The prehospital patient pathway and experience of care with acute heart failure: a comparison of two health care systems

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Abstract

Aims This study aimed to analyse community management of patients during the symptomatic period prior to admission with acute decompensated heart failure (ADHF).

Methods and results We conducted a prospective, two-centre, two-country observational study evaluating care pathways and patient experience in patients admitted to hospital with ADHF. Quantitative and qualitative data were gathered from patients, carers, and general practitioners (GPs). From the Irish centre, 114 patients enrolled, and from the English centre, 50 patients. Symptom duration longer than 72 h prior to hospitalization was noted among 70.4% (76) Irish and 80% (40) English patients, with no significant difference between those with a new diagnosis of HF [de novo HF (dnHF)] and those with known HF [established HF (eHF)] in either cohort. For the majority, dyspnoea was the dominant symptom; however, 63.3% (31) of these Irish patients and 47.2% (17) of these English patients did not recognize this as an HF symptom, with no significant difference between dnHF and eHF patients. Of the 46.5% (53) of Irish and 38% (19) of English patients reviewed exclusively by GPs before hospitalization, numbers prescribed diuretics were low (11.3%, six; and 15.8%, three, respectively); eHF patients were no more likely to receive diuretics than dnHF patients. Barriers to care highlighted by GPs included inadequate access to basic diagnostics, specialist support and up-to-date patient information, and lack of GP comfort in managing HF.

Conclusion The aforementioned findings, consistent across both health care jurisdictions, show a clear potential to intervene earlier and more effectively in ADHF or to prevent the need for hospitalization.

Keywords Heart failure; Admission avoidance; Care pathways; Early intervention; Primary care; Patient experience

Introduction

Heart failure (HF) is a chronic condition that places a heavy burden on health care systems. The prevalence of HF among the adult population in developed countries is ~1–2% and rises to >10% for those >70 years of age.¹ Despite advances in medical and device therapies for HF, admission rates remain high.²,³ Not only does this result in increased morbidity, compromised life expectancy, and high financial cost, but also questions whether the care structure designed to help this patient cohort functions optimally.

Studies have shown that admission with acute decompensated HF (ADHF) is an independent risk factor for worse outcomes.⁴⁻⁶ Accordingly, admission avoidance has now become a key focus in overall HF management. Several strategies have been employed including self-care advice to patients encouraging early reporting of emerging problems, community monitoring of metrics sensitive to emerging clinical dete-
oration, and strategies to provide therapy escalation in the outpatient setting to reduce the need for admission. Despite these efforts, admission remains a major challenge in HF care. This underlines the need for close analysis of the care pathway leading up to hospitalization. In doing so, this would provide a more comprehensive understanding of typical management strategies employed in this period, highlight deficiencies in care, and therefore allow strategies to be developed to deal with these issues. Furthermore, analysis of potential similarities in acute HF care between different national health care systems would provide insight as to whether any identified deficiencies in care are specific to certain countries or potentially applicable to the international arena.

Methods

This study was developed to analyse acute HF management and the patient journey during an episode of ADHF. It incorporated the prehospital period in the community and subsequent hospitalization through inpatient management and discharge. The study was designed as a two-centre, two-country, prospective, observational study involving patients who had an unplanned admission to a secondary care/district general hospital with a primary diagnosis of ADHF. The centres included in the study were in Dublin, Ireland, and in Portsmouth, UK. This report focuses on the prehospitalization phase of care. Patients were invited to participate in the study while they were inpatients, and quantitative data were collected by a research nurse via medical chart reviews from November 2014 to September 2016 in the Irish centre and October 2016 to February 2018 in the English centre. Qualitative data were also collected via two methods: questionnaires and semi-structured interviews. Qualitative questionnaires were administered to patients, their relatives, and, via mail, patients’ primary care physicians [general practitioners (GPs)] in both jurisdictions. We also undertook semi-structured interviews with patients, their relatives, and health care professionals at the Irish centre involved in the study, St. Vincent’s University Hospital in Dublin. These qualitative data provide a wider understanding of the patient experience prior to hospitalization as well as the community medical response to patients’ symptoms and the GP’s view on structures available to them to aid in the management of HF. The analysis presented in this paper focuses on the patient experience and management strategies employed in the community prior to hospitalization. A subgroup analysis was also performed to look at differences, if any, between those patients with a new diagnosis of HF [de novo HF (dnHF)] and those with an established background of HF [established HF (eHF)]. Ethical approval for this project was granted by the Ethics and Medical Research Committee, St. Vincent’s Healthcare Group (Reference Number EI PROG Sept 14), and by the East Midlands-Leicester South Research Ethics Committee, Portsmouth Hospitals NHS Trust (Reference Number 16/EM/0305). All study participants gave informed consent prior to enrolment.

Statistical analysis

The data are presented using descriptive statistics. The \( \chi^2 \) test and, where appropriate, Fisher’s exact test were applied using SPSS Statistics (Version 25) to assess for any significant differences in the patient experience and care pathway between dnHF and eHF patients in each cohort. In cases where data were missing or unavailable for patients, these were excluded from the analysis. A \( P \) value < 0.05 was taken as statistically significant. The study sponsors had no role in the study design, data collection, analysis, or interpretation.

Results

A total of 114 patients were enrolled from the Irish centre, 57 of whom had dnHF and 57 of whom had eHF. A total of 50 patients were enrolled from the English centre, 16 of whom had dnHF while 34 had eHF. Median ages were 75 and 71 years for the Irish and English cohorts, respectively. Baseline demographics are outlined in Table 1.

Patient/family experience during worsening heart failure

Symptom recognition

There were several aspects of the patient response to symptoms evaluated during this analysis, the first of which was recognition of symptoms among patients and their primary carers (i.e. a patient’s relative or main carer). As already mentioned, qualitative data were collected to give a more comprehensive understanding of the patient experience. These qualitative data were gathered via questionnaires administered to 70 patients (39 dnHF and 31 eHF) within the Irish cohort and 49 of the English cohort (19 dnHF and 30 eHF). Dyspnoea was the dominant symptom reported by 70% (49) of Irish patients and 73.5% (36) of English patients, as shown in Table 2. However, recognition of this as a symptom of HF was poor among these patients in both cohorts: 63.3% (31) and 47.2% (17) did not recognize dyspnoea as a symptom of HF, respectively. Strikingly, the same lack of recognition among eHF patients was observed in 52% (13) and 47.6% (10) in each cohort with no significant difference found between eHF and dnHF patients (\( P = 0.10 \) and \( P = 0.96 \), respectively). Furthermore, qualitative measures were gathered from 40 relatives of Irish patients and nine relatives of English patients regarding their...
### Table 1 Baseline demographics

|                                | Irish cohort                  | English cohort                  |
|--------------------------------|-------------------------------|---------------------------------|
|                                | Total | De novo HF | Established HF | Total | De novo HF | Established HF |
| Number of patients (%)         |       |           |               |       |           |               |
|                                | 114   | 57 (50%)  | 57 (50%)      | 50    | 16 (32%)  | 34 (68%)      |
| Age, median years              | 75    | 71        | 78            | 71    | 64        | 62.5% (10)    |
| Gender, % male (n)             |       |           |               |       |           |               |
|                                | 60.5% (69) | 54.4% (31) | 66.7% (38)   | 54%   | 27%       | 62.5% (10)    |
| Years since diagnosis, median  |       | 3         |               |       | 5         |               |
| Emergency department/ hospitalization within previous 3 months |       |           |               |       |           |               |
|                                | 30.7% (35) | 17.5% (10) | 43.9% (25)   | 28%   | 14%       | 43.8% (7)     |
| HF-related admission within previous 3 months |       |           |               |       |           |               |
|                                | —     | —         | 29.8% (17)    | —     | —         | 14.7% (5)     |
| Attend GP at least once every 3 months |       |           |               |       |           |               |
|                                | 56.8% (63) | 35.7% (20) | 78.2% (43)   | 58%   | 29%       | 37.5% (6)     |
| Lives alone                    |       |           |               |       |           |               |
|                                | 40.4% (46) | 35.1% (20) | 45.6% (26)   | 40%   | 20%       | 31.3% (5)     |
| Daily contact with primary carer a |       |           |               |       |           |               |
|                                | 93% (106) | 93% (53)  | 93% (53)      | 84%   | 42%       | 93.8% (15)    |
| Median number of co-morbidities | 3     | 3         | 4             | 3     | 4         | 3             |
| Ischaemic heart disease        | 46.9% (53) | 35.1% (20) | 58.9% (33)   | 30%   | 15%       | 25% (4)       |
| Atrial fibrillation            | 49.6% (56) | 40.4% (23) | 58.9% (33)   | 5%    | 27%       | 56.3% (9)     |
| Chronic obstructive pulmonary disease | 23% (26) | 15.8% (9)  | 30.4% (17)   | 16%   | 8%        | 12.5% (2)     |
| Hypertension                   | 43.4% (49) | 43.9% (25) | 42.9% (24)   | 48%   | 24%       | 56.3% (9)     |
| Chronic kidney disease         | 25.7% (29) | 17.5% (10) | 33.9% (19)   | 24%   | 12%       | 18.6% (3)     |
| Diabetes                       | 22.1% (25) | 22.8% (13) | 21.4% (12)   | 44%   | 22%       | 25% (4)       |
| Anaemia                        | 13.3% (15) | 8.8% (5)   | 17.9% (10)   | 14%   | 7%        | 12.5% (2)     |
| Cognitive impairment b         | 27.7% (18) | 27% (10)   | 28.6% (8)    | —     | —        | —             |
| Cancer                         | 12.4% (14) | 7% (4)     | 17.9% (10)   | 12%   | 6%        | 6.3% (1)      |
| Thyroid disease                | 8% (9)  | 5.3% (3)   | 10.7% (6)    | 14%   | 7%        | 12.5% (2)     |
| Arthritis                      | 8.8% (10) | 5.3% (3)   | 12.5% (7)    | 26%   | 13%       | 25% (4)       |
| Alcohol dependence             | 2.7% (3) | 3.5% (2)   | 1.8% (1)     | 4%    | 2%        | 6.3% (1)      |
| Other co-morbidities           | 63.7% (72) | 61.4% (35) | 66.1% (37)   | 40%   | 20%       | 37.5% (6)     |
| HF phenotype c                 |       |           |               |       |           |               |
| Reduced ejection fraction (rEF) | 67.3% (76) | 75% (42)  | 59.6% (34)   | 66%   | 31%       | 87.5% (14)    |
| Preserved ejection fraction (pEF) | 32.7% (37) | 25% (14)  | 40.4% (23)   | 34%   | 16%       | 12.5% (2)     |
| Baseline HF medications for HFrEF patients d |       |           |               |       |           |               |
| ACEI/ARB/ARNI                  | —     | —         | 75% (32)     | —     | —        | 76.4% (13)    |
| Alpha-blocker                  | 75% (32) |           |               | 88.2% (15) |             |
| Mineralocorticoid Receptor Antagonist | 37.5% (12) |           |               | 64.7% (11) |             |

ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin II receptor blocker; ARNI, angiotensin receptor-neprilysin inhibitor.

aPrimary carer defined as the relative or carer who is most responsible for knowing about the patient’s heart failure, caring for, and supporting the patient when needed in the community.

bBased on the Mini-Cog assessment. The Mini-Cog was administered during hospital admission and only to 65 Irish patients. A further 15 patients within the Irish cohort were unable to complete the assessment for a number of reasons including visual or hearing impairment, inability to hold a pen, early discharge, and in-hospital death.

cDefined as EF < 50%, pEF defined as EF ≥ 50%. Ejection fraction unavailable for one patient in Irish cohort and for three patients in English cohort.

dData unavailable for two patients in Irish cohort.

As data collection initially began in 2014 in the Irish centre and 2016 in the English centre, there was little routine use of ARNI, and so patients taking ARNI were not categorized separately from those on ACEI or ARB during data collection.

### Table 2 Dominant presenting symptom

|                                | Irish cohort (n = 70) | English cohort (n = 49) |
|--------------------------------|-----------------------|------------------------|
|                                | Total | De novo HF | Established HF | Total | De novo HF | Established HF |
| Dyspnoea                       | 70%   | 61.5% (24) | 80.6% (25)     | 73.5% | 79.8% (15) | 70% (21)       |
| Ankle swelling                  | 10%   | 15.4% (6)  | 3.2% (1)       | 16.3% | 10.5% (2)  | 20% (6)        |
| Other a                         | 20%   | 23.1% (9)  | 16.1% (5)      | 10.2% | 10.5% (2)  | 10% (3)        |

*Most commonly non-specific symptoms such as fatigue, general malaise, and cough.

Data from our qualitative interviews provide some understanding of a patient’s assessment of their symptoms. Patients related their understanding of the symptoms they associated with heart disease to what they heard described in the mass media or by families and friends. They referred to ‘heart palpitations’ or ‘pain’ as indicators of heart disease:
symptoms they had not experienced. Rather, they described non-specific symptoms of feeling generally unwell, tired, or ‘off their food’ in the days and months leading up to their hospital admission, while breathlessness was often put down to pre-existing lung disease or a chest infection.

**Duration of symptoms**

With regard to duration of symptoms, the majority of patients in both Irish and English cohorts experienced symptoms for >3 days before presenting to hospital (70.4%, 76% vs. 80%, 40, respectively). This finding remained true when specifically looking at eHF patients, with no significant difference between eHF and dHF patients in either the Irish cohort (64.2%, 34; vs. 76.4%, 42, respectively; P = 0.17) or English cohort (82.4%, 28; vs. 75%, 12, respectively; P = 0.71). At interview, patients did not describe a clear understanding of HF and often described waiting for their symptoms to disappear spontaneously or respond to their self-care actions before seeking professional help.

I went from about eight days before this [hospital admission] feeling reasonably good, and I went very rapidly downhill. If I were to draw a graph it would be at 45 degrees down. (Diagnosed on admission) I couldn’t breathe really at all. On and off really for days. (Diagnosed with HF more than 3 years ago)

**Patient self-care**

For patients with a known diagnosis of HF, daily weight monitoring is advised as a method of self-care to alert patients to possible evolving clinical deterioration. The adherence to and efficacy of daily weight measurement were evaluated as part of this study among all eHF patients. Adherence to weight monitoring was found to be suboptimal with 73.7% (42) of Irish and 57.6% (19) of English patients weighing themselves daily. Just over half of those monitoring their weight noticed a gain of ≥2 kg over 2 days (57.1%, 24; vs. 52.6%, 10, respectively). When these patients noticed this weight gain, the majority did seek medical advice. However, overall due to the suboptimal adherence to and the low sensitivity of weight monitoring, only 35.1% (20) of all Irish eHF and 24.2% (eight) of all English eHF patients sought medical advice earlier as a consequence of daily weight measurement. However, at interview many patients described non-specific symptoms of feeling generally unwell and undertaking general self-care actions.

**Health care system response to the decompensating patient**

**Site chosen by patient for community care**

There was a high number of patients seeking a medical assessment in the community prior to hospitalization across both cohorts: 67.5% (77) of Irish patients and 80% (40) of English patients. These medical assessments took place in a general cardiology clinic, an HF clinic, or a primary care practice. The breakdown of the different clinics attended is shown in Table 3.

The most common clinic visited prior to hospitalization was the GP practice. Data from our qualitative interviews describe patients’ ease of accessing a GP for health care advice with many describing ‘same-day’ appointments in close geographical proximity. Patients perceived the GP as the gatekeeper to the emergency department and someone who therefore gave legitimacy to their presentation to the emergency department.

A small number of patients were reviewed both in a GP surgery and also in a cardiology or HF clinic. As it was often difficult to establish in which clinic certain therapies were prescribed, these patients, who attended more than one clinic type, were excluded from the analysis looking at therapies prescribed in the primary care setting in order to obtain a true reflection of acute HF management in the community among unsupported primary care physicians.

**Care provided in community by general practitioner**

From each cohort, 46.5% (53) of Irish patients and 38% (19) of English patients were reviewed solely by a GP and were not seen in a cardiology or HF clinic before presenting to hospital. Among these patients, the numbers prescribed HF-directed therapies (defined as a new diuretic or alteration of an established diuretic regimen) by GPs were low across both cohorts: only 11.3% (six) of Irish patients and 15.8% (three) of English patients. These figures also remained low among eHF patients specifically, who were no more likely to receive HF-directed therapies from GPs than dHF patients in either the Irish cohort (11.8%, two; vs. 11.1%, four,

Table 3 Types of medical assessments in the community

|                          | Irish cohort (n = 114) | English cohort (n = 50) |
|--------------------------|------------------------|------------------------|
|                          | Total                  | De novo HF             | Established HF |
| General cardiology clinic| 1.8% (2)               | 1.8% (1)               | 1.8% (1)      |
| HF clinic                | 19.3% (22)             | 1.8% (1)               | 36.8% (21)    |
| GP practice              | 50.9% (58)             | 63.2% (36)             | 38.6% (22)    |
| GP practice exclusively* | 46.5% (53)             | 63.2% (36)             | 29.8% (17)    |

|                          | Total                  | De novo HF             | Established HF |
|--------------------------|------------------------|------------------------|----------------|
| General cardiology clinic| 18% (9)                | 18.8% (3)              | 17.6% (6)      |
| HF clinic                | 30% (15)               | 12.5% (2)              | 38.2% (13)     |
| GP practice              | 62% (31)               | 56.3% (9)              | 64.7% (22)     |
| GP practice exclusively* | 38% (19)               | 37.5% (6)              | 38.2% (13)     |

GP, general practitioner.
*Patients who were seen exclusively in a GP practice and not in a cardiology/HF clinic.

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respectively; \( P = 0.49 \) or the English cohort (15.4%, two; vs. 16.7%, one, respectively; \( P > 0.99 \)). The breakdown of therapies prescribed during these GP assessments is outlined in Figure 1. Therapies prescribed from all prehospital medical assessments are outlined in Tables 4 and 5.

**General practitioner opinion on care structure for heart failure in the community**

A response was received from 46 GPs in Ireland and 21 GPs in the UK to a postal questionnaire (Table 6). The majority view of these GPs was that lack of access to basic diagnostics, specialist support, and up-to-date patient information were hindering their management of HF. Interestingly, 48.7% (19) of Irish GPs and 42.9% (nine) of English GPs agreed or strongly agreed that a lack of GP understanding of and comfort in managing HF was also a barrier to optimal HF care. During qualitative interviews, GPs also reported other factors which impacted their management of patients and the decision to refer these patients to the emergency department. These included having a low threshold for referring an anxious patient or one in need of social supports to the emergency department. GPs highlighted a wider issue within health care of inadequate social resources in the community to support such patients in their homes.

**Discussion**

The period leading up to hospitalization for ADHF is a poorly researched component of the patient pathway in HF. Although there have been studies evaluating management of HF in primary care, these have focused primarily on treatment of stable chronic HF patients and not on the period of emerging clinical deterioration. With the use of quantitative and qualitative techniques, this two-jurisdiction study was carried out to address these gaps in knowledge. Important observations have been made with respect to duration of symptoms, patient and family involvement in care, and the prehospital medical response to clinical deterioration. As observations were consistent across two health care systems, a potential exists to evolve more effective, widely applicable care strategies designed to manage emerging deterioration more effectively and avoid or reduce the need for hospitalization.

Patient and family/carer-supported self-care is a critical pillar of HF management. Its importance is underlined by the time devoted to patient/carer education by HF services and the excellent education tools provided by international HF societies. In that setting, data presented herein on patient/carer understanding and involvement in self-care are somewhat concerning. Notably, in both jurisdictions, there was a disturbing failure to recognize worsening of dyspnoea as a potential indicator of a deterioration in HF status in many of those with eHF. It is noteworthy that a similar study focusing on self-care in the Irish centre almost two decades ago demonstrated similar problems. However, it should be noted that during qualitative interviews, many patients also described general non-specific symptoms, which can limit the application of self-care. Adherence to weight management and reaction to weight change was also assessed as a
metric of self-care. While not robustly sensitive for clinical change, it is still advised as a tool of self-care for its use as an indicator of deterioration and also as a non-specific prompt to other aspects of self-care including medication adherence. Again, among the patient cohorts with eHF, there was a concerning failure to adhere to this aspect of care. Collectively, these observations suggest that additional or alternative strategies to support individuals in self-care are required. In addition, more precise definition of what type of patient is not recognizing symptoms or adhering in general to self-care may allow for supplemental strategies, including telehealth methods, to be applied in these sub-populations.

A further important observation of this study was the confirmation that in the majority of cases, again in both jurisdictions, symptoms of clinical deterioration were present for >72 h before hospitalization. As one of the main goals of this

Table 4 Therapies prescribed during prehospital medical assessments—Irish cohort

|                                      | Total      | De novo HF | Established HF |
|--------------------------------------|------------|------------|----------------|
| General cardiology clinic (n = 2)    |            |            |                |
| • HF therapiesa                       | 0% (0)     | 0% (0)     | 0% (0)         |
| • Non-HF therapiesb                   | 0% (0)     | 0% (0)     | 0% (0)         |
| • Nothing                             | 100% (2)   | 100% (1)   | 100% (1)       |
| HF clinic (n = 22)                    |            |            |                |
| • HF therapies                        | 59.1% (13) | 0% (0)     | 61.9% (13)     |
| • Non-HF therapies                    | 13.6% (3)  | 0% (0)     | 14.3% (3)      |
| • Nothing                             | 27.3% (6)  | 100% (1)   | 23.8% (5)      |
| GP practice (n = 58)                  |            |            |                |
| • HF therapies                        | 13.8% (8)  | 11.1% (4)  | 18.2% (4)      |
| • Non-HF therapies                    | 36.2% (21) | 38.9% (14) | 31.8% (7)      |
| • Nothing                             | 50% (29)   | 50% (18)   | 50% (11)       |
| GP practice exclusively (n = 53)      |            |            |                |
| • HF therapies                        | 11.3% (6)  | 11.1% (4)  | 11.8% (2)      |
| • Non-HF therapies                    | 34% (18)   | 38.9% (14) | 23.5% (4)      |
| • Nothing                             | 54.7% (29) | 50% (18)   | 64.7% (11)     |

aHF therapies, a new diuretic, or alteration to an established diuretic regimen.
bNon-HF therapies, any therapy not directed towards treating acute heart failure; most commonly antibiotics, steroids, inhalers, beta-blockers, or a combination of these.
cIncludes five patients who were also seen in a GP practice prior to hospitalization.
dIncludes all patients who were seen in a GP practice prior to hospitalization; five of these patients were also seen in a heart failure clinic.
eIncludes only those patients who were seen exclusively in a GP practice prior to hospitalization and not those who were also in seen in either a cardiology or heart failure clinic.

Table 5 Therapies prescribed during prehospital medical assessments—English cohort

|                                      | Total      | De novo HF | Established HF |
|--------------------------------------|------------|------------|----------------|
| General cardiology clinic (n = 9)    |            |            |                |
| • HF therapiesa                       | 44.4% (4)  | 33.3% (1)  | 50% (3)        |
| • Non-HF therapiesb                   | 22.2% (2)  | 33.3% (1)  | 16.7% (1)      |
| • Nothing                             | 33.3% (3)  | 33.3% (1)  | 33.3% (2)      |
| HF clinic (n = 15)                    |            |            |                |
| • HF therapies                        | 46.7% (7)  | 0% (0)     | 53.8% (7)      |
| • Non-HF therapies                    | 20% (3)    | 100% (2)   | 7.7% (1)       |
| • Nothing                             | 33.3% (5)  | 0% (0)     | 38.5% (5)      |
| GP practice (n = 31)                  |            |            |                |
| • HF therapies                        | 25.8% (8)  | 22.2% (2)  | 27.3% (6)      |
| • Non-HF therapies                    | 22.6% (7)  | 33.3% (3)  | 18.2% (4)      |
| • Nothing                             | 51.6% (16) | 44.4% (4)  | 54.4% (12)     |
| GP practice exclusively (n = 19)      |            |            |                |
| • HF therapies                        | 15.8% (3)  | 16.7% (1)  | 15.4% (2)      |
| • Non-HF therapies                    | 15.8% (3)  | 16.7% (1)  | 15.4% (2)      |
| • Nothing                             | 68.4% (13) | 66.7% (4)  | 69.2% (9)      |

aHF therapies, a new diuretic or alteration in established diuretic regimen.
bNon-HF therapies, any therapy not directed towards treating acute heart failure; most commonly antibiotics, steroids, inhalers, beta-blockers, or a combination of these.
cThe heart failure clinic in the English centre was a nurse-led clinic.
dIncludes all patients who were seen in a GP practice prior to hospitalization; 12 of these patients were also seen in either a cardiology or heart failure clinic prior to hospitalization.
eIncludes only those patients who were seen exclusively in a GP practice prior to hospitalization and not those who were also in seen in either a cardiology or heart failure clinic.
Table 6 General practitioner questionnaire responses

| % who agree or strongly agree that better access to the following would improve diagnosis and management of HF | Irish GP responses (n = 46) | English GP responses (n = 21) |
|----------------------------------------------------------------------------------------------------------|---------------------------|-----------------------------|
| Natriuretic peptide                                                                                      | 95.6% (44)                | 94.7% (18)                  |
| Echocardiography                                                                                         | 95.6% (44)                | 94.7% (18)                  |
| Chest X-ray                                                                                              | 85% (34)                  | 89.5% (17)                  |
| Same-day HF services                                                                                    | 95.1% (39)                | 78.9% (15)                  |
| Virtual consultation                                                                                    | 76.9% (30)                | 60% (12)                    |
| % who agree or strongly agree that the following are barriers to optimal HF care:                         |                           |                             |
| Lack of community HF nurses                                                                             | 70% (28)                  | 90.5% (19)                  |
| Patient lack of understanding of HF                                                                    | 82.5% (33)                | 85.7% (18)                  |
| Level of knowledge of HF among GPs                                                                     | 48.7% (19)                | 42.9% (9)                   |
| Lack of HF clinics                                                                                       | 67.5% (27)                | 70% (14)                    |
| % who lack up-to-date patient information*                                                                |                           |                             |
| Frequently                                                                                              | 26.8% (11)                | 14.3% (3)                   |
| Sometimes                                                                                                | 26.8% (11)                | 47.6% (10)                  |
| Rarely                                                                                                   | 41.5% (17)                | 38.1% (8)                   |
| Never                                                                                                    | 4.9% (2)                  | 0%                          |

*Defined as new prescriptions, alterations to medications, or recent clinic or discharge letters.

The project is to define new methods of community care to reduce the need for hospitalization, this relatively long time-window of emerging symptoms underlies the potential to intervene effectively in the community. Limited data indicate that the capacity to meaningfully intervene is available, but the challenge will be twofold: addressing the issue of self-care outlined earlier to get the critical early warning from the patient/carer and then to be able to react at the medical level to this warning.

The capacity to react at a medical level is a further important analysis point of this project. The high number of patients who sought medical assessment in the community, again noted in both jurisdictions, illustrates a clear opportunity to potentially intervene earlier in the disease process. However, the low frequency of diuretic prescribing by GPs during these assessments shows that this opportunity is being underutilized. The number of co-morbidities seen in patients in this study and in the ‘typical’ HF population can make it difficult to differentiate the cause of new, often non-specific symptoms in this patient cohort. However, there is also a clear lack of comfort and knowledge in managing HF among GPs, particularly in light of the finding that eHF patients were no more likely to receive diuretics than dHF patients during their assessment in primary care. This is supported by GP questionnaire responses, wherein almost half of those responding agreed that their level of HF knowledge was a barrier to optimal care. These findings add to similar results in a recent study evaluating initial investigation and management of dHF patients in primary care, which showed a significant delay in diagnosis and often failure to follow guideline-supported investigation and referral pathways. Further compounding the issues highlighted in primary care management are the inadequate structures in place to support GPs in diagnosing and treating HF in the community, with lack of access to specialist input, basic diagnostics, and up-to-date patient information highlighted by GPs as obstacles to better care. Although similar difficulties have been illustrated in previous studies from the early 2000s,12,13 it is telling that they continue to present significant constraints to community management of HF to this day as evidenced by both our data and recent publications.14

Possible solutions to these outlined issues could be aimed at both individual and systems levels. At an individual level, improving patient and relative self-care education is crucial. In particular, education of relatives or carers should play an important role given the relatively advanced age and the prevalence of cognitive impairment among HF populations.15

Improving public awareness of HF and its symptoms could also prove beneficial as seen in other areas of medicine such as stroke.16,17 In addition, more precise definition of what type of patient is not recognizing symptoms or adhering in general to self-care may allow for additional strategies, including telehealth methods,18 to be applied in these specific subgroups.

At a systems level, improving how primary care and specialist services interface is a necessity. The first aspect of this is improving data transfer and access to up-to-date patient information across all sectors of health care. Secondly, streamlined access to specialist input and support is also needed in aiding primary care physicians, for example, by ensuring dedicated timeslots for same-day referrals in HF clinics. Other methods of streamlining specialist input with the use of online forums could also be explored. One such example would be a virtual consultation clinic. This has been shown to increase GP comfort in managing HF and to reduce the need for referrals to conventional, hospital-based outpatient clinics with often lengthy waiting lists.19 Finally, universal access to basic diagnostics, in particular, natriuretic peptide...
(NP) measurement, would also improve community-based management of HF.

The main limitation of this study is sample size; however, the fact that similar findings were seen across both health care systems gives weight to the findings highlighted in this study. A further limitation was the need to exclude a proportion of GP assessments when evaluating the therapies prescribed in the primary care setting, the reasoning for which has been previously outlined earlier. Data pertaining to the availability of NP measurement among GPs and the source and timing of referral to hospital, none of which were included in the dataset, would also have aided in interpretation of the findings outlined in this study. Finally, the Irish and English health care systems, while not exactly the same, are quite similar; and a comparison of two systems with more obvious differences may have provided additional or alternate observations.

Despite the aforementioned limitations, it is the belief of the authors that this study provides a thorough insight into the prehospital period and exposes deficiencies in this phase of care. Owing to the two-centre, two-country design, it is also reasonable to assume a degree of generalizability of the findings across the international arena. Furthermore, the incorporation of both quantitative and qualitative data provides a more comprehensive and rounded understanding of the patient experience and the care pathway during this time period. From this analysis, it is clear that there is both time and opportunity to implement earlier HF intervention in an attempt to prevent further deterioration and admission to hospital. However, improved patient and public awareness of HF, continued medical education, and better infrastructure supports for primary care physicians are needed to improve the standard of HF care in the community.

Conflict of interest

None.

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References

1. The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. Eur Heart J 2016; 37: 2129–2200.
2. Ambrosy AP, Fonerow GC, Butler J, Chioncel O, Greene SJ, Vaduganathan M, Lam CSP, Sato N, Shah AM, Gheorghita M. The global health and economic burden of hospitalizations for heart failure. J Am Coll Cardiol 2014; 63: 1123–1133.
3. Bottle A, Goudie R, Bell D, Aylin P, Cowie MR. Use of hospital services by age and comorbidity after an index heart failure admission in England: an observational study. BMJ Open 2016; 6: e010669.
4. Solomon SD, Dobson J, Pocock S, Skali H, McMurray JJ, Granger CB, Yusuf S, Swedberg K, Young JB, Michelson EL, Pfeffer MA. Influence of nonfatal hospitalization for heart failure on subsequent mortality in patients with chronic heart failure. Circulation 2007; 116: 1482–1487.
5. Setoguchi S, Stevenson LW, Schneeweiss S. Repeated hospitalizations predict mortality in the community population with heart failure. Am Heart J 2007; 154: 260–266.
6. Pocock SJ, Wang D, Pfeffer MA, Yusuf S, McMurray JJ, Swedberg KB, Östergren J, Michelson EL, Pieper KS, Granger CB. Predictors of mortality and morbidity in patients with chronic heart failure. Eur Heart J 2006; 27: 65–75.
7. Ryder M, Murphy NF, McCaffrey D, O’Loughlin C, Ledwidge M, McDonald K. Outpatient intravenous diuretic therapy; potential for marked reduction in hospitalisations for acute decompensated heart failure. Eur J Heart Fail 2008; 10: 267–272.
8. heartfailurematters.org [Internet]. Heart Failure Association of the European Society of Cardiology; 2019 [cited 2019 Mar 5]. https://www. heartfailurematters.org/en_GB Accessed 5 March 2019.
9. Horan M, Barrett F, Mulqueen M, Maurer B, Quigley P, McDonald K. Heart failure: an ongoing survey of management practice and patient understanding in a regional teaching hospital. J Card Fail 1998; 4: 52.
10. Koehler F, Koehler K, Deckwart O, Prescher S, Wegsneider K, Kirwan BA, Winkler S, Vettorazzi E, Bruch L, Oeff M, Zugck C, Doerr G, Naegle H, Störk S, Butler C, Sechtem U, Angermann C, Gola G, Prondzinsky R, Edelmann F, Spethmann S, Scheliong S, Schulze C, Bauersachs J, Wellge B, Schoebel C, Tajic M, Dregel H, Anker SD, Stangl K. Efficacy of telemedical interventional management in patients with heart failure (TIM-HF2): a randomised, controlled, parallel-group, unmasked trial. Lancet 2018; 392: 1047–1057.
11. Bottle A, Kim D, Aylin P, Cowie MR, Majeed A, Hayhoe B. Routes to diagnosis of heart failure: observational study using linked data in England. Heart 2018; 104: 600–605.
12. Fuat A, Hungin AP, Murphy JJ. Barriers to accurate diagnosis and effective management of heart failure in primary care: qualitative study. BMJ 2003; 326: 196–200.
13. Khunti K, Hearnshaw H, Baker R, Grimshaw G. Heart failure in primary care: qualitative study of current management and perceived obstacles to evidence-based diagnosis and management by general practitioners. Eur J Heart Fail 2002; 4: 771–777.
14. Hancock HC, Close H, Fuat A, Murphy JJ, Hungin APS, Mason JM. Barriers to accurate diagnosis and effective management of heart failure have not changed in the past 10 years: a qualitative study and national survey. BMJ Open 2014; 4: e003866.
15. Vogels RL, Schelten P, Schroeder-Tanka JM, Weinstein HC. Cognitive impairment in heart failure: a systematic
review of the literature. *Eur J Heart Fail* 2007; 9: 440–449.

16. Mellon L, Hickey A, Doyle F, Dolan E, Williams D. Can a media campaign change health service use in a population with stroke symptoms? Examination of the first Irish stroke awareness campaign. *Emerg Med J* 2014; 31: 536–540.

17. Bray JE, Mosley I, Bailey M, Barger B, Bladin C. Stroke public awareness campaigns have increased ambulance dispatches for stroke in Melbourne, Australia. *Stroke* 2011; 42: 2154–2157.

18. Gallagher J, James S, Keane C, Fitzgerald A, Travers B, Quigley E, Hecht C, Zhou S, Watson C, Ledwidge M, McDonald K. Heart failure virtual consultation: bridging the gap of heart failure care in the community—a mixed-methods evaluation. *ESC Heart Fail* 2017; 4: 252–258.