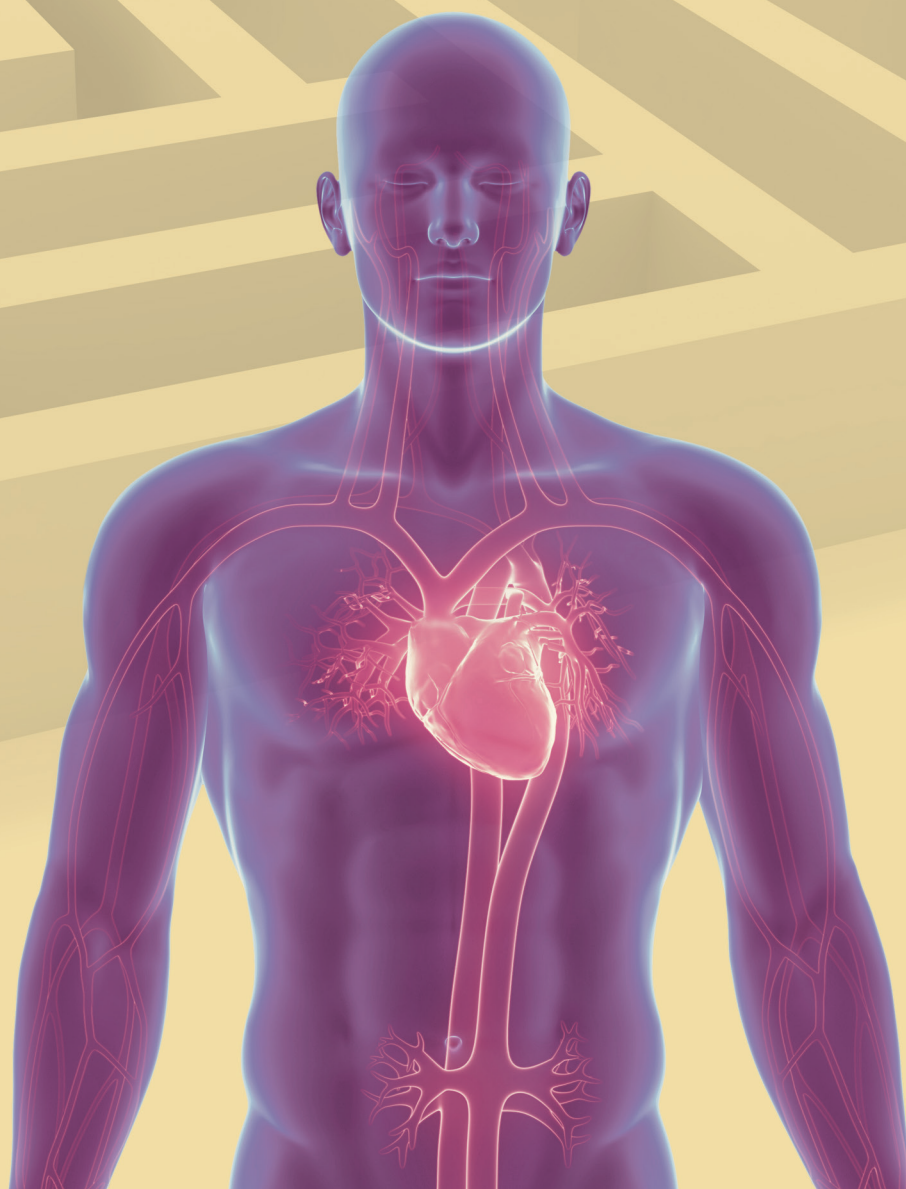# Improving care for patients with acute heart failure

Before, during and after hospitalization

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HEART FAILURE
ASSOCIATION
OF THE ESC

The recommendations contained in this report have been endorsed and adopted by the Heart Failure Association of the European Society of Cardiology as part of their Global Heart Failure Awareness Programme

The views expressed in this publication are not necessarily those of the sponsor or publisher.

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Contents

Executive summary

For millions of people throughout the world, acute heart failure is a life-threatening medical emergency, and it is one of the most common reasons for admission to hospital. One in ten patients with acute heart failure dies in hospital, and one in three dies within the year following an episode. Despite advances in long-term care, no new treatments for **acute** heart failure have emerged during the past two decades. Demands on services and the need for treatment will rise as the number of people with heart failure increases in our ageing populations.

It is time to address the needs of patients with acute heart failure by means of clear policy initiatives and rational redesign of patient management pathways and healthcare provision. Change at the policy level has the power to save lives and the potential for more efficient use of resources, as this report shows.

The symptoms of acute heart failure are distinct from those of a heart attack. Breathlessness, fatigue and swelling of the lower legs or ankles are surprisingly often not recognized by patients and clinicians as the life-threatening symptoms of declining heart function. The underlying causes of acute heart failure are varied, and patients exhibit different patterns and severity of symptoms. This means that many patients experience complex transitions between different healthcare providers and facilities.

For patients who survive a first episode of acute heart failure, modern evidence-based treatments can reduce the risk of another episode, but require careful management. These potentially life-saving treatments are often not prescribed appropriately on discharge from hospital, and about 25% of patients are readmitted within a month. Good management reduces readmission rates, improves survival rates, uses resources efficiently and may reduce costs. It is time to ensure that excellent care becomes routine.

We know that patients with heart failure are more likely to survive when treated and followed up by specialist cardiology units. Many patients with heart failure have other medical conditions, requiring treatment by a variety of specialists. Ensuring the best care in hospital involves a multidisciplinary team, supported and often led by an expert in heart failure. Excellent care involves developing and implementing guidelines and protocols for treatment, and introducing a system of audits to ensure they are properly applied.

When discharged from hospital, patients need a smooth and swift transition to follow-up care, as well as the right medications at the right doses. In addition, they need support and education to help them to engage actively in their own care, take the medications prescribed and ensure that any future deterioration is identified quickly. The level of knowledge about heart failure is low among the general public, and even among patients. Surveys show that many patients who have had acute heart failure remain unable to recognize warning symptoms of future episodes. Education programmes directed at patients and the public could have a dramatic effect on improving outcomes for patients.

By designing rational, evidence-based healthcare systems appropriate to each individual setting, the high standards of acute heart failure care already achieved in some hospitals and clinics could be made universal. Emerging information technology could support existing measures, by allowing remote monitoring of patients outside hospital and sharing of medical records among healthcare professionals. Where needed, access to end-of-life care and support for all patients, families and caregivers should form part of a revitalized service.

Continuing clinical research is needed to develop new medications and devices for acute heart failure in order to reduce death rates and improve patients' quality of life. However, it would be unwise merely to wait for new treatments. Much-needed changes in management, protocols and procedures can and should be initiated now.

Policy recommendations

- Acute heart failure is a common and deadly disease that contributes to about 5% of all emergency hospital admissions in Europe and the USA. Numbers of admissions for heart failure are growing as its prevalence increases.

- Most patients with heart failure are over 75 years of age, and approximately half of these will die within a year of hospital admission. Of patients aged under 75 years, about one in five will die within a year of admission.

- We therefore urge policy-makers at international, national, regional and local levels to act on the following recommendations.

1. Optimize care transitions
Better integration of hospital care, community care and the emergency services will improve patient outcomes and enable more efficient use of resources. Currently, hospital admission and discharge planning are often poorly organized and inconsistently implemented, indicating a need for closer relationships among all those involved in patient care.

2. Improve patient education and support
Better education and support for individuals with heart failure, and their families and caregivers, are essential to improve outcomes and patients' experience of care. Patients frequently lack the knowledge, confidence and support to be actively involved in their own care, and their adherence to measures important for long-term health is often poor.

3. Provide equity of care for all patients
All patients should have timely access to an appropriate range of diagnostic procedures, therapies and long-term follow-up care. Currently, the quality of care varies considerably among hospitals, and across regions and countries.

4. Appoint experts to lead heart failure care across disciplines
A multidisciplinary team led by a heart failure expert should oversee the care of patients with acute heart failure and the development of protocols, training and local auditing to make excellent care the norm.

5. Stimulate research into new therapies
Increased funding is needed for research into new and more effective therapies, medical devices and care strategies for acute heart failure. New approaches are urgently required to address unmet needs.

6. Develop and implement better measures of care quality
Performance measures based on robust, evidence-based clinical recommendations should be developed and used to improve the quality of care for patients with acute heart failure. Current performance measures are variable and lack an evidence base, and their use may have unintended consequences.

7. Improve end-of-life care
Effective approaches to palliative and end-of-life care, addressing emotional and physical well-being, need to be made an integral part of the care of patients with heart failure, both in hospital and in the community.

8. Promote acute heart failure prevention
Country-wide efforts to decrease risk factors for heart failure, including high blood pressure and coronary artery disease, should be intensified. Once heart failure develops, progression of the disease should be prevented or slowed by ensuring that appropriate evidence-based care is implemented promptly.

Introduction and aims

This report summarizes the evidence and consensus findings from structured discussions among the author group, comprising clinicians and researchers, an advanced practice nurse and the head of a patient action group, all with expertise and experience in the field of heart failure. The report presents the evidence base for eight policy recommendations aimed at improving care and preventing deaths of patients with acute heart failure.

Heart failure is common, affecting around 1–2% of adults in developed countries.[1] It occurs predominantly in older individuals, with more than 10% of those aged 75 years or above affected.[2] In all, about one in five of us will develop heart failure over the course of our lives.[1]

Most patients experience episodes of acute heart failure – sudden worsening of the symptoms and signs of deteriorating heart function. Acute heart failure is often a life-threatening event requiring urgent medical attention and can mark a transition to a more debilitating phase of the disease. Up to 10% of patients with acute heart failure die in hospital and 20–40% die within a year, while 20–25% are back in hospital within a month.[3–10]

Patients' progression from an initial diagnosis of acute heart failure to the terminal stages of the disease will place changing demands on their families and caregivers, and on healthcare services. The acute episodes that typically punctuate chronic disease make increasing demands on healthcare resources. Finally, in the terminal stages of heart failure, patients may need end-of-life care.

The number of people with heart failure is predicted to increase substantially over the coming decades, through a combination of an ageing population and increased survival of patients with heart problems, thanks to improved treatments.[11,12] Greater numbers of patients will increase the pressure on healthcare resources in the future. Hospitalizations for heart failure are predicted to rise substantially,[13] increasing the projected costs of treatment.[14] There is therefore a need to seize the opportunities highlighted in this report in order to use existing resources more efficiently.

This report examines the care of patients with acute heart failure in Europe and the USA and makes evidence-based recommendations for policy change. In presenting the evidence, the following sections will:

- reveal the impact of acute heart failure on patients, their families and caregivers, and on society (Section 1)

- describe the complex healthcare trajectories followed by patients with acute heart failure (Section 2)

- demonstrate the need for improved diagnosis and recognition of acute heart failure (Section 3)

- show why continued research into new and more effective medications and devices is necessary (Section 4)

- highlight the variation in care of patients with the disease and present ways of providing better care to all (Section 4)

- explain the importance of patients' transition to long-term care and the role of disease management (Section 5)

- set out practical approaches for improving the care of patients with acute heart failure for policy-makers and other stakeholders (Section 6).

We present the evidence base for eight policy recommendations

Pressure on resources for heart failure care will increase in the future

1. Acute heart failure and the burden of disease

Key points

- Acute heart failure is serious, requires urgent attention and usually results in admission to hospital.

- Acute heart failure is characterized by breathlessness at rest or on exertion, and by fluid retention, resulting in swollen ankles and legs.

- Heart failure is common – one in five people will develop it at some point – and it affects mainly older people, so patient numbers are increasing as the population ages.

- Heart failure can lead to social isolation, anxiety and depression, as symptoms make patients less able to participate in work and in social and leisure activities.

- Management of acute heart failure makes extensive demands on healthcare resources, with many patients requiring repeated hospitalization.

- Despite continuing improvements, many patients with acute heart failure die in hospital or soon after leaving hospital, and most die within 5 years.

Development of heart failure symptoms often leads to emergency hospitalization

What is acute heart failure?

Acute heart failure is a life-threatening event requiring urgent medical attention. It is characterized by breathlessness (dyspnoea) at rest or on exertion, and worsening fluid retention, apparent as lung congestion and/or swollen ankles and legs. Definitions of acute heart failure vary, with the ESC treatment guidelines referring to the "rapid onset of, or change in, symptoms" of heart failure,[15] whereas another definition includes gradual changes.[16] For large numbers of patients, the sudden appearance or reappearance of heart failure symptoms leads to an emergency room visit and hospitalization.

One in five individuals will develop heart failure[1]

A wide range of abnormalities in cardiac structure or function can cause heart failure, including disorders of the heart muscle, valves and rhythm. This complexity makes heart failure difficult to define precisely. Definitions differ between the ESC, ACCF/AHA and NHFA treatment guidelines (**Table 1.1**),[15,17,18] while the one provided by the HFSA is more extensive.[19] Symptoms can also vary considerably among patients, and are not specific to heart failure, so diagnosis can be challenging.[15]

Impact of heart failure on individuals and society

Heart failure is a major health issue in society today, because it is associated with ill health, death and consumption of healthcare resources. Heart failure affects approximately 1–2% of adults in developed countries, and prevalence increases markedly with age.[11] Few individuals under 50 years of age are diagnosed with heart failure, whereas more than 10% of those aged 75 years or above have the disease.[2,20]

In all, about one in five individuals will develop heart failure at some point.[1] The Framingham Heart Study in the USA showed that the lifetime risk of developing heart failure was similar in men and women, and that it did not change with increasing age, being around 20% at both 40 and 80 years of age.[1]

Table 1.1. Three of several accepted definitions of heart failure.	
Treatment guideline	**Heart failure definition**
ESC[15]	"...an abnormality of cardiac structure or function leading to failure of the heart to deliver oxygen at a rate commensurate with the requirements of the metabolizing tissues, despite normal filling pressures (or only at the expense of increased filling pressures)."
ACCF/AHA[17]	"...a complex clinical syndrome that results from any structural or functional impairment of ventricular filling or ejection of blood."
NHFA[18]	"...a complex clinical syndrome with typical symptoms (e.g. dyspnoea, fatigue) that can occur at rest or on effort, and is characterised by objective evidence of an underlying structural abnormality or cardiac dysfunction that impairs the ability of the ventricle to fill with or eject blood (particularly during physical activity)."

ACCF, American College of Cardiology Foundation; AHA, American Heart Association; ESC, European Society of Cardiology; NHFA, National Heart Foundation of Australia.

The number of patients with heart failure is predicted to increase substantially over the coming decades, through a combination of an ageing population, improvements in treatment and the survival of patients with heart problems.[11] In the USA, an estimated 3% of the adult population – 8.5 million people – will have heart failure by 2030.[14]

Most patients with heart failure experience acute episodes (also known as acute decompensation) over the course of the disease, which typically result in visits to the emergency department and hospital admission. Hospitalization data for heart failure therefore reflect the high healthcare activity associated with acute episodes.

High hospitalization and death rates

Hospitalization and death rate data for patients with heart failure are available from several different sources, including government health service statistics, healthcare databases (such as Medicare in the USA), patient registry data and studies in patients hospitalized with acute heart failure. The range of data sources can mean that results are not directly comparable across countries.

Hospitalization

The high numbers of hospitalizations for heart failure place a substantial burden on healthcare systems. Health service data for a number of European countries show that hospitalizations with a primary diagnosis of heart failure generally account for 1–2% of all hospital admissions, while in the USA they comprise about 3% (**Figure 1.1**).[21–31] In England, the proportion of hospital admissions with a primary diagnosis of heart failure was low (0.4%), but hospitalizations with any mention of heart failure occurred in approximately 2.6% of all cases.

Hospital discharge data may underestimate the extent of heart failure, partly because it can coexist with other conditions and might not therefore be recognized. For example, an analysis in the UK showed that heart failure was present but not recorded in a substantial proportion of patients with a discharge diagnosis of atrial fibrillation, a common comorbidity of heart failure.[32]

Hospitalizations due to heart failure have increased over the past decade in many European countries (**Table 1.2**).[22–28,33] A particularly large rise in admissions has been observed in Germany (40% between 2000 and 2007), where heart failure is now the most common reason for hospitalization.[24] Data from England showed that hospitalizations with any mention of heart failure have increased by 57% since 2006,[34] although admissions with a primary diagnosis of heart failure have declined over 10 years.[22] In the

Heart failure accounts for 1–3% of all hospital admissions in Europe and the USA

In Germany, heart failure is the most common reason for hospitalization[24]

USA[30,31] (2007)
Total: 34.4 million
HF (1°): 982 000
HF/total: 2.9%
LoS: 5.3 days

Norway[26] (2008)
Total: 819 184
HF (1°): 8735
HF/total: 1.1%

Sweden[28] (2011)
Total: 1.49 million
HF (1°): 33 550
HF/total: 2.2%
LoS: 6.43 days

Netherlands[25] (2010)
Total: 1.97 million
HF (1°): 29 670
HF/total: 1.5%

Poland (2012)[a]
(Lower Silesia region)
Total: 544 401
HF (1°): 10 425
HF/total: 1.9%
LoS: 8 days

England[22] (2011–12)
Total: 15.0 million
HF (1°): 61 130
HF (any): 386 401
HF (1°)/total: 0.4%
LoS: 7 days

Germany[24] (2007)
Total: ~17 million
HF (1°): 335 000
HF/total: 2.0%

Spain[27] (2011)
Total: 3.64 million
HF (1°): 63 754
HF/total: 1.8%
LoS: 7.46 days

France[23] (2008)
HF (1° and 2°): 148 292
LoS: 9.9 days

Switzerland[29] (2011)
Total: 1.34 million
HF (1°): 14 398
HF/total: 1.1%

Austria[21] (2010)
Total: 2.67 million
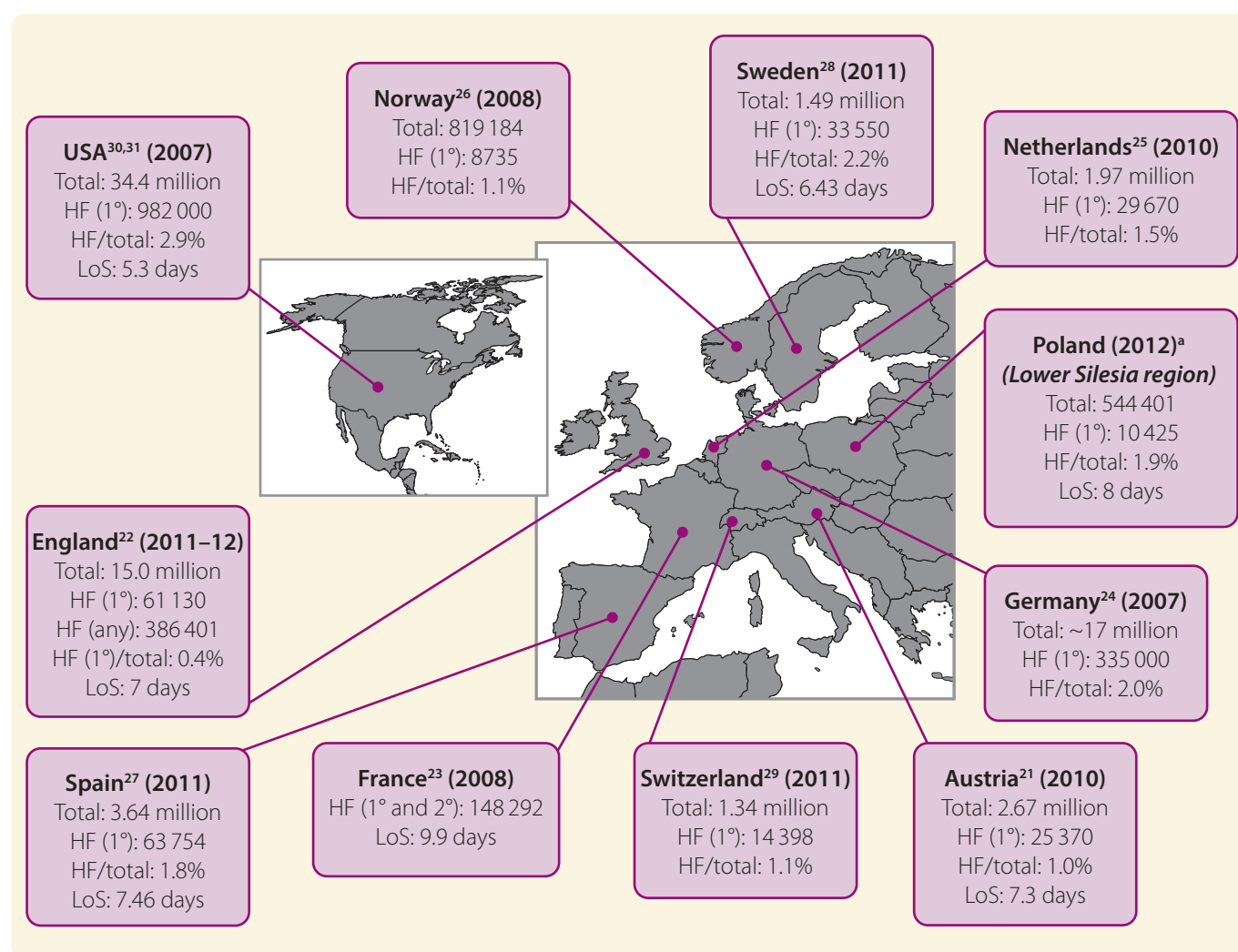HF (1°): 25 370
HF/total: 1.0%
LoS: 7.3 days

Figure 1.1. Hospitalizations for heart failure in Europe and the USA.

[a]Data supplied by regional health system representatives in Poland.
HF (1°/2°), number of hospitalizations for heart failure as primary/secondary diagnosis; HF (any), number of hospitalizations for heart failure as any diagnosis; HF/total, heart failure hospitalizations as a proportion of all hospitalizations; LoS, average length of hospital stay; total, total number of hospitalizations. All data shown include planned admissions.

Heart failure is the most common cause of hospitalization in patients aged over 65 years in developed countries[36]

USA, Medicare data revealed a reduction in hospitalizations with a principal diagnosis of heart failure,[33] whereas US National Hospital Discharge Survey (NHDS) data indicated that the numbers of hospitalizations in 2000 and in 2010 were similar.[35]

The increasing prevalence of heart failure with age means that the elderly make up a high proportion of patients hospitalized for heart failure. In the USA in 2010, there were about 1 million hospitalizations with heart failure as the principal diagnosis; patients aged 65 years and over comprised 71% of these admissions, while those aged 85 years and over accounted for 25%.[35] Data from several European countries show that more than half of hospitalizations for heart failure occur in patients aged 80 years or above.[26,28,29] Overall, in developed countries,

heart failure is the most common cause of hospitalization in patients aged over 65 years.[36]

Heart failure also accounts for a high proportion of emergency department visits. Acute heart failure accounted for 10.5 million visits or 2.9% of all emergency department visits by patients aged 40 years or over in the USA between 1992 and 2001.[37] Almost 75% of these visits resulted in hospitalization. In the UK, heart failure makes up 5% of all *emergency* hospital admissions.[13]

Heart failure is associated with an even greater usage of hospital resources than heart attack (acute myocardial infarction [AMI]). In the USA, there were 982 000 hospital discharges with an initial diagnosis of heart failure in 2007, compared with

Table 1.2. Trends in hospitalizations for heart failure.

Country	Percentage change in number of hospitalizations	Time period	Reference
England	−13.1	2001–02 to 2011–12	HSCIC[22]
France[a]	14.4	2002 to 2008	Pérel et al.[23]
Germany	39.8	2000 to 2007	Neumann et al.[24]
Netherlands	21.0	2000 to 2010	Statistics Netherlands[25]
Norway	2.4	1999 to 2008	Statistics Norway[26]
Spain	22.3	2000 to 2011	Sistema Nacional de Salud[27]
Sweden	11.4	2001 to 2011	Socialstyrelsen[28]
USA (Medicare)	−19.3	1999–2000 to 2007–08	Chen et al.[33]

Data based on total number of hospital admissions (emergency and planned) for a primary diagnosis of heart failure (except for France[a]).

[a]Primary diagnosis, or secondary diagnosis with a primary diagnosis of either hypertensive heart disease or heart and renal disease with heart failure, or pulmonary oedema, or chronic passive congestion of liver.

HSCIC, Health and Social Care Information Centre.

577 000 for heart attack.[30] Hospital data for England for 2011/2012 showed more hospital admissions with a primary diagnosis of heart failure (61 130) than of AMI (50 708), and a longer average length of stay for heart failure (7 days) than for AMI (4 days).[22]

Length of hospital stay

Length of hospitalization for heart failure is typically between 5 and 10 days, with longer stays generally reported in Europe than in the USA. Longer stays may benefit some patients. Findings are consistent between health service data (**Figure 1.1**) and data from patient registries and other studies (**Figure 1.2**).[3,5,7,9,10,23,38–45]

The average length of a hospital stay has decreased by 1–2 days in European countries over the past 10 years.[22,23,27,28] In the USA, the average length of stay decreased from 5.6 days in 2001 to 5.3 days in 2009.[31] However, the average length of stay tends to increase with patient age. In Sweden, it was 5.2 days for patients aged 60–64 years compared with 7.2 days for those aged 85 years and above;[28] in England, it was 5 days for those under 65 years old and 9 days for those aged over 85 years.[22]

Hospital readmissions

Rehospitalization is common among patients with acute heart failure following their initial discharge (**Table 1.3**).[4,8,10,38,46–52] The majority of readmissions are related to cardiovascular disease,[8,46,47,50] with recurrence of heart failure the most common single reason, accounting for about 30% of all cases.[4,6,38,46,49,51]

In European studies, reported rehospitalization rates range from 24% at 12 weeks[10] to 44% at 1 year after discharge.[4] In the USA, 30-day readmission rates were about 20–25%;[8,49,51] however, readmission rates of 60–67% have been reported with longer follow-up.[8,38,50] An analysis of Veterans Affairs (VA) healthcare data between 2002 and 2006 showed an increase in 30-day rehospitalization for heart failure, and improved survival (in hospital, and at 30 days and 1 year) over this period.[52] This analysis suggests that the timely post-discharge visits used by the VA system accompanied by early rehospitalization for heart failure (when needed) are associated with improved patient outcomes. Similar systems are in use in other countries or regions.

Within one month of leaving hospital, about 25% of patients with acute heart failure are re-admitted[8,10,49,51]
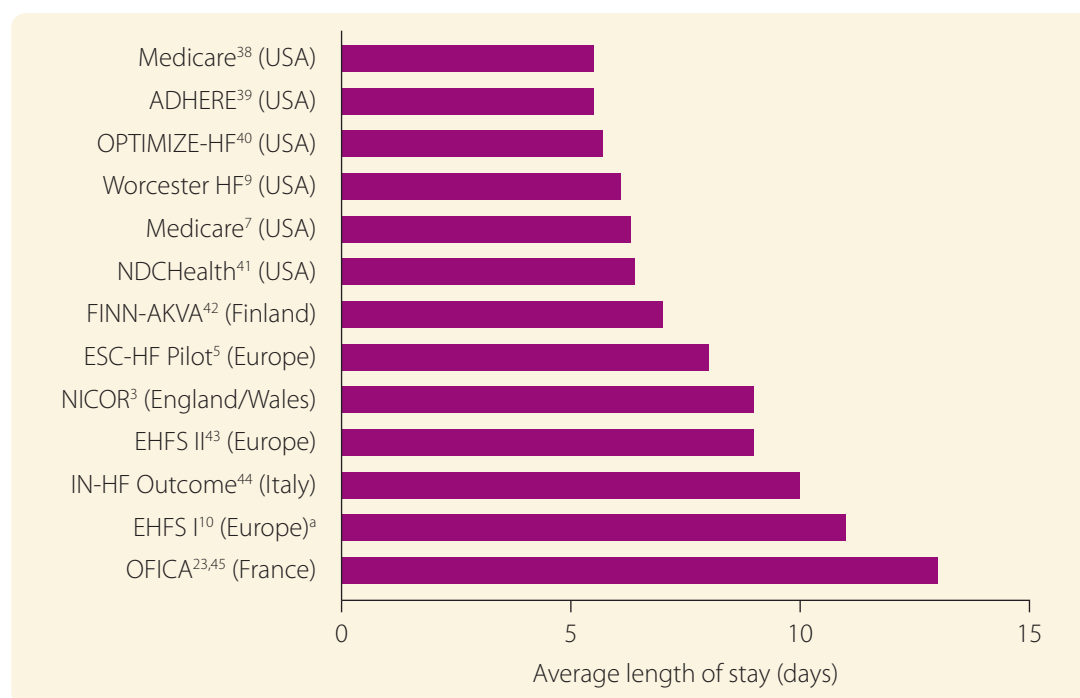
Figure 1.2. Length of hospital stay in acute heart failure studies.

Length of stay values are means in US studies and medians in European studies.
[a]Data for 24 individual countries also reported.
ADHERE, Acute Decompensated Heart Failure National Registry; EHFS, EuroHeart Failure Surveys; ESC-HF, European Society of Cardiology – Heart Failure; FINN-AKVA, Finnish Acute Heart Failure Study; IN-HF, Italian Registry on Heart Failure; NDCHealth, National Data Corporation Health; NICOR, National Institute for Cardiovascular Outcomes Research; OPTIMIZE-HF, Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients with Heart Failure; OFICA, Observatoire Français de l'Insuffisance Cardiaque Aiguë.

Table 1.3. High hospital readmission rates in acute heart failure studies.

Study	Country/region	Rehospitalization rate (%)	
Medicare[49]	USA	30-day	24.8
Medicare[51]	USA	30-day	26.9
VA health care system[52]	USA	30-day	22.5
ADHERE[8]	USA	30-day	22.1
		1-year	65.8
Medicare[50]	USA	30-day	22.7
		1-year	67.0
Medicare[38]	USA	6–9-month	60
EHFS I[10]	Europe	12-week	24.2
ESC-HF Pilot[4]	Europe	1-year[a]	43.9
EAHFE[48]	Spain	1-year	27.2
CCU[47]	Italy	6-month	38.1
IN-HF Outcome[46]	Italy	1-year	30.7

[a]Data for other time periods also reported.
ADHERE, Acute Decompensated Heart Failure National Registry; CCU, cardiac care unit; EAHFE, Epidemiology Acute Heart Failure Emergency; EHFS, EuroHeart Failure Surveys; ESC-HF, European Society of Cardiology – Heart Failure; IN-HF, Italian Registry on Heart Failure; VA, Veterans Affairs.

Short-term survival rates

Death rates remain high for patients hospitalized with heart failure, both in hospital and during follow-up.

In-hospital death rates are age related and typically range from 4% to 10% for patients with acute heart failure in database and registry studies (**Figure 1.3**),[3,4,9,10,33,40,42–46,48,50,52,53] although higher rates have been observed in some analyses.[54,55] Short-term survival is also poor, with 1-year death rates typically between 20% and 40% (**Figure 1.3**).

Some improvements in short-term and in-hospital death rates have been observed in recent years.[7,33,50,56,57] In an analysis of over 6.5 million heart failure hospitalizations in the USA, the unadjusted in-hospital death rate fell from 8.5% in 1993 to 4.3% in 2006, and the 30-day death rate decreased from 12.8% to 10.7% over the same period.[7] Another Medicare analysis also reported a decreased in-hospital death rate, from 5.1% in 2001 to 4.2% in 2005, although 180-day and 1-year all-cause death rates remained fairly constant at approximately 26% and 37%, respectively.[50] A reduction in the 1-year death rate from 31.7% in 1999 to 29.6% in 2008 was reported in an analysis of data from 55 million Medicare patients.[33]

Long-term survival rates

Despite some ongoing improvement, long-term survival of patients after an episode of acute heart failure also remains poor, with reported 5-year death rates of around 70% (**Figure 1.4**).[3,9,58–61] A population study in Scotland showed improvements in patients' 1-year and 5-year survival rates between 1983 and 2004 following their first hospitalization for heart failure, but the

20–40% of patients with acute heart failure die within 1 year of hospitalization
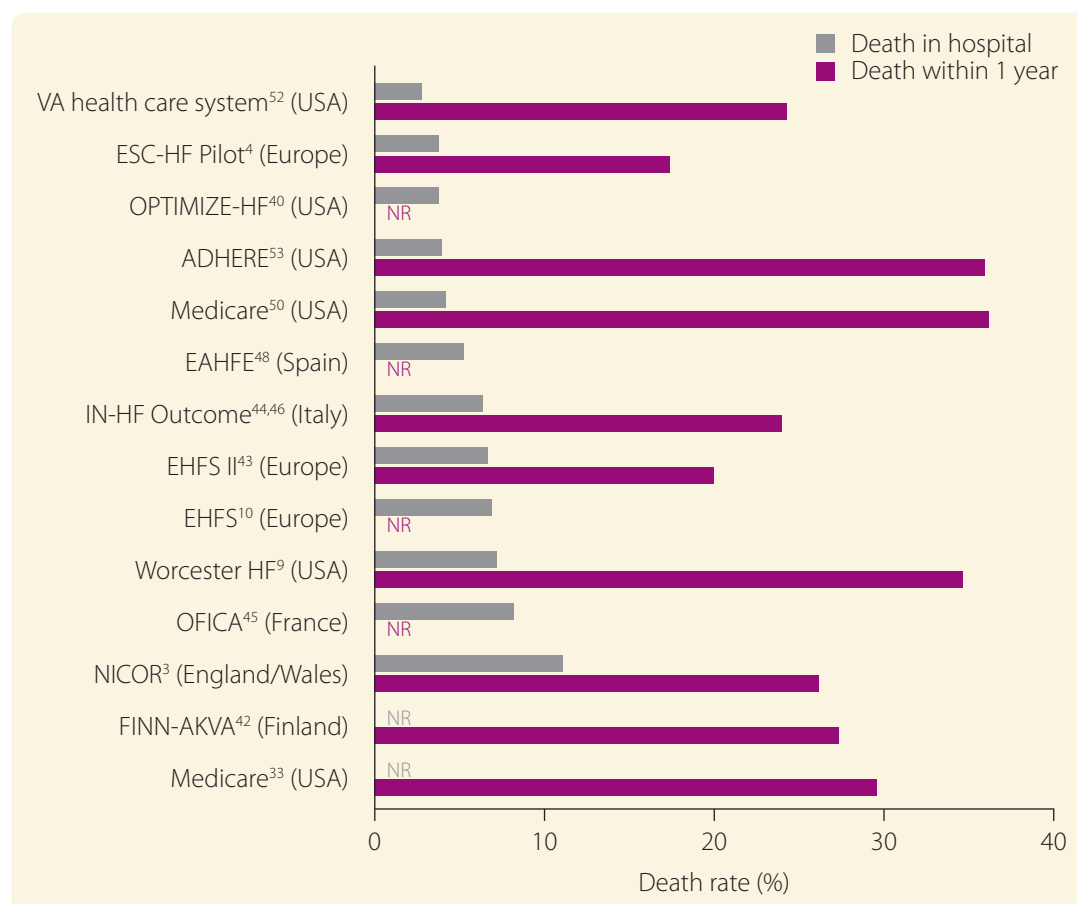

Figure 1.3. High in-hospital and short-term death rates due to acute heart failure.

ADHERE, Acute Decompensated Heart Failure National Registry; EAHFE, Epidemiology Acute Heart Failure Emergency; EHFS, EuroHeart Failure Surveys; ESC-HF, European Society of Cardiology – Heart Failure; FINN-AKVA, Finnish Acute Heart Failure Study; IN-HF, Italian Registry on Heart Failure; NICOR, National Institute for Cardiovascular Outcomes Research; NR, not reported; OPTIMIZE-HF, Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients with Heart Failure; OFICA, Observatoire Français de l'Insuffisance Cardiaque Aiguë; VA, Veterans Affairs.
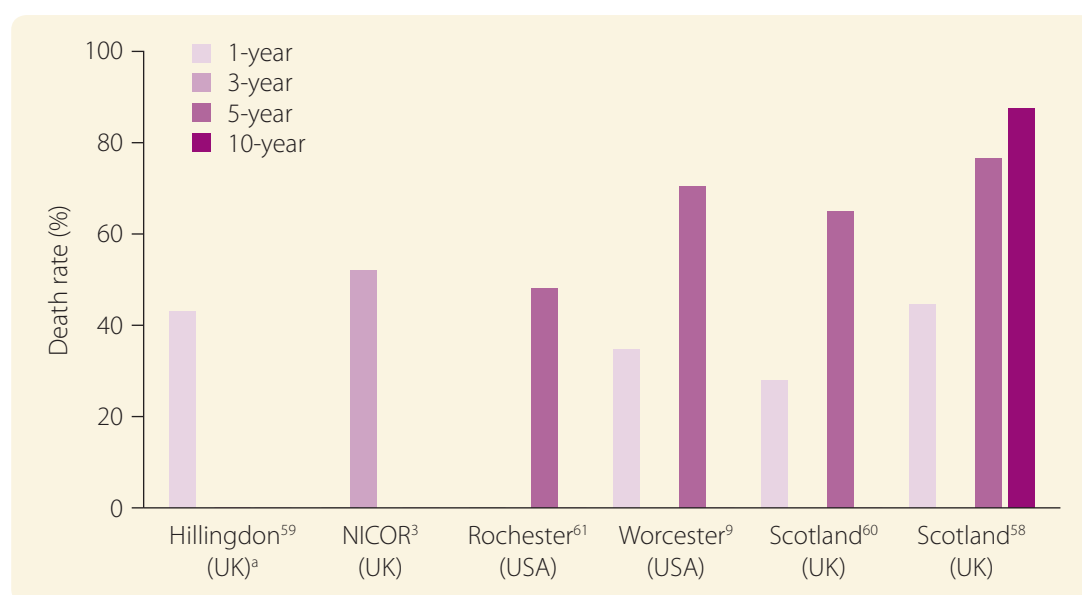
Figure 1.4. High long-term death rates due to acute heart failure (UK and US data).

[a]18-month death rate.
NICOR, National Institute for Cardiovascular Outcomes Research.

In 2010, heart failure cost $39.2 billion in the USA, about 2% of the healthcare budget[62]

5-year death rate was still about 65% at the end of this period.[60] In a community-based study in the USA, the 5-year death rate improved from 57% for patients newly diagnosed with heart failure in 1979–1984 to 48% for those diagnosed in 1996–2000.[61] In another community-wide survey of acute heart failure, 2-year and 5-year post-discharge death rates improved for patients hospitalized in 2004 (45.3% and 70.5%, respectively) compared with those admitted in 1995 (57.4% and 80.3%, respectively).[9]

Economic costs of heart failure treatment

As a result of the high level of hospital activity, the costs of heart failure treatment to society are substantial, accounting for approximately 1–2% of direct healthcare expenditure in Western industrialized countries.[24] In Germany, the total direct treatment costs for heart failure were €2.9 billion in 2006, of which inpatient hospital care made up 60%.[24]

In the USA, overall costs of heart failure in 2010 have been estimated at $39.2 billion, or about 2% of the healthcare budget,[62] although estimates vary.[14] Hospitalization comprised approximately 80% of direct treatment costs for heart failure in the USA.[14] In an analysis of 1.1 million Medicare patients in 2010, hospitalization costs for

heart failure were $91.9 million, accounting for 3.1% of the total expenditure.[63]

The use of healthcare resources is predicted to rise over the coming decades as the number of patients with heart failure increases. Hospitalizations for heart failure in the UK are projected to rise by 50% over the next 25 years,[13] while the costs of heart failure treatment in the USA are predicted to more than double by 2030.[14]

Impact of heart failure on patients and their families

For patients, the physical limitations brought about by shortness of breath, loss of energy and fatigue associated with heart failure affect work, social and leisure activities.[64] Patients commonly experience social isolation, reporting limited ability to travel, socialize or take part in recreational activities.[65]

Psychological effects, including fear, anxiety and depression, are common among individuals with heart failure.[64] Furthermore, heart failure can have a marked effect on personal relationships, with the increasing reliance on others leading to feelings of guilt and frustration.[65] In addition, family members often feel the burden of caring for a patient with heart failure, and these demands can have physical, emotional and financial effects on them.[66]

2. Clinical course of acute heart failure

Key points

- Symptoms and signs may worsen gradually or abruptly, and the subsequent clinical course of heart failure can vary considerably.

- As the disease progresses, episodes of acute heart failure are likely to happen more often, and patients become less likely to make a good recovery.

- High blood pressure, diabetes, kidney disease, obesity, physical inactivity, excessive alcohol intake and smoking all increase the risk of developing heart failure.[19]

What is the outlook for patients with heart failure?

The clinical course of heart failure can vary considerably. Patients may present following gradual or sudden onset of typical symptoms – breathlessness, fatigue and/or swollen ankles and legs – with rapid deterioration being more common.[67] After successful initial treatment for acute heart failure, patients may enter a plateau phase where heart function remains stable (**Figure 2.1**). The length of this phase varies among individuals, and can last several years. Over time, most patients experience multiple episodes of acute heart failure, which typically become longer and separated by shorter intervals as the ability of the heart to recover declines.[67,68] These episodes are also referred to as acute decompensation or acutely decompensated chronic heart failure: the heart fails to maintain adequate blood flow by adjusting its output in response to demand. For some patients, however, the decline in heart function follows a steeper path. Throughout its course, patients with heart failure are at risk of sudden death due to acute decompensation.[67] Subsequent prognosis is generally poor for patients who are resuscitated following one such episode.

Differences in outcomes between patients in the acute and chronic phases of heart failure are apparent from observational studies that enrolled both types of patient. In the European Society of Cardiology – Heart Failure (ESC-HF) Pilot study, death rates at 1 year were 7.2% in outpatients with chronic heart failure and 17.2% for patients hospitalized with acute disease.[4] In the Italian Registry on Heart Failure (IN-HF) Outcome study, 1-year death rates were 5.9% in patients with chronic heart failure and 24.0% in those with acute heart failure.[46] Hospitalization rates in the year after enrolment were also lower for those with chronic disease than with acute disease.[4,46]

For many individuals, underlying abnormalities of cardiac function may be present for some time before the appearance of heart failure symptoms.[15] In population studies, up to 21% of individuals showed changes in measures of left ventricular function but no symptoms of

Most patients have multiple life-threatening episodes of acute heart failure as heart function deteriorates over time

Patient perspective

"…they [discharged me from hospital] after 6 days, and I seemed to be okay. And then in 1998 the symptoms they started again. And in 1999 I had a bad attack, but I didn't go to the hospital. … This last time in March was probably the third time I was—my wife said the fourth time—I was hospitalized for the same symptoms."
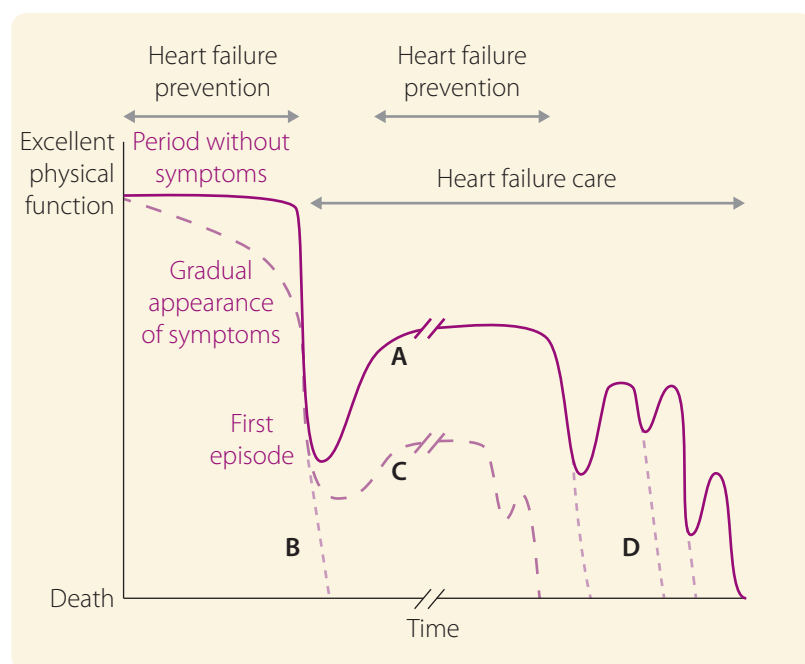
From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

Figure 2.1. Typical progression of acute heart failure, showing a range of clinical courses.

A, good recovery after first episode followed by stable period of variable length; **B**, first episode not survived; **C**, poor recovery after first episode followed by deterioration; **D**, ongoing deterioration with intermittent crises and unpredictable death point.

heart failure (referred to as asymptomatic left ventricular dysfunction).[70–72] This was associated with an increased risk of symptomatic heart failure and an increased risk of death.[72] These individuals are a key target for approaches aimed at preventing the development of heart failure, such as improving diet and exercise, stopping smoking and controlling high blood pressure (see below).[73]

What goes wrong in patients with heart failure?

Fluid build-up in the lungs and tissues during heart failure results in breathlessness and swelling

Numerous cardiovascular abnormalities can lead to the development of heart failure, although the functional changes that underlie the disease are complex and incompletely understood. These abnormalities result in a number of physiological changes, including water and sodium retention, constriction of blood vessels and increased heart function, that act to maintain blood flow. However, prolonged activation of these compensatory mechanisms leads to detrimental changes in the heart, circulatory system and other organs.[74]

The structural changes that occur in the failing heart mean that functioning of the ventricles is impaired (**Figure 2.2**).[15,75,76] Initially, blood flow to the body is usually maintained, but as the disease progresses the ability of the heart to supply blood to the tissues is reduced. In addition, the changes to the heart and circulation lead to the build-up of fluid in the lungs and tissues, known as pulmonary and peripheral oedema, or congestion. This results in the characteristic heart failure symptoms of breathlessness and swollen legs and ankles, and patients can experience increases in body weight as a result of fluid retention. Changes to skeletal muscle are also seen in heart failure, contributing to fatigue and patients' limited ability to exercise.

Reducing the risk of developing heart failure

Several factors have been identified that increase the risk of individuals developing heart failure, including high blood pressure, hyperlipidaemia (high levels of fat in the blood), atherosclerosis, diabetes, obesity, physical inactivity, kidney disease, excessive alcohol intake and smoking.[19] Clinical trials have shown that treatment to reduce blood pressure can reduce the risk of developing heart failure. In the Hypertension in the Very Elderly Trial (HYVET), such medications reduced the risk of heart failure by 72% compared with placebo in elderly patients (≥ 80 years old) with high blood pressure.[77] Drugs to treat high blood pressure also significantly reduced the risk of heart failure in individuals at high risk of cardiovascular events in the Heart Outcomes Prevention Evaluation (HOPE) trial.[78] Identifying individuals at risk of heart failure and managing these factors through treatment and/or behavioural changes could help to prevent the development of the disease.

A model predicting the 5-year risk of heart failure has been developed, based on factors such as age, smoking history, systolic blood pressure (SBP), heart rate and fasting glucose levels.[79,80] This could prove useful in the identification of high-risk patients by healthcare professionals, allowing prevention programmes to be targeted at these individuals.
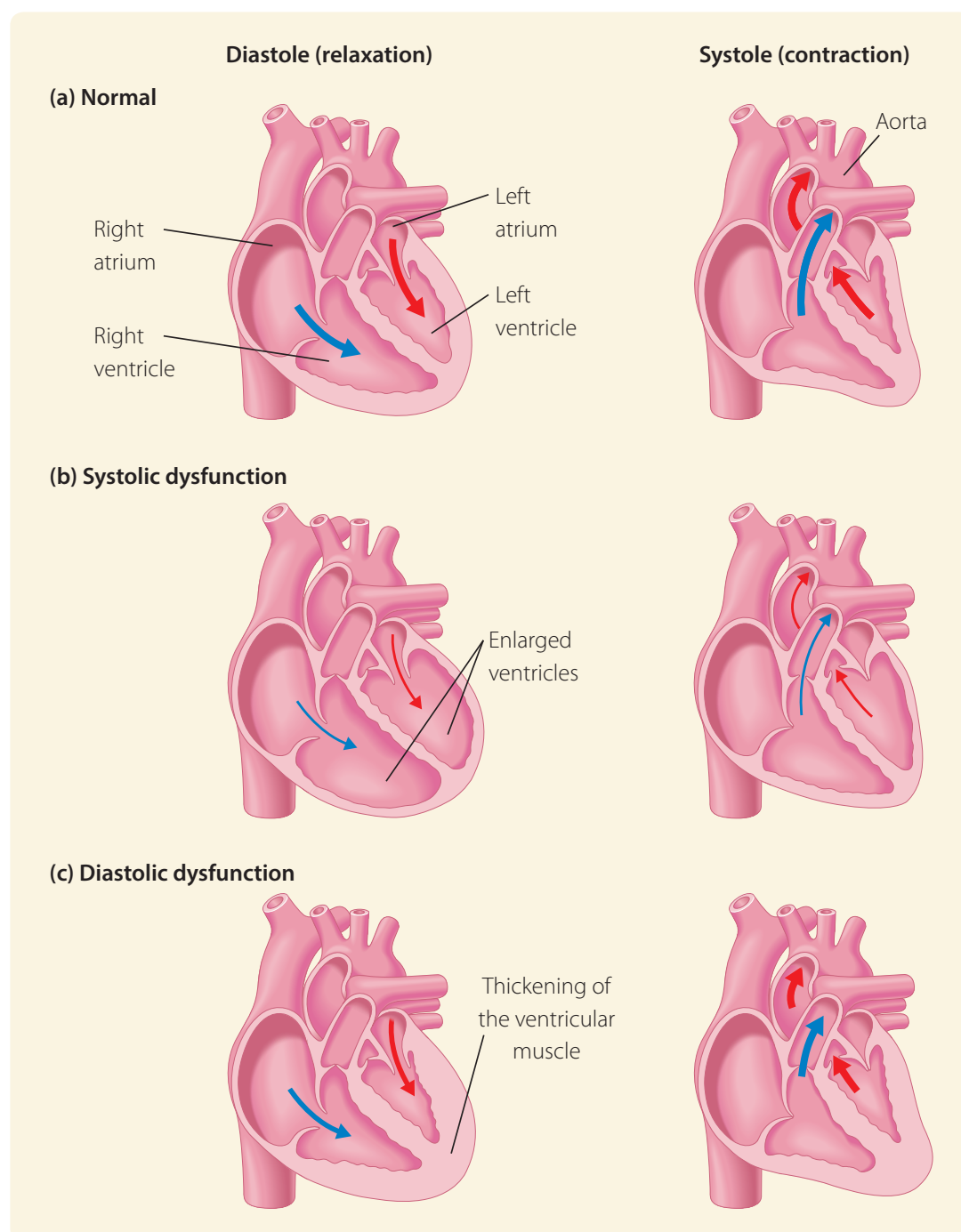
Figure 2.2. Systolic and diastolic heart failure.

Systolic heart failure: Approximately half of patients with heart failure have left ventricular systolic dysfunction, in which the ability of the left ventricle (LV) to contract and pump blood to the body is reduced. In the normal heart (**a**), about 50% of the blood in the LV is ejected into the aorta and the body as the chamber contracts; this is known as the ejection fraction. In systolic heart failure (**b**), changes to the LV (enlargement of the chamber and impaired contractility) mean that a much smaller proportion of the blood in the LV before contraction (typically < 40%) is ejected. Systolic heart failure is therefore also known as heart failure with reduced ejection fraction (HF-REF). The total amount of blood leaving the LV in HF-REF may be similar to normal, as the enlarged LV contains more blood than in the normal heart.

Diastolic heart failure: Impaired filling of the LV (diastolic dysfunction) is the main factor underlying development of diastolic heart failure (**c**). Characteristic changes to the heart include thickening of the left ventricular wall and enlargement of the left atrium. The proportion of blood ejected from the LV is normal or near normal although the changes to the LV wall mean that the total volume of blood may be lower than normal and pressure inside the heart may be higher than normal. Diastolic heart failure is also known as heart failure with preserved ejection fraction (HF-PEF). Compared with HF-REF, patients with HF-PEF are generally older, more frequently female and most have a history of high blood pressure.[15,75] HF-PEF is becoming more common; however, there are currently few effective treatments for HF-PEF.[76]

Most people do not recognize the symptoms of acute heart failure and do not regard them as serious

In addition, public education programmes about heart failure are needed to highlight the seriousness of the disease, raise awareness of its signs and symptoms and promote heart failure prevention messages such as smoking cessation, healthy diet and exercise. Only 3% of respondents correctly identified heart failure from a description of typical signs and symptoms ("breathlessness, tiredness, or swollen ankles") in the Study of Heart Failure Awareness and Perception in Europe (SHAPE) survey of almost 8000 people in nine European countries.[81] By contrast, 28% identified heart attack/angina and 48% identified stroke or its equivalent from a description. Moreover, only 29% of respondents considered heart failure "a severe complaint" based on the description of signs and symptoms, and 34% perceived it to be "a normal consequence of getting older".[81]

Essential steps in the care of patients with acute heart failure

Optimal management of acute heart failure can be broken down into three key stages:

- timely and accurate diagnosis of the disease

- rapid treatment of patients in the acute failure setting

- seamless transition to therapies, management strategies, information and support for patients in the chronic phase of the disease.

Effective care is required at all three stages to achieve the best possible outcomes. These three aspects of acute heart failure management are discussed in the following Sections.

Our evidence-based policy recommendations

Improve patient education and support

Better education and support for individuals with heart failure, and their families and caregivers, are essential to improve outcomes and patients' experience of care. Patients frequently lack the knowledge, confidence and support to be actively involved in their own care, and their adherence to measures important for long-term health is often poor.
(Recommendation 2)

Promote acute heart failure prevention

Country-wide efforts to decrease risk factors for heart failure, including high blood pressure and coronary artery disease, should be intensified. Once heart failure develops, progression of the disease should be prevented or slowed by ensuring that appropriate evidence-based care is implemented promptly.
(Recommendation 8)

3. Diagnosis of acute heart failure

Key points

- Rapid identification of patients with acute heart failure is the first step in providing effective care.

- Diagnosis can be challenging because symptoms vary at presentation, and many different factors can cause an episode of acute heart failure.

- Poor recognition of the signs and symptoms of acute heart failure frequently leads to delays in diagnosis and treatment.

- Education is needed to increase symptom awareness among everyone involved in care – healthcare professionals, patients, their families and caregivers – to ensure early diagnosis and treatment.

Importance of early and accurate diagnosis

Timely and accurate diagnosis is the first step in the treatment of patients with acute heart failure. However, acute heart failure can be difficult to differentiate from other conditions, because the symptoms are not specific to heart failure and may vary widely among patients. Furthermore, poor awareness of the symptoms of acute heart failure often leads to a time lapse between the development of symptoms and seeking medical attention, delaying diagnosis and treatment.

Education is a key factor in improving the early identification of episodes of acute heart failure, although approaches will differ for newly diagnosed patients and those already being treated for heart failure. Many individuals who are newly diagnosed with heart failure have a history of other conditions such as coronary heart disease and hypertension. Educating such patients and the healthcare professionals involved in their care about the signs and symptoms of acute heart failure should speed up the identification of new cases. For patients already diagnosed with heart failure, symptom monitoring by patients and their family and caregivers is important for the early detection of acute episodes.

Challenges of acute heart failure diagnosis for healthcare professionals

Diagnosis of acute heart failure relies on a combination of clinical evaluation, patient history, electrocardiography, cardiac imaging and laboratory tests (**Figure 3.1**).[15] The main symptoms of heart failure are non-specific, so they do not differentiate heart failure from other conditions such as chronic obstructive pulmonary disease (COPD), while other, more specific symptoms (such as orthopnoea [breathlessness when lying flat]) are less common.[15,19]

Symptoms also vary among patients at presentation. In a national audit of patients

Poor awareness of the symptoms of acute heart failure often leads to delayed diagnosis and treatment

Patient perspective

"All of a sudden, I was developing sleep apnea or wasn't breathing right but [shrugged] it off until I could hardly breathe at all the last few days. I did ignore the original symptoms. The last day, I woke up and couldn't breathe well and told my kid to get me to the hospital. I was unconscious when I got to the hospital."

From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

Patient perspective

"Oh, I've been having breathing problems for about 8 to 10 years, [but my physicians] were always blaming it on my other health problems… The breathing, they are contributing it to the toxicity of the chemicals, because I was a painter and inhaled a lot, and different things like that, and the soreness and fatigue they were contributing it to the hepatitis C… I'm a very difficult person to diagnose".

From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

in the UK with heart failure, 30% had severe shortness of breath at admission, 40% had breathlessness that limited activity, and 43% had moderate or severe peripheral oedema.[82]

Patient history can prove a useful guide to diagnosis, as approximately 65% of patients with acute heart failure also have pre-existing chronic heart failure. Electrocardiography and echocardiography
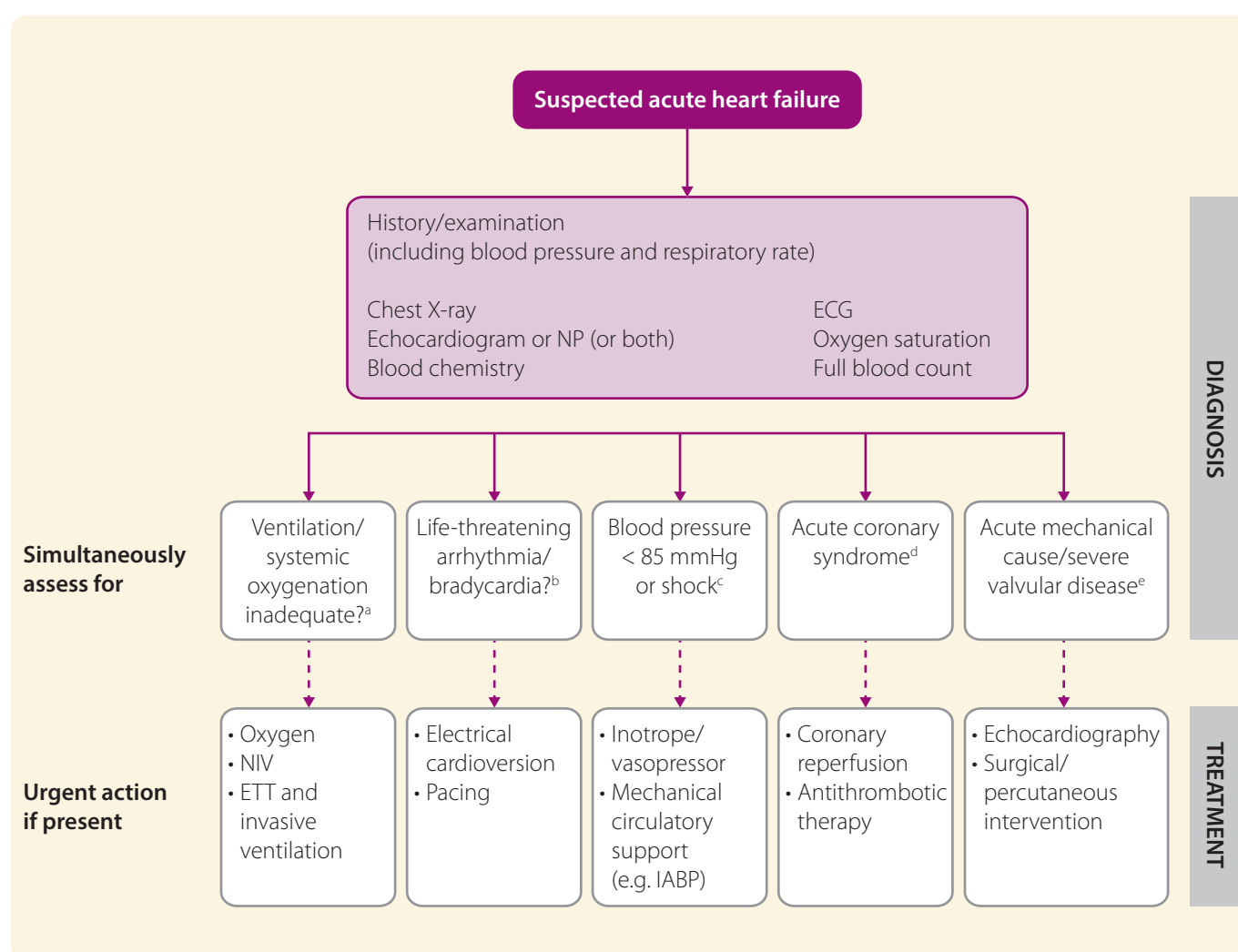

Figure 3.1. European Society of Cardiology treatment guidelines: initial assessment of suspected acute heart failure.

[a]For example, respiratory distress, confusion, $SpO_2 < 90\%$ or $PaO_2 < 60$ mmHg (8.0 kPa).
[b]For example, ventricular tachycardia, third-degree atrioventricular block.
[c]Reduced peripheral and vital organ perfusion – patients often have cold skin and urine output ≤ 15 mL/h and/or disturbance of consciousness.
[d]Percutaneous coronary revascularization (or thrombolysis) indicated if ST-segment elevation or new left bundle branch block.
[e]Vasodilators should be used with great caution, and surgery should be considered for certain acute mechanical complications (e.g. inter-ventricular septal rupture, mitral valve papillary muscle rupture).
Reproduced by permission of the European Society of Cardiology from McMurray *et al*. Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2012;33:1787–847.[15]
ECG, electrocardiogram; ESC, European Society of Cardiology; ETT, endotracheal tube; IABP, intra-aortic balloon pump; NIV, non-invasive ventilation; NP, natriuretic peptide; PaO_2, partial pressure of oxygen in arterial blood; SpO_2, oxygen saturation of arterial blood measured by pulse oximetry.

are key diagnostic tests in heart failure, providing information on heart rhythm and conductance, and on structural and functional changes. The levels of the natriuretic peptides in the blood (such as B-type natriuretic peptide [BNP] and N-terminal proBNP [NT-proBNP]), released by cardiac muscle cells in the ventricles in response to excessive stretching, are useful in ruling out heart failure. However, some primary care centres, hospitals or regions may not have the full range of diagnostic tools at their disposal.

Diagnosis in the emergency room can prove a challenge, as symptoms may be life threatening, so diagnosis and treatment are usually carried out together. In this situation, the key aims of therapy are to relieve symptoms, stabilize blood pressure,

maintain blood oxygen levels and prevent organ damage. This requires:

- rapid and accurate diagnosis of heart failure, differentiating it from other possible conditions (e.g. COPD, pulmonary embolism, renal failure)

- identification of any precipitating factor (and its treatment)

- treatment of any potentially life-threatening conditions (**Figure 3.1**).[15]

Many precipitating factors exist for acute heart failure, and several may co-exist in a single patient (**Figure 3.2**).[15,17,83] Heart attack, atrial fibrillation and other heart rhythm and valve disorders are all common triggers for acute decompensation. Other non-
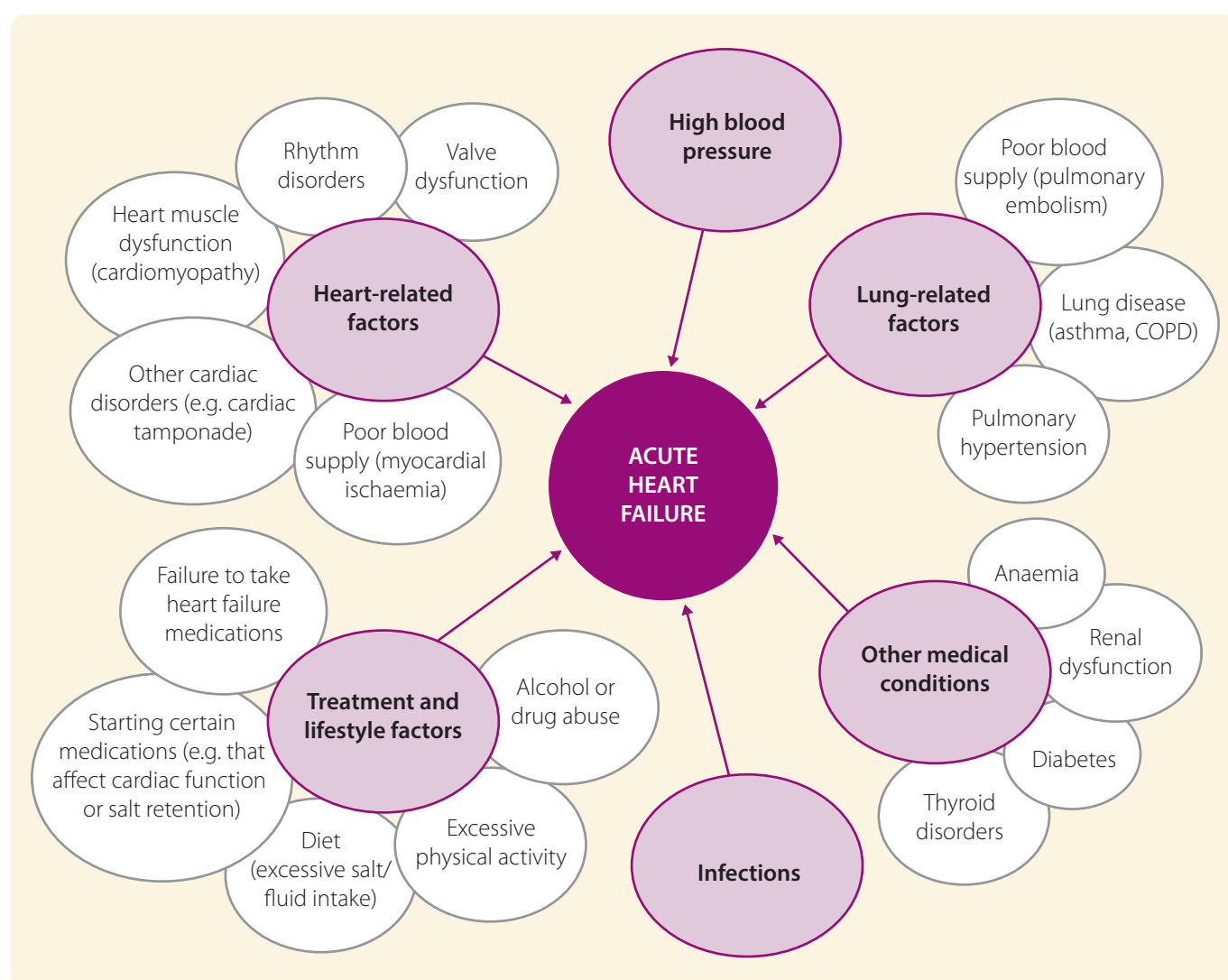
Tools for reliable diagnosis of heart failure may not be available in all hospitals

Figure 3.2. Overview of selected causes of acute heart failure.

COPD, chronic obstructive pulmonary disease.

Acute heart failure differs from patient to patient in its immediate cause and underlying contributing factors

cardiovascular factors, such as infections and lack of treatment adherence, can also trigger its onset.

Cardiac and non-cardiac comorbidities are another source of variation in patients with acute heart failure. A high proportion of patients have underlying coronary heart disease and/or high blood pressure, while kidney disease, diabetes and lung disease are also common. High blood pressure (73%), coronary artery disease (57%) and diabetes (44%) were the most common comorbidities in the Acute Decompensated Heart Failure National Registry (ADHERE) study.[53] In the EuroHeart Failure Survey (EHFS) II, coronary heart disease and hypertension were each present in over 50% of patients, while atrial fibrillation/flutter, diabetes and valvular disease were each present in at least 30%.[43]

Challenges of early symptom recognition for patients

The delay between a patient developing symptoms of acute heart failure and seeking medical attention is often considerable,[84] and is influenced by the speed of onset and severity of the symptoms. The sudden development of breathlessness (dyspnoea) from the accumulation of fluid in the lungs (acute pulmonary oedema) usually prompts rapid contact with medical services, whereas the gradual appearance of swollen legs and ankles (peripheral oedema) is more likely to be associated with delays in seeking care.

Many patients with previous acute heart failure do not recognize worsening symptoms and delay seeking medical attention

The average delay between symptom onset and hospital admission ranged from 2 hours to 7 days in six studies involving a mix of patients with and without a history of heart failure.[84] Breathlessness was among the symptoms associated with short delays between symptom appearance and hospital presentation in one study of patients hospitalized for acute heart failure, whereas peripheral oedema was linked to prolonged delays.[85] Breathlessness when lying flat (orthopnoea), oedema and weight gain have also been associated with long delays in hospital admission.[84] However, findings vary among studies and can be contradictory, with breathlessness also associated with increased delays in admission.

When the reasons for delay were examined, many patients reported not realizing the importance of their symptoms, or not recognizing them as worsening heart failure. The fact that the symptoms of heart failure often develop gradually and appear non-threatening could potentially explain the long delays in seeking care. Surprisingly, more knowledge about heart failure was associated with an increased delay in one Dutch study, possibly as a result of patients attempting to manage the symptoms themselves.[86] It is therefore important that care plans educate patients as to when it is appropriate to seek medical attention.

Other factors such as depression may affect the ability of patients to assess their symptoms effectively, and so delay care. Depressive symptoms are relatively common in heart failure, affecting 20–40% of patients with the disease.[87] In the Coordinating Study Evaluating Outcomes of Advising and Counselling in HF Patients (COACH), conducted in the Netherlands, average delay between symptom onset and hospitalization was significantly longer in patients with depressive symptoms (120 hours) than in those without such symptoms (54 hours).[87] Depressive symptoms independently increased the risk of a delay of over 72 hours by almost 50%.

The delay between the development of acute symptoms and the seeking of medical attention has implications for outcomes in patients with acute heart failure. Evidence from ADHERE suggests that early treatment with vasoactive agents (to control blood pressure) and intravenous diuretics (to control fluid retention) are both associated with lower risk of death during hospitalization than is delayed treatment.[88,89]

Symptoms at presentation affect subsequent management

For patients with shortness of breath at rest, presentation will typically be through the emergency department with subsequent admission to inpatient care, where treatment should involve input from a cardiologist. For patients with less severe symptoms of decompensation, such as those who are comfortable at rest but have shortness of breath on slight exertion, initial presentation
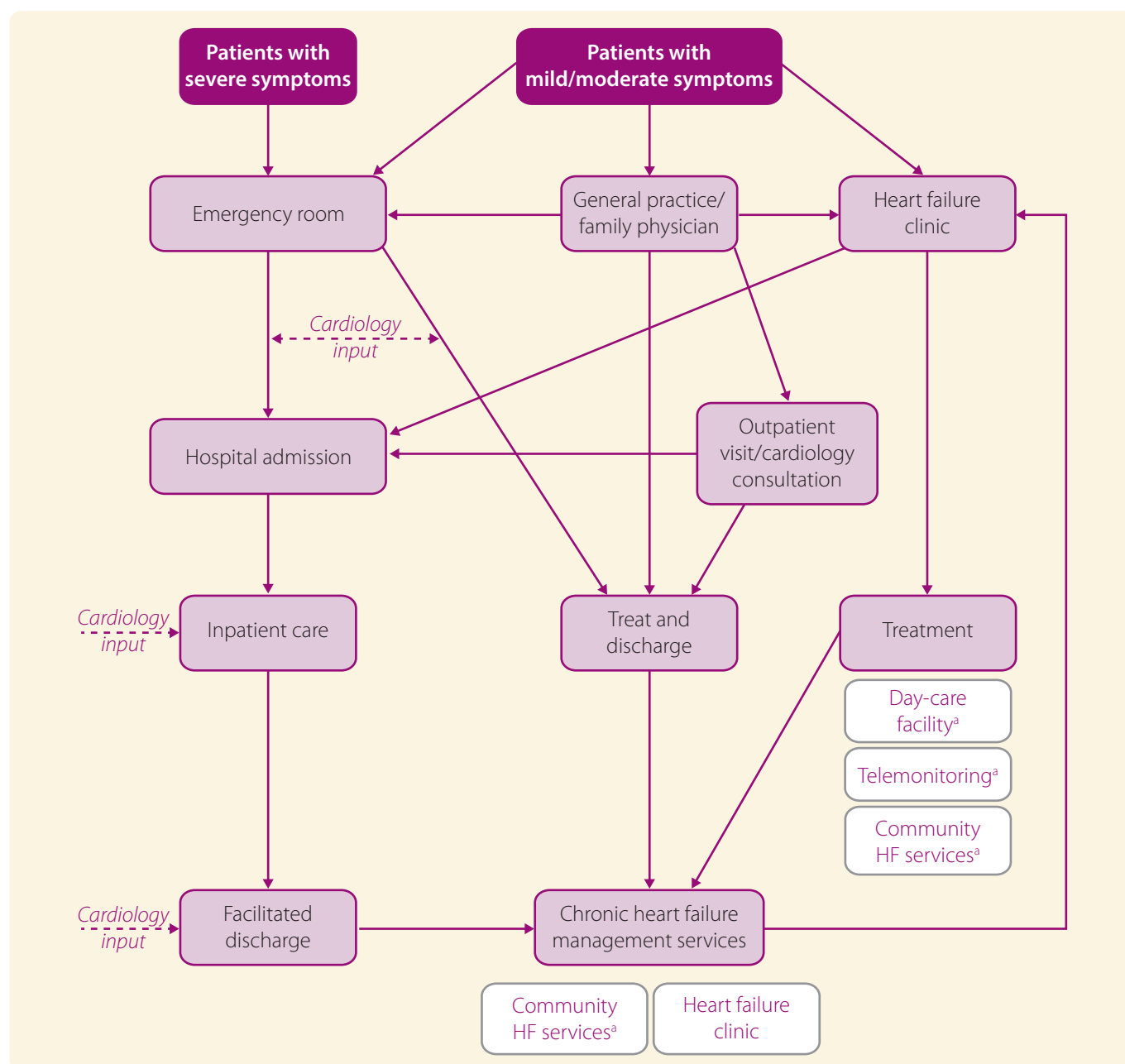
Figure 3.3. Healthcare experience for patients with acute heart failure, depending on symptoms at presentation. Patient experience also varies across countries and regions, depending on service provision.

[a]Possible future provision.
HF, heart failure.

might be to their family physician or at a heart failure clinic, as well as at the emergency department. The experience of these patients will be more varied, depending on the severity of their illness (**Figure 3.3**). They could be treated and sent home to receive long-term follow-up care, or care could involve consultation with a cardiologist or an outpatient visit for further assessment and treatment. However, there is often an over-reliance on hospitalization because of the limited availability of other care options such as non-hospital facilities or heart failure clinics for supervised daily care and treatment. A review of symptoms in patients hospitalized for acute heart failure showed that at presentation, only 38% had severe breathlessness at rest while 62% were comfortable at rest but breathless on slight exertion.[90] This suggests that the provision of more options for patient care could help to reduce the number of hospitalizations for heart failure.

Our evidence-based policy recommendations

Optimize care transitions

Better integration of hospital care, community care and the emergency services will improve patient outcomes, and enable more efficient use of resources. Currently, hospital admission and discharge planning are often poorly organized and inconsistently implemented, indicating a need for closer relationships between all those involved in patient care.
(Recommendation 1)

Improve patient education and support

Better education and support for individuals with heart failure, and their families and caregivers, are essential to improve outcomes and patients' experience of care. Patients frequently lack the knowledge, confidence and support to be actively involved in their own care, and their adherence to measures important for long-term health is often poor.
(Recommendation 2)

Provide equity of care for all patients

All patients should have timely access to an appropriate range of diagnostic procedures, therapies and long-term follow-up care. Currently, the quality of care varies considerably among hospitals, and across regions and countries.
(Recommendation 3)

4. Treatment of acute heart failure

Key points

● Symptom relief is the first priority in the treatment of acute heart failure. Available treatments are effective for many patients, but have changed little over the past two decades.

● More research is needed to identify new treatments for acute heart failure, but clinical research in the emergency setting is challenging.

● The quality of acute heart failure care varies considerably among hospitals, regions and countries, as shown by differences in death rates and hospital performance measures.

● Patients' prospects are improved when experts in heart failure are responsible for or involved in their care.

● Socio-economically deprived, disadvantaged and older patients are at a particularly high risk of developing heart failure, and of dying as a result.

● Applying our knowledge of the best treatment practices across all patients can provide better outcomes for acute heart failure with currently available therapies.

Importance of timely and appropriate treatment

Rapid treatment in the acute care setting is the second step in the management of patients with acute heart failure. However, effective treatment of patients with acute heart failure remains a challenge.

Outcomes for patients with acute heart failure have shown only modest improvements over the past two decades, death rates remain high, and patients experience frequent hospital readmissions. The options for treating acute heart failure have generally changed little over this time. By contrast, for patients in the stable, chronic phase of the disease, the introduction of new treatments and therapeutic approaches has been accompanied by considerable reductions in death and ill health.[15] Two approaches are therefore needed to improve the treatment of patients with acute heart failure:

● the development of new treatment options

● better use of patient-management strategies and existing therapies.

While research efforts continue into the development of new, more effective therapies for acute heart failure, making better use of the currently available treatments, management strategies and resources should substantially improve the outcomes and quality of care for patients with acute heart failure.

The first part of this Section considers the available treatment options for acute heart failure and the challenges of developing new therapies. The second part looks at how organization and delivery of inpatient care can affect patient outcomes. The transition to long-term care after stabilization of an acute heart failure episode is covered in the next Section.

Treatment options for acute heart failure have not changed for 20 years

Current approaches to the treatment of acute heart failure

Diuretics, vasodilators and intropic agents form the basis of acute heart failure treatment, and current approaches using these three main types of drug are summarized below. More detailed evaluations of the therapeutic options for acute heart failure are provided by a number of treatment guidelines, including those from the ESC,[15] ACCF/AHA,[17] CCS[91] and HFSA,[19] but are beyond the scope of this report.

Diuretics promote the production of urine and increase water excretion. They are the mainstay of treatment, as the majority of patients hospitalized with acute heart failure have lung congestion and/or swollen legs or ankles (peripheral oedema) and so require the removal of excess fluid to relieve symptoms. Treatment guidelines recommend intravenous administration of diuretics, as absorption following oral dosing can vary substantially among patients.[15,17,19] Therapy leads to rapid relief of breathlessness in the majority of patients, and individuals should be monitored regularly to assess the efficacy and safety of treatment.[15,17,19]

Increased doses or addition of a second diuretic may be needed for some patients, if symptoms persist. Careful monitoring is required to avoid excessive reductions in fluid volume, which could lead to low blood pressure and/or affect kidney function; and/or result in low potassium levels, which could increase the risk of heart rhythm disorders.[15,17,19]

Vasodilators act to widen blood vessels, and can be added to diuretic therapy to reduce the build-up of fluid in the tissues and lungs in acute heart failure; they should be avoided in patients with low blood pressure.[15,17,19] These agents can reduce pressure in the circulatory system, which may relieve breathlessness and congestion. Careful monitoring is needed to avoid low blood pressure and reduced blood flow to the organs, which may affect kidney function.[15,19]

Inotropic agents act directly on the heart muscle to increase the force of contraction.

They can increase the volume of blood pumped by the heart, raise blood pressure and improve the flow of blood to the tissues; however, their use in acute heart failure is limited because of concerns over potential adverse effects. Guidelines therefore recommend that inotropic agents should be used only for critically ill patients in whom low blood pressure and/or reduced cardiac output means that blood flow to vital organs is compromised.[15,17]

The use of evidence-based cardiovascular medications for chronic heart failure is important for the effective long-term care of patients following an acute episode (see Section 5).

Barriers to the development of more effective treatments

Effective clinical trials are key to the development of new, evidence-based treatments for acute heart failure. However, their design presents a number of challenges in terms of patient enrolment, the timing of treatment administration and selection of appropriate measures of success ('outcome endpoints').[92]

Trials assessing the effects of therapies on the symptoms of acute heart failure require early patient enrolment and rapid treatment administration, within hours of admission.[92] Allowing later enrolment 1–2 days after admission means that early treatment effects cannot be assessed, and could also affect the characteristics of the patient population. For example, many patients experience improvements in acute dyspnoea within 3–24 hours with current therapies; the subsequent enrolment of symptomatic patients could capture a disproportionately high proportion of those with refractory symptoms and a particularly poor prognosis.[92] Patient enrolment in the emergency department can, however, prove challenging. Study protocols need to ensure that staff are available to identify and enrol patients effectively, with careful consideration given to obtaining informed consent, as this may prove difficult in acutely ill patients.[93]

A wide range of outcome measures is potentially of interest in acute heart failure,

Treatments for acute heart failure reduce fluid build-up, alter blood pressure or increase the force of heart contractions

Design of clinical trials for drugs used in hospital emergency rooms is challenging

and care is needed to select the most appropriate endpoints for the aims of the trial (**Figure 4.1**).[92] Death from cardiovascular causes or from all causes offer the most rigorous endpoints, but it is not known whether a short-term therapy for acute heart failure would be capable of reducing long-term death rates (for example by preventing damage to heart muscle).[92] Assessment of symptoms such as breathlessness (dyspnoea) may be an alternative endpoint; however, the ability to detect changes in dyspnoea depends on how it is measured and on variations in patient disease characteristics.[92] There is therefore a lack of consensus on the most effective assessment measures to use in clinical trials.[92]

The heterogeneity of patients with acute heart failure presents another challenge, as patients with different symptoms and underlying causes may respond very differently to a particular therapy. Classifying individuals according to presenting symptoms, type of cardiac dysfunction (i.e. reduced or preserved ejection fraction) and underlying cardiac cause would provide a better-defined patient population.[94] Particular therapies could then be assessed in the subpopulations most likely to benefit from a given treatment approach.

Despite the challenges of clinical research in acute heart failure, new medications are being developed. Determining whether promising results in early clinical trials translate into reduced death rates during acute decompensation or in the subsequent chronic phase of treatment will require additional larger-scale studies. New or improved medicines for acute heart failure would have the greatest impact in the context of high standards of care. It is also important that access to newly licensed medications is not limited, so that their introduction can benefit the maximum number of patients.

Tools for improved medical decision-making in acute heart failure

Several factors affecting outcomes, including kidney function, SBP, age and ischaemia, have been identified in patients with acute heart failure.[95] This has led to suggestions that these factors could be used to help to direct resources to those patients who need them most.

Acute heart failure has diverse causes and consequences, so evaluating the efficacy of new treatments is complex
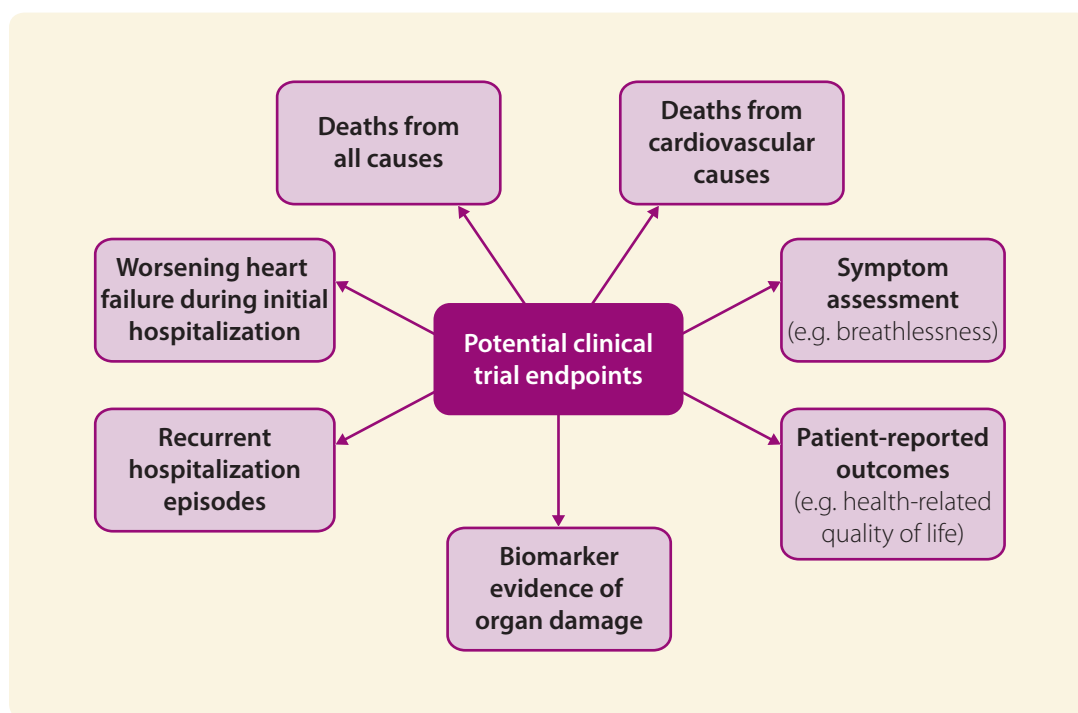

Figure 4.1. A range of potential endpoints for major clinical trials in acute heart failure.

Reproduced and adapted by permission of the European Society of Cardiology from Zannad F *et al*. Clinical outcome endpoints in heart failure trials: a European Society of Cardiology Heart Failure Association consensus document. *Eur J Heart Fail* 2013;15:1082–94.[92]

Studies have consistently shown that impaired kidney function is significantly associated with increased long-term death rates and more frequent readmission in patients hospitalized with acute heart failure.[40,96] Abnormally high or low SBP at discharge was associated with increased death rates at 1 year in the Canadian Enhanced Feedback for Effective Cardiac Treatment Heart Failure (EFFECT-HF) study.[97] In the Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients with Heart Failure (OPTIMIZE-HF), low SBP at admission was associated with an increased death rate, both in hospital and following discharge.[98] In the same study, patients whose hospitalization was precipitated by poor blood flow to the heart (e.g. a heart attack) showed a significant increase in risk-adjusted death rate.[99]

Although various factors are known to affect the prognosis for individuals with acute heart failure, there are no clear, established guidelines for assessing the likelihood of a patient having acute heart failure and for using this to help to determine their care. The aim of this so-called 'risk stratification' is to manage patients more effectively, directing resources to those who need them most. It could allow for the identification of low-risk patients who present to the emergency department but who are suitable for treatment in observation units or for early discharge home, rather than being kept in hospital.[100,101] Alternatively, it could help to identify high-risk patients who would benefit from close follow-up after discharge.[102]

Care of patients with heart failure by cardiology-led specialist units reduces the risk of death in hospital or after leaving hospital

Several models for risk stratification have been proposed, ranging from schemes based on a few assessments (such as admission SBP and oxygen saturation,[103] age and renal function,[104] or SBP and renal function[105]) to complex models involving multiple factors.[102,106] However, none of these is sufficiently well developed for widespread adoption, mainly because of the variation in presentation and underlying causes of acute heart failure.

The use of blood-based biomarkers to aid the diagnosis, admission, discharge and treatment management and to reduce readmissions in acute heart failure is also being investigated.

What is needed for more effective in-hospital care?

The organization and delivery of in-hospital care has an important effect on outcomes for patients treated for acute heart failure. Adopting the most effective management strategies across all patients should substantially improve the outcomes and quality of acute heart failure care. Teamwork between cardiologists and physicians and nurses in other hospital departments (e.g. emergency, internal medicine, intensive care) and outside hospital is essential to improve outcomes and care quality.

Cardiologist versus non-cardiologist care

The type of care (cardiologist or non-cardiologist) received in hospital is associated with differences in the outcomes for patients with acute heart failure. A national audit of heart failure care in England and Wales showed lower in-hospital death rates for patients treated on cardiology wards (7.8%) than on general medical wards (13.2%) or on other wards (17.4%).[3] Findings were similar for post-discharge death rates (**Figure 4.2**), and the differences remained even after adjusting for possible variation in patient characteristics. Studies of patients hospitalized for heart failure in North America also reported lower 30-day[107,108] and 1-year[107,109] death rates for those treated by cardiologists than for those treated by other specialist healthcare professionals.

Differences in hospital care, discharge medications and follow-up recommendations have also been reported across specialties. Patients were more likely to undergo diagnostic procedures such as echocardiography and exercise testing when treated by a cardiologist rather than by a non-cardiologist.[107,109–111] Medications shown to be effective in chronic heart failure were more likely to be prescribed to cardiologist-treated patients at discharge than to those cared for by other specialists.[3,107,109,111] Increased use of medications at discharge was also reported for patients treated in a heart failure unit.[112] In England and Wales, patients were more likely to receive specialist follow-up by a cardiologist and/or in a heart

failure clinic if treated on a cardiology ward than if treated on other wards.[3] The establishment of a dedicated in-hospital heart failure unit can also enhance outcomes in acute heart failure, with marked reductions reported in avoidable readmissions for heart failure[113] and in a composite measure of readmission and death.[112]

Quality improvement programmes and care pathways

Quality improvement programmes have proved successful in enhancing the level of care for patients with acute heart failure. In OPTIMIZE-HF, hospitals were provided with a variety of tools to improve heart failure management, including best-practice treatment algorithms and discharge checklists.[114] Marked improvements in two performance measures were observed over the 2-year study period: the issuing of complete discharge instructions (increased from 47% to 67%) and smoking cessation counselling (up from 48% to 76%). The use of medications for chronic heart failure at discharge either increased (from 76% to 86%) or was unchanged (at just over 80%), depending on drug class, indicating that further efforts are needed to promote their use. The use of specific process-of-care improvement tools increased over time and was associated with lower in-hospital and post-discharge 60- to 90-day death and rehospitalization rates.[114]

The use of care pathways – systematic plans for the care of particular patients over a particular time – has been shown to improve outcomes in patients hospitalized with acute heart failure. Studies have reported reductions in readmission and in-hospital death rates and in the length of hospital stay compared with usual care.[115]

Variations in the quality of acute heart failure care

Equal access to high-quality care is essential in ensuring the best outcomes for all patients with acute heart failure. However, marked variations in the quality of care can be seen in different hospitals.

Quality performance indicators for heart failure management reveal substantial differences in care across hospitals. Analysis
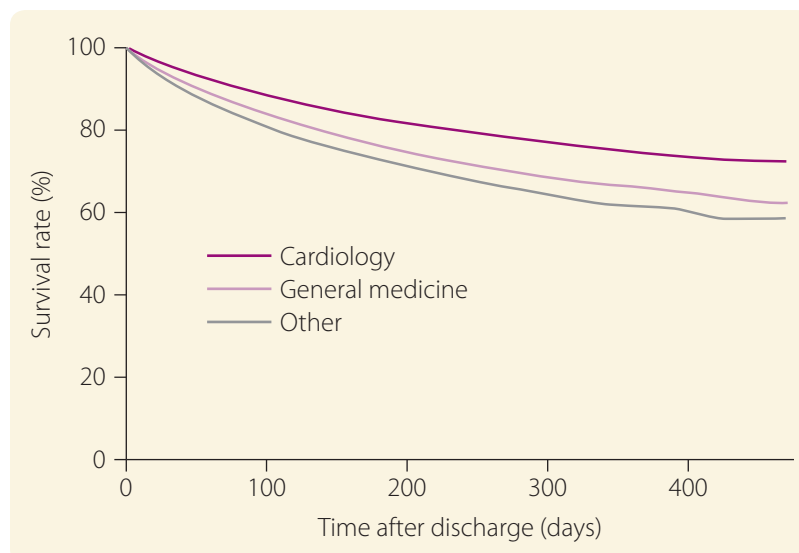

Figure 4.2. Cardiology wards have better post-discharge survival rates for patients with heart failure than general medical or other wards.

Reproduced wth permission from National Institute for Cardiovascular Outcomes Research (NICOR), University College London, UK.[3]

of ADHERE data for patients with acute heart failure showed marked variations among hospitals in management practices measured by four core care performance indicators (known as HF-1 to HF-4) relating to good patient communication and appropriate prescribing practice.[116] Across different hospitals the rate of compliance with the practice defined by each performance measure varied widely, from 70–95% in the most compliant hospitals to 0–70% in the least compliant (**Figure 4.3**). In addition, the analysis showed marked differences among hospitals in the length of hospital stay (ranging from 2.3 to 9.5 days) and in rates of death in hospital (ranging from 0% to 11.1%).[116] Increasing compliance with these core care performance indicators should therefore improve the overall quality of care for patients.

An analysis of data from over 3000 hospitals in the USA also reported wide variations in care quality across hospitals, as measured by these four performance indicators, although it improved over the 2-year study period.[117] In England and Wales, the National Heart Failure Audit revealed considerable differences across hospitals in a number of areas of heart failure care, including the proportions of patients undergoing key diagnostic tests, receiving cardiovascular medications on discharge and being referred to cardiology follow-up services.[3]

Use of checklists, protocols and care pathways for managing patients with acute heart failure can reduce deaths

Many hospitals in Europe and the USA do not apply known best practice in heart failure care
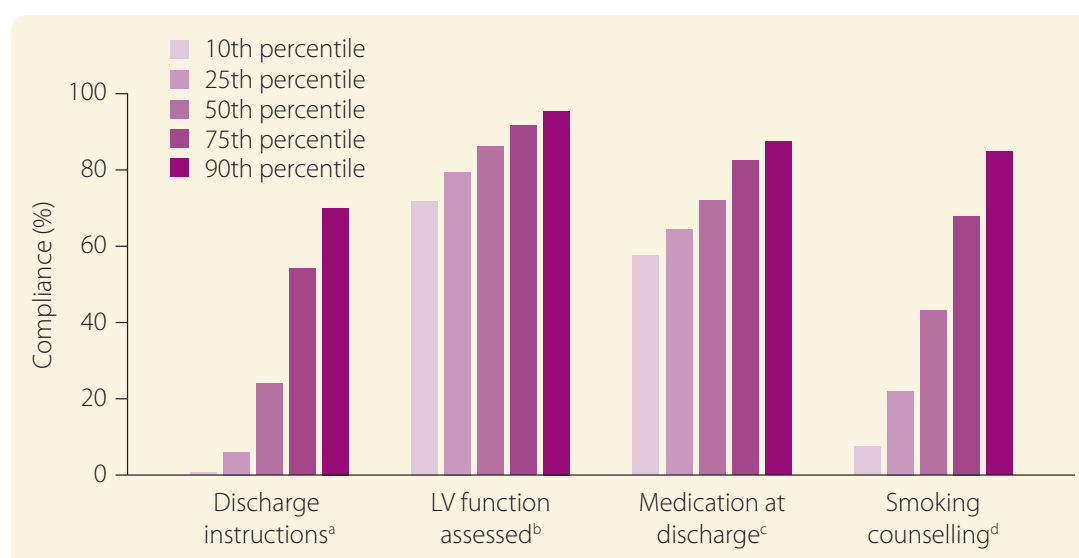
Figure 4.3. Compliance with core performance measures for heart failure varies widely among hospitals.[116]

The graph shows the distribution of compliance rates across the 223 hospitals analysed. Hospitals were ranked according to compliance rate for each measure, and values are shown for hospitals at the 10th (low compliance), 25th, 50th, 75th and 90th (high compliance) percentiles of the ranking distribution.
[a]Discharge instructions or guidance.
[b]Left ventricular function documentation obtained or scheduled.
[c]Specific medication prescribed at discharge for left ventricular systolic dysfunction, if indicated.
[d]Smoking cessation counselling, if indicated (n = 220).
LV, left ventricle.

Wide variations in hospital performance in acute heart failure have been reported[119,120]

Differences in patient outcomes and the use of healthcare resources also illustrate variations in heart failure care among hospitals and across regions. Significant regional differences in outcomes were seen for patients hospitalized for acute heart failure in Canada, with readmission rates and in-hospital death rates varying across provinces (**Figure 4.4**).[118] Wide variations in hospital performance have been reported for Medicare patients hospitalized with a principal diagnosis of heart failure in the USA.[119] Rates were adjusted to take account of different patient characteristics, and ranged from 6.6% to 18.2% for in-hospital death and from 17.3% to 32.4% for 30-day readmission. Substantial differences in death and 30-day rehospitalization rates were also seen among hospitals in Scotland for patients following their first hospitalization for acute heart failure.[120]

Analysis of six teaching hospitals in California, USA, revealed wide variations in death rates across the sites for patients with heart failure, with 180-day rates ranging from 17.0% to 26.0% (when adjusted for differences in patient characteristics between hospitals).[121] Days spent in hospital and treatment costs also varied considerably over the 180-day period after initial hospitalization, with a two-fold difference in the number of hospital days reported across sites. There was an inverse correlation between patient outcome and use of hospital resources as measured by treatment costs and days in hospital. Hospitals with higher resource use had lower death rates, even after taking into account the differences in patient characteristics.[121]

Impact of social factors on treatment and quality of care

The social make-up of patients with heart failure could affect their management and may contribute to the low profile of the disease. Patients with heart failure are typically elderly; in the USA, almost one in four patients diagnosed with heart failure is aged 80 years or above.[14] Age at first hospitalization for heart failure averages

Patient perspective

"It seems like a heart doctor will look at your heart [but] if you have any other problems, the doctor will just tell you to 'go to that clinic, go to this clinic, go to that clinic.'"

From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

70–75 years.[5,6,9,10,40,53] Women comprise slightly more than 50% of patients with heart failure in the USA[9,40,53] and 40–45% of patients in European studies,[5,10,45] and are on average about 5 years older than men at hospitalization.[3,6,55]

Age has several important implications for the management of patients with acute heart failure. Prescription of medications according to treatment guidelines has been shown to decrease with patient age,[3] so the oldest patients might not receive the most effective therapy. This is compounded by the fact that older patients are likely to have complex disease with multiple comorbidities, which may limit the treatment options available. Furthermore, women make up a greater proportion of the oldest patients,[6] and are more likely to have heart failure with preserved ejection fraction, for which the treatment options are limited.[17]

Heart failure is particularly common among socially disadvantaged individuals. Studies have shown that lower socio-economic status is independently associated with a greater risk of developing heart failure and an increased risk of readmission after hospitalization compared with higher socio-economic status, even after adjusting for other demographics and risk factors.[122] Several other studies have reported an increased risk of death with lower socio-economic status,[60,123–125] although one study in England reported no such differences.[56] Most evidence suggests that medication use is not related to socio-economic status, although data are limited and one study has reported lower prescribing rates for some classes of drug among more deprived patients.[122]

Socio-economic factors are likely to have a particular impact on older women with heart failure.[126] Data from the USA show marked socio-economic disparities between genders among older people, with more elderly women than men living in poverty.[126] Furthermore, more older women than men live alone, and may lack the social and/or family support that is associated with better outcomes in patients with heart failure.[126] Women with heart failure frequently report a lack of psychological and social support in studies examining patient experiences and perceptions of their illness.[64]
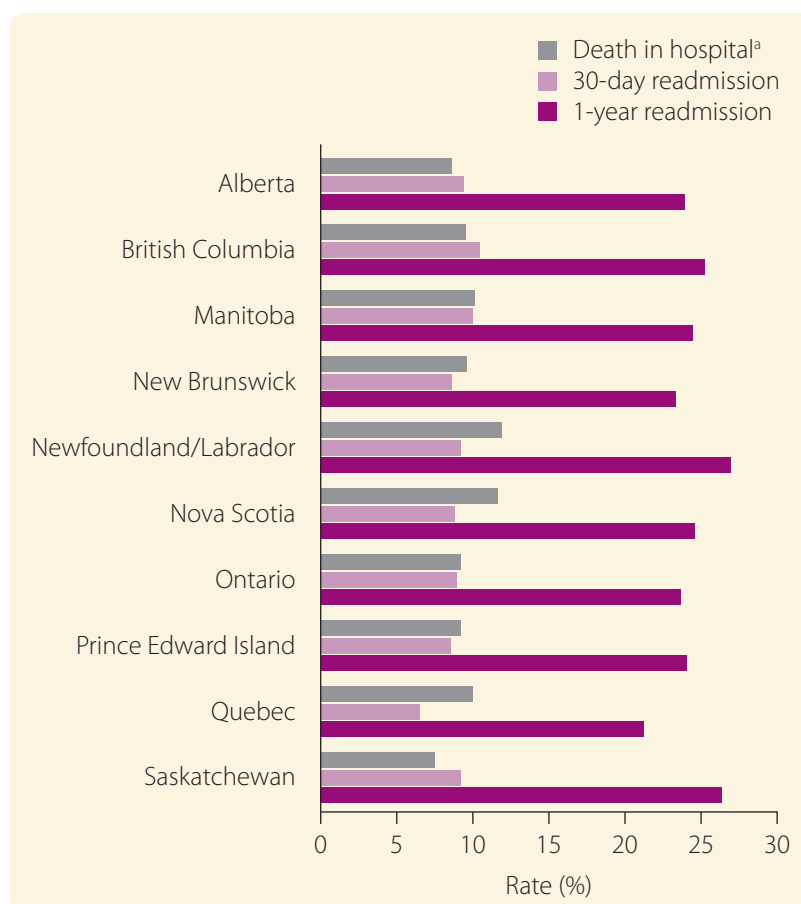
Figure 4.4. Variation in readmission and in-hospital death rates for acute heart failure across provinces in Canada.[118]

[a]Age- and sex-adjusted.

Need for better measures of care quality

Several performance measures are used to evaluate the quality of hospital care for patients with heart failure. Each measure defines a particular management practice, such as prescription of a particular class of medication at discharge. Differences in compliance with these measures among hospitals are used as an indicator of variation in the quality of care.[117,127] For this approach to be valid, there should be a close link between the individual measures and patient outcomes, but evidence suggests that this is not the case for many performance indicators.[128–131]

An analysis of over 5700 patients hospitalized for heart failure showed that only one of the five measures of inpatient care recommended by the ACCF/AHA was associated with death or rehospitalization rate following discharge.[128] By contrast, a non-recommended measure (prescription of antihypertensive medication for left

Socially and economically disadvantaged people, especially older women, have a heightened risk of heart failure

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New performance measures are needed to assess quality of care for patients hospitalized with heart failure

ventricular systolic function at discharge) was a predictor of both death and death or rehospitalization during the 60- to 90-day follow-up period. Compliance with this measure was also associated with lower death rates over 1 year of follow-up in a larger study, whereas no associations were seen for the four ACCF/AHA measures analysed.[129] A study of more than 15 000 patients hospitalized for heart failure showed that socio-economic status and hospital characteristics, such as its type and the number of heart failure admissions, were stronger predictors of death and readmission rates in the 30 days after discharge than hospital compliance with the ACCF/AHA performance measures.[130]

Using current performance indicators to rank the quality of care provided by hospitals also appears problematic. The use of two different groups of measures showed little or no correlation with 30-day death rates or 30-day readmission rates, and most of the individual measures also showed no correlation with outcomes.[131] The ranking of individual hospitals varied considerably according to which set of performance or outcomes measures was used.

Readmission within 30 days of the initial hospitalization for heart failure is also a focus of attention as a potential indicator of care quality.[132,133] However, a study of over 17 000 patients with heart failure showed that 30-day readmission was not associated with 30-day death rates: indeed, higher readmission rates were associated with increased compliance with other performance measures.[132] Other studies have shown reductions in death rates even when rehospitalization rates increased, suggesting that rehospitalization alone is not a useful measure of poor heart failure care.[52,134,135] Furthermore, the imposition of financial penalties for 30-day readmissions, as in the USA,[136] could discourage appropriate in-hospital treatment of a patient during an acute episode.

The problems with existing performance measures indicate a need for new metrics to assess the quality of care for patients hospitalized with heart failure. To be effective, these measures should cover hospital care and the transition to community care, and show a clear link with patient outcomes or improved efficiency.[127] Performance measures will also need to take into account factors such as the severity of illness and socio-economic status in order to provide an accurate picture of the differences in care quality among hospitals.

Our evidence-based policy recommendations

Provide equity of care for all patients

All patients should have timely access to an appropriate range of diagnostic procedures, therapies and long-term follow-up care. Currently, the quality of care varies considerably among hospitals, and across regions and countries. (Recommendation 3)

Appoint experts to lead heart failure care across disciplines

A multidisciplinary team led by a heart failure expert should oversee the care of patients with acute heart failure and the development of protocols, training and local auditing to make excellent care the norm. (Recommendation 4)

Stimulate research into new therapies

Increased funding is needed for research into new and more effective therapies, medical devices and care strategies for acute heart failure. New approaches are urgently required to address unmet needs. (Recommendation 5)

Develop and implement better measures of care quality

Performance measures based on robust, evidence-based clinical recommendations should be developed and used to improve the quality of care for patients with acute heart failure. Current performance measures are variable and lack an evidence base and their use may have unintended consequences. (Recommendation 6)

5. Transition from hospital to community care

Key points

- Patients with acute heart failure who have been stabilized in hospital need effective long-term care to reduce the likelihood of another episode.

- The major unmet need for managing acute heart failure is to enable rapid discharge from hospital while preventing recurrent admission and death.

- The use of evidence-based medications, in line with treatment guidelines, is important to the success of long-term care.

- Self-care reduces patients' risks of rehospitalization and death, and it comprises self-maintenance, self-monitoring and self-management.

- Education and support for patients, their families and caregivers are required to ensure that patient self-care is effective.

- The value of palliative and end-of-life care should be communicated more widely and sooner to patients and their families, to encourage discussion and timely decision-making.

Importance of effective long-term care

Effective long-term care is essential for good outcomes for patients following an episode of acute heart failure. The challenge is to ensure a seamless transition from inpatient to outpatient care for all patients, and integration with chronic heart failure management.

Several factors are important to ensure continuity of care for these patients, including:

- an effective disease-management programme

- use of evidence-based treatments

- adoption of patient self-management behaviours

- effective education and support for patients, families and caregivers.

The first part of this Section examines the transition to long-term care; the second part considers the role of palliative care services in the management of patients with heart failure.

Disease-management programmes and multidisciplinary teams

Discharge from hospital and the transition to outpatient care and follow-up is an important stage in the management of patients with acute heart failure. The goal is to provide a high-quality transition to outpatient care and ensure integration with chronic care services. Disease-management programmes have been developed as a tool to facilitate the transition process. These typically include in-hospital patient education and multiple follow-up visits, although the length and intensity of the programmes can vary considerably.[137] The components recommended by the ESC guidelines are shown in **Table 5.1**.[15]

Table 5.1. Components of heart failure management programmes recommended by the European Society of Cardiology guidelines.[a]

- Optimized medical and device management
- Adequate patient education, with special emphasis on adherence and self-care
- Patient involvement in symptom monitoring and flexible diuretic use
- Follow-up after discharge (regular clinic and/or home-based visits; possibly telephone support or remote monitoring)
- Increased access to healthcare (through in-person follow-up and by telephone contact; possibly through remote monitoring)
- Facilitated access to care during episodes of decompensation
- Assessment of (and appropriate intervention in response to) an unexplained increase in weight, nutritional status, functional status, quality of life, and laboratory findings
- Access to advanced treatment options
- Provision of psychosocial support to patients and family and/or caregivers

[a]Professional bodies in North America[17,19,91] and Australasia[18,138] have also published guidelines. Reproduced by permission of the European Society of Cardiology from McMurray *et al*. Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2012;33:1787–847.[15]

Heart failure management programmes for patients leaving hospital improve outcomes and reduce deaths

Numerous studies have demonstrated the benefits of disease-management programmes on patient outcomes, with reported reductions in rates of readmission[139–141] and death after discharge,[141] and improvements in quality of life,[139,140] compared with usual care. Although the types of intervention differ across studies, with not all studies showing improved outcomes,[137] simple approaches such as early patient follow-up have been shown to be effective.[142] Nurse-led transitional care has been well studied and can prove effective.[139] Programmes involving patient and family/caregiver education, home visits and regular telephone support have been shown to reduce readmission and death rates, and to improve quality of life.[134,143] Patient education is another important component of disease-management programmes. In France, the national education programme for heart failure patients (Insuffisance Cardiaque: Éducation Thérapeutique [I-CARE]) has proved effective in reducing deaths from all causes in patients with chronic heart failure.[144]

Evidence suggests that the type of follow-up care can also have an impact on outcomes for patients with heart failure. Follow-up by cardiologists or specialist nurses was associated with reduced death rates in England and Wales.[3] Studies have shown reductions in rates of rehospitalization[113,145,146] and death,[135,145,147] and improvement in quality of life,[146] during follow-up at a specialist heart failure clinic compared with usual care.

Not all studies have reported benefits for heart failure clinics. A study in Denmark reported similar rates of death and hospital admission in patients with heart failure who received extended follow-up care from a heart failure clinic or from their own primary care physician.[148] All patients were, however, stabilized on optimal therapy and received education in heart failure self-management before entering the study, and the majority of patients in the primary care physician group also received regular follow-up.[148] This suggests that the quality and level of care, rather than the location, are important for good outcomes.

Evidence-based medications improve long-term outcomes

The introduction of new treatments and therapeutic approaches has improved outcomes for patients in the stable, chronic phase of heart failure. It is therefore important that all patients receive these medications following stabilization of acute heart failure.

Large randomized controlled clinical trials have shown reductions in death and ill health for patients with stable heart failure and reduced left ventricular ejection fraction with a range of medications that act on the cardiovascular system.[15] Implanted pacemaker and defibrillation devices have also proved effective for some types of patient.[15] These benefits have translated into everyday clinical practice: registry and community-based studies show improved outcomes for patients with chronic heart failure associated with increasing use of evidence-based treatments.

Hospitalization rates for patients with chronic heart failure decreased with greater compliance with guidelines for the use of appropriate heart and blood pressure medication in the Medical Management of Chronic Heart Failure in Europe and its Related Costs (MAHLER) survey, conducted in six European countries.[149] Patients who were prescribed all three medications in line with the guidelines (complete guideline compliance) had lower hospitalization rates for heart failure and for any cardiovascular problem during the 6-month follow-up than those receiving fewer medications (moderate or low guideline compliance) (**Figure 5.1**).[149]

In a German registry study, marked reductions in 1-year and 3-year death rates coincided with an increase in the proportion of patients who received all three recommended heart and blood-pressure medications according to treatment guidelines.[150] The death rate was lowest among patients with high adherence, highlighting the importance of interventions to increase the implementation of treatment guidelines among healthcare professionals.
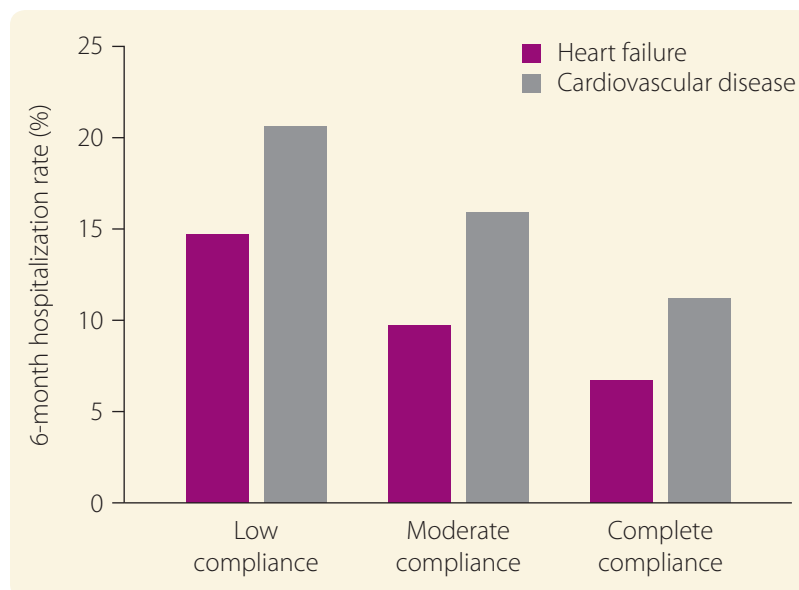

Figure 5.1. Compliance with treatment guidelines reduced the need for hospitalization in a large European study.[149]

Compliance with guidelines for the use of three treatments: complete, all three treatments; moderate, two treatments; low, no or one treatment.

Patients with heart failure typically experience several acute episodes interspersed with periods of stable, chronic disease (see **Figure 2.1**). Following an acute episode, it is therefore important to ensure that all patients receive and continue to receive the medications known to be effective in chronic heart failure. Halting or slowing the progression of the disease is important, as most deaths due to heart failure occur during episodes of acute decompensation, for which very few new evidence-based medicines have been developed in the past 20–30 years.

Programmes to improve discharge and transition to follow-up care

Evidence shows that disease-management programmes can improve the quality of care and outcomes in patients with acute heart failure. However, in one survey, only seven of 26 European countries reported that heart failure management programmes were being used in more than 30% of hospitals.[151] Even when programmes are in place, they are often underused; a survey in Canada showed that only 15% of patients hospitalized for heart failure were referred to a specialist heart failure clinic for follow-up.[152] Furthermore, a web-based survey

Not all patients with heart failure receive appropriate medication in accordance with treatment guidelines

reported wide variations in the implementation of key practices by hospitals enrolled in a quality-improvement initiative to reduce preventable patient readmissions after hospitalization for heart failure or a heart attack.[153] About 15% of hospitals employed all four discharge and follow-up practices, and only 5% had all three medication management practices in place. There are therefore grounds for optimism that redesign of the processes for treatment of heart failure and their widespread implementation will allow reduction of death and disease due to heart failure.

Use of technology in heart failure management

The increased use of technology for monitoring patients with heart failure following discharge may help to improve outcomes, and prevent future acute episodes, although results from studies have been mixed.[154] One telemonitoring approach involves automated transmission of patient-measured weight, blood pressure, heart rate and heart rhythm data to the medical centre. In one study, death rates after 1 year were lower among patients receiving telemonitoring (29%) or regular telephone support from a nurse (27%) compared with usual care (45%).[155] In contrast, a later study revealed no differences in death rate between the telemonitoring and usual care groups over 12–28 months' follow-up.[156] However, this study involved stable, lower-risk patients who were already well managed, suggesting that there was little opportunity for telemonitoring to provide additional benefits over usual care.

More research is needed into the development and use of telemonitoring systems. A study of blood pressure monitoring via an implanted wireless device for up to 15 months showed that hospital admissions for heart failure and the length of stay were reduced compared with usual care, as a result of more adjustments to medications.[157] Use of an automated telephone-based interactive voice-response system did not, however, lead to differences in death or readmission rates compared with usual care over 6 months' follow-up in

another study.[158] Monitoring of fluid accumulation via an implanted device is another approach, but requires further development for routine daily use.[159] A survey of heart failure clinics in the Netherlands showed that telemonitoring did not deliver the anticipated benefits in terms of patient care, reduced workload or lower treatment costs,[160] suggesting that attention should also be paid to how systems are implemented.

Technology offers other opportunities to help patients and healthcare professionals improve heart failure management. Interactive Internet-based education programmes may help patients with self-care, while online groups are a useful source of support for patients and their families. The use of telemonitoring to supervise and monitor patients remotely during exercise (telerehabilitation) could help to increase physical activity among patients with heart failure,[161] while online consultations making use of video links and digital stethoscopes could reduce the need for face-to-face consultations.[162]

Crucial role of patient self-care

The patient plays a key role in the long-term management of heart failure after hospitalization for an acute episode.[163] Even with frequent contact with healthcare professionals, the active involvement of patients (supported by family, friends and/or caregivers) in the management of their disease is important in ensuring good outcomes. Three different components make up patient self-care: maintenance, monitoring and management (**Figure 5.2**).[164] Maintenance involves adherence to medication and lifestyle changes, while monitoring of the signs and symptoms of heart failure includes activities such as daily weighing to assess fluid retention. Self-care management means responding appropriately to any changes in symptoms – for example, by increasing the dose of medications prescribed for use as needed.

Effect of medication adherence on treatment outcomes
Ensuring that patients take their prescribed medications for heart failure improves
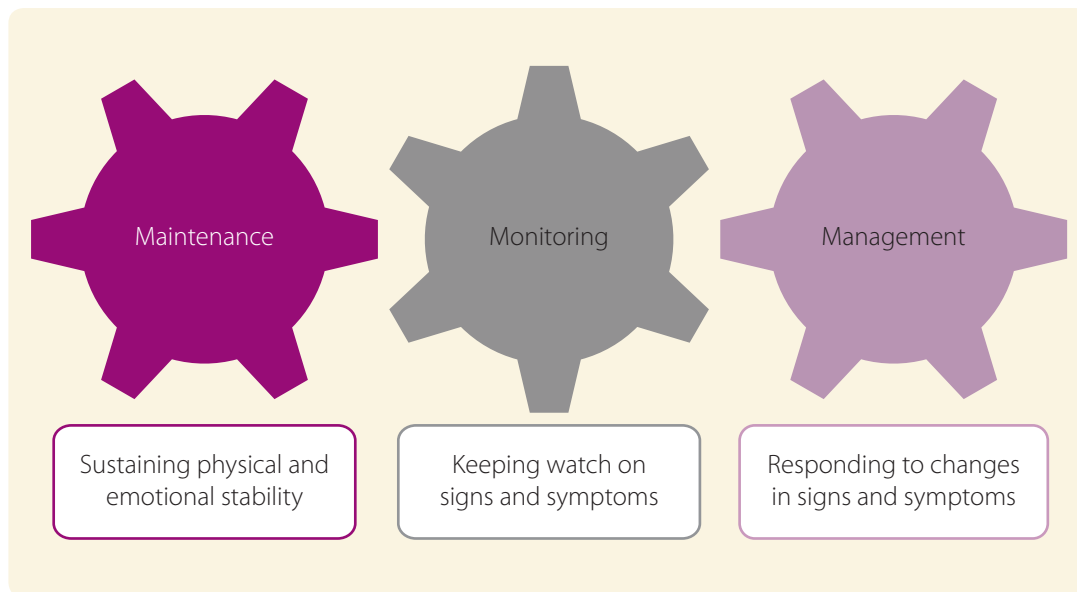
Hospital heart failure management programmes are often underused

New technologies may help to improve monitoring and outcomes after discharge

Figure 5.2. The three components of patient self-care.[164]

outcomes. In the CHARM studies in patients with heart failure, good adherence to prescribed medications was associated with lower death rates from all causes than was poor adherence.[165] Poor treatment adherence has also been linked to exacerbation of heart failure, with increased rates of hospitalization and emergency department visits.[166–168]

Nevertheless, wide variations in adherence to cardiovascular medications have been reported for patients with heart failure, with rates ranging from 10% to 96% depending on how adherence was measured and defined.[169,170] A study of patients after hospitalization for heart failure showed that, among patients prescribed a medication at discharge, only 80% were adherent to medication after 1 month.[171] Adherence was approximately 60–65% between 3 months and 1 year after discharge.

Clear, easy-to-follow instructions about medication use are important for patient adherence. Of patients newly discharged home following hospitalization for heart failure, only 34% were taking all medications as prescribed shortly after discharge, despite written discharge instructions.[172] A lack of understanding of the discharge instructions and confusion about apparently conflicting instructions between the discharging physician and the primary care physician were the main reasons for non-adherence. Many patients also continued to take their previous medications, even though they were no longer prescribed.[172]

Symptom monitoring and management

Routine monitoring of the signs and symptoms of heart failure is important for early detection and management of any deterioration in the disease. Adherence to daily weight monitoring has been linked to a reduced risk of emergency department visits and hospitalizations for heart failure.[174] Despite this, daily weighing to monitor changes in fluid retention is reported by fewer than half of all patients,[175] and is even uncommon among individuals newly discharged from hospital following an acute episode.[172,176] Furthermore, many patients do not recognize changes in weight as a potentially important indicator of clinical deterioration.[177] In one study, 31% of patients newly discharged after heart failure hospitalization could not name any symptom of worsening heart failure.[172] The

Confusing or conflicting advice are major reasons why patients do not take medication as prescribed[172]

31% of newly discharged patients could not name any symptom of worsening heart failure[172]

Patient perspectives

"I could make neither head nor tail of it, because in the hospital they had other names for the same tablets."

"I have so many tablets, well, I have to take 500 mL water with the medication. But that is no 'tasty drink,' so I take the tablets and hop [makes a drinking gesture], so I don't count that." [patient with severe heart failure who was prescribed a fluid restriction of 1500 mL].

From van der Wal *et al. Heart Lung* 2010;39:121–30.[173]

Few patients with heart failure take regular exercise, stop smoking or limit alcohol consumption[182,183]

limited ability of patients with heart failure to recognize changes in their condition contributes to the often long delays seen between developing symptoms and seeking medical attention.[84]

Responding appropriately to changes in heart failure signs and symptoms is an important part of effective patient self-care.[163] By initiating treatment strategies in response to changing symptoms – for example, by reducing fluid intake or increasing the dose of diuretic in response to fluid retention – and monitoring their effects, patients can play an active role in the management of their disease. Improved education and support are needed so that patients feel willing and able to participate fully in self-care behaviours.

Exercise and other lifestyle changes
Regular exercise has been linked to reductions in hospitalizations for heart failure and improvements in survival time.[163] Furthermore, physical activity can provide valuable improvements in exercise duration, lung function and blood flow in patients with stable heart failure, and may improve patients' quality of life and reduce depression and anxiety.[163] In Heart Failure: a Controlled Trial Investigating Outcomes of Exercise Training (HF-ACTION), involving

over 2300 patients with stable heart failure, exercise training was safe, led to improved quality of life, and was associated with a lower combined rate of death and hospitalization (adjusted for differences in patients' disease characteristics and prognosis), compared with usual care.[178] The study also suggests that exercise training may be as effective as cardiovascular medication in improving outcomes for patients with heart failure.[178–180]

Despite the benefits of regular exercise, and recommendations for exercise training or regular physical activity in the latest treatment guidelines,[15,17] few patients with heart failure report taking regular exercise.[182,183] Over 50% of patients in one study reported doing no physical activity.[177] Maintaining adherence to exercise programmes is also a challenge. In HF-ACTION, weekly exercise decreased over time, with only 30% of patients achieving the target level at the end of the 3-year study.[178]

Several other lifestyle changes are also recommended for patients with heart failure, including smoking cessation, limited alcohol consumption and restricted dietary sodium and fluid intake.[163] However, adherence to these recommendations is often poor.[182,183]

Selective adherence to self-care recommendations
Large variations in adherence to different self-management behaviours have been observed among individuals with heart failure.[182,183] In a worldwide study, most patients reported taking their medication as prescribed, but exercise levels were typically low, with over 50% of individuals not engaging in regular exercise in 16 of the 21 patient populations studied.[183]

Large variations in adherence to self-management behaviours were also reported in a study of patients with heart failure in the USA, even though individuals received self-care education at regular clinic visits (**Figure 5.3**).[182] Only 9% of patients showed good adherence to all eight behaviours. Good adherence was associated with fewer hospital admissions, fewer days in hospital and reduced emergency department visits,

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Patient perspective

"They keep saying, you got to lose this weight, here's the stuff you should and shouldn't eat, and all that. If I'm sitting here more or less 24 hours a day, 7 days a week in front of this TV… [I] can't lose weight just by not eating a potato chip or something like this. It's impossible… And I can't breathe even if I did exercise… Ten years—I know I'm overweight. I don't need them to tell me that. But there's not too much a person can do about it just by eating rice or cardboard… It just—it's frustrating."

From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

Partner perspective

"I like to stay fit, keep exercising. Swinging [sic], cycling, and walking. But he doesn't, he thinks it's not important. Not necessary. And I've given it a rest. He knows it is important for cardiac patients, but it's not in his nature."

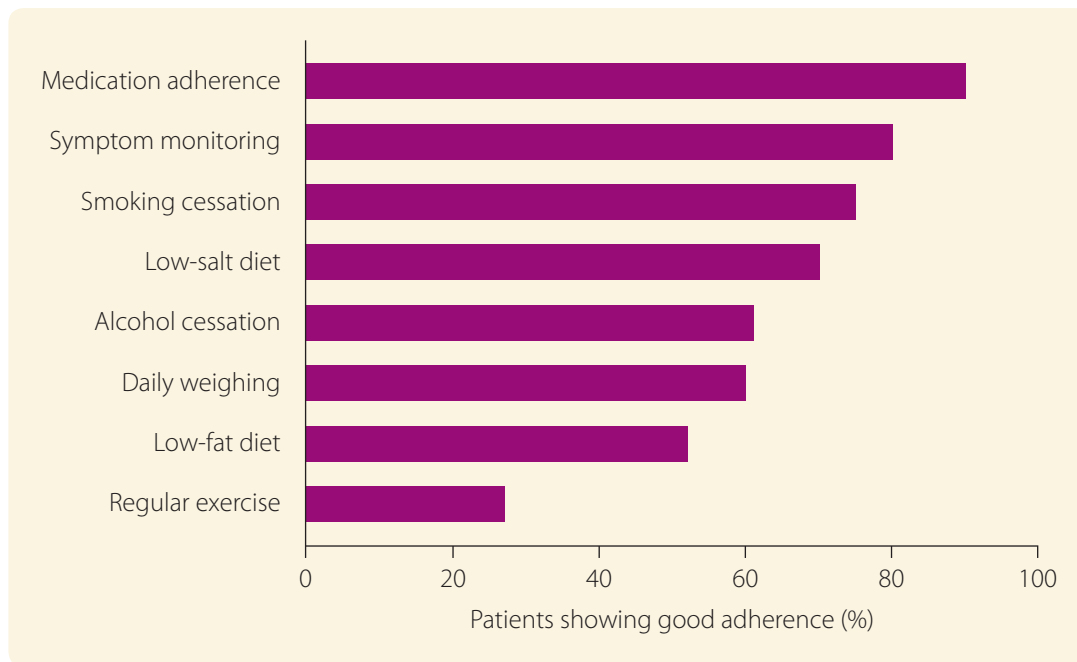From Luttik *et al. J Cardiovasc Nurs* 2007;22:131–7.[181]

Figure 5.3. Large variations in good adherence to self-care behaviours among patients with heart failure.[182]

Good adherence was defined as patients reporting adherence to a given behaviour 'all of the time' or 'most of the time' over the past 4 weeks.

and better health status compared with poor adherence in this study.[182]

Supportive role of family and friends

Support from family and friends (social support) can have beneficial effects for patients with heart failure. It has been linked to improved quality of life and reductions in hospitalizations, and can promote self-management behaviours in patients.[184] Higher levels of social support are associated with increased medication adherence[185,186] and improved dietary adherence[186] in patients with heart failure.

The quality of support provided by family and/or friends is important. Self-care was significantly better among patients with heart failure who had a high level of support from their partner than in those who received moderate levels of support or did not have a partner.[187] High levels of social support had significant beneficial effects on a number of behaviours, including medication adherence, regular exercise, fluid restriction and seeking medical attention for weight gain. However, no differences in self-care behaviours were observed between patients receiving moderate support and those with no partner.[187]

The family may also have a negative influence on patient self-management. In a survey, one in four patients regularly missed self-management behaviours because of the influence of family,[188] suggesting a need for more effective ways of involving family and friends in the care of patients with heart failure.

Social support is important to improve the care of patients with heart failure, but the burden it places on caregivers can affect them physically, emotionally and financially.[66,190] Almost one in three partners of patients with heart failure experienced a moderate level of caregiver burden, and higher caregiver burden was linked to poorer mental and physical health in

Partner perspective

"He comes first, but it isn't easy for me either, I don't mean to complain but if you are used to going out and now you have to stay home all the time, you know all the time. My daughter lives around the corner and I go out a lot with her, with the dog, to keep my mind off things… I dare not stay away much longer. My daughter wants me to come along to go to the seaside and we will also take the dog with us, but I am afraid to go. To go out for a whole day is much too long."

From Luttik *et al. J Cardiovasc Nurs* 2007;22:131–7.[181]

caregivers.[191] Family caregivers reported that patient care had a marked impact on their daily schedule, so that activities seemed centred around providing care.[189] Caregiving limited social activities in particular, and negatively affected caregivers' ability to cope with stress and their emotional and financial well-being.[192] However, some caregivers experienced positive feelings from the responsibilities and rewards of caring for a family member.[66,190]

Caregivers could benefit from improved education and support[189]

Caregivers reported receiving a lack of social and emotional support themselves, as well as the need for more information and advice on caring for patients.[189] Furthermore, low levels of perceived social support increased the burden felt by caregivers, suggesting that caregivers would benefit from improved education and support.[189]

Appropriate palliative and end-of-life care

The aim of palliative care is to improve the quality of life for patients facing life-threatening illness and their families.[193] It is therefore surprising that limited use is made of specialist palliative care services in heart failure, given the seriousness of the disease and its high death rate. In England and Wales, only 3.1% of patients were referred to palliative care services in 2012 following their first admission for acute heart failure, with 7.3% of patients referred after readmission.[3] There is therefore a clear need to increase awareness about, and improve access to, palliative care services for individuals with heart failure.[194]

Palliative care services take a broad approach to disease management, addressing the psychological, social and spiritual needs of patients and their families, in addition to other aspects of care such as pain and symptom management. Palliative care can also play an important role in discussions about the likely course of the disease and wishes regarding end-of-life care.

A review of end-of-life care conversations revealed that the majority of patients with heart failure did not feel they had discussed the subject with their healthcare professional.[195] Studies revealed an unwillingness on the part of both healthcare professionals and patients to initiate conversations about end-of-life care.[195] A broader approach to patient management involving palliative care could improve communication with patients and their families, increase understanding of the disease and aid decision-making.

For palliative care to be most effective for individuals with heart failure, it should be available throughout the course of the disease, and not just considered in the terminal stages.[194] Such an approach would, however, require its integration into disease-management programmes and involve effective coordination among healthcare professionals involved in palliative care and in the management of patients with heart failure.

Patient perspective

"A year ago, I was in the hospital… for 3 weeks, and I was told by one of the cardiologists I was seeing that I should make plans and arrangements [such as] looking for a nursing home, drawing up a will. I think he was really worried about me at that time. At the time, I was sort of shocked. I didn't know what to say. I came home after 3 weeks in the hospital, and I was really sort of afraid to do anything."

From Rodriguez *et al. Heart Lung* 2008;37:257–65.[69]

Our evidence-based policy recommendations

Optimize care transitions
Better integration of hospital care, community care and the emergency services will improve patient outcomes and enable more efficient use of resources. Currently, hospital admission and discharge planning are often poorly organized and inconsistently implemented, indicating a need for closer relationships among all those involved in patient care.
(Recommendation 1)

Improve patient education and support
Better education and support for individuals with heart failure, and their families and caregivers, are essential to improve outcomes and patients' experience of care. Patients frequently lack the knowledge, confidence and support to be actively involved in their own care, and their adherence to measures important for long-term health is often poor.
(Recommendation 2)

Provide equity of care for all patients
All patients should have timely access to an appropriate range of diagnostic procedures, therapies and long-term follow-up care. Currently, the quality of care varies considerably among hospitals, and across regions and countries.
(Recommendation 3)

Improve end-of-life care
Effective approaches to palliative and end-of-life care, addressing emotional and physical well-being, need to be made an integral part of the care of patients with heart failure, both in hospital and in the community.
(Recommendation 7)

Promote acute heart failure prevention
Country-wide efforts to decrease risk factors for heart failure, including high blood pressure and coronary artery disease, should be intensified. Once heart failure develops, progression of the disease should be prevented or slowed by ensuring that appropriate evidence-based care is implemented promptly.
(Recommendation 8)

6. Recommendations for wider implementation

This report promotes eight policy recommendations (see page 9) based on the evidence presented in sections 2 to 5. Not only policy-makers, but also healthcare professionals, professional associations, organizations that fund healthcare, industry, the public, caregivers and patients themselves have a role to play in improving care in acute heart failure.

This section highlights opportunities for other stakeholders to implement changes that will benefit patients with acute heart failure, grouped under the heading of each policy recommendation.

1 Optimize care transitions

More effective coordination and communication between healthcare professionals would help to simplify the complex trajectories that patients follow through the healthcare system. Patient pathways vary according to the symptoms at presentation, the underlying disease processes, the suitability of particular short- and long-term treatments, and the presence of other medical conditions. Effective mechanisms should be put in place for sharing information between different specialties and centres to enable patients to be closely followed during hospitalization and after discharge.

Effective disease-management programmes should improve patient outcomes. They should include pre-discharge education, post-discharge treatment optimization and long-term patient monitoring, and should connect to outpatient services for chronic heart failure care, as well as taking account of coexisting illnesses. Use of such disease-management programmes should be audited to improve compliance with recommendations.

Clear information for patients and caregivers about the organization and provision of care should be available to help them to navigate the healthcare system.

2 Improve patient education and support

Active involvement of patients with heart failure and their caregivers in the management of the disease should be encouraged. Engagement in the daily monitoring of their condition will enable patients to recognize changes in signs and symptoms and to respond appropriately (e.g. by increasing medication dose or seeking medical attention as needed).

Teaching of self-care behaviours, such as symptom monitoring, treatment adherence and regular exercise, is important for patients' long-term health. Family members should also be able to recognize and act on changes in symptoms.

Good communication between healthcare professionals and patients should include discussions to identify treatment goals and the needs and concerns of the patient and their family and/or caregivers. Where possible, patients should have an identified individual they can contact.

Increased research and development is needed to determine the most effective approaches to potentially helpful new technologies, such as telemonitoring.

3 Provide equity of care for all patients

Management protocols need to be in place so that best practice is followed across all centres, ensuring high-quality care for all, irrespective of age or economic status.

Appropriate diagnostic procedures, including echocardiography and blood biomarker tests, should be available to all patients, and not just in hospital.

More flexible care options, better tailored to patient needs, would help to increase the range of management strategies available for patients with acute heart failure – many of whom are admitted to hospital in the absence of other suitable alternatives.

4 Appoint experts to lead heart failure care across disciplines

Advocacy by healthcare professionals with expertise in heart failure is required to make sure that excellent care becomes the norm across hospitals, and education is needed so that patients and public can recognize 'good care'.

5 Stimulate research into new therapies

Improved patient management and better targeting of existing treatments offer the promise of immediate benefit to patients. Ensuring that the best management strategies are in place will create the environment in which new treatments can have the most impact on patient outcomes.

6 Develop and implement better measures of care quality

Reassessment of reimbursement systems would remove perverse incentives that damage patient care. It is important to reduce preventable admissions for heart failure, but a financial penalty for 30-day readmission may discourage the appropriate in-hospital treatment of a patient during an acute episode.

Optimal distribution of healthcare resources would help to ensure adequate provision for an increased number of patients.

Quality-improvement programmes and improved performance measures would enable delivery of better care to patients. Effective and efficient alternatives to hospitalization (where appropriate) could provide more appropriate, cost-effective options for patients.

7 Improve end-of-life care

End-of-life care protocols should be in place to ensure that issues are raised by the healthcare team at the appropriate time, and that these involve family members and caregivers as well as the patient.

Suitable communication skills training should be given to healthcare professionals and other specialists, where appropriate.

8 Promote acute heart failure prevention

Education programmes for the general public should raise awareness of risk factors for heart failure, symptoms of the disease, and actions that can help to prevent it.

Education for healthcare professionals should extend to primary care physicians, nurses, pharmacists and ambulance staff.

More research is needed into the effects on heart failure prevention of treating other medical conditions that increase the risk of heart failure (or are underlying factors in its development).

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Glossary

Acute coronary syndrome	The general term for a group of conditions characterized by **myocardial infarction** and **unstable angina**, which arise from obstruction of blood flow to heart muscle
Acute illness	A brief worsening of a **chronic illness**, or a temporary illness
Acute myocardial infarction	Another name for a **heart attack**
Adherence	The extent to which a patient's behaviour – taking medications, and/or making lifestyle changes – corresponds with healthcare provider recommendations. Adherence requires patients' participation in taking responsibility for their healthcare
Angina	Chest pain or discomfort that occurs when heart muscle does not receive enough oxygen as a result of insufficient blood flow
Arrhythmia	A problem with the rate of the heartbeat (too fast or too slow) or its rhythm (irregular heartbeat)
Asymptomatic	Causing no symptoms
Atherosclerosis	Abnormal thickening and hardening of the artery wall as a result of accumulation of fatty deposits (plaque) in the vessel wall
Atria	The upper chambers of the heart
Atrial fibrillation	A heart rhythm abnormality that occurs when the **atria** tremble irregularly rather than beating regularly and effectively
Biomarker	A distinctive biological indicator of a particular process, condition or disease
Cardiomyopathy	Structural or functional disease of the heart muscle
Cardiovascular	Relating to the heart and blood vessels
Chronic illness	A long-term, continuous illness
Comorbidity	A disorder that coexists with another, such as **hypertension** or diabetes in an individual with heart failure
Compliance	The extent to which healthcare providers follow the published clinical guidelines
Decompensation	Failure of the heart to maintain adequate blood flow by adjusting output in response to demand
Diastole	Relaxation of the heart, during which the heart fills with blood
Diuretic	An agent that promotes urine production, increasing the excretion of water from the body

Dyspnoea	Breathlessness or difficulty in breathing
Echocardiography	An imaging technique that uses ultrasound to examine the structure and function of the heart
Ejection fraction	The proportion of blood in the **ventricles** at the end of filling (**diastole**) that is ejected during contraction (**systole**), expressed as a percentage
Electrocardiography	A technique for recording the electrical activity of the heart
Heart attack	Death of a section of heart tissue following interruption of its blood supply (also known as **myocardial infarction** or **acute myocardial infarction**)
Hyperlipidaemia	High levels of lipids (fat) in the blood
Hypertension	High blood pressure
Incidence	The number of new cases of a disease or condition in a population over a given period of time
Inotropic agent	A medication that affects the force of muscle contractions
Myocardial infarction	Another name for a **heart attack**
Myocardial ischaemia	Inadequate blood flow to the heart resulting from obstruction of the coronary arteries
Myocardium	The middle layer of the heart wall, consisting of cardiac muscle
Oedema	Abnormal accumulation of fluid in the tissues or body cavities
Orthopnoea	Breathlessness when lying flat, which is relieved by sitting or standing
Prevalence	The total number of cases of a disease or condition in a population
Pulmonary	Relating to the lungs
Pulmonary embolism	Obstruction of a **pulmonary** artery or one of its branches, usually by a blood clot, affecting blood flow to the lungs. Its signs and symptoms include difficulty breathing, chest pain and rapid heart rate
Renal	Relating to the kidney
Systole	Contraction of the heart
Telemonitoring	The remote monitoring of patients (usually in the home) by the healthcare provider, involving the collection of patient data (e.g. weight, blood pressure)
Unstable angina	A type of **angina** characterized by sudden changes in symptoms
Vasodilator	An agent that causes widening of the blood vessels
Ventricles	The lower chambers of the heart

Abbreviations

ACCF	American College of Cardiology Foundation
ADHERE	Acute Decompensated Heart Failure National Registry
AHA	American Heart Association
AMI	Acute myocardial infarction
BNP	B-type natriuretic peptide
CCS	Canadian Cardiovascular Society
CCU	Cardiac care unit
CHARM	Candesartan in Heart Failure – Assessment of Reduction in Mortality and Morbidity
COACH	Coordinating Study Evaluating Outcomes of Advising and Counselling in HF Patients
COPD	Chronic obstructive pulmonary disease
EAHFE	Epidemiology Acute Heart Failure Emergency
ECG	Electrocardiogram
EFFECT-HF	Enhanced Feedback for Effective Cardiac Treatment Heart Failure
EHFS	EuroHeart Failure Surveys
ESC	European Society of Cardiology
ESC-HF	European Society of Cardiology – Heart Failure
ETT	Endotracheal tube
FINN-AKVA	Finnish Acute Heart Failure Study
HF	Heart failure
HF-ACTION	Heart Failure: a Controlled Trial Investigating Outcomes of Exercise Training
HF-PEF	Heart failure with preserved ejection fraction
HF-REF	Heart failure with reduced ejection fraction
HFSA	Heart Failure Society of America
HOPE	Heart Outcomes Prevention Evaluation
HSCIC	Health and Social Care Information Centre
HYVET	Hypertension in the Very Elderly Trial
IABP	Intra-aortic balloon pump
I-CARE	Insuffisance Cardiaque: Éducation Thérapeutique
IN-HF	Italian Registry on Heart Failure
LV	Left ventricle

MAHLER	Medical Management of Chronic Heart Failure in Europe and its Related Costs
NDCHealth	National Data Corporation Health
NHDS	National Hospital Discharge Survey
NICOR	National Institute for Cardiovascular Outcomes Research
NHFA	National Heart Foundation of Australia
NIV	Non-invasive ventilation
NP	Natriuretic peptide
NT-proBNP	N-terminal pro B-type natriuretic peptide
OFICA	Observatoire Français de l'Insuffisance Cardiaque Aiguë
OPTIMIZE-HF	Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients with Heart Failure
PaO$_2$	Partial pressure of oxygen in arterial blood
SBP	Systolic blood pressure
SHAPE	Study of Heart Failure Awareness and Perception in Europe
SpO$_2$	Oxygen saturation of arterial blood measured by pulse oximetry
VA	Veterans Affairs

For millions of people throughout the world, acute heart failure is a life-threatening medical emergency, and it is one of the most common reasons for admission to hospital. One in ten patients with acute heart failure dies in hospital, and one in three dies within the year following an episode. Despite advances in long-term care, no new treatments for acute heart failure have emerged during the past two decades. Demands on services and the need for treatment will rise as the number of people with heart failure increases in our ageing populations.

This report presents the evidence base for eight policy recommendations aimed at improving care and preventing deaths of patients with acute heart failure. The report summarizes the evidence and consensus findings from structured discussions among the author group, comprising clinicians and researchers, an advanced practice nurse and the head of a patient action group, all with expertise and experience in the field of heart failure.

" Heart failure accounts for 1–3% of all hospital admissions in Europe and the USA "

" Most people do not recognize the symptoms of acute heart failure and do not regard them as serious "

" Socially and economically disadvantaged people, especially older women, have a heightened risk of heart failure "

" Many hospitals in Europe and the USA do not apply known best practice in heart failure care "