

Heart failure symptom burden in outpatient cardiology: observational cohort study

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ABSTRACT

Objectives To assess the self-reported symptom burden in patients with a diagnosis of heart failure attending an outpatient cardiology clinic through the utilisation of validated patient-reported outcome measures.

Methods Eligible patients were invited to partake in this observational cohort study. Participant demographics and comorbidities were recorded, followed by participants recording their symptoms using the Integrated Palliative care Outcome Scale (IPOS) and Brief Pain Inventory (BPI) outcome measure tools.

Results A total of 22 patients were included in the study. The majority were male (n=15). The median age was 74.5 (range 55–94) years. Atrial fibrillation and hypertension were the most common comorbidities (n=10). Dyspnoea, weakness and poor mobility were the most prevalent symptoms, affecting 15 (68%) of the 22 patients. Dyspnoea was reported as being the most troublesome symptom. The BPI was completed by 68% (n=15) of the study participants. Median average pain score was 5/10; median worst pain score in the preceding 24 hours was 6/10 and median pain score at time of BPI completion was 3/10. The impact of pain on daily living during the preceding 24 hours ranged from impacting on all activities (n=7) to not impacting on activities (n=1).

Conclusions Patients with heart failure experience a range of symptoms that vary in severity. Introduction of a symptom assessment tool in the cardiology outpatient setting could help identify patients with a high symptom burden and prompt timely referral to specialist palliative care services.

INTRODUCTION

Heart failure (HF) is a progressive, life-limiting condition from structural and/or functional cardiac abnormalities along with objective evidence of pulmonary or systemic congestion.¹ Most recent data available from Ireland estimate 90 000

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients with advanced heart failure experience a range of symptoms impacting on quality of life.

WHAT THIS STUDY ADDS

⇒ Symptoms can be captured by using patient-reported outcome measures (PROM).
⇒ PROM tools are accessible in the outpatient setting.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Symptom assessment tools in the cardiology outpatient setting could ensure timely referral to specialist palliative care services.

Irish people [2% of the population] are living with HF.² An American study estimates the number will rise to >8 million in the USA by 2030.³ Globally, HF affects >64 million people; a global pandemic.⁴ Persons with HF can experience significant symptom burden with a high rate of hospital admission⁵ and lower quality of life.⁶

Palliative care is focused on improved quality of life in life-limiting illness. Early referral to palliative care services prevents and relieves suffering⁷ with clear health gains.^{8 9} Randomised controlled trials reveal improved symptom control, quality of life and mood.^{7 10} WHO estimates that up to one-third of adults diagnosed with cardiovascular disease would benefit from palliative care. The American Heart Association guidelines recommend palliative care be integrated into the care of all patients diagnosed with advanced cardiovascular disease.¹¹ A recent position paper from the Heart Failure Association of the European Society of Cardiology advised that all patients with HF be considered for palliative care throughout the disease

trajectory.¹² Despite this, there remains a shortfall in timely referral of end-stage HF to palliative care services, with most patients referred too late to maximise the benefits.¹³

Many symptoms have been reported by those living with advanced HF.^{6 14 15} Pain is an under-reported and undertreated symptom.¹⁶ The European Association for Palliative Care Task Force expert position statement of 2020 highlighted the need for symptoms to be assessed in a systematic fashion to identify those requiring specialist palliative care.¹⁷ The use of validated assessment tools is recommended. These can identify uncontrolled or escalating symptoms that should trigger a referral.

The aim of this study was to assess self-reported symptom burden in patients with a diagnosis of HF attending an outpatient cardiology clinic. Objectives included quantifying symptom burden and assessing pain scores through validated patient-reported outcome measures (PROM), specifically the Integrated Palliative care Outcome Scale (IPOS) and Brief Pain Inventory (BPI).

METHODS

Patients attending routine cardiology outpatient appointments at an acute general hospital were invited to participate in this observational cohort study. Inclusion criteria consisted of adult patients (>18 years of age) with a formal diagnosis of HF made by a consultant cardiologist. Eligible patients were identified by co-investigators (MW and EB) after review of medical charts—those without a diagnosis of HF were excluded. An information sheet was distributed to all patients suitable for study participation, and informed consent obtained (by MW or EB) before data collection. Patient demographics and comorbidities were recorded, with all data pseudoanonymised and stored on a password-protected laptop in compliance with General Data Protection Regulation standards.

The IPOS is a 20-part patient questionnaire about physical, psychological, emotional, spiritual and support needs (online supplemental appendix 2). Question 1 invites participants to highlight their main problems or concerns in an open format, focusing on their experiences over the preceding 3 days. The remainder of the questions use a Likert scale—ranging from ‘not at all’ to ‘overwhelmingly’—to measure the impact of specific symptoms on participants. Participant and family distress and practical concerns were also assessed. The feasibility and acceptability of the IPOS in a HF outpatient clinic has been successfully demonstrated.¹⁸ The BPI (Short Form) assesses severity and pain interference with activities of daily living (online supplemental appendix 1). Participants are asked to rate their pain severity at its worst, least and average during the previous 24 hours, and the time of questionnaire completion; 0 represents no pain and 10 the worst pain imaginable. Subsequent questions measure the impact of pain on daily function and quality of life on a similar 11-point scale, with 0 as pain that does not interfere and 10 complete interference. The BPI has been validated in both non-malignant and malignant pain.¹⁹

Patients completed the IPOS and BPI while waiting to be reviewed in the cardiology outpatient clinic. Those who could not complete the questionnaires independently were assisted by family members or a member of the research team. Data were collected over a 3-month period to facilitate a sample size of greater than 20, in alignment with a prior feasibility study within a similar population and context.¹⁸

RESULTS

A total of 22 patients were included. The majority were male (n=15). The median age was 74.5 (range 55–94) years. Atrial fibrillation and hypertension were the most common comorbidities (n=10). Sixty-seven per cent had three or more comorbidities (figure 1).

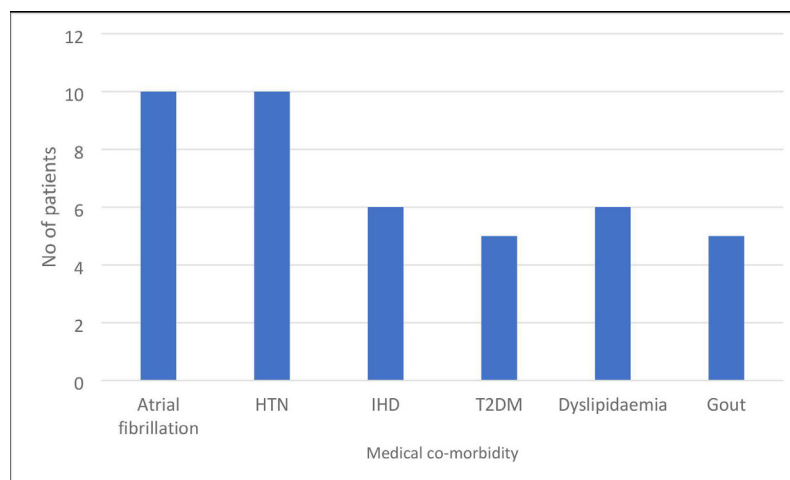


Figure 1 Patient comorbidities. HTN, hypertension; IHD, ischaemic heart disease; T2DM, type 2 diabetes mellitus.

Patients were at various disease stages, and New York Heart Association classification was inconsistently captured.

All participants completed the IPOS. Dyspnoea, weakness and poor mobility were the most prevalent symptoms, affecting 15 (68%) of the 22. Dyspnoea was the most troublesome symptom, with over 55% moderately and 13% severely overwhelmingly affected. Most of those affected by weakness/lack of energy described it as having a slight-moderate impact; similarly, 55% of patients affected by poor mobility described it as a slight-moderate effect. Participants who responded to the question ‘what have been your main problems or concerns over the past 3 days’ recorded dyspnoea (n=6), pain (n=2) and a range of other symptoms including oedema and altered bowel pattern. A third (36%) of participants did not answer this question.

Over two-thirds felt anxious or worried about their health (n=16) and a similar number reported family concerns (n=15). Most patients (77%) felt at peace most of the time or always, and only three felt depressed. Most (n=15) felt able to share how they were feeling with their family or friends; however, two did not feel able to share their feelings at all. Regarding information sharing, 77% of participants had as much information as they wanted (most of the time or always) and 82% described practical problems to their illness as addressed mostly or all of the time.

The BPI was completed by 68% (n=15), five of whom denied any pain on the day of study. Analgesics identified via a free-text question included paracetamol (n=3) and duloxetine (n=1). Median average pain score was 5/10; median worst pain score in the prior 24 hours was 6/10 and median pain score by BPI was 3/10. The impact of pain on daily living during the preceding 24 hours ranged from all activities (n=7) to none (n=1) (see figure 2).

DISCUSSION

There is value in using PROM to determine symptom burden in advanced HF given the inherent subjectivity of all symptoms. IPOS revealed that dyspnoea is one of

the most common symptoms and substantially impacts patients’ lives. Those experiencing shortness of breath often describe associated anxiety that can have a negative effect on quality of life,²⁰ and breathlessness is a leading cause of presentation to the emergency department.²¹ Poor mobility and weakness were highlighted as the other most frequent symptoms, both of which can be exacerbated by dyspnoea. Specialist palliative care teams have dyspnoea management expertise.^{22–24} There is significant scope for optimisation of breathlessness with appropriate and timely referral.

Almost half of the patients described pain. Further evaluation of causative factors is indicated—most patients with end-stage HF are elderly with multiple comorbidities.^{16 25} Pain management in life-limiting conditions can be challenging, particularly when pain encompasses all of a person’s physical, psychological, social, spiritual and practical struggles²⁶ and requires a multidimensional approach. Palliative care clinicians have a pivotal role in the education and support of non-specialist colleagues managing complex pain in this setting.

Strengths of our study include the use of PROM tools validated in both palliative care and HF populations. IPOS was deemed to be a feasible and acceptable method of identifying symptoms in HF.¹⁸ While the BPI was initially used to assess pain in cancer it has since been used in various populations with non-malignant diagnoses.¹⁹ The tools are accessible—patients were invited to participate in the waiting room of a busy clinic. Another potential method of administration would be their inclusion with appointment letters, so patients could complete the questions at home before medical review. Availability of PROM tool results at the review would allow focused interventions and help monitor the impact of symptoms on patients’ lives longitudinally.

This was a single-site study with a small number of participants, which limits generalisability. Patients were recruited from a general cardiology clinic rather than a dedicated HF clinic, with small numbers of eligible patients. Fifty per cent of participants completed the

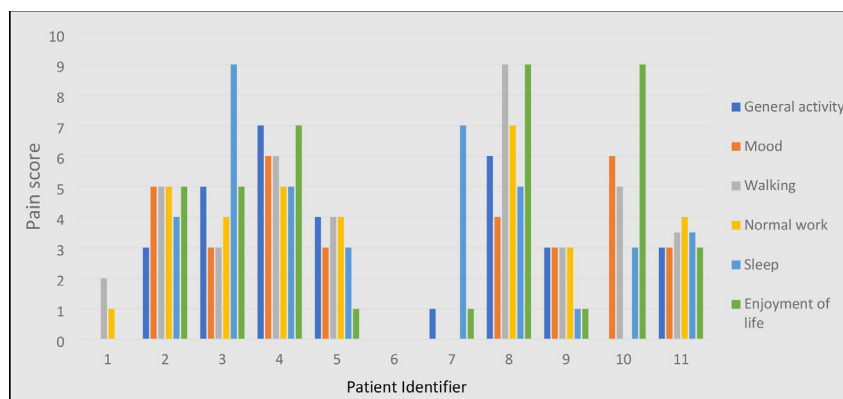


Figure 2 Impact of pain on patient's daily living.

questionnaires independently, giving the most accurate reports of symptom burden. Previous studies demonstrated that families tend to over-report patient symptoms when members are involved in completing symptom assessment scales, while in contrast health-care professionals may under-report symptom impact on patients.^{27–29}

CONCLUSIONS

Patients with HF experience a range of symptoms that vary in severity. Given the varied disease trajectory and uncertain prognosis in advanced HF brief interventions by the specialist palliative care team may be most beneficial if made in a timely manner, depending on need and patient wishes. Introduction of a symptom assessment tool in the cardiology outpatient clinic could help identify those with a high symptom burden and prompt timely referral to specialist palliative care.

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Contributors All authors contributed to the study. MW, CV and FK conceived and developed the study design. MW and EB carried out the data collection. MW and FK analysed and interpreted the results and all authors were involved in draft manuscript preparation. All authors have read and approved the manuscript, and consented to manuscript submission and to subsequent publication. MW acted as guarantor for the study.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC), Cork, Ireland (Ref No ECM 4 (ccc) 12/02/19). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; internally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

Author note In 2022 the IAPC hosted its 21st Education and Research Seminar which was a virtual event given Covid19 restrictions. The IAPC have teamed with BMJ SPC for the last two years where the winner of the platform presentation is invited to submit their research and have it published by BMJ SPC. This is a prestigious award and we are grateful to Dr. Declan Walsh for continuing to support this initiative. The presentation winner Dr. Maria Walsh.

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STUDY ID #: _____ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: _____

Brief Pain Inventory (Short Form)

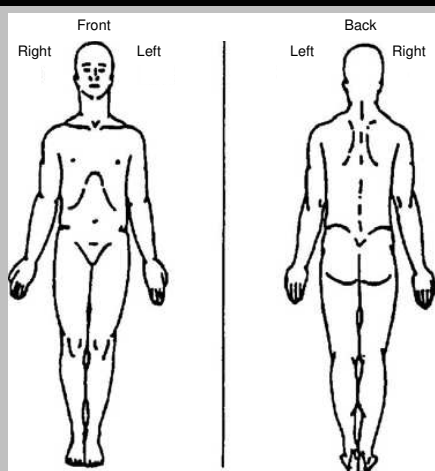
Date: ____ / ____ / ____ Time: _____

Name: _____
Last First Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these every-day kinds of pain today?

1. Yes 2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by circling the one number that best describes your pain at its **worst** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its **least** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the **average**.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have **right now**.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

STUDY ID #: _____ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: _____

Date: _____ / _____ / _____ Time: _____

Name: _____

Last

First

Middle Initial

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

No Complete
Relief Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

B. Mood

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

C. Walking Ability

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

D. Normal Work (includes both work outside the home and housework)

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

E. Relations with other people

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

F. Sleep

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

G. Enjoyment of life

0 1 2 3 4 5 6 7 8 9 10

Does not Completely
Interfere Interferes

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For staff use
 Patient number:

IPOS Patient Version



www.pos-pal.org

Name:

Date (dd/mm/yyyy): / /

Please write clearly, one letter or digit per box. Your answers will help us to keep improving your care and the care of others.

Thank you.

Q1. What have been your main problems or concerns over the past 3 days?

1. _____
2. _____
3. _____

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past 3 days.

	<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Severely</i>	<i>Overwhelmingly</i>
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past 3 days.

1.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
2.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
3.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Over the past 3 days:

	<i>Not at all</i>	<i>Occasionally</i>	<i>Sometimes</i>	<i>Most of the time</i>	<i>Always</i>
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>Always</i>	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Not at all</i>
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>Problems addressed/ No problems</i>	<i>Problems mostly addressed</i>	<i>Problems partly addressed</i>	<i>Problems hardly addressed</i>	<i>Problems not addressed</i>
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>On my own</i>	<i>With help from a friend or relative</i>	<i>With help from a member of staff</i>
Q10 How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse