

THE PATIENT PERSPECTIVE ON HEART FAILURE

August 2017



Funded by:



This report was written by The Health Policy Partnership and funded by Novartis Pharma AG.

About The Health Policy Partnership

The Health Policy Partnership is a London-based consultancy with specialist expertise in the facilitation and support of multi-stakeholder platforms on given disease areas, and developing evidence-based engagement tools for policymakers. For further information please see: www.healthpolicypartnership.com

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CONTENTS

Introduction	3
1 Knowledge and understanding of HF	5
1.1 The role of patient information and education	6
1.2 Self-care for people with HF	8
2 Quality of life for people with HF	10
2.1 Impact of HF on quality of life	10
2.2 Assessing quality of life in patient care and research	15
3 Interactions with healthcare professionals	16
3.1 Providing a more supportive environment for people with HF	17
3.2 Multidisciplinary approaches to HF care	18
Conclusions and recommendations	19
References	21



INTRODUCTION

*Heart failure is the big unknown,
yet it is the condition of the future.*

Maite San Saturnino, Predidenta Cardioalianza, Spain

We know that people with heart failure (HF) have multiple readmissions to hospital, debilitating symptoms and poor prognosis. What is less known, however, is how people with HF experience and manage their condition in their day-to-day life.

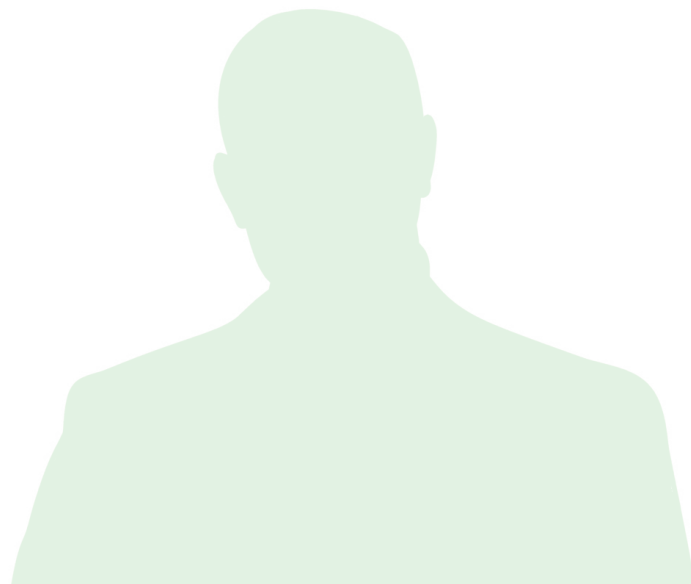
The patient advocacy presence on HF is limited, with only a few countries worldwide having well-established patient organisations or awareness campaigns. The lack of investment and attention given to HF in comparison with other diseases and conditions has led to low awareness and understanding of this chronic condition among the general public, healthcare professionals, patients and carers.

What's more, the term 'failure' implies that the heart is no longer working (it has failed) and, in the minds of many people, suggests a 'lost cause'. In other words, HF is often viewed as a condition which results from other diseases and comorbidities, not a condition in itself that is amenable to treatments.

Existing research on the patient perspective of HF is limited and patchy – and many untested assumptions are made about what we think is best for people with HF and what matters to them most – with little confirmation that these are meaningful or correct.

Furthermore, we know many different people can develop HF. It affects both men and women, people of all ages and from all backgrounds, and can manifest itself quite differently depending on those affected. All of these different situations, perspectives and clinical experiences need to be reflected in any meaningful interpretation of 'the patient view' on HF.

This is the focus for the **'Patient Voice' project**, which aims to develop a credible reference point on the patient perspective on HF, and to clarify the most important changes needed in policy and practice to help improve patient outcomes.



This report

This Research Synthesis report, funded by Novartis Pharma AG, is the first output from the Patient Voice project. From February–May 2016, The Health Policy Partnership conducted a comprehensive literature review on the patient perspective on HF. In addition, we interviewed leading patient representatives from the UK, Mexico, Egypt and Spain to complement and validate our findings from desk-research. These stakeholders were selected due to their links to iHHub (the international hub for patients with HF) and the existence of patient groups with a strong advocacy presence on HF in each country.

The report aims to provide an overview of the patient perspective on HF across three main areas:

- 1 Knowledge and understanding of HF**
- 2 Quality of life for people with HF**
- 3 Interactions with healthcare professionals.**

We see this project as being a truly collaborative effort with people living with HF, and our aim is to develop outputs that are reflective of their needs, and can be beneficial for HF patient organisations around the world.

We would like to thank the following patient experts for their valuable contributions to this report:

Nick Hartshorne-Evans,

Chief Executive (Founder), Pumping Marvellous Foundation, UK

Dr Mahmoud Hassanein,

Cardiologist, Founder of the Egyptian Association for Care of Heart Failure Patients, Egypt

Carlos Castro,

President of ALE/PACO, Mexico and President of iHHub,
The Global Heart Failure Alliance

Maite San Saturnino,

Presidenta Cardioalianza, Spain

Thank you

1 | KNOWLEDGE AND UNDERSTANDING OF HF

Unlike other conditions of the heart such as angina or heart attack, HF is largely unknown among patients and the general public. Very few countries have patient advocacy groups dedicated to HF, and public awareness of the signs and symptoms of HF is low worldwide.¹

This chapter focuses on people's knowledge of HF, with particular reference to the barriers to achieving self-care. It also examines the role of patient information and education in supporting self-care practices, and identifies unmet needs in different countries.

Key findings

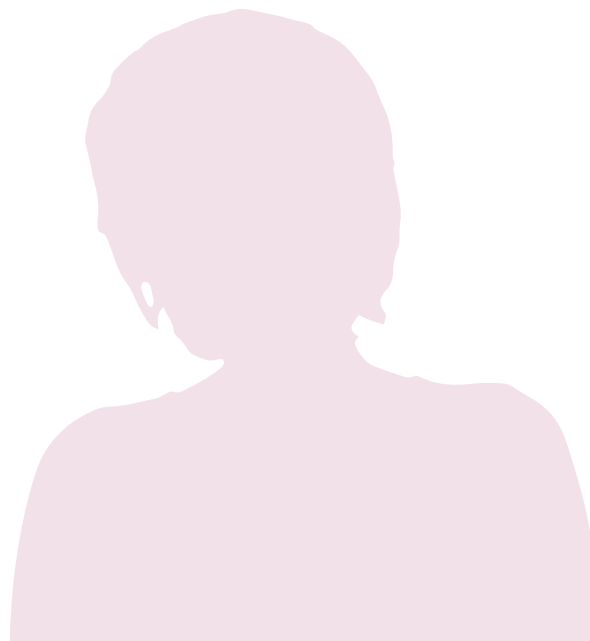


There is no gold-standard approach to the provision of HF information and education, and a variety of different methods are used worldwide.

Learning styles and preferences are unique to the individual, and many people with HF have unmet needs around self-care.

Effective self-care can lead to better outcomes for people with HF.

However there are many physical, emotional, environmental and social barriers to self-care.



1.1 The role of patient information and education

Patient information and education is recognised as paramount to the management of HF.^{2,3}

Guidelines recommend that all people with HF are offered education and advice about how to live with their condition and improve self-care.^{4,5}

People with HF receive information and education about their condition in a number of ways,⁶ depending on the availability of resources and the structure of healthcare systems. There is currently no 'gold-standard approach' to HF education – and outcomes for different interventions are hard to compare.

Examples of unmet education needs for people with HF

Country-specific challenges exist in the delivery of patient information and education.

From our interviews with patient association leaders, we gathered important insights into some of these challenges in their countries, which are described below.



Mexico

'Patients who are able to afford private healthcare in Mexico have access to HF patient education programmes and resources, but these services are critically under-resourced in the public healthcare system. As a result, the majority of the population does not have access to HF education, creating huge disparities in knowledge between different socioeconomic groups in Mexico.'

Carlos Castro, President of ALE/PACO, Mexico



UK

'Patients often feel as if they are not given enough information at the point of their diagnosis. This is the most important time for the patient and the healthcare professional in terms of setting the tone on how to self-care. Diagnosis is the "patient activation" point leading to collaborative engagement between the patient and the healthcare professional. Unfortunately, the vast majority of patients are left in the dark about what to do when they return home. Appropriate discharge planning and early identification of the patient's multidisciplinary care team is crucial to ensure patients feel supported to self-care.'

Nick Hartshorne-Evans, Chief Executive (Founder), Pumping Marvellous Foundation, UK



Egypt

'Patients are not well-informed about their condition in Egypt, and doctors do not have time to educate their patients about HF and how to self-care. From the patient's perspective, many people believe HF is simply a natural result of ageing and therefore do not seek treatment.'

Dr Mahmoud Hassanein, Cardiologist, Founder of the Egyptian Association for Care of Heart Failure Patients, Egypt



Spain

'We talk about the need for patient empowerment, but we shouldn't take it for granted that all patients are ready or able to feel empowered. Empowerment really depends on the readiness and desire of each individual to receive information.'

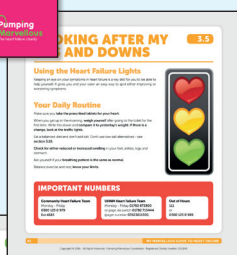
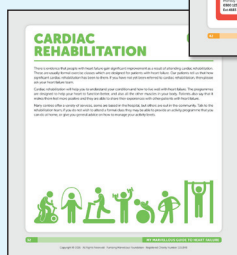
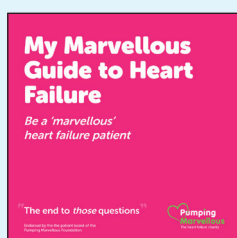
Maite San Saturnino, Predidenta Cardioalianza, Spain

Given patients' unique needs and preferences, it is paramount that educational interventions adopt a more person-centred approach – taking into consideration all the factors that can enable or inhibit learning for individuals and their carers.

From the patient's perspective, research has shown that educational materials are more effective when based upon an assessment of the individual's learning style and preferences prior to implementation.⁶ For example, some people with HF may have lower levels of health literacy or different learning styles to others. Also, people who are cognitively impaired may require a different approach.⁶

In addition, different people prefer different levels of information – while some may want to protect themselves from the burden of knowledge, by simply taking their medication and ignoring their symptoms⁷ others may want all the information given to them at once.⁸ The presentation of information is another consideration – some people may prefer printed materials compared to verbal information alone.⁶ People's needs also change over time depending on changes in their condition.

Example of best practice



'My Marvellous Guide to HF', by Pumping Marvellous Foundation, UK

Pumping Marvellous has produced *My Marvellous Guide to HF* – a printed resource created by patients, for patients. The guide is structured in a way that people can pick and choose the information they wish to read. It also provides answers to specific questions, which may not be covered by healthcare professionals, based around the day-to-day challenges that patients have to deal with and the psychological challenges they face.

The resource introduces the concept of the multidisciplinary care team to the patient and drives home the messages around the importance of the relationship between the patient and their healthcare professional, as well as the ability of the patient to shape their care. It is written in a 'patient friendly' way and, most importantly, covers information that matters most to people with HF.

<http://pumpingmarvellous.org/wp-content/uploads/2016/09/Full-Marvellous-Guide-to-Heart-Failure.pdf>



Patient information and education: policy recommendations

- ✓ **Continue efforts to raise awareness and understanding of HF** among the general public, healthcare professionals and individuals.
- ✓ **Invest in the development of free-of-charge and accessible patient information** and education to all people with HF.
- ✓ **Ensure patient education programmes not only focus on 'what' the patient needs to know but 'how' and 'when' they can apply learning** in the reality of their daily lives.
- ✓ **Work with patient groups and encourage greater collaboration between HF patients and healthcare professionals.**

1.2 Self-care for people with HF

Unfortunately, HF symptoms do not end once a person is diagnosed and, although treatment often begins in hospital, a large proportion of ongoing care takes place at home.¹⁰

Self-care is defined by the most recent clinical guidelines of the European Society of Cardiology (ESC) as 'actions aimed at maintaining physical stability, avoidance of behaviour that can worsen the condition, and detection of the early symptoms of deterioration.' Patients are encouraged to take an active role in understanding their condition. This means knowing what causes their symptoms or makes them worse and how to manage at times when they get worse.

While it is of the utmost importance that patients are adequately diagnosed and they follow advice and prescriptions from their physician, self-care has an important additional role to play.

Some patients may go long periods without contact with their physician and so self-care becomes an important part of managing their HF. Activating, engaging and empowering people with the knowledge and confidence to effectively self-care can give them greater control over their own health and allow them to adopt a positive mental attitude, which can lead to better health outcomes in the long-term. For instance, self-care for people with HF is thought to improve the performance of the heart and promote general wellbeing.¹⁰ It has also been shown to improve medication adherence, ensure timely use of health services, reduce hospital readmissions and lower mortality rates.¹⁰⁻¹²

Barriers to effective self-care for people with HF

Many people with HF find self-care and adopting an active role in managing their condition challenging, but the reasons remain unclear.¹³ It is often assumed that lack of knowledge of HF is the only barrier to effective self-care – however, people with HF often know what to do, but choose not to do it.

I thought I was doing myself good by cleansing my body and getting rid of anything in there (by drinking large quantities of water).⁷

A patient with HF

Evidence has shown that knowledge of HF does not always lead to behaviour change,⁷ and a range of other factors need to be considered. For example, physical limitations caused by HF symptoms (such as breathlessness, fatigue and coughing) can prevent people from maintaining an active lifestyle through taking regular exercise. This is particularly challenging for those with multiple comorbidities.⁷ A number of people also have misconceptions about how to self-care,^{7 14} due to not fully understanding the information that healthcare professionals provide. This may mean that they do not yet recognise that changes to their diet and lifestyle could support their health or that symptoms such as lack of appetite can be a part of HF.

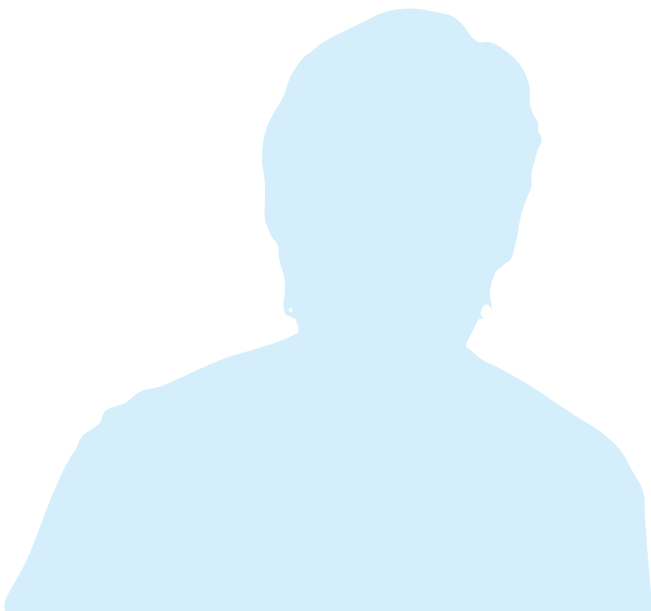
It is also common for personal struggles (such as financial hardship, difficult life situations, emotional issues etc.) to negatively impact on ability to self-care as people already perceive that they have little hope, and a lack of resources limits their opportunities to exercise or seek healthier food options. Managing weight and understanding that weight gain may be oedema is a key part of self-care, but some patients have reported being unable to afford scales.^{7,14}

Belief and engagement are crucial to self-care. There are currently negative associations with the term 'heart failure', and many patients feel as if they can't do anything to improve their situation. There needs to be a shift in attitudes among HF patients – they need to believe they have the power to self-care.

Nick Hartshorne Evans, Chief Executive (Founder),
Pumping Marvellous Foundation, UK

Furthermore, environmental factors can play a part^{12,14} – such as adverse weather conditions preventing exercise, and lack of healthy food options in the local area. Older people with reduced cognition may also fail to recognise and respond to changes in their symptoms.¹⁴

It is also evident that cultures and countries have distinct norms and practices that are likely to influence self-care.¹² A comparison of self-care behaviours across 15 countries found suboptimal self-care practices in all countries, with large differences in specific self-care activities between countries.¹² For example, exercise levels among people with HF were influenced by specific factors such as weather and cultural perceptions about exercises. The availability of resources and services was also shown to have an impact on self-care behaviours (e.g. access to cardiac rehabilitation programmes or specialised sports groups).¹²



2 | QUALITY OF LIFE FOR PEOPLE WITH HF

HF is a chronic lifelong condition, which has a significant impact on overall health and wellbeing. Symptoms of HF can cause significant disruption to people's lives on a physical level – which can, in turn, greatly impact on their quality of life.

This chapter focuses on quality of life for people with HF. It examines the physical, emotional and social consequences of life with HF, and discusses the importance of drawing on these unique experiences to improve patient care.

Key findings

A diagnosis of HF is life-changing – HF can have an enormous impact on quality of life and can impact individuals on both a physical and mental level.

Not enough consideration is given to the impact of HF on quality of life from the patient's perspective, such as how a particular person copes with their condition and treatment.

In recent years, attempts have been made to measure quality of life among people with HF – yet HF patients are often not involved in the development of these measures, raising many questions regarding their validity.

2.1 Impact of HF on quality of life

While the effects of HF on quality of life can be unique to the individual, a number of common themes have emerged in the qualitative literature, which highlight some of the emotional, social and physical consequences of living with HF. These are described below.

If I exert, I'm fighting for breath.¹³

A patient with HF

The debilitating nature of HF symptoms

Symptoms of HF vary for person to person, but are most likely to include shortness of breath, fatigue and swelling (e.g. legs, ankles and abdomen).¹⁵ There are also less commonly reported symptoms such as dizziness, loss of concentration, poor memory, pain, weakness and insomnia.^{7,16}

Symptoms of HF can cause substantial functional limitations,¹⁷⁻¹⁹ as well as being very distressing for people and their carers or family.¹³ For example, breathlessness and swelling can cause insomnia and may exacerbate other symptoms such as fatigue and anxiety.²⁰

In order to cope with physical limitations, some people with HF learn to adapt certain activities to make the most out of the situation,¹⁵ such as changing how tasks are undertaken, thinking through activities before doing them, restricting activities, being careful, and taking longer to perform tasks.¹⁷

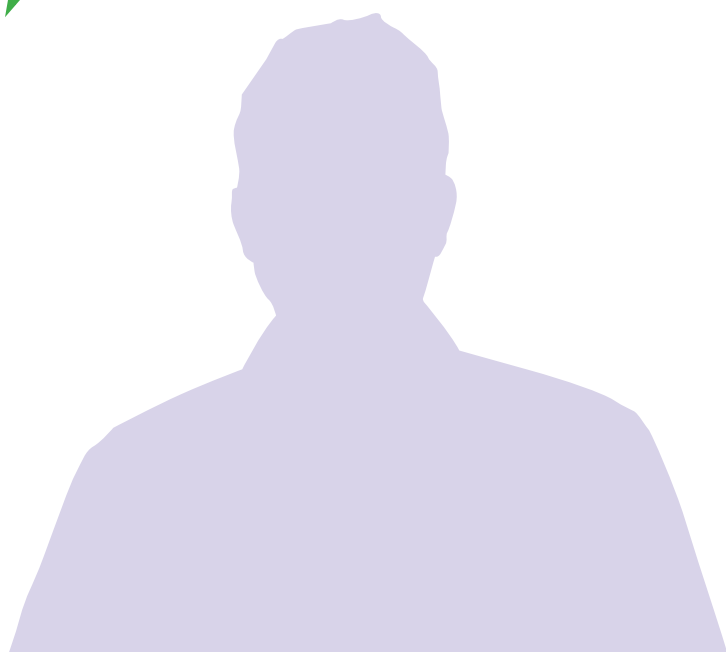
People have described how they have learnt to accept their losses and focus on the things they can do.^{15,21} Some people have learnt to achieve, what Lindsey (1997) calls 'health within illness' – i.e. living productive lives within their capabilities, which can lead to greater contentment and wellbeing.²¹

I cannot do a lot of the things that I used to do, but I try and find something to substitute it, not physical, but something to keep me mentally alert. I don't dwell. I try to find some other alternative like reading or talking to somebody about something completely unrelated.¹⁶

A patient with HF

I've been tired and exhausted for a long time... I'm worse now than I ever was with walking. I tried to walk up [to] the health centre Monday before last... it must have taken an hour and 15 minutes to get back home... it's only a 10 minute walk.²⁰

A patient with HF



Social isolation

Socialising with friends and family can be harder for people living with HF. An intense lack of energy, alongside other debilitating symptoms such as shortness of breath, can limit participation in social events and activities. Consequently some people experience a loss of social support and become disconnected from their community.^{17 19}

As well as various physical limitations, there are other reasons why people may not wish to participate in social activities, such as fears of being misunderstood or being let down by others.¹⁵ Family members and friends may not fully 'grasp' what it means to live with HF, due to poor understanding and knowledge of the condition. This can mean that people living with HF struggle to discuss their condition or ask for help from those close to them.

It is important to recognise that while some people withdraw from an active social life after they receive their diagnosis, others may feel more determined to maintain their social life despite their condition.¹⁷ Some people seek practical, psychological and emotional support from others close to them as a way of coping with their illness.^{13 15} In addition, forming social networks with other people living with HF can provide relief and comfort,¹⁵ and enhance individuals' knowledge and confidence to manage their HF.²²

Fear and uncertainty

People with HF are likely to face fears and uncertainty regarding their own future, their health, and their families' future.²¹ The fear of decline in health should not be underestimated, and can be particularly extreme for people who experience increased severity of HF symptoms.¹⁷ Acute episodes of HF, for example, can be very distressing – some people are unable to forget the event or are frightened it may happen again. This can relate to fears about an uncertain future, and not maintaining the lifestyle they were used to.²⁰

Patients have used the terms such as 'a roller coaster of life' and 'knocking on death's door' to describe living with HF.¹³

I just feel, you know, next week I might not be here... that's my initial sort of fear, you know, oh my God how much longer have I got?²⁰

A patient with HF

Sadness, anxiety and depression

HF can cause a range of debilitating symptoms leaving people with many negative emotions.¹³

Feelings of sadness, anxiety and stress – if very severe – can lead to depression, with many people experiencing depression over the course of their lives.

In addition, people with advanced HF (NYHA class III and IV) are likely to experience their condition differently than people with milder symptoms (NYHA class I and II). Reduced quality of life as the condition progresses can lead to feelings of loneliness, boredom, sadness and indifference, which may even increase a person's wish to die. This can be particularly true when pain and suffering dominate everyday life.⁸

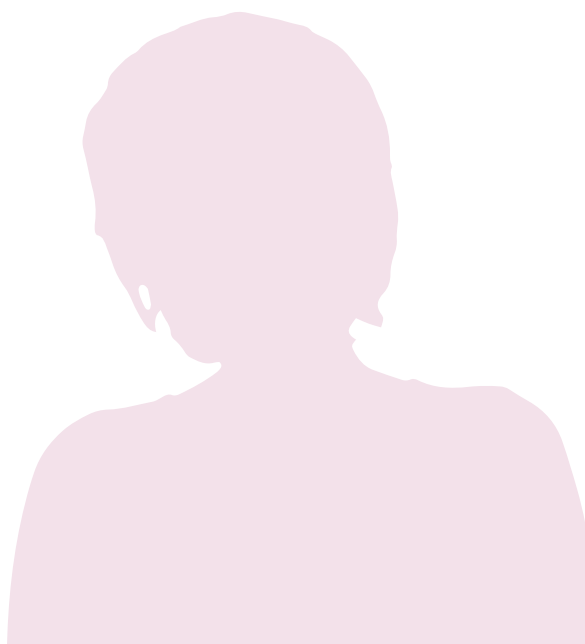
I'm not depressed... not really depressed... it's just a low feeling and it's not a happy feeling, and you just never feel your life's worth anything at times.¹

A patient with HF

Feelings of powerlessness and frustration

People living with HF may feel as if they have little influence or control over the outcome of their lives,¹⁹ which can lead to reduced self-confidence and increased levels of worthlessness.¹⁹ These feelings of powerlessness can impact on relationships and social life,^{13 15} and may even lead to a deterioration in physical health such as an increase in blood pressure, shortness of breath and sleeplessness.¹⁵

A number of different coping strategies are utilised by people living with HF to regain control, such as modifying their environment, setting realistic goals and expectations and increasing knowledge of the condition.¹⁹ Many people refuse to accept that they are powerless to influence what happens to them.²¹



Loss or changing of roles and responsibilities

Living with HF can reduce someone's independence and affect their psychosocial and economic capacity.¹⁵ Many people with HF have to rely on their relatives, carers or friends to help them to undertake tasks that they would have normally done on their own before their diagnosis.¹⁷ Research has shown that these changes are usually perceived as negative because of the dependence that people feel on others.^{17,20}

Some men have discussed specifically how the loss of abilities has impacted on their expected 'masculine' roles in the household, as well as loss of sexual intimacy.¹⁶

The loss of roles is worse for men, because that's the way you [men] were raised, you are the breadwinner, you are the one going out looking to do everything, and all of a sudden it's knocked out from under you and there is nothing you can do about it.

A patient with HF

These changes can also greatly impact family members and those closest to people living with HF, with carers reporting how their lives had changed since a diagnosis of HF for those they care for.²⁰

In addition, carers report having to give up work and feeling the strain of providing physical care, monitoring medication and managing symptoms, often with little rest for themselves.²⁰

I rung him [the doctor] again. I said, 'his condition is worsening, he's really poor.' I can't remember what he told me, ... yes he told me give him the heart spray, which I did, and then he start getting sick and then about... I think it were about 4 o'clock in the morning, I rung the doctor again and said, 'listen I don't want this responsibility, I just can't take it, cos the man is blue.'

Wife of patient aged 76²⁰

A disconnect between the body and the self

Some people with HF also experience a feeling of disconnect between the 'self' and the 'body', and have referred to this as 'feeling imprisoned in illness.'¹⁵ They have described how their 'disabled' bodies can restrict their ambitions, or the possibilities that life has to offer.¹³

2.2 Assessing quality of life in patient care and research

As discussed, **quality of life is influenced by a multitude of different physical, emotional and social factors, which are unique to the individual.**²³ Yet despite this, not enough consideration is given to these highly individualised experiences, such as how a particular person copes with their condition and treatment.²³ This has resulted in a narrow understanding of the impact HF can have on quality of life.

It is usual for researchers to rely on clinical parameters, such as mortality and hospitalisation rates, to measure outcomes for HF patients.²³⁻²⁵ **Yet from the patient's perspective, quality-of-life-related parameters (such as functional capacity and psychological status) can be just as significant.** For instance, physicians may think that patients are more concerned with length of life, but in circumstances where no cure is available, patients may prefer an improvement in their quality of life for the time they have left, even if this does not improve survival.²³

In recent years, there has been an increase in specific quality of life outcome measures used in HF management.²³ These measures are often derived from medical experts rather than the patients themselves, which raises many questions regarding their validity from the patient perspective.^{17 23} Qualitative research has shown that some topics are left out of health-related quality of life measures, including themes related to changes in relationships/roles, maintaining social connections and pain severity.^{17 26}

Example of best practice



The International Consortium for Health Outcomes Measurement (ICHOM)

ICHOM was established in partnership with Novartis. Its aim is to create patient-reported outcome measures, based on what matters most to patients. Its goal is to develop 'Standard Sets' of outcomes across disease areas, which will be used by physicians to refer to when treating patients, and to help compare outcomes across different countries and cultures.

The organisation has produced Standard Set for HF, as well as a number of other conditions. By 2017, ICHOM aims to have published Standard Sets for more than 50% of the global disease burden.

ICHOM firstly researches and identifies existing outcome measures, and then considers the instruments that are most relevant to patients. This process is undertaken in close collaboration with patient representatives and leading clinicians from across the world.

For further information, please visit: www.ichom.org



Quality of life: policy recommendations

- ✓ **Invest in further research on the impact of HF on quality of life, from the patient's perspective.**
- ✓ **Ensure all stakeholders, including healthcare professionals, patient groups, patients and carers, understand the impact of HF on quality of life,** and how these experiences can differ vastly between individuals.
- ✓ **Ensure systems are in place to measure and track quality of life over time,** and use this information to inform decisions about HF treatment and care.
- ✓ **Use quality of life outcome measures that have been designed for patients by patients,** and ensure these tools are used alongside more conventional clinical measures.

3 | INTERACTIONS WITH HEALTHCARE PROFESSIONALS

Interactions and relationships between healthcare professionals and their patients can play an important role in shaping people's understanding of their condition and their ability and willingness to engage in their care.

This chapter discusses people's experiences with their healthcare professionals and some of the challenges they may face in these relationships. It also offers potential solutions for more supportive and collaborative interactions between patients and healthcare professionals.

Key findings

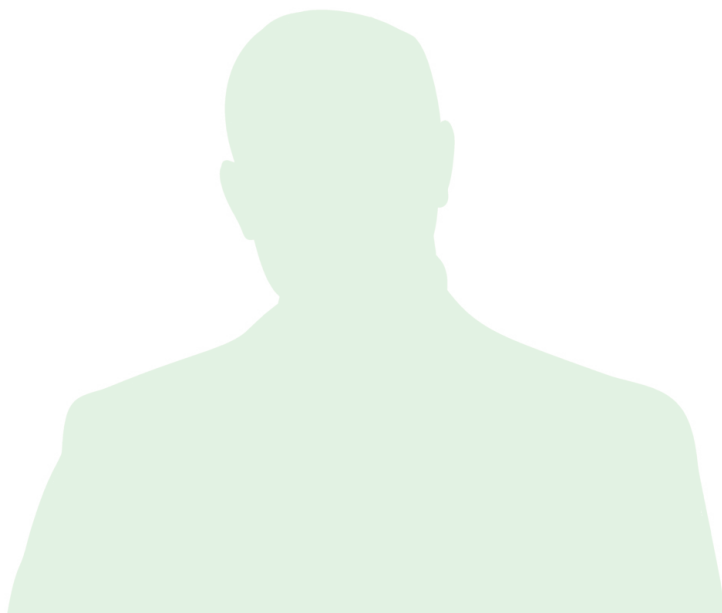


Many people with HF feel unsatisfied with their interactions with healthcare professionals – due to time constraints, difficulty in obtaining information and perceived lack of empathy.

The challenge for busy healthcare professionals is to adopt a more hands-on and person-centred approach in the management of HF.

Multidisciplinary care teams, involving a wide range of stakeholders, have been shown to be effective in the management of HF patients – by delivering comprehensive and coordinated care.

HF specialist nurses can play a key role within the multidisciplinary care team – and many patients feel HF nurses provide them invaluable support.



3.1 Providing a more supportive environment for people with HF

Many people with HF feel unsatisfied with their interactions with healthcare professionals.⁸

Research has shown that some people feel that they do not have enough time with their doctors, or do not receive sufficient information from healthcare professionals about their diagnosis and condition, which can affect their confidence in care providers.¹⁵ In addition, people may feel they do not want to waste the doctor's time by asking questions, and therefore leave the consultation without adequate information.²⁷

The way in which a diagnosis of HF is communicated can have a significant impact on people's ability to adopt a positive attitude and take responsibility for their self-care. If the news of a diagnosis of HF is delivered poorly, for example, it may adversely affect the person and their family for years to come.²⁷

What is important is the way we tell people about their diagnosis, and the information we give them at that point. Healthcare professionals need to learn to be the patient's coach and supporter, where possible. A good coach always validates understanding. However, we should not underestimate that many do not want to be coached or engaged in their care. We are looking for the tipping point where patients learn and see the benefits of self-care by their peers.

Nick Hartshorne-Evans, Chief Executive (Founder), Pumping Marvellous Foundation, UK

Some healthcare professionals may not have adequate knowledge and skills to be able to effectively diagnose, treat and manage HF.²⁸ For example, some GPs in community settings may not be trained on how to best support their patients in monitoring their condition and responding to condition-related changes.⁸

Misdiagnosis is a major problem for people with HF – doctors don't recognise the symptoms therefore they misdiagnose, and patients don't know which questions to ask.

Maite San Saturnino, Predidenta Cardioalianza, Spain

The challenge for busy healthcare professionals is to adopt a more hands-on and person-centred approach, so that patients feel confident in their ability to self-care despite their personal obstacles. Equally, it is important to recognise that people with HF and their carers should also try to communicate their needs to their clinicians as clearly as possible and take responsibility for their health, as this is likely to improve outcomes in the long term.

3.2 Multidisciplinary approaches to HF care

An approach that has been shown to be effective in improving the management of HF is the development of multidisciplinary care teams, consisting of a range of stakeholders working together to deliver comprehensive and coordinated care – with patients and their families at the centre. Effective multidisciplinary care teams should involve a range of stakeholders, including healthcare professionals (GPs, cardiologists, nurses, pharmacists, physiotherapists, psychologists, dieticians etc.),²⁹ as well as patient groups and non-profit organisations. The composition of the team can also change to reflect the changing needs of the patient over time.

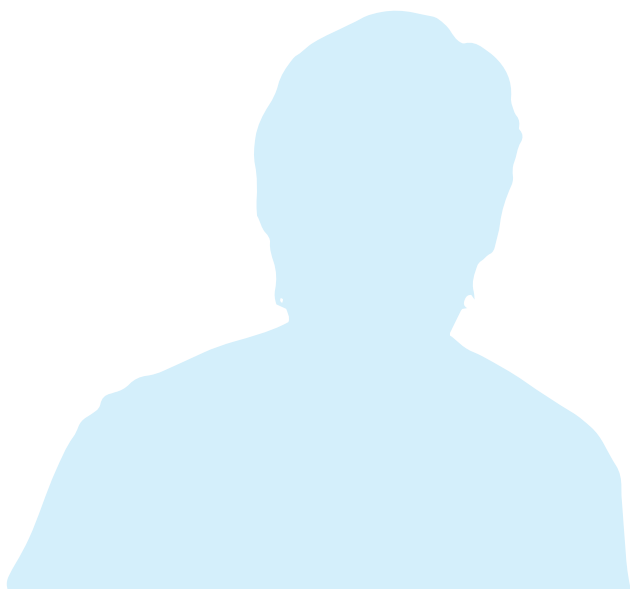
HF specialist nurses can play a key role in the multidisciplinary team, acting as a primary contact for patients and offering continuity of care across community and hospital settings. Nurses can also play a vital role in helping relatives to become more aware of what to expect in the future and how to prepare themselves.¹⁹

Research suggests that people with HF often feel specialist nurses are better equipped to inform them of the nature and prognosis of their condition rather than clinicians. Patients speak of being more at ease with specialist nurses as they have more time to discuss and ask questions than with a hospital doctor or their GP.²⁷



Support from healthcare professionals: policy recommendations

- ✓ **Ensure all patients, regardless of where they are treated, have access to multidisciplinary care teams** for the management of their HF. These should involve a wide range of stakeholders including healthcare professionals, patient groups and non-profit organisations – with patients and their carers at the centre.
- ✓ **Implement person-centred approaches for the management of HF** – which support shared decision-making and empower individuals to manage their own health and care.
- ✓ **Invest in the development of HF specialist nursing roles** to provide greater coordination of care within multidisciplinary teams.



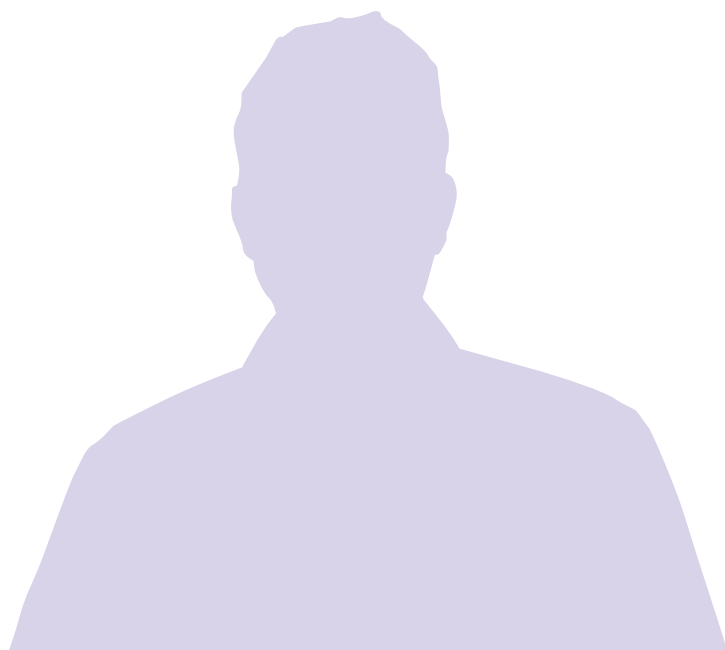
CONCLUSIONS AND RECOMMENDATIONS

A diagnosis of HF is life-changing and can affect every aspect of an individual's life.

However, there is very poor awareness and understanding of HF as a condition. This can mean that the unique experiences of people with HF are often forgotten or misunderstood, resulting in a number of unmet healthcare and education needs among people with HF.

No two people living with HF are the same. The impact of HF on quality of life, and the ability to cope, is unique to the individual and is influenced by a range of factors, including personality, age, gender, socioeconomic situation, health status, and social networks. People with HF face specific challenges in learning to accept a diagnosis of HF, living with their condition day-to-day, and developing a positive attitude towards self-care.

It is vital that we actively engage and activate HF patients, their families and carers to develop the most appropriate information materials, policies and models of care. This is essential if we are to improve the quality of healthcare from the patient's perspective and ensure services are responsive to the needs of people living with HF.



CONCLUSIONS AND RECOMMENDATIONS



Key policy recommendations – a summary



1 APPROPRIATE PATIENT INFORMATION AND EDUCATION

Invest in the development of **free-of-charge** and **accessible** patient information and education to all people with HF, which not only focuses on *what* the patient needs to know but *how* and *when* they can apply learning into the reality of their daily lives.



2 GREATER UNDERSTANDING OF THE TRUE IMPACT OF HF ON QUALITY OF LIFE

Invest in **further research** on the impact of HF on quality of life, from the patient's perspective, to inform treatment and care decisions. Use **quality of life outcome measures** that have been developed for patients by patients.



3 SUPPORT FROM MULTIDISCIPLINARY CARE TEAMS

Ensure all patients, regardless of where they are treated, have access to specialist-led **multidisciplinary care teams** for the management of their HF. Invest in HF **specialist nursing** roles to provide continuous support and coordination of care for patients.



4 MEETING THE INDIVIDUAL NEEDS OF PEOPLE WITH HF

Ensure the implementation of **person-centred approaches** for the management of HF, which support shared decision-making and empower individuals to manage their own health and care.



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