)
China	933 (38)
Colombia	116 (5)
France	72 (3)
Japan	154 (6)
Mexico	195 (8)
Russia	379 (15)
Saudi Arabia	31 (1)
Turkey	152 (6)
<b>Employment status, n (%)</b>	n=2,446
Working full-time	299 (12)
Working part-time	111 (5)
Student	9 (<1)
Unemployed	85 (3)
Homemaker	219 (9)
Retired	1,615 (66)
Other	55 (2)
Did not know	55 (2)
Unemployed or retired owing to HF <sup>b</sup>	158 (10)
<b>HF phenotype, n (%)</b>	n=2,196
HFrEF (LVEF <40%)	566 (26)
HFmrEF (LVEF 40%–49%)	694 (32)
HFpEF (LVEF ≥50%)	936 (43)
<b>NYHA classification, n (%)</b>	n=2,442
I	589 (24)
II	1,230 (50)
III	547 (22)
IV	76 (3)

**Notes:** <sup>a</sup>Missing gender information from 2 patients. <sup>b</sup>Proportion of unemployed or retired patients who answered the question (n=1,634) and reported that they were unemployed or retired owing to HF.

**Abbreviations:** BMI, body-mass index; HF, heart failure; HFmrEF, HF with midrange ejection fraction; HFpEF, HF with preserved ejection fraction; HFrEF, HF with reduced ejection fraction; LVEF, left ventricular ejection fraction; NYHA, New York Heart Association.

a moderate–high or very high risk of death within the next 12 months. This increased to 50% for the 888 patients who reported having been informed by their cardiologist that their HF was moderate and 75% for the 332 patients who reported having been informed that their HF was severe. Conversely, cardiologists perceived the risk of death in the next 12 months to be low or very low in 25% of the 332 patients who reported having been informed that their HF was severe.

## Patient input on HF-treatment decision-making

Of matched patient–cardiologist pairs (n=2,228), almost a third (30%) of patients stated in the PSC that they had had

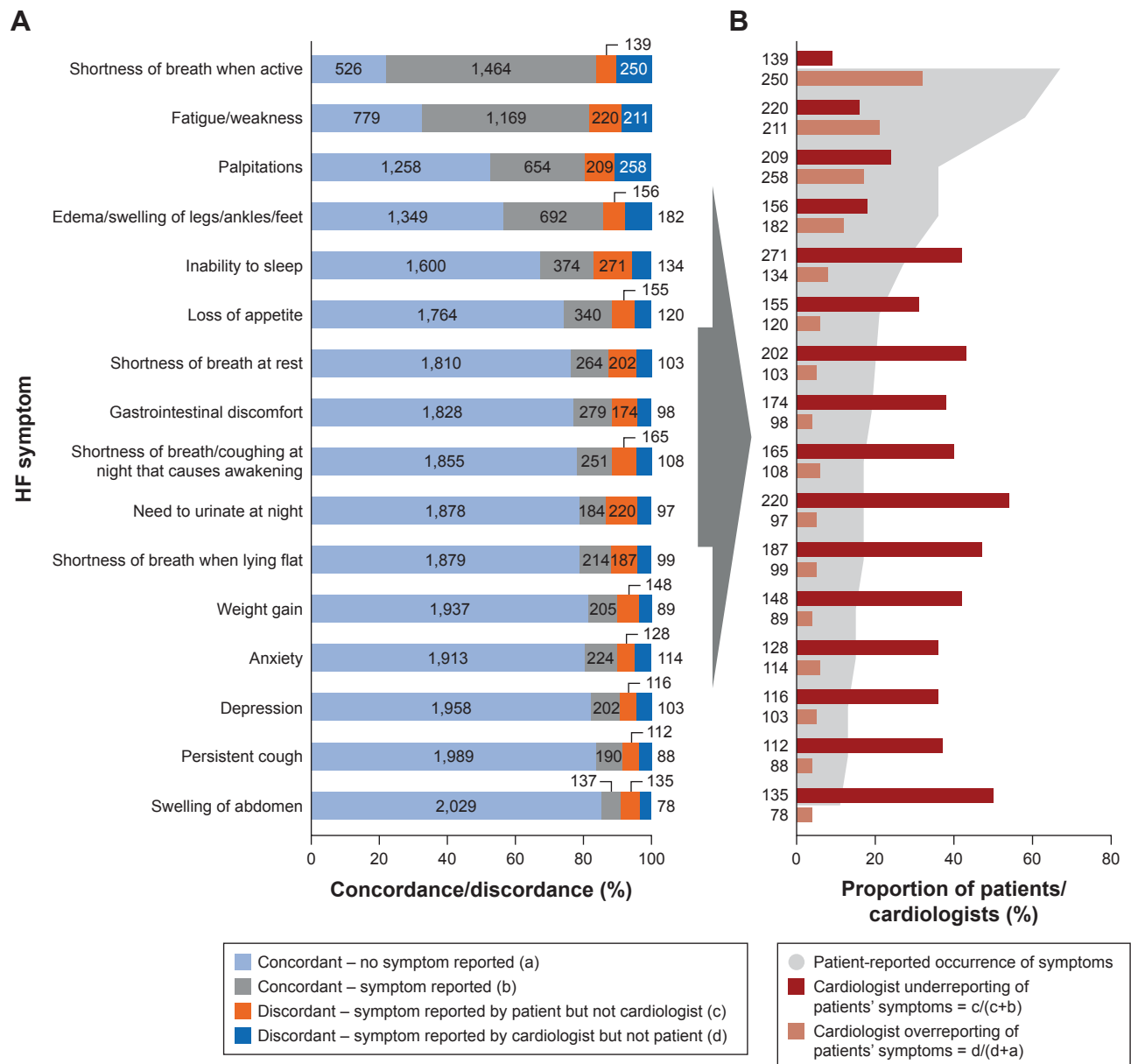
no opportunity to influence the choice of their HF therapy. In total, 1,540 patients (69%) reported that they had had the opportunity to influence their treatment options. Most (n=1,442; 94%) of these recorded in the PSC that the cardiologist had made the final treatment decision, while 6% stated that they had made the final decision. A high level of concordance (74%) between matched patient–cardiologist pairs was observed for the degree of patient input into treatment decisions, though patient input was overreported and underreported by cardiologists for 14% and 12% of matched pairs, respectively.

## HF-treatment side effects

Concordance was high between matched patient–cardiologist pairs (n=2,385) for the occurrence of side effects of HF treatment, ranging from 77% for fatigue/tiredness to 98% for gout, rash, and swelling of lips, tongue, throat, or face (Figure 3A; blue and gray bars). Individual side effects were reported by 1%–22% of patients (Figure 3B). Cardiologists more often underreported than overreported the occurrence of side effects of treatment reported by patients (Figure 3B). Results from HF-treatment side effects relied on patient and physician reporting, and a confirmed diagnosis could not be established by the methodology used in our research.

## Discussion

This analysis covering ten countries was conducted to generate quantitative evidence on concordance of patient and cardiologist perceptions regarding HF symptoms, disease severity, treatment decisions, and treatment-associated side effects. We found that while cardiologists were aware of the most common HF symptoms experienced by patients (ie, dyspnea when active and fatigue/weakness), they tended to underreport the less common symptoms, such as need to urinate at night, swelling of the abdomen, and shortness of breath when lying flat. Moreover, cardiologists were aware of more common or potentially severe side effects of HF treatment, including tiredness and swelling of the lips, tongue, throat, or face, but frequently underreported their occurrence. However, caution should be taken in the interpretation of these findings, as these symptoms may not necessarily reflect a diagnosis of angioedema, and the methodology used in this study did not allow verification of the accuracy of diagnoses made in the clinic. The findings of this survey also indicated that having been informed of the severity of HF by their cardiologist, patients often underestimated it, indicating a misalignment in understanding. Importantly, almost a third of patients reported having no involvement (including any



**Figure 2 (A)** Patient–cardiologist concordance for occurrence of HF symptoms; **(B)** cardiologist underreporting and overreporting of occurrence of HF symptoms in relation to patient-reported occurrence.

**Notes:** The HF symptoms presented on the Y-axis of **(A)** are also applicable to **(B)**. **Abbreviation:** HF, heart failure.

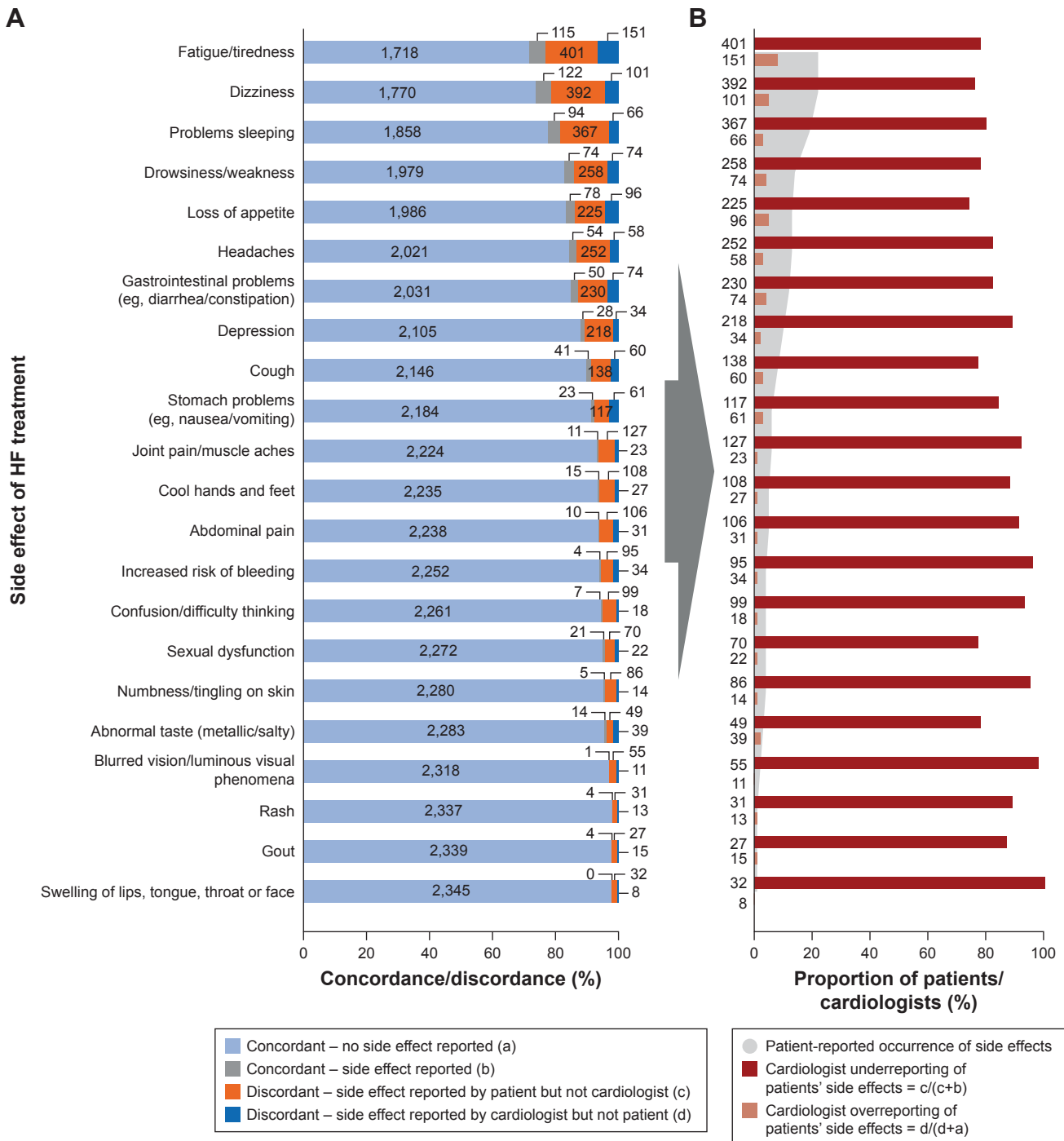
discussion) in the most recent decision regarding their HF treatment.

These results indicate a need for improvement in open communication between cardiologists and patients. Other studies have found misaligned perceptions between patients and HCPs with regard to symptoms experienced and disease severity.<sup>13–15</sup> In a study by Rogers et al, patients tended to attribute their symptoms to the normal aging process or treatment side effects, and consulted their HCP only when such symptoms as breathlessness became unmanageable.<sup>13,14</sup> Additionally, some patients were unaware of their unfavorable

prognosis,<sup>13</sup> a situation that has been reported in other studies in which patients did not conceptualize HF as an incurable condition.<sup>1,2</sup>

HF is a complex syndrome to manage: patients tend to be elderly, have additional chronic illnesses, and receive numerous pharmacotherapies.<sup>16</sup> Findings from qualitative studies have also shown that patients often have concerns about their treatment, but fail to discuss such issues, trusting their physician.<sup>13,14</sup> Shared decision-making is the central goal of patient-centered care,<sup>17</sup> whereby the HCP educates the patient about their condition, available treatment options, possible





**Figure 3** Patient–cardiologist concordance for occurrence of side effects potentially derived from current HF treatment; **(B)** cardiologist underreporting and overreporting of occurrence of HF side effects potentially derived from current HF treatment in relation to patient-reported occurrence.

**Notes:** The side effects of HF treatment presented on the Y-axis of **(A)** are also applicable to **(B)**.  
**Abbreviation:** HF, heart failure.

outcomes and side effects of therapy, and considers the patient’s preferences, in order to reach an informed treatment decision by mutual consent.<sup>9</sup> This process, which allows for an effective and open relationship between patient and HCP, is considered fundamental to optimized patient management.<sup>18</sup> Indeed, there is evidence that collaborative HCP–patient

communication is associated with achievement of treatment goals and improved patient satisfaction.<sup>19,20</sup> Therefore, interventions that encourage the patient’s active participation (eg, increased questioning) during medical visits, as well as interventions aimed at improving cardiologists’ communication skills (eg, improvements in the degree of

friendliness, sensitivity, and supportiveness) may enhance the collaborative relationship between patient and cardiologist.<sup>20</sup> Encouragingly, the American College of Cardiology recently reported that 78% of 400 patients with heart disease surveyed actively engaged with their HCP during an office visit to clarify treatment issues or other personal illness-related problems, suggesting that the concept of shared decision-making is becoming more and more mainstream.<sup>21</sup>

From the standpoint of future research, the high concordance across all queried individual HF symptoms and treatment-associated side effects in matched patient–cardiologist responses holds good promise. When conducting research, collecting outcomes from both patients and HCPs can be challenging, while our results suggest that using one perspective is largely representative. The observed concordance could potentially have been further improved by additional validation of the questionnaires from the perspective of the respondents, eg, it is plausible that many patients adapted their activity levels owing to their disease, and so a question on shortness of breath when active might have been misinterpreted by the patient (stemming from the fact that they were not active).

## Conclusion

Ensuring patient education and increasing patient–cardiologist dialogue and shared decision-making may lead to increase awareness of HF-associated risks and treatment-related side effects. Improved communication between patients and their cardiologists may encourage patients to seek help from HCPs earlier in their disease progression, leading to optimized HF treatment and outcomes.

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## Author contributions

All authors contributed to data analysis, drafting and revising the article, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

## Disclosure

SBW is an employee of Novartis Sweden. BB was an employee of Novartis Pharma at the time of the study, and is now an employee of Hoffmann La Roche, Basel, Switzerland. CCP is an employee of Wellmera AG, Switzerland. SC, JJ, HB, and ZP are employees of Adelphi Real World, UK. The authors report no other conflicts of interest in this work.

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