Impact of living in the community with heart failure

Research · March 2017

2 authors:

Sally Doherty
Royal College of Surgeons in Ireland
39 PUBLICATIONS **696** CITATIONS
SEE PROFILE

Maureen D'Eath
National University of Ireland, Galway
30 PUBLICATIONS **474** CITATIONS
SEE PROFILE

Impact of living in the community with heart failure

Experiences of heart failure patients, their families and allied healthcare providers

2016

Report prepared for the Irish Heart Foundation by the Department of Psychology, Division of Population and Health Sciences, Royal College of Surgeons in Ireland

IRISH HEART FOUNDATION
Fighting Heart Disease & Stroke

RCSI

Supported by
NOVARTIS

Impact of living in the community with heart failure

Experiences of heart failure patients, their families and allied healthcare providers

2016

"I'm like somebody in slow motion. … I seem to have gone from being a young person to an old person overnight because of it …"

(Patient 9)

"No pain involved in this, but it's like your entire being is being sucked out of you. It's like your soul is leaving you".

(Patient 10)

The Irish Heart Foundation is the national charity fighting heart disease and stroke. We support, educate and train people to save lives, campaign for patients, promote positive health strategies, support research and provide vital public information. We need your support – through donations, as a volunteer or on our training courses.

www.irishheart.ie

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

We would like to thank and acknowledge the support of all the people who shared their stories to allow us to have a unique insight into their world. We hope we have done justice to their experience and that this report will make a difference to their lives and the lives of many others with heart failure.

We would like to thank the heart failure nurses and the consultants who provided initial insight and support for the study in each of the hospital regions surveyed. Thank you for your time and patience. Thanks also to the many healthcare professionals who completed questionnaires.

Thanks to our steering committee members: Professor Anne Hickey, Associate Professor Karen Morgan and Professor Ken McDonald.

Special thanks to Colette Clyne, research assistant.

Finally we acknowledge the support and assistance of the Irish Heart Foundation and Novartis for the funding, support and opportunity to conduct this study.

Dr Sally Doherty,
(SD) RCSI Dublin sallydoherty@rcsi.ie

Maureen D’Eath,
(MD) RCSI Dublin

2016

FOREWORD

This study, examining the experiences of people with heart failure in the community, paints a stark picture of a growing community of often unsupported heart failure sufferers trying hard to cope with inadequate services, barriers to proper care, a dearth of community supports and particularly psychological support. And yet, it also shows that people living with the condition are stoic and highly motivated to maximise their health and quality of life.

It is noteworthy how patients with access to a heart failure unit are coping better with the condition and are more confident about what the future holds. Their testimony shows this is due in no small part to the constant access they enjoy to information and advice from heart failure nurses. They also have the benefit of the near-halving of rehospitalisation rates due to the effectiveness of these units.

However, the research shows there is a strong feeling among many heart failure patients that they are on their own following discharge from hospital, which is exacerbated by the absence of public awareness and virtually any public, media, or policy discourse on heart failure. This is in spite of the fact that 90,000 people are living with the condition in Ireland.

The Irish Heart Foundation has direct experience of the corrosive effect of this sense of invisibility among patients and professionals – and how to combat it – through our work in stroke, particularly how we used awareness-raising of the condition to build a community powerful enough to assert its case for fairer allocation of healthcare resources. In addition, the research clearly identifies the need to increase heart failure education and support for primary care teams. This will not only increase the expertise available to help patients remain healthy and at home, but reduce the rate of unnecessary rehospitalisation.

Given the demands on the health service, there is no easy path to securing the major investment in services needed to improve the management of heart failure. However, a lot of the assistance required by people living with the condition in the community identified in this report is neither unduly costly, nor difficult to deliver. On foot of the evidence provided in this report by people living with heart failure, their carers and health professionals, the Irish Heart Foundation has resolved to place a major emphasis on supporting heart failure patients.

On behalf of the Irish Heart Foundation, I would like to thank everyone who participated in the study and Novartis for providing the funding for the project. Finally, and most particularly, I would like to commend the heart failure patients and their carers who gave so generously of their experiences and insights in this research so that supports can be developed for all those touched by heart failure into the future.

Dr Angie Brown
Medical Director, Irish Heart Foundation

EXECUTIVE SUMMARY AND KEY FINDINGS

The Irish National Cardiovascular Health Policy (2010-2019) identified that heart failure in Ireland could increase by 63% by 2019 creating a national concern for future healthcare burden. Research evidence suggests that heart failure patients, in common with other patients with chronic conditions, would prefer to live at home and to manage their condition in the community. Care in the community could improve quality of life and reduce use of costly hospital services. Exploring the experiences of people living with heart failure will allow for better community-based management planning and resourcing for optimized care in the future.

The objective of this research is to document the experiences of Irish patients living with heart failure and identify their needs and views on the provision of community-based services. We also explore the views of caregivers and allied healthcare professionals in order to optimise our understanding of the patient experience and inform future development for patient community-based services. This research advises on how best to serve patients in relation to support, information, education and advice.

The participants in this study were in the chronic, stable stage of their illness. The relative good health and positive outlook of the participants in this study gives a relevant, useful and interesting perspective to our understanding about living with heart failure in the community and how such patients and their families and caregivers can best be supported. Their lives were impacted by heart failure but they were determined and resolute that they could accommodate the negative impacts of their condition.

A literature review was conducted focusing on international community service provision and multidisciplinary models of care for heart failure management. This review informed our approach to conducting four separate studies with 190 participants. The initial study was conducted using semi-structured interviews to explore the views of sixteen heart failure patients in face-to-face interviews. Ninety-seven patients with heart failure and thirty-one of their caregivers, recruited from four regional hospitals, were also surveyed via postal questionnaires. Forty-six allied healthcare providers from both urban and rural locations in the Republic of Ireland, including GPs, nurses, pharmacists and hospice staff, returned questionnaires documenting their views of, knowledge of and barriers to caring for patients with heart failure.

The overarching conclusion from these studies is that heart failure patients with whom we spoke to reported good health and remained highly motivated and capable of managing their diagnosis within the community. The respondents in this report were a relatively ‘well treated’ population, most of whom had access to good heart failure services. Many patients do not have access to this level of care and therefore their needs may not be reflected in this report.

Caregivers did not perceive their role as burdensome, however they expressed a greater need for clear guidelines on support services, symptom recognition and what to do in an emergency. In addition, allied healthcare professionals identified a significant need for more community resources, referral systems and education for healthcare professionals.

KEY FINDINGS

Study one: Qualitative interviews

- Sixteen patients and two caregivers were interviewed.
- Patients with heart failure value timely diagnosis with regular follow-up, so as to build rapport and trusting relationships with healthcare staff.
- Patients felt their GPs and pharmacists were not part of their integrated care plan.
- Some patients reported some GPs had a lack of knowledge and awareness of heart failure symptoms.
- Information overload following a patient's initial diagnosis and the use of generic educational material was problematic.

Study two: Healthcare professionals

- A total of 46 healthcare providers returned questionnaires, 21 of whom were GPs, 18 nurses and 5 pharmacists and two hospice staff.
- GPs agreed there was a geographic disparity in equity of service provision for heart failure patients.
- Two-thirds of GPs reported that they would like to know more about clinical guidelines, while 27% were unsure about the New York Heart Association (NHYA) classification of heart failure.
- Half of the GPs surveyed indicated that they would like to know more about the association between depression and heart failure.
- GPs reported a sense of reluctance or felt unable to manage heart failure with the complexity of co-morbidities and the amount of time required supporting their patients, preferring to refer the patient back to hospital-based services.
- GPs perceived that some of their patients could manage their self-care better than others.
- Over half of all healthcare professionals surveyed reported that they would like to know more about where patients can access community health services.
- Two-thirds of allied health professionals indicated that accessing psychological support was a challenge.
- Pharmacists appear to be an unrecognised resource in the community for patients with heart failure.

Study three: Patient survey

- A total of 97 patients returned questionnaires.
- Patients were generally well in this survey, over half were classified as having heart failure NYHA stage II *(slight limitation of physical activity; comfortable at rest; ordinary physical activity results in fatigue, palpitation, dyspnoea (shortness of breath).*
- Many patients reported no major issues of self-care and management of their disease.
- Patients were satisfied with the cardiac care they received, with almost two-thirds attending a heart failure clinic.
- Some patients expressed feelings of vulnerability when treated in hospital Emergency Departments (EDs) by non-cardiac specialists. They perceived that such doctors lacked knowledge and expertise about the care of heart failure patients.

- Nine per cent of respondents reported a probable/definite anxiety disorder while 6% of patients indicated probable/definite depression levels.
- Patients with heart failure were at risk of social isolation; almost 30% reported being isolated or moderately isolated.
- Patients reported contacting their doctor or nurse in two situations in particular – if they gained weight, or if they experienced fatigue; these were the lowest rated self-care behaviours.
- Recognition of serious symptoms such as sudden weight gain or fatigue, which could lead to acute episodes, were problematic and hampered patients in decision-making of when to seek help.
- Eighty-four per cent of patients stated that they did not attend a support group, with half of patients stating a support group was not available in their area. Two-thirds of patients reported that a support group for people with heart failure would be helpful.

Study four: Caregiver survey

- Thirty-one caregivers returned questionnaires.
- Recognition of heart failure symptoms and when to seek help was identified as a problem for caregivers.
- Thirteen per cent of caregivers reported a probable/definite anxiety disorder.
- Overall, reflecting the patient sample, respondents reported experiencing low levels of caregiver burden.

RECOMMENDATIONS

Several recommendations are outlined below derived from the views of the participants and the literature. The majority of respondents in this study had mild to moderate heart failure and were attending a heart failure service and therefore may not fully represent a group of patients who are in the later stages of heart failure and who may have very different needs.

Patients

1. Deliver patient information at incremental stages to prevent overload. Ideally, deliver information in face-to-face meetings allowing patients the opportunity to allay any fears and seek clarification on medication and daily routines if required. Health literacy should be assessed as part of this process.
2. Patients need specific tailored information to enable them to recognise symptoms which may require alteration of their medication or to seek medical advice, such as *sudden* weight gain (when weighed on the same scales at the same time), dizziness, shortness of breath, and swelling of feet, ankles, legs or stomach. This specific information can aid in decision-making processes.
3. Greater awareness of available patient resources is required. Patients reported a need for information about everyday health behaviours with clearly identified goals or targets on how best to optimise their health in an easy to remember manner.
4. Nationwide support groups would be appreciated by both patients and caregivers to alleviate social isolation. Create public awareness for the services already being developed in Dublin South, Wicklow, North Wexford, Galway, etc. and extend support groups to increase their availability for the wider population.
5. Nationwide information meetings with expert speakers for patients, caregivers and health professionals were identified as an important resource to increase understanding and decrease social isolation. Though with the extension of support groups there may be less need for this resource.
6. Advocacy from patient organisations on behalf of patients for government support for lower medication costs would be welcomed.
7. The benefit of regular physical exercise for patients with heart failure is stressed within the international guidelines. Increasing access to appropriate facilities through partnerships and linkages with community resources would help to support patients to participate in such initiatives.
8. Anxiety and depression are often components of chronic illness and the uncertain trajectory of heart failure can increase psychological impacts on the patient. Referrals to appropriate mental health services are an important component of comprehensive heart failure management.
9. Palliative care options should be discussed openly by healthcare providers with patients and their families. This communication should be included in the patient's management programme.

Caregivers

1. Caregivers require specific educational information to (a) include recognition of potentially harmful symptoms (b) when and how to seek health professional advice and (c) how to recognise the potential side-effects of medications.
2. Caregivers require practical, everyday training in skills for heart failure management. Useful skills including preparation of healthy food and weight management, simple everyday safe exercise regimes and the importance of balancing this with rest periods.
3. Caregivers require training in first aid and cardiopulmonary resuscitation (CPR).
4. The development of resources such as carer support groups to alleviate the isolation which caregivers may experience and provision of education for both patients and caregivers on best evidence-based models of care is recommended.
5. Development of practical skills to aid in coping with living with a partner with heart failure and how to self-care for both their own physical and mental health, as well as that of the patient is recommended.

Healthcare professionals

1. Implementation of an integrated care plan with resources is required for GPs.
2. Education relating to heart failure symptoms and management should be made accessible to all non-cardiology healthcare staff with whom patients may come into contact, such as those in emergency departments and pharmacists, who are often the first point of contact for patients experiencing an acute episode.
3. GPs require support to develop specific resources to share the care of heart failure patients. The use of a patient log-book may aid in the consultation process and needs to be made readily available to all GPs.
4. Promotion of the role of the pharmacist in managing heart failure in the community is recommended.

Policy

1. The findings from this report demonstrate evidence of inequity of provision of services for heart failure patients in Ireland. While efforts have been made in some regions there remains a geographical disparity between those who are cared for through heart failure clinics and those who do not have access to such clinics. The fulfilment of the aims of the HSE's National Clinical Programme for Heart Failure should be expedited.
2. Heart failure patients are often on multiple medications which may have serious financial implications. As patients with a chronic disease, heart failure patients would be greatly financially assisted if provided with full medical cards as opposed to GP only cards.
3. Policymakers need to encourage research engagement to investigate the efficacy and efficiency of recent technological advances in heart failure management, aimed at improving quality of life and increasing survival rates. Such advances include virtual consultations and tele-monitoring technology.

Healthcare services

1. The Clinical Programme for Heart Failure sets out a vision for co-ordinated, multi-disciplinary and patient-focused disease management across the country. Primary care services should be part of an integrated services model, providing seamless care between hospital and community care. Patients interviewed for this study perceived that care and management is still hospital-based with the expertise firmly based in heart failure nurses and cardiologists. The aims of the Clinical Programme for Heart Failure should be expedited in this regard.
2. Self-care is important in the management of heart failure. However, such self-care is often a complex and involved process. Access to self-management programmes for all suitable patients and caregivers would be very beneficial in supporting patients and their families to confidently manage heart failure at home.
3. Patients who had attended cardiac rehabilitation valued it greatly. Expansion of cardiac rehabilitation services to be widely accessible and specifically inclusive of heart failure patients would serve to enhance patient's understanding of their condition and its management.
4. The gap between patients who have access to specialist heart failure services and those who do not needs to be bridged through the continued development of a widespread, structured and fully supported heart failure service. The recently developed virtual consultation service using web-conference technology, initiated and driven by the Heartbeat Trust and St Vincent's, could serve to help reduce inequity in access to health services. Such interventions have the capacity to reduce heart failure related hospitalisation and improve the quality of life of patients with heart failure.
5. A national database of heart failure patients would greatly enhance the capacity to identify need and to target specific resources.

Public awareness

1. Patients and caregivers perceived that the public are unaware of the impact of heart failure. In its 'call to action' the European Society of Cardiology recommends, *inter alia*, that policy makers at local, national and international levels should develop and implement public awareness campaigns about heart failure. These should define and explain heart failure in an accessible way, explaining how to recognise the symptoms of heart failure and what can be done to prevent it.
2. A national information and awareness campaign in Ireland could include media and social media initiatives, newsletters, and providing ongoing public talks from experts in health and wellbeing relevant to chronic disease and heart failure management.

GLOSSARY OF KEY TERMS

AHA	American Heart Association
ESC	European Society of Cardiology
IHF	Irish Heart Foundation
HSE	Health Service Executive
NICE	National Institute for Health and Care Excellence
NYHA	New York Heart Association
ED	Emergency Department
GP	General Practitioner
TILDA	The Irish Longitudinal Study on Ageing
COPD	Chronic Obstructive Pulmonary Disease

BACKGROUND

Heart failure is a serious cardiovascular illness; it is controllable but not curable and is often associated by the patient with normal signs of ageing. In recent years quality of life has improved for patients due to the availability and advances in heart failure therapies (1). Heart failure patients, in common with other patients with chronic conditions, would prefer to live at home and to manage their condition in the community.

The average age at diagnosis is 76 years-old. The overall prevalence rate of heart failure in Ireland is approximately 2% which equates to approximately 90,000 people with a five year mortality rate of 36% (2). One in five men and women will develop heart failure over their lifetime with prevalence rates increasing with age. Rates are expected to double by 2019 (3). Prevalence rates are increasing due to better management and prognosis of heart failure, better survival after myocardial infarction, improvement in management of hypertension and the fact that people are living longer. The cost of heart failure in Ireland is estimated to amount to €660 million each year with hospital related costs reaching 47% of the total direct cost of heart failure management (4).

The trajectory of heart failure is unpredictable with many patients requiring multiple hospital admissions (5). The current management of heart failure for Irish patients is somewhat reactive, like many health services they respond best to the needs of the acutely ill patient and are poorly suited to those with chronic illness such as heart failure. In Ireland, there is a need for a clearly defined national care strategy following diagnosis. Delayed diagnosis mainly due to difficulties for GPs in accessing diagnostic testing is estimated to lead to an increase of 23% in hospitalisation of patients with heart failure symptoms (1). Currently in Ireland there is a geographical disparity of structured care plans and a lack of continuity within primary care services (6).

However, there have been improvements in recent years with a focus on prevention and the establishment of screening and early interventions strategies (4). The National Cardiovascular Health Policy 2010-19 (3) recommends that heart failure care should be reoriented from mainly hospital care to structured, proactive care in GP and primary care, supported by specialist ambulatory services. The aim of this reorientation is to keep people out of hospital and to provide them with on-going care at home. According to this policy the shift from hospital to community care will require: early detection of heart failure in primary care, treatment in primary care by GPs with heart failure training; GP and patient access to specialist opinion with a seven day referral system; seven day cover by heart failure consultants; appointment of specialist heart failure nurses in community services; technological developments so that patients can be monitored remotely by hospitals; a multi-disciplinary approach to care with psychologists, nutritionists, physiotherapists and occupational therapists; and the development of agreed models of care based on national guidelines (3).

Irish heart health services operate within the framework of the Irish National Cardiovascular Health Policy 2010-2019, within which the potential impending epidemic of heart failure was acknowledged. In 2010, the Health Service Executive (HSE) established the Clinical Programme for Heart Failure to implement a co-ordinated, multi-disciplinary and patient focused disease management plan nationally. The HSE Service Plan 2011 provided €1.6 million for the provision of structured heart failure programmes in 12 acute hospitals by year end. The 2012 Service Plan reiterated the commitment to establish 12 programmes. It is believed that 10 programmes are currently operational. One of the stated underlying principles of this new model of care for Irish heart failure services was that heart failure is a chronic disease and not a terminal illness. As such, the aim of the care services would focus on *prevention* for those who do not have heart failure, *maintaining* the quality of life of those who do, and *minimising* the need for hospital intervention through structured and integrated care. The objectives of the programme include:

- Every patient with heart failure would be managed in a structured programme
- A reduction of recurrent hospital admissions by 1,000
- A reduction in the length of hospital stay for heart failure patients, saving 20,000 hospital days per year
- The implementation of a targeted heart failure prevention programme
- The programme also committed to work towards the development of a rapid access diagnostic service for new onset heart failure and the integration of care and support to place a new emphasis on care of heart failure patients in the community.

Research from St Vincent's University Hospital in Dublin indicated very positive results following the implementation of the heart failure programme. This programme demonstrated a reduction of repeat hospitalisations of more than 80% with direct care cost savings of over 700 euros per person treated over a care period of three months (2).

The central role of the primary care services was also recognised as part of the clinical care programme in achieving a community-based approach to care which would strive to keep heart failure patients out of hospital. It was envisaged that primary care services would be organised as part of an integrated services model, providing seamless care between hospital and community care. As part of the community based treatment and care of heart failure, the programme envisaged that adherence to treatment would be managed by the GP practice and the community pharmacist. In recent times, the North-South GP Specialist Care Initiative has been actively involved in improving the links between primary and secondary care (7).

A principle of the heart failure programme is that patients and their families are actively involved in the day-to-day management of heart failure. Heart failure, the programme states, should be seen as a shared responsibility between patients, their caregivers and healthcare professionals. Following on from this programme several initiatives and campaigns from the Heartbeat Trust (7) and Croí (8) have been implemented in recent times to help people identify symptoms and bring education and support to patients, and also to create much needed public awareness.

Based on the aims and objectives outlined below, this report documents an overview of the current literature on the best evidenced based information for patients with heart failure living in their community. We build on a previous Irish study carried out by Tully et al. (2009) commissioned by the Health Service Executive (HSE) reporting on the quality of life and quality of care for heart failure patients (5). The Tully et al. study called for the need for structured management care programmes and integrated primary and secondary services in order to improve education, early detection and reduce hospital admissions. Finally, they highlighted the need for an audit of heart failure patients hospitalised with heart failure. Since the Tully et al. study there has been service developments alongside a rise in the number of people in Ireland living with heart failure. Heart failure units have been established in some hospitals and a number of community and outreach initiatives have been developed. Some heart failure support groups have been set up supported, in the main, by patient organisations which have also developed patient and caregiver information materials. However, we do not know whether such developments have had an impact on those they are intended to benefit.

There is a further need for information on how best to plan for the future needs of patients with heart failure availing of community services at a national level. We know that care in the community could improve quality of life and also reduce the use of costly hospital services. What is not known is how heart failure patients are managing across the island of Ireland in terms of following structured programme initiatives, recommendations and guideline implementation (5, 9-11).

We report on findings from four studies we conducted with heart failure patients, their caregivers and allied healthcare professionals to investigate the perspectives and experiences of people living with heart failure in Irish communities, in order to influence health policy for better management of heart failure and to increase public awareness.

AIMS AND OBJECTIVES

There is a need to minimise the impact of heart failure through community health services and maximise patient quality of life. Therefore this report aims to:

1. Assess the needs of patients with heart failure, living their day-to-day lives in their communities with their families.
2. Inform how service providers can best serve the needs of those diagnosed with heart failure in relation to support, information, education and advice in the context of best practice to deliver important social, personal and health information services.
3. Inform public awareness campaigns of what it is like to live with a chronic condition such as heart failure.
4. Inform future healthcare policy makers of the specific needs of heart failure patients and their families.

Research questions

1. What are the views, knowledge and attitudes of health service providers (including nurses, general practitioners (GPs), pharmacists and hospice staff) of community services for heart failure patients and their families?
2. What are the patients' experiences of living in the community with heart failure?
3. What are the experiences of the caregivers of patients with heart failure?
4. What support can the Irish Heart Foundation (IHF) provide for people with heart failure?
5. What is required to increase public awareness and inform health policy?

Four research studies were conducted in order to meet the study objectives

1. Healthcare professionals including nurses, GPs, pharmacists and hospice staff were surveyed.
2. Qualitative interviews were conducted with patients and caregivers in a place of their choice.
3. A nationally representative group of patients with heart failure were surveyed.
4. A nationally representative group of caregivers were surveyed.

Main outcome

This report provides several recommendations extracted from the current literature review and the findings from the research studies we conducted with patients, caregivers and healthcare professionals in order to inform policymakers and service delivery to improve the lives of patients with heart failure.

DEFINITION OF HEART FAILURE

Heart failure can be a severely debilitating cardiovascular condition. The heart either does not pump enough blood out of the heart and /or there is impaired filling of the heart. This failure of relaxation and/or contraction prohibits the heart to meet all the needs of the body. Heart failure often develops after other conditions have damaged or weakened the heart (12). Risk factors usually include a combination of conditions such as; coronary artery disease due to atherosclerosis (build-up of fatty deposits); hypertension (high blood pressure); cardiomyopathy (muscle abnormality) that may be due to infection, alcohol abuse, and the toxic effect of some drugs used in chemotherapy; myocarditis (often due to inflammation of the heart muscle); congenital heart defects; heart arrhythmias (abnormal heart rhythms); valvular heart disease; and other chronic conditions, such as diabetes, HIV and lifestyle factors such as obesity and tobacco use (13, 14).

As a clinical syndrome heart failure may be described as acute, sub-acute or chronic (long term). Acute deterioration of the status in heart failure patients is referred to as 'decompensated' heart failure. Acute heart failure is rapid in onset and is a serious condition; chronic heart failure is a more persisting condition; while sub-acute is between acute and chronic and indicates a recent onset that was less rapid than acute. Acute decompensation is the major cause of hospital readmission for heart failure patients and a source of significant morbidity and mortality (15). People who are not known to have heart problems can develop acute heart failure. It can also occur in people with chronic heart failure if their worsening heart condition results in severe symptoms.

Patient symptoms typically include fatigue, ankle swelling, and/or breathlessness at rest or exercise, sudden weight gain from water retention and a persistent cough. Although these signs and symptoms may be due to heart failure, there are many other possible causes including life threatening heart and lung conditions.

Heart failure is not amenable to a single diagnostic test (16). The diagnosis of heart failure involves the patient's history, a physical history, laboratory testing including B-type natriuretic peptide (BNP) testing, chest x-ray and echocardiography (a heart scan which allows the doctor to see how the heart pumps and fills and is used in the diagnosis of heart failure). The ejection fraction (EF) can be measured with an echocardiogram or cardiac MRI. It is an assessment used to measure how well the heart pumps blood and is used to help classify heart failure and guide treatment. In a healthy heart the ejection fraction is 50 percent or higher, meaning that more than half of the blood that fills the ventricle is pumped out with each beat (13). Heart failure is manageable and treatment can relieve the symptoms and improve patient outcome (14).

Comorbidities are very common among heart failure patients and may complicate the diagnosis, management and care of heart failure. Such comorbidities include respiratory, liver, renal and cognitive dysfunction, anaemia, diabetes, arthritis and depression, and lead inevitably to polypharmacy (multiple medications) (17). Greenberg (2012) argues that attention to these conditions should be an important part of the management of heart failure given the impact they may have on the patient's outcomes (18). The European Society of Cardiology's guidelines for heart failure (14) support this contention and point out that whereas patients with heart disease tend to have a high level of comorbidities and chronic conditions, most treatment guidelines focus on treating the single condition of heart disease without any required modifications of regime or follow-up care.

CLASSIFICATION AND ASSESSMENT

The most commonly used classification of heart failure is the New York Heart Association (NYHA) classification, which is based on limitations during physical activity. It places patients in one of four categories ranging from class I to IV.

New York Heart Association (NYHA)

Class		New York Heart Association Classification
Class	I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnoea (shortness of breath).
Class	II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea.
Class	III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea.
Class	IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

These physical limitations may be considered alongside an objective assessment of cardiovascular disease summarized below:

Objective assessment of cardiovascular disease

Class	Objective Assessment
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

The next section of this report will explore the current literature on living with heart failure in the community. This literature indicated current knowledge and prevalent themes which were further explored in the four surveys conducted in this report.

CHAPTER ONE: LITERATURE REVIEW

Introduction

A broad review of the literature was conducted with a focus on the current state of knowledge relating to community provision of heart failure care. This is important in order to identify current themes and valid survey instruments to inform the methodological approach of this report. The literature search was conducted in 2016 with the following search engines: PubMed, EMBASE, Cochrane Library, PsychInfo EBSCO, CINAHL and SCOPUS. Grey literature reports and hand searches from relevant article reference sections were also used. Search terms included, heart failure, community, self-care management, patient, caregiver, general practitioner, nurse, and pharmacist.

A summary of the key themes identified in the literature are outlined below.

Prevalence

Unlike most other cardiovascular conditions, the prevalence of heart failure is increasing for reasons that include increased survival rates from acute cardiac events, inadequate treatment of risk factors such as diabetes and hypertension (18), increased longevity and improvements in care for people with cardiovascular disease. Up to one-third of heart failure patients may have had their condition precipitated by acute coronary syndrome (19) and Greenberg (2012) points out that, paradoxically, the improved survival of patients with chronic heart failure also adds to the increasing prevalence of this disease (18).

Heart failure is more prevalent among socially disadvantaged individuals (9). Jaarsma et al. (2013) estimate a prevalence in the extended European area of over 15 million people, representing a significant challenge to health budgets and a growing burden on many health services (20). Much of this financial cost is due to repeated hospital readmission (11). Early hospital readmission of people with heart failure is extremely common (21). Cowie et al. (2014) cite European studies which report a rehospitalisation rate of 24% at 12 weeks and 44% at one year after discharge from hospital (9). The reduction of readmission rates is a focus of many interventions for people with heart failure, especially those which focus on care in the community within disease management programmes (12).

Heart failure carries a higher mortality rate than most cancers (22) and approximately half of patients die within 4-5 years following their diagnosis (23). However, a recent Irish study suggests a much more optimistic outlook for community dwelling patients with new onset heart failure cared for within a disease management programme. This study demonstrated that early diagnosis, appropriate investigations, application of effective therapies and self-care education was extremely beneficial and resulted in 64% survival of patients five years post diagnosis (2).

What is life like for a patient with heart failure?

Many patients with heart failure experience uncertainty and fear, social isolation and symptoms of depression and anxiety. The loss of a sense of control and poor quality of life are common, with many experiencing frequent hospital admissions (24). The symptoms of advanced heart failure are distressing and include breathlessness, pain and anxiety, nausea and vomiting (25). Although each heart failure patient may experience a different disease trajectory, the pattern is one of a gradual decline interspersed with episodes of acute deterioration (26). The uncertainty of the trajectory of the disease and the potential for sudden death may exacerbate patients' distress (27).

Fear, anxiety and depression are common psychological effects of the disease (9). Over one-third of patients with heart failure can experience severe and prolonged depressive illness (28). A 2006 meta-analysis indicated that heart failure patients with depression have a greater level of re-hospitalisation, clinical events and general care use (29). Heart failure patients with depression often experience a lack of social support and patients with low levels of social support have a higher level of re-admission to hospital, a lower level of adherence to treatment and is associated with increased mortality (15). Patients with heart failure experience a poorer quality of life (5, 26, 30) across all domains of quality of life measures (31, 32). Poor health-related quality of life is associated with higher frequency of hospital readmission (33). An Irish study identified that health-related quality of life measurement can be useful as a predictor of long-term mortality and morbidity in heart failure patients cared for in a disease management programme; younger patients (less than 65 years) with a low quality of life score were shown to be at a higher risk of an adverse outcome. However, in patients of 80 years and older, the health-related quality of life measurement was not useful in predicting outcomes (34). Improved quality of life is an important treatment goal for patients with heart failure (31). However improved quality of life, the relief of symptoms and increased functional capacity has not traditionally been the primary focus of research in this area (35).

How can patients with heart failure manage their condition?

Several aspects of managing heart failure are discussed in the literature focusing on self-care. This entails the maintenance, monitoring and management of physical, mental and social aspects of heart failure by the patient and their caregiver.

Self-care is defined as a naturalistic decision-making process involving choices in activities to maintain and promote physical health (maintenance) and purposeful actions taken in response to symptoms (monitoring) to restore health (management) (36). Effective self-care is espoused to be the cornerstone of management in heart failure; self-care optimises health, wellbeing and quality of life, and reduces both hospitalisation (37) and mortality (38, 39). The two most modifiable self-care factors which result in the re-hospitalisation of patients with heart failure are (a) non-adherence with diet and medication and (b) patient failure to respond to a change in symptoms (40).

A recent meta-analysis of 20 systematic reviews of Randomised Control Trials (RCTs) reported that the clinical effectiveness of heart failure self-management support interventions “provides a complex picture” (40, p vii). Pooled estimates indicated limited effect although, as the authors stated, studies had several methodological shortcomings, such as small sample sizes and short follow-up times for interventions. While some studies were effective, others were not. The authors called for routine evaluations of interventions to assess effectiveness and efficiency (41).

What is required to maintain and manage self-care?

The ‘maintenance’ aspect of self-care of heart failure requires the development of self-care skills and the adoption of lifestyle changes; these include managing and adhering to a medication regime, dietary changes including reducing salt intake, fluid intake management and engaging in a tailored exercise programme (42). Such a regime can prove very demanding on patients with heart failure and is often complicated by their older age, cognitive decline, polypharmacy (use of several medications) and low levels of social support (43). Self-care also encompasses the maintenance of social relationships (44).

The ‘management’ aspect of self-care involves patients being vigilant of symptoms (monitoring) that may indicate a worsening of the condition and acting appropriately, for instance, adjusting medication or seeking help from a health professional. Symptom monitoring may be particularly difficult for many patients; patients may struggle to distinguish symptoms of heart failure from those of other comorbid or less serious diseases (45). A study of 15 countries worldwide concluded that although self-care behaviours vary widely across countries, there is markedly poor adherence to most self-care behaviours regardless of country and although self-reported medication adherence was high, levels of exercise was consistently low (20).

What are the barriers to self-care and seeking help?

A patient’s capacity to self-care can be impacted by their cognitive status, their health literacy, their mental health and their self-efficacy or self-confidence and an inability to recognise and interpret symptoms (45). A meta-synthesis of barriers and facilitators to self-care in chronic heart failure reviewed twenty-three relevant qualitative studies (39). The range of barriers and facilitators identified were classified into three categories: (a) symptoms of chronic heart failure and self-care processes (b) factors related to personal characteristics and health and (c) caregiver factors. Barriers included: the atypical and puzzling symptoms of heart failure, the complexity of the self-care process, and the burden of co-morbidities.

Following a systematic review, Strachan et al. (2014) emphasised the importance of addressing contextual factors in any intervention which seeks to promote effective heart failure self-care. Such factors, they noted, included disease-related factors as well as physical, social and financial factors. They argue self-care interventions fail to acknowledge these factors and their interactions and continue to focus on the individual (44).

Jaarsma et al. (2014) identified that cultural factors, geographic and climate factors and financial factors such as being able to afford weighing scales, also impact on patients' self-care behaviours (46). A recent review identified the importance of tailored self-management interventions (37). Women may face particular difficulties with self-care as they are often older than men when diagnosed with heart failure, more likely to be widowed and/or have little social support (47).

Buck et al. (2015) explored heart failure patients' beliefs and behaviours of self-care and found that whereas diet, education and exercise were endorsed as self-care maintenance items by patients, equally important items such as fluid restriction, smoking cessation and preventative behaviours were less frequently reported. Only one of the 13 participants in the study identified that daily weighing was part of their self-care maintenance activities. However, patients did identify many activities as part of their self-care activities which are not included in any of the heart failure guidelines (48, 49).

A mismatch of understanding the barriers to self-care was highlighted in a 2009 qualitative study; GPs characterised the patients as non-participatory in self-care despite receiving what they considered to be 'easy' instructions. However, the patients considered that the regime of self-care was 'hard work'. This reflects a disconnection in the perceptions of the effort associated with self-care between patients and GPs. Patients identified that they knew what to do, but required assistance on how to do it; GPs believed that the patients did not understand the instructions that they had been given (50).

A recent systematic review exploring the effectiveness of randomised controlled interventions, which included education about self-care, concluded that while self-care improved, clinical symptoms did not. Jaarsma et al. (2014) also noted that, across geographic locations, advice on self-care behaviour tended to be very similar, while ideally it should be tailored to suit the individual's circumstances (45).

Following a qualitative systematic review seeking to understand the process of help-seeking among heart failure patients, Clark et al. (2012) identified some of the barriers to seeking help as confusing, ambiguous or disruptive, avoidance-based coping, fear of hospitals and a concern of being burdensome. They also report a lack of professional support to interpret the presence and significance of symptom changes (51).

The key facilitators of timely help-seeking were noted as trusting relationships and good communication between patients, caregivers and health professionals, and a sense of elevated risk (51). Sethares et al. (2015) note a commonality among several of the studies included in their review was patients' inability to recognise and interpret heart failure symptoms. They argue that regardless of the cause of the patient inability, this lack of interpretation should be recognised in educational strategies to support patients and their families. Social support is also key to patients seeking care (52). This difficulty in interpretation of symptoms is a common theme across the literature and is indicative of the complexity of heart failure.

In interviews with patients with end-stage heart failure, Lowey et al. (2014) identified fear of returning to the hospital as a key reason for delay in seeking help. Hospitals were associated with hassle and setbacks and patients feared losing their independence or their lives following another readmission. A study of 131, predominantly older, patients with heart failure concluded that three attitudes were statistically significant determinants of a long delay time in seeking help: (a) waiting to see if the symptoms would ease (a wait and see response) (b) a passive response (a don't worry response) to the symptoms and (c) living in a rural area. Thus, the authors argue, patient education will not by itself be effective in decreasing the delays in seeking help; instead efforts should be directed at enhancing the decision-making of patients and their family members (53).

Overcoming the barriers and maintaining self-care through education and skills training

Given the importance of self-care, enhancing patient and caregiver knowledge is essential to the maintenance of health and the quality of life of the person with heart failure. A delay in hospital treatment of as little as 4-6 hours following the onset of symptoms such as struggling to breathe increases the possibility of death (54).

The purpose of patient education is the improvement of knowledge and skills so as to influence attitudes and behaviours in order to maintain or improve health (55), improve quality of life and reduce hospital admissions (56). The importance of enhancing self-care skills rather than just improving a patient's knowledge of their disease has been emphasised (10). Patient education is classified as a highly recommended non-pharmacological treatment for heart failure and is characterised as essential to patient care (28).

While patient education is the most commonly included component of disease management programmes for heart failure (57), the heterogeneity of education programmes and the lack of a precise description and detail of the intervention process has restricted the development of evidence-based guidelines for the development of effective programmes. Albano (2014) compiled a list of 23 items, which the author proposes should be components of an 'ideal' therapeutic education programme for heart failure patients. These items were divided into four sections: (a) patient characteristics (b) competencies that the patients are expected to acquire (c) intervention modalities and (d) evaluation and outcomes measures. Considering these items against those reported in 19 published randomised controlled trials of education programmes, the authors concluded that although many of the major elements were present, most reports were missing important information about the patient's educational needs, health literacy, expectations regarding therapeutic patient education and psychosocial status, the educational methodology used, outcomes evaluation, and follow-up strategies (56). These missing elements have important implications for future educational interventions.

Boyde and Peters (2014) noted the importance of tailoring education strategies to the health literacy of individual patients and, likewise, Sperry, Luiz and Najjar (2015) emphasised the importance of health literacy as an indicator of a patient's ability to read, understand and manage their health care and recommend that patients with a low level of health literacy should be offered more intense educational programmes (15, 57).

Caregivers' role for patients with heart failure

Caregivers are often the key to the maintenance of the health and wellbeing of patients with heart failure and have been described as important partners in providing long-term care (58). The contribution of caregivers ranges widely from concrete activities such as weighing the patient with heart failure to providing interpersonal support to the patient (48). Dunbar et al. (2008) reported that caregivers of patients with heart failure tend to be older women who may have their own health difficulties (59).

Caregiving can have significant and frequently negative impacts on the family caregivers of patients with heart failure. Caregivers of patients with heart failure experience more psychosocial distress than caregivers of patients with other cardiovascular diseases (60). A systematic review and meta-analysis of caregivers' experiences of caring for a person with heart failure reported the importance of support for the caregiver in alleviating stress. Such support most frequently came from family, whereas professional support was consistently deemed to be inadequate, leaving the caregiver without adequate knowledge of skills to provide the care required. In addition, caregiving may have serious financial impacts on the caregiver (58).

A recent qualitative study categorised the expressed needs of caregivers into (a) assistance in supporting the management of heart failure (b) assistance in developing the skills which they need to become a caregiver to a patient with heart failure and (c) assistance in developing the skills to engage social support and voluntary and formal services (61). However, a review of randomised controlled trials indicated that only one-third of the included trials actually included caregivers in the interventions. This is despite such involvement previously being described as a 'critical' component of interventions (62). Future researchers should be mindful of this issue and ensure that key stakeholders, particularly caregivers, are included in studies.

Public awareness

Despite its prevalence, there is little public knowledge or awareness about heart failure and even patients who have experienced an episode of acute heart failure remain unable to recognise the warning symptoms of another episode (9). An Irish survey conducted in 2011 demonstrated that 93% of respondents said that they were aware of the term heart failure, yet 62% understood the term to mean a heart attack or that the heart stops beating (2). In 2014, the Heart Failure Patient Alliance advocated for public awareness campaigns focusing on the signs and symptoms of heart failure which it suggested had great potential to improve outcomes for patients and to save lives (54).

Allied healthcare professionals

Guidelines for the treatment and management of heart failure patients are available for clinicians and allied healthcare professionals. The American College of Cardiology Foundation (ACCF) and the American Heart Association (AHA) first produced guidelines for care in cardiovascular disease in 1980 (16). Ireland has endorsed the European Society of Cardiology guidelines (63).

There are a number of clinical practice guidelines for the diagnosis and treatment of heart failure including:

- American College of Cardiology Foundation/American Heart Association (AHA) Task Force on Practice Guidelines 2013 (16).
- European Society of Cardiology (ESC) guidelines for the diagnosis and treatment of acute and chronic heart failure 2012 & 2016 (14, 35).
- National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand 2011 (64).
- NICE guidelines 2016. Chronic heart failure in adults: management (65).

Treatment of heart failure aims to relieve symptoms and signs, prevent hospital admissions and improve survival. Treatment is through the use of medications, non-surgical devices, surgical devices and non-pharmacological or lifestyle modifications (35). Although some patients with heart failure benefit from implantable devices, treatment mostly comprises an often complicated regime of medication and lifestyle modifications (66). Cowie et al. (2014) noted that although the treatment options for patients with advanced heart failure have changed little over the last two decades, new treatments and therapeutic approaches to patients in the stable, chronic stages of the condition have shown considerable reductions in death and ill-health (9). Treatment and care plans need to employ a multidisciplinary approach involving cardiologists, GPs, nurses and pharmacists, who are competent and educated in heart failure management, and should target high-risk symptomatic patients. The ESC recommended components of care are outlined below (14, 35).

Table 1.1 *Characteristics and components of management programmes for patients with heart failure with reduced ejection fraction and heart failure with preserved ejection fraction*

1	Optimised medical and device management
2	Adequate patient education with special emphasis on adherence and self-care
3	Follow-up after discharge (regular clinic and/or home-based visits, possible telephone support or remote monitoring)
4	Increased access to healthcare (through in-person follow-up and by telephone contact possibly through remote monitoring)
5	Facilitated access to healthcare during episodes of decompensation
6	Assessment of (and appropriate intervention in response to) an unexplained increase in weight, nutritional status, functional status, quality of life, and laboratory findings
7	Access to advanced treatment options
8	Provision of psychological support to patients and family and/or caregivers

Multidisciplinary approach

Multidisciplinary care can be based in an inpatient or outpatient setting, in the patient's home or remotely using technology (67). The guidelines for the management of heart failure issued by the European Society of Cardiology identified that ensuring optimal management of heart failure patients 'from the beginning to the end of their healthcare journey (14, 35) involves a seamless system of care 'embracing both the community and hospital' (p. 1837). Such a seamless and optimal service requires close collaboration between hospital-based heart failure experts and other health professionals including pharmacists, dieticians, physiotherapists, psychologists, primary care providers, and social workers. Likewise, an Irish study (11) identified that models of shared care should be established to optimise care in the community. The Irish National Cardiovascular Policy recommended that capacity within primary care should be developed to provide proactive care in the community stating heart failure management requires an integrated community-based approach, led by primary care teams, with a focus on keeping affected people out of the hospital setting. Shared care for patients with moderate to severe heart failure has been described as more effective than care by either specialist physicians or primary health professionals alone (68).

In reality, the integration of care across different levels of service provision is rarely optimal and service is often characterised by discontinuity between primary and secondary care providers. However, Jaarsma and Luttik (2011) assert that although the structural involvement of primary care practitioners such as GPs and/or specialised community-based heart failure nurses in heart failure management programmes has been limited to date, it is important to continue to strengthen the role (69). The results of a recent multi-centre randomised controlled trial concluded that, while mortality and hospital re-admission rates were similar between randomised groups, there was a similar level of guideline adherence and patient adherence between patients with heart failure who are discharged to primary care for long-term follow-up compared to those treated through a specialised heart failure unit (70). Such results may provide an impetus towards the further development of primary-care based heart failure services as these are usually easier for patients to access and are less expensive for health services to provide.

Although the results of individual trials have been mixed, a systematic review of multi-disciplinary interventions for patients with heart failure concluded that such interventions within primary care are effective in reducing mortality and hospital admissions (71). Jaarsma et al. (2013) note that, while multidisciplinary management and follow-up are known to improve patient adherence, reduce re-admissions to hospital and improve survival rates, the optimal model of heart failure care has not yet reached a consensus (20).

Home-based care delivered by multidisciplinary team

Interventions delivered, at least partially, in the home have been identified as particularly effective in reducing re-admission to hospital (68, 71) although contrary evidence also exists about its impact on all-cause mortality and rates of hospitalisation (72). In a guide to home-based care, Jaarsma, Larson and Strömberg (2013) defined home care as care delivered for heart failure management to a patient with sessions in the patient's own home. A recent Cochrane Review update suggests that structured telephone support and non-invasive home tele-monitoring reduce the risk of all-cause mortality and heart failure-related hospitalisations (73). However, an exploration of the prevalence of home-based care in Europe concluded that very few heart failure management programmes included home care and that there was an unsatisfactory level of collaboration across the primary-secondary care interface (74).

Individual disciplines within the multidisciplinary team (MDT) frequently have different perspectives on home-based care for patients with heart failure, which are often overlooked as the MDT is viewed as a homogenous group. It is important to have an understanding of these different perspectives and involvement with patients. Thus, the literature was reviewed to examine differences for GPs, nurses, pharmacists and hospice providers in views on providing care in the community to patients with heart failure.

General practitioners

Recent qualitative UK research reported that GPs may not feel confident about the management of heart failure in the community, in particular with regard to medication initiation and titration, and struggle with the demands on their time that heart failure patients require (75). A 2013 meta-analysis of 35 studies exploring interventions used in multi-component outpatient heart failure management programs indicated that GPs had limited involvement in interventions designed to support heart failure patients, were rarely involved in the direct delivery of interventions and did not receive information about the progress of their patients who are involved in trials (62). A recent European study of the reasons why GPs do not adhere to clinical practice guidelines in the care of their patients with heart failure revealed barriers including lack of knowledge and poor communication and organisational skills on the part of some GPs. Patients' mind-set and their expectations were also identified as barriers and some GPs questioned the relevance of the clinical guidelines for their heart failure patients who were elderly and who may have many comorbidities (76). However, research into the advantages of a primary care based model of heart failure care concluded that patients' multi-morbidity and psychosocial issues can best be understood and coordinated by a GP within primary care, wherein patients will be treated by health professionals who are familiar to them and who will treat them in a holistic manner rather than as 'heart failure patients'. This large qualitative UK study also highlighted that even though there has been considerable investment in improving heart failure services, many of the same issues persist and continue to be reported over the past ten years (77). Conclusions from a 2015 Dutch study also conceded that there is still much to be done in the patient-GP interaction to successfully promote self-management abilities in heart failure patients (78). The findings from the literature with GPs suggest there are areas of improvement required in time management, timely diagnosis and confidence in delivery of care and communication.

Nurses

Nurses are an omnipresent professional group in the care and management of heart failure both in hospital and community-based services and nurses play a coordinating or leading role in many interventions (79). A meta-analysis of 35 randomised controlled trials with patients reported that 83% of these were delivered, primarily, by nurses many of whom were either advanced nurse practitioners or heart failure nurse specialists (62). Specialist nurse care has been demonstrated to improve patient outcomes, reduce mortality and hospital re-admissions (80-82). The European Society of Cardiology recommends the implementation of nurse led heart failure programmes. An analysis of a number of studies identified that the responsibilities of heart failure nurses includes:

- The provision of education about heart failure and about treatment options
- Facilitating self-care management by both the patient and the family and caregivers
- Providing access to clinics or telephone support
- The provision of social support to patients and carers (83).

Nurses play a key role in providing home-based care to patients (79). However, a recent review concluded that many were ill-prepared as existing care guidelines were focused on physician-provided activities, leading Radhakrishnan et al. (2012) to recommend the development of specific, relevant guidelines to support the work of nurses (84). A recent qualitative in-depth interview study conducted in the UK identified two particular challenges for nurses when working with heart failure patients as part of a multidisciplinary team - communication with patients in explaining their diagnosis and, secondly, communication with other members of the team in relation to managing comorbidities and drug regimens (85).

Pharmacists

The role of pharmacists in the management of heart failure has been explored in the literature. Cheng and Cooke-Ariel (2014) identified that the two major areas of responsibilities of pharmacists are medication reconciliation and patient education and characterised the role of the pharmacist within a multi-disciplinary heart failure team as ‘pivotal’ (86). Koshman et al. (2008) reviewed 12 randomised controlled trials of pharmacist-directed care or pharmacist collaborative care of patients in both inpatient and outpatient settings. The authors concluded that the involvement of pharmacists in the treatment of patients with heart failure greatly reduces the risk of all-cause mortality and hospitalisation and encouraged the inclusion of pharmacists in heart failure care teams (87). Molloy et al. (2012) included 16 randomised controlled trials in their systematic review of interventions to increase medication adherence among patients with heart failure and concluded that intensified patient care, particularly involving pharmacists, may be beneficial in this regard (88). However, a UK-based randomised controlled trial of an intervention comprising a drug review and symptom self-management and lifestyle advice concluded that it failed to achieve a reduction in hospital admissions (89).

Palliative care and hospice management

Palliative care is an approach that provides relief in the later stages of illness, in the form of physical, psychosocial and spiritual supports for patients and their families (90). Currently access to palliative services is prognosis-based which can mitigate against patients with heart failure, making them ineligible for palliative hospice care at the end of their life. A 2008 Irish Hospice Foundation report recommended that all patients who have a diagnosis of life-limiting disease should have equal access to all levels of palliative care, with appropriate management of their physical, psychological, social or spiritual symptoms (91).

However, patients with heart failure are less likely to receive timely palliative interventions than patients with cancer; the reasons for this include (a) the unpredictable trajectory of heart failure (b) the likelihood of sudden death (c) the reluctance of some physicians to discuss the poor prognosis associated with heart failure and (d) potentially the lack of heart failure specific beds in hospices. In the position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology, the authors suggest that although some patients may be reluctant to consider their own mortality, this should be addressed through a sensitive approach from a member of the heart failure team. Patients with heart failure often fear that they will suffer at the end of their lives and have concerns about the symptoms of heart failure including pain and dyspnoea (26). A UK study found that one-third of heart failure patients in their review had been registered with palliative services only one week before their death. Apart from depriving patients of the expertise of palliative care the authors of this study noted that it also deprived them of the opportunity to make end-of-life decisions (92).

Addressing the unmet needs of patients with heart failure for palliative care will require that clinicians be better equipped to assess and address these needs (93). A 2011 Irish study of cardiology staff (94) reported that:

- 97% have no qualification in palliative care
- 98% had not attended palliative care training in the last two years
- 94% were interested in attending palliative care education for heart failure patients
- 69% did not know the principles of palliative care

In 2015, an Irish action research project followed on from these findings to examine how palliative care could be extended to heart failure patients. This report (96) concluded that while there are a number of community based heart failure service models of care being established throughout Ireland, they do not have a palliative care component. This research is on-going and the next phase intends to develop programmes within the expanded chronic care model as a multidimensional solution to this complex problem (95, 96).

Summary of the themes from the literature review

The literature revealed various themes outlined below. Many are complex, conflicting issues with a lack of consensus on best evidenced based care. There is an agreement on the uncertain trajectory of the disease and the difficulty experienced by service providers to efficiently manage and serve their heart failure patients.

Table 1.2 *Common themes extracted from the literature reviewed*

Common themes extracted from literature	Summary findings
Prevalence	■ Increase in rates of heart failure due to better medical treatment and people living longer. ■ Heart failure prevalence rate is higher among socially disadvantaged. ■ Heart failure presents a significant challenge to health budgets.
Patient	
Living with heart failure in the community	■ Patients are in older age range groups. ■ Comorbidities are common and patients are on multiple treatment regimes. ■ Negative impact on quality of life related to both psychological and physical aspects of the condition. Common themes are - fear, depression, anxiety, social isolation, pain, nausea and general health decline. ■ There is a paucity of information for patients and service providers in relation to improving quality of life.
Managing the condition	■ Patients need knowledge, service provision, support and empowerment to manage heart failure. ■ Management includes self-care regimes such as diet, weight management and medication adherence and monitoring. ■ Complex attitudes to effectiveness of interventions depending on study and methodology.
Barriers in self-care management	■ Negative psychological, physical, social, cultural and financial implications impact ability to self-manage. ■ Patient and healthcare provider disconnect in relation to ability to self-manage. ■ There is an overall lack of resources, with geographical disparity of resource availability. ■ There appears to be a lack of awareness among patients to recognise symptoms and distinguish those requiring an emergency response.

Overcoming barriers to self-care	■ Education to improve knowledge, skills and attitudes to symptoms, maintenance and management. ■ Health literacy is an important consideration.
Caregiver	■ Typically caregivers are partners in the patients' long term care programme. ■ Distress is common. ■ There is a need for support and education.
Multidisciplinary approach to care	■ Several guidelines and treatment regimens are available. ■ Seamless approach required involving hospital-based heart failure experts and other health professionals including pharmacists, dieticians, physiotherapists, psychologists, primary care providers, and social workers. ■ Home-based interventions, tele-health and exercise regimes appear to be effective. There is limited robust research on efficacy of interventions.
General Practitioner (GP)	■ Role of GP in care of heart failure patients can be problematic in relation to time; time with patients and time to achieve accurate diagnosis. ■ Comorbidities and medication problems are recognised as being best dealt with by the GP in a holistic manner.
Nurse	■ Nurses can play an important lead role in coordinating multidisciplinary teams, following the patient from first hospitalisation through to home visits and telephone support.
Pharmacist	■ Role of the pharmacist is important to reduce hospitalisation but appears to be an under-utilised resource in the community.
Palliative care	■ Heart failure patients are less likely to avail of palliative care due to: (a) the unpredictable trajectory of heart failure (b) the likelihood of sudden death (c) the reluctance of some physicians to discuss the poor prognosis associated with heart failure and (d) potentially the lack of heart failure specific beds in hospices.
Public Awareness	■ Symptoms are not well recognised by the public. Heart failure patients reported difficulty recognising signs of an acute attack.

CONCLUSION

This literature review was conducted as a backdrop to inform the study about current best evidence and practice and recent developments in the care of heart failure patients. The key themes from the literature and, in particular, the Tully et al. (2009) study mentioned in the background section were taken into consideration when we came to devise the surveys with patients, caregivers and allied health care providers. A summary of the study methodology is outlined below and is described in more detail in each of the study chapters.

STUDY METHODOLOGY

Based on our research questions and a review of the most current literature, a mixed-methods approach was adopted for this research, including both qualitative and quantitative methodology. Ethical approval was granted by the Research Ethics Committees of RCSI, Dublin and four regional hospitals: Northwest (Letterkenny General Hospital), West (Galway University Hospital), South East (Waterford General Hospital) and Dublin (Mater Misericordia Hospital Dublin). A brief overview of the study methodology is outlined below and further described in each of the subsequent chapters describing the research findings.

Study one: Qualitative study with patients and caregivers

Two approaches were taken to gathering data from heart failure patients, firstly a qualitative interview with 16 patients and two caregivers.

A qualitative interview in line with the previous study conducted by Tully et al. (2009) was conducted with 16 patients and two caregivers in order to seek their personal experiences of living in the community with heart failure. Patients were recruited from the IHF database and patients from across Ireland were included. The findings from the interviews are reported in Chapter 2. Several key themes derived from the interviews were included in the main patient and caregiver postal questionnaires. (See appendix for all study documents.)

Study two: Healthcare providers

Forty-six healthcare professionals were sampled to maximise a geographical spread across the country. GPs and pharmacists were randomly selected from the Irish Medical Guide 2015. Nurses were selected from a database of heart failure nurses and cardiac rehabilitation nurses which was initially developed by the IHF and updated by the project researcher. The hospices were selected on the basis of geographical location.

Study three: Patient quantitative study

Postal questionnaires were returned by 97 patients. These patients were recruited through four national regional hospitals and the Irish Heart Foundation (IHF) database. We aimed to recruit approximately 30 patients from each hospital and the IHF, representing a total of 150 patients. Power analysis was based on TILDA 2011 (97) sample of 89 participants reporting heart failure. We achieved a 65% response rate in relation to our target number of 150.

Study four: Caregivers

Caregivers or family members were recruited through the patients. Patients who had consented to complete the questionnaire were also sent a caregiver pack containing a questionnaire in a separate envelope with all relevant study documents, which they were asked to give to a family member or caregiver. A total of 31 caregivers returned completed questionnaires.

CHAPTER TWO: QUALITATIVE PATIENT AND CAREGIVER INTERVIEWS

The interview schedules were developed from the wider heart failure literature, with a specific focus on including the components of the Tully et al. (2009) study. The current study sought to capture quality of life and quality of care in patients with heart failure living in the community. Questions derived from the literature related to self-care problems, poor symptom recognition and the importance of structured management programmes such as cardiac rehabilitation programmes (5).

The rationale for conducting a qualitative study was to document the views and experiences of people with heart failure and their caregivers about living in the community with heart failure, the supports which they receive and the supports which they think should be available. A semi-structured schedule guided the interviews. Schedules were used as a guide to the interviews but the interviews proceeded flexibly to focus on the issues that were most pertinent to each participant. The interview schedule was also designed to elicit information which would inform the follow-up study, a quantitative survey of heart failure patients and their caregivers.

Recruitment

Interviewees were recruited through the IHF. A letter of invitation, an information leaflet and consent forms were sent either by post or by email depending on the preference that the individuals had expressed to the IHF. Recipients returned the consent form to the researcher. A Freephone number was provided for any further information required. Participants who had indicated their willingness to be interviewed but had not returned a signed consent form prior to meeting the researcher did so at the interview.

One hundred and thirty-five people in the IHF database were informed about the interviews and invited to volunteer to participate, although not all would have had diagnosis of heart failure. Nineteen people responded to the invitation of which sixteen identified themselves as patients diagnosed with heart failure. All those who responded to the invitation were contacted by phone or by email and arrangements were made to meet with the 16 patients. Interviews were scheduled at a time and location chosen by the interviewees. Subsequent to the interviews, the researchers were contacted by a heart failure patient who had heard about the study and who was keen to contribute. This patient wrote two detailed accounts of his experiences of living with heart failure on one of Ireland's western islands and his account was included in the analysed data.

The interviewed patients came from a wide geographical spread, Limerick, Waterford, Meath, Dublin, Donegal and Kildare. Thirteen of the patients were men and three were women. Two caregivers also completed interviews, one male and one female. The age range of the patients was between 43 and 79, with ten of the patients aged less than 70 years old. Eight of the patients had received their diagnosis seven years or more ago; the length of time since diagnosis ranged between three and twelve years. Patients volunteering to participate in this study were a particularly young cohort of heart failure patients, who are typically in older age ranges (Bui et al. reported that 80% are 65 years or older (22)). There were more men than women among the interviewees. Although women make up about half of the heart failure patients in Europe and the USA (98, 99), they tend to be older and sicker than their male counterparts (100, 101). Co-morbidities are common in patients with heart failure. However, a minority identified that they had other common co-morbidities - eight participants reported that they had high blood pressure, four had diabetes, three had angina, two had COPD and two patients had also had a stroke.

Analysis of the qualitative data

The qualitative interviews were digitally recorded with the consent of the interviewees and the recordings were professionally transcribed. Transcripts were imported into the qualitative software package – NVIVO – which was used to manage the data. The analysis sought to produce a rich description of the experiences of the patients and a qualitative, descriptive design was employed. The initial reading of the transcripts, open coding and data collection took place concurrently to form an "integrated activity". The transcripts were re-read again before categories and themes were developed from the coded data. The descriptive content was then developed. Two researchers (MD and SD) were involved in this analysis to maximise the credibility and confirmability of the findings. Substantial quotes are included in the descriptive content to maximise the participants' voices in the data and to enhance the validity of the analysis.

Results

Heart failure: cause and diagnosis

Cause

For many patients it was clearly important that they understood the reason that they developed heart failure. Some were clear about the cause of their condition. Two patients developed heart failure following treatment for cancer; a few attributed it to their former lifestyle:

> *Well, with me I know the cause - the cause was smoking. I smoked all my life and I never gave it up and unfortunately that's what happened you know. (Patient 13)*

For a number of the interviewees, heart failure followed a heart attack and several patients discussed a strong family history of cardiac problems:

> *Everyone there, my mother was fifty six when she got a heart attack and I was fifty seven, you know. And my mother was one of eight and one of them got the pension. … One of them got to sixty. My mother died at sixty two. (Patient 6)*

Participants who could not attribute the development of their heart failure to any particular reason were more likely to be struggling to understand why they were suffering the condition. None of the participants were aware of heart failure as a condition before their own diagnosis or the diagnosis of their family member.

Diagnosis

Three interviewees were given the diagnosis of heart failure following treatment for myocardial infarction. However, a number of the interviewees considered that their diagnosis was delayed and/or importantly that their symptoms were not taken seriously by the doctors whose care they were under:

> *I had been very tired for three years. I was totally wrongly diagnosed. Okay, I was sweating, I had different things. I changed GPs, I done everything in the three years, nobody diagnosed it. So in the end, I was in the hospital. I said to him, 'I'm not going home, until you try and do something for me'. (Patient 6)*

Symptoms which the patient now recognise with the passage of time were over-looked by the medical profession and/or not given the urgency of response that the patients would have preferred:

> *Now, my doctor that I was seeing at the time, he missed the thing. And he has a big, this electro ECG apparatus in his surgery. And he never used it. He then made a routine appointment for me with the cardiac unit. Which would've been months away. I needed oxygen, I couldn't breathe properly. The only way I could breathe properly was to sit on the edge of something and lift myself like this to get a decent breath. Because there was so much bloating due to water intake, my body was retaining water, water retention. And so this was interfering with my organs, like my lungs. … and then I thought I'd hold out and I held out. And then I was extremely sick and my wife took me to ED. And they put me straight away into the cardiac unit. (Patient 7)*
>
> *I got very sick and I was in hospital for maybe three weeks. And in the local hospital they missed the diagnosis. I got so tired that I couldn't walk from here to twenty paces. So it must have been obvious to them. Yeah and the other thing they always ask about how many pillows you sleep on. That's it, the kind of standard question. I wasn't lying down at all. I was propped up in the bed which straight away should have been a signal something was wrong. (Patient 9)*

This patient wondered whether the outcome would have been different if the diagnosis had been made more promptly:

> *But I often wondered if it had been picked up at that stage, would it have made a difference? Maybe not. (Patient 9)*

Term: heart failure

A number of patients had no concerns about the term 'heart failure' and felt that things should be named as they are, or that it was an apt description:

> *…there is nothing wrong with calling it 'heart failure', I mean your heart has failed, my heart is damaged. So, you know, I think heart failure strikes me as being the more appropriate term because it is generic, there is a weakness in your heart, you know your heart has failed compared to most people. (Patient 3)*

Others, however, were strongly opposed to the term:

> *The minute they say 'failure', you just suddenly get... Failure's an awful word, isn't it? It's not a word we use. Or if somebody said you were a failure. It's the most horrid word you could use, isn't it like? (Patient 9)*

The word 'failure' was perceived as a doom-laden term in a medical context though one that it was possible to adjust to:

> *I wasn't happy about it, you know. I felt that heart failure meant that you could drop dead. Which I presume you could drop dead at any time. (Patient 17)*

Living with heart failure

The interviewees were a particularly young cohort of heart failure patients and many did not experience the co-morbidities that are so common among people with heart failure. So it may be unsurprising that some of the interviewees considered that having heart failure did not impact greatly on their lives; others, however, experienced a serious impact:

> *But, (hesitates), heart failure is a debilitating thing. (Patient 4)*

A patient gave a graphic description of a symptom that he experienced:

> *And it's a strange feeling you get. You would be just sitting there say for example just watching the television and there would be this ahhh…no pain involved in this, but it's like your entire being is being sucked out of you. It's like your soul is leaving you. (Patient 10)*

Some patients discussed the extent to which breathlessness was a constant feature of their lives, however, for most patients the main impacts of the condition stemmed from fatigue and lack of energy.

Patients described an insatiable need to sleep and an overwhelming tiredness. One patient spoke of how a complete deficit of energy has left her feeling old beyond her years:

> *I'm like somebody in slow motion. I seem to have gone from being a young person, to an old person overnight because of it. (Patient 9)*

Another likened living with heart failure to living without a 'reserve tank':

> *I don't have a reserve tank anymore. Once my body is exhausted, it stays exhausted… And this …it's the strange thing, tiredness accumulates. But rest doesn't. … [You have to] keep putting back and back. You make all your withdrawals to go into overdraft and then red lights. (Patient 7)*

The tiredness and lack of energy resulted in some participants giving up employment, reducing their work load or, in one case, selling a business. However, many of the interviewees continued to work – often out of financial necessity:

> *See, being self-employed I didn't get to have the luxury of simply… Look, if you're self-employed you say that stopping your work isn't an option. (Patient 7)*

Patients who had to give up work or reduce their work hours clearly suffered a financial consequence from developing heart failure. However the on-going costs of doctor visits and, more particularly, the cost of medications was cited as a concern for others. Patients queried why heart failure was not recognised as a chronic illness that would give them access to free medical care, arguing that it was not an illness for which there would be a cure.

Diuretics

For many of the interviewees, the diuretics, (medication to reduce fluid retention) are the most troublesome aspect of having heart failure and the aspect most likely to impact on their daily lives. The lack of predictability about the impact of the diuretics from one day to the next exacerbated the difficulty:

> *…it's most peculiar. Monday was a bad day. Monday, it must have been two o'clock before the madness went, if you want to call it that. Yesterday, there was no problem. Today, it's somewhere in between to the two of them. But Monday now was horrific.... I'd get my bum back in the chair, I was back up again. (Patient 8).*

Adapting to life on diuretics was described as a learning curve for some participants as they learned how to time both their activities and the taking of the medicine to minimise the impact on their day. Timely advice and support was identified as a key support to making this adjustment. One patient discussed being hospitalised twice with health crises because of not taking his diuretic before he was informed that he could choose the timing of taking it to fit in with his daily tasks. For another patient, the occasional loss of bladder control because of the urgency of the need to urinate was a matter of great distress:

> *... you become very aware of it and even though you clean around and wash, you have in your mind if you are talking to someone, you wonder if they can smell you. (Patient 17)*

This patient wondered about products that might help him but felt embarrassed and unable to ask for help:

> *... you wouldn't talk to a doctor about it, it's too embarrassing. (Patient 17)*

Attitude and outlook

Despite the impact of the condition, most of the participants were stoical. In many instances this is because they considered living with heart failure to be better than the alternative which, they identified, was death.

> *But ah no, I think you should, when you are lucky like me… I could have been dead. (Patient 15)*

Patients spoke of trying to keep perspective:

> *…oh like some days I'm there and I'm thinking "oh I have to take all these bloody tablets" you know, but then I try and rephrase it "well if I didn't have the tablets I'd be sitting here crying saying I wish there was a tablet I could take for this, and there is, and I'm taking it, so shut up, stop giving out!" (Patient 1)*

And of the importance of maintaining a positive and accepting attitude:

> *The fact that I'm alive, it means so much to me. … I didn't find it difficult, I accepted it. (Patient 5)*

Having a reason to keep going and push oneself was seen as a great help:

> *Well, some days it could be an effort, yeah, to get out of the bed, you know. But then I just say to myself "well I have to get out because I have to collect the kids" so that's an incentive in itself. (Patient 4)*

The positive attitude of many of the patients may reflect their optimistic outlook on their future:

> *I mean I will not get better in the sense that my heart won't recover, it's kind of where it is, is where it's at, but I can do everything I want to do, play golf and all of that. So, I don't look or think about it getting worse. (Patient 3)*

Some patients were heartened by substantial improvements in their ejection fraction (described earlier in the definition of heart failure section) but even patients with a small improvement or a deteriorating ejection fraction were optimistic about their future:

> *It has improved, now albeit minutely. You know, a half a percent or a one percent, but it was going the right direction, which is a great boost. (Patient 15)*

Caregivers

The impact for family members (not necessarily all of which are caregivers) of living with someone with heart failure can be significant. Family members may themselves have to adapt to the restricted diet of the heart failure patient, their social lives may be restricted, the family income may drop and they may live with a constant fear for the health of their loved one. For family members of older, more severely affected or co-morbid patients the responsibilities may be overwhelming:

> *And then I also had to supervise the scheduling of her medicines. She was on medicines three or four times a day, all kinds of medicines. I had to weigh her every morning. I had to check her food intake because she would tell me she had her food, but she wouldn't, you know. I had to order her incontinence pads and make sure that she had a supply of those and all the rest of it. I had to arrange for the GP visits*

> *every so often. And then I had to go to the chemist to get all her medicines. And I had to do the shopping for the house. I had to arrange for her appointments with the doctors and with physiotherapists and so on. And the Warfarin Clinic, and bring her to the Warfarin Clinic. And I had to then seek appointments when, you know, when she wasn't responding, or wasn't well, or something like that. So, I had all that sort of thing to do. And very often I had to interpret her symptoms and her perceived needs, as she couldn't articulate them herself. Then I'd do the ordinary things of the house, preparing meals and all that kind of stuff. And I had to assure her that I was there for her at all times and that her immediate problems would be taken care of, and that not to worry, keep her calm. (Caregiver 1)*

This caregiver also described the impact of losing his medical card during this stage of his wife's ill-health and the consequences that this had on his ability to access home help and occupational therapy services for his wife.

Self-care

Self-care is a key component of the management of heart failure. The interviewees identified a number of self-care routines to which they adhered to manage their condition. The most commonly cited of these was daily weighing and blood pressure monitoring. Patients were clear that if they detected an unusual trend in their weight then they would take action either by increasing their diuretics or by contacting a health professional:

> *Oh, I have to take extra medication; I have to take extra diuretics. (Patient 4)*
>
> *I have to weigh myself every day and if my weight goes up one kilogram that's ok. But if it goes up two kilograms overnight or in the one day I have to ring them then. (Patient 17)*

Likewise, most patients described that they were diligent about exercise and some were very committed to exercise and the benefits of their exercise regime. However, having an Implantable Cardioverter Defibrillator (ICD) was also cited as a barrier to exercise:

> *I'd be afraid to run now with this thing inside me. (Patient 10)*

Patients may also have co-morbidities which prevent them from undertaking the exercise that they have been advised to take and this can cause frustration when this is not managed in a holistic way by the health professionals who manage their care. Patients who underwent a cardiac rehabilitation programme in their local hospital spoke very positively about it and it was seen as having important physical benefits supporting patients to increase their activity levels with confidence. This programme is a structured, nurse-led, generally eight-week programme incorporating exercise and psychosocial education programmes:

> *And you see from the time you go in until you come out you are monitored, you have the whole lot there, and they know exactly what way your heart is performing under pressure and everything like that. (Patient 4)*

The importance of cardiac rehab to some patients is evident in that some chose to complete more than one rehabilitation course:

> *I actually did that twice. And the reason I did it twice was because personally, I think I was actually over doing it. You know see, but they give no real guidelines. (Patient 6)*

Another patient described how worried he was when his period of rehabilitation ended because he considered it to be a 'safe' place during a time when he felt very vulnerable.

Diet

Many of the patients discussed modifications which they had made to their diets and becoming more aware of what they eat, even if their follow-through was not yet ideal. Interestingly, a number of patients undertook a complete revamp of their diets and considered that they had taken control of their condition through weight loss and exercise. Many experienced an improvement in their ejection fraction and some expressed frustration that they had not been advised to take the measures that they believed improved their condition:

> *And they are saying like 'oh you've lost weight, that's the cause of it'. Now, all I can say to that is that if weight is the root cause of my problem, or was the root cause, they should have told me to lose the weight. (Patient 10)*

> *This is the thing that I said I'll take it upon myself. Because I know my heart has to work much harder to get me upstairs and all that kind of thing. So if I could lose 10%, that's 10% less work my heart has to do. Actually I've got nearly 20% less work to do now. (Patient 7)*

One of these patients considered that the treatment ambition of the hospital that he was treated in was too passive, aiming at holding a condition in place rather than seeking to improve it and that this advice also failed to take into account his need to work and support his family:

> *We hold what we have. (Patient 10)*

He felt that, at the age of 50 years, he had been written-off and that the services had no aspiration to improve his health or quality of life:

> *Yeah, it was freely given to me it was that I should take it easy at all times and if I had a rocking chair I should use it. (Patient 10)*

Medication

Apart from the difficulty which some patients experienced with diuretics, participants identified that they took any prescribed medication as directed. A number of patients were on large amounts of medication:

> *Like for instance now I'm on medication, I'm on twenty-four tablets a day. (Patient 4)*

Some participants had concerns about the lack of review of their medications:

> *…after I had the heart attack I was on a series of medications obviously. I am still on that same medication three years later and no one has said whether I should still be on it or not. … But as I say it's now over three years and I still haven't seen a specialist to say whether I should still be on the same medication you know. My own doctors say you have to stay on the medication until someone tells you differently. (Patient 13)*

Experiences with health services

Hospital services

Patients who had undergone emergency treatment, including surgery, considered that the care and treatment which they received was excellent. Many interviewees characterised the care they received from their health service team as exemplary:

> *Absolutely out of this world. They are just the most amazing team and, you know, I might've been unfortunate to get heart failure but I couldn't have been more fortunate. (Patient 9)*

However, follow-up or outpatient care was deemed less satisfactory. Patients described a lack of service or review which causes them concerns about their condition and many believed that services were deteriorating in this regard:

> *I have an actual appointment tomorrow, after they have cancelled five appointments. And he said 'oh I will see you again in six months' and now that's two years and three months ago. … And now it's another year and three months, sorry, two years and three months later and I haven't seen anyone since. And I don't think that is right, I honestly think it should be a bit more frequent. (Patient 13)*

A complete review was seen as the best reassurance for patients and this review amounts to more than the provision of information:

> *I know I can get information if I want it. That is not a problem. It's the reassurance is the word we're using, that is the thing, has my heart maintained the way it was? Has it got better? Has it got worse? (Patient 15)*

Patients spoke of being happy to bypass local services to travel to perceived centres of excellence particularly if they were in a crisis situation:

> *I mean it would be nicer if it was done locally but I think when you are in the likes of my position, you have had a heart attack, you have problems. I think you will go any road. (Patient 15)*

Patients from the more peripheral areas of the country may be particularly disadvantaged in the provision of on-going care and review:

> *I haven't even seen a consultant yet. That's a year and a half since I was put in for urgent. I haven't even met the consultant yet. Probably be another two years before I meet him. Well sure what can you do, it's the way the system is like. (Q: And have you seen a cardiologist in your hospital?) A: No, not since I had the heart surgery. (Q: No, and did you expect you would?) A: Oh sure, I thought there would be check-ups like every so often you know. But I haven't seen anyone. (Patient 14)*

Interestingly, another category of patient who considered that they were disadvantaged in terms of on-going care was a patient who is under the care of a cardiologist who she sees privately. She described the onus for follow-up as falling completely on her:

> *That's about the size of it. I would never have been called back, only I decided myself. And I went to him. And the last day I went was in May and he said to me, 'oh I haven't seen you for a while'. I said, 'thank God' in me own mind.*

And a caregiver contrasted the availability of health professionals in the heart failure unit with that of a consultant in the private sector:

> *He scheduled all his appointments on the basis of his own availability and his own readiness. (Caregiver 1)*

Some patients considered that the generic health service providers were not well informed about heart failure and this, combined with a lack of a holistic perspective, left them very vulnerable. A number of patients described being admitted to hospital under a speciality other than cardiology and believed that the diagnosis and care that they received was not appropriate or adequate. These patients experienced an early return to hospital in emergency situations. A patient described how he was admitted to a major hospital but, despite being diagnosed with heart failure, was not told of the diagnosis or seen by a cardiologist during his ten day stay. He was discharged home on medication and learned of his diagnosis when he was re-admitted through ED two weeks later and he and his family put pressure on the hospital for him to be seen by a cardiologist. Another patient described the experience of being put on an IV drip while being treated in hospital for pneumonia, despite being fluid-restricted because of the heart failure diagnosis:

And yet they had the drip you know pumping in. The doctor was only looking after the pneumonia. He wasn't looking after the heart failure… I see in the hospital they read the top page of your file. They spend forever filling the bloody file and nobody ever reads it. (Patient 9)

The lack of a holistic approach to health and well-being was a point of frustration for a number of patients. For example, a number of the interviewees required joint replacements and had been told that their heart condition may preclude the necessary surgery but considered that there was insufficient liaising between the orthopaedic and the cardiac services to ensure that decisions were made on an informed and a 'joined-up' basis.

Heart failure clinics

Almost all patients who attend heart failure clinics or heart failure units spoke extremely positively about them:

> *Yeah, because they encourage you to keep going, they monitor you so closely. They are an essential part of heart failure; those people are you know. (Patient 4)*

The patients valued very highly the amount of time that the nurses gave to them during their appointments:

> *Yeah, they're very good like that you know. You go in to them and you sit down with them for an hour, and they go through all the, you know the pros and cons, and they have all your bloods there, and they analyse the bloods. … Yeah I'd know them all now on first-name terms you know, and it's very reassuring I think to be able to go in there and sit down and discuss your problems. (Patient 4)*
>
> *Patients also commented on the thoroughness and the personal attention that they experienced in the heart failure clinics:*
>
> *And you're not dealt with as a number. You're taken in and you're spoken to and you're asked and they tell you to do this, or do that, you know. (Patient 5)*

The service was seen as flexible and responsive to the needs of the patient:

> *It could be every fortnight, you might have it. Depending on what they found with you on the previous one. … They'd actually ring you, they'd ring you, personal, very personal, yeah want to change your medication, I'll post you out a prescription. You know fantastic, it's absolutely fantastic. (Patient 5)*

A service offered by the heart failure units which was particularly valued by the patients was the telephone contact whereby a patient can phone the nurses if they have any concerns or queries:

> *I can pick up the phone and contact them. And you know if they are not there I can leave a message and they'll get back. (Patient 4)*

A caregiver described the point at which his wife was referred to a heart failure unit as:

> *A great moment in both our lives. (Caregiver1)*

One of the services most valued by the caregiver was the telephone contact:

> *The beauty of the heart failure clinic was that it was available on the phone. I could ring them up and it was a great assurance for me as a carer, and if there was a problem they would say 'bring her in to the clinic' and so I knew that I could bring her in any day into the clinic if her problem was serious enough you know, like I didn't have to have a previous appointment. So it was truly wonderful to have her there. (Caregiver 1)*

The continuity offered by the nurses was also seen as a very important aspect of the care and was said to contrast strongly to the lack of continuity with the doctors:

> *But the doctors are trainees, so they are rotating through there, so they are probably there for six months. But, as I say, the nurses are the same, and that is important and maybe they are more important than the doctors. (Patient 3)*

Many of the patients were happy that the nurses were a conduit between themselves and the cardiologists and were confident that the nurses knew when to consult the cardiologist:

> *Oh without fear of contradiction they would be on the ball straight away, and if they were unsure of anything they would endeavour to see a cardiologist that day. … And if they are unsure of the problem that you have, well there's a cardiologist or doctor there working close by, and they'll go and discuss it with them. (Patient 4)*

A number of patients however, expressed concern that, in terms of access, the service that they are getting has deteriorated recently and spoke of cancelled appointments and increasing lengths of time between appointments. This gave rise to concerns because patients feared that the gap was not one that was planned based on a clinical decision but rather a consequence of health service deficits:

> *…just shortly before July I got a letter saying that would I defer it until September because they were short staffed. In the meantime just before that visit in September I actually was taken into hospital for the water with the fluid on the lung. (Patient 17)*
>
> *Well this is the problem. I was supposed to get, as I say, an annual MOT from them. But I think I'm overdue now by about six months. (Q: Are you?) A: Yeah and there's still no sign of an appointment coming. Now if they, maybe they don't deem it necessary but I can't see how they would know. (Patient 8)*

Community health professionals

The care of the patients interviewed for this study was almost entirely given by heart failure nurses and/or cardiologists. It may be a consequence of their relative good health that they did not receive any services from Public Health Nurses or community based physiotherapists or occupational therapists. However, all the participants had GPs and used their community pharmacies. Most participants spoke highly of their GP:

> *Yeah, they're very good. The GP and his nurse, they're absolutely brilliant, because they monitor my Warfarin situation on a regular basis as well, and they always keep a check on you know the bloods and everything like that you know. (Patient 4)*
>
> *So, yeah, so I know him well, like he's our family doctor and that, and I'd have a lot of time for him. (Patient 3)*

However, most reported limited involvement of the GP in monitoring their heart failure condition. Some GPs were perceived as lacking in the knowledge about heart failure that would allow them to treat a person with heart failure with confidence:

> *We kind of by-passed him, you know. … If he was prescribing something for me, he'd be always iffy. He hates having to give me anything. (Patient 9)*

GPs were described as reluctant to deal with issues concerning heart failure, preferring to send patients to the hospital:

> *He would send me straight to hospital; straight to hospital … Yeah, he doesn't mess around that way. Just straight to hospital. (Patient 10)*

GPs were also said to be reluctant or unable to revise medications that have been prescribed by hospital doctors and therefore did not take an active role in optimising drug therapy:

> *'I'm not going to do it, I didn't prescribe them for you … I haven't the power'. (Patient 11)*

Pharmacists

Some of the interviewees did not identify that their pharmacists had a significant role in the management of their heart failure. For these patients, the pharmacy was the place from which they collected the medications that had been prescribed by doctors:

> *Well, they supply me with all the medication that I need … Because I said they are very obliging like that that's all I can say you know, but I don't know how other than filling your prescriptions that we give them, what they could do. I don't know. (Patient 13)*

However, for some patients, pharmacists represent a crucial safety net for prescribing errors:

> *Then he said to me 'that's not right'. I said 'why?' 'Well they are prescribing 600 milligrams that's a fatal dose'. So, he rang the hospital. It was 600mg, should have been 200. Yes, he's as sharp as a razor. He's great and then a few other times when there was stuff looking for and he said that 'that doesn't go with what you are on'. No, he is very good believe me, so yes we would go around to talk to him looking for advice, or what does he think. (Patient 11)*

An approachable and knowledgeable pharmacist was also seen as a valuable source of information for patients:

> *Ah well, he's only round the corner from me, and again he's absolutely brilliant, you know. You can go up and discuss your medication with him and he will. He's as good as any GP or anything like that. He understands all the medication, what clashes with what, and what will won't suit, you know, and that's reassuring as well. (Patient 4)*

Information

Patients who were diagnosed with heart failure as inpatients in hospitals described receiving an abundance of advice and information in the form of leaflets. To some this represented information overload when more targeted and practical information may have been of more immediate concern. An information overload was thought not to be conducive to retaining the information:

> *Also, when you get hit with a barrage of a whole lot of new medical things, you just cannot take it all in. (Patient 2)*

Newly diagnosed patients may not be in a position to identify their own information needs. They may lack the knowledge to know what they needed to know:

> *…you don't know what questions to ask. (Patient 8)*

Thus, patients discussed the need for on-going or a re-capping of information when they had settled into their diagnosis.

A caregiver argued that caregiver needs are not recognised or met by the health professionals who, maybe understandably, focus on the patient. However, caregivers and family members also have information needs and these may be different, or expressed at different times, than those of the patients. Caregivers may need practical information and help to develop skills to support and care and to recognise when medical help is required. These needs may be particularly felt by the caregivers of patients who do not attend a heart failure unit, as such support and training is given to family members by the heart failure nurses. As a means of receiving information, some of the interviewees thought that leaflets were of limited use. Several admitted that they did not read them:

> *Well you see leaflets; you don't always read those things like. (Patient 5)*

> *Because you just look at the leaflets and you say that's fine and you put it to one side and you don't look at it for a long time. But most of the time you don't bother. (Patient 16)*

> *(Q: If there were leaflets and things would you be interested in those?) A: Oh that would be good to have aye, but I'm not a great, I haven't time for reading to be honest. (Patient 14)*

Others were frustrated by the generic nature of the information in the leaflets:

> *Yes, yes, so I picked up a few of those and they all tell you to lose weight and not to eat butter. (Patient 13)*

A number of patients expressed dissatisfaction about what they perceived to be a lack of precision in the advice that they are given particularly when it amounts to being told to 'do everything in moderation':

> *…yeah you're given leaflets, you're given all that and it's all about know your limits. I try not to let myself get tired. But I just, you'd love to know your limits. I suppose you know them yourself. (Patient 6)*

The internet was a useful source of information for a few of the participants; they claimed different levels of expertise and whereas some used the internet and email comfortably, others had more limited skills in the area:

> *(Q: Do you use the internet?) A: I can't work it unfortunately no, I can't even text. (Patient 14)*

A number of the interviewees had attended information evenings on heart failure hosted, in their area, by the Irish Heart Foundation. These were very highly regarded and the patients welcomed the opportunity to ask questions of the expert presenters and, also, to hear about and learn from the experiences of others:

> *We were invited to a meeting in a hotel and my wife and I went and loads of people went, it was hundreds of people there, it was fantastic. And various doctors, surgeons, specialists talked and told us exactly about what was happening with the Irish Heart Foundation and heart failure. (Patient 13)*

This opportunity to share experiences was identified by a number of patients as a great 'added-value' benefit of attending heart failure clinic. Several spoke of meeting others at the heart failure clinics or during rehab as the only contact that they have with others with heart failure:

> *No, only when I met them in the rehab program, that's where I met them. They are the only people I know who have heart failure. (Patient 10)*

Indeed, the heart failure clinics may function as an informal support group with patients exchanging information and learning from each other:

> *It's amazing the amount of knowledge you pick up at the clinic, observing other people gives you a lot of information. (Patient 9)*

Likewise, patients who attend the heart failure clinics considered that they have continuous access to information and heart failure nurses were identified as a key source of information. They were perceived to be knowledgeable and some patients expressed confidence in the staff in the heart failure units to keep them up to date with any information that they need:

> *If new information comes forward well and good but at the moment I know everything, when I go to the heart failure clinic. The nurse there will go through a whole list of things the pillows, the tablets, the weight. She will go through the whole lot so she does that all the time. So therefore there is nothing more at the moment that I can know about. (Patient 17)*

Patients who attend a heart failure unit consistently described themselves as well informed and having the amount of knowledge that they themselves want to have. This was not the case for most of the patients who did not have access to a heart failure clinic, many of whom considered themselves to be lacking information and to be without access to immediate information. Patients who do not have access to such a service expressed a need for access to immediate information:

> *It would be good maybe if there was a helpline some place, you know that you could ring. (Patient 6)*

Lack of information was also considered by a number of interviewees in the context of the level of awareness about heart failure among both the general public and some members of the medical profession. This patient was not aware of the IHF national heart and stroke helpline. Creating awareness was identified as important:

> *…an awareness campaign or something just to show people you know. For my condition that you could be made aware of heart failure as you know everything these days is sort of directed towards stroke. And that kind of thing. But heart failure doesn't come into it, it's not mentioned really. (Patient 7)*

Patient information

Several interviewees had received information booklets developed by the Irish Heart Foundation which they had found very useful. Indeed, the IHF booklets and leaflets were the only leaflets which patients identified that they received. One man spoke of the benefits that he received through his contact with the IHF:

> *…going into their information days and their work, it was the heart foundation who were very good I'm getting books now on what to cook (laughs). We were at one of those up in the airport hotel, they were good they were good. (Patient 11)*

The lack of public awareness was felt strongly by some patients who described heart failure as an invisible condition, the implications of which were not understood by others:

> *One of the things is that, everybody around here, if I walked around with a cast on my leg people would move out of my way because I'm obviously invalided or whatever. Whereas, when I was really sick I looked normal, you know, and people wouldn't do anything for you. Because they don't know anything about it, you know. (Patient 10)*
>
> *I live in a rural area and I think people would think I'm out for a stroll. They're probably saying; look at the state of your one strolling up and down the road. But that takes me as much effort, as it would take somebody's who's going to run it, you know. (Patient 9)*

It was also suggested that the Irish Heart Foundation would take on a greater role in lobbying on behalf of patients with heart failure and, specifically, in relation to the cost of medication.

A caregiver spoke very passionately about the need for information and support specifically for family members and caregivers. She described the experience of caring for a person with heart failure as an isolating one and suggested that the impact on a patient's loved ones should be acknowledged:

> The patient isn't the only one who's suffering. (Caregiver2)

The Irish Heart Foundation was identified as an organisation that could provide practical training for family members including skills such as taking a pulse, understanding blood pressure and carrying out CPR. A further suggestion was that the IHF would be available in hospitals to offer information and support to family members:

> *I think if there was somebody from the Irish Heart Foundation in the hospitals. If they had a little stand somewhere or just outside the cardiac unit, do you know what I mean. 'We're from the Irish Heart Foundation. Your loved one has just had a heart attack, do you mind if we speak to you? Would you like to speak to us? And if you're not getting the information in there, we can help you here.' … And it would just be nice to have somebody who shows they care, whether they do or not, at least you feel they care what's happening to you. Because the nurses and the doctors are in there looking after your loved one but nobody is there to talk to the relatives, not even his mother. His poor mother was up the walls, you know, and she wouldn't understand at all any of the medical terminology (Caregiver 2)*

It was suggested that given the age profile of most patients with heart failure, particular attention should be paid to the needs of family caregivers:

> *And I've seen them out there, you know, with their carers sitting beside them, the carers need caring as much as they do you know. (Caregiver 1)*

DISCUSSION AND SUMMARY

Qualitative research does not seek to generalise but rather to provide an insight into the lives, views and experiences of the study participants. This qualitative study provides an interesting insight into the lives and experiences of a small number of heart failure patients who agreed to take part in this study. The picture which has emerged is of patients who are well-motivated and optimistic despite restrictions caused by their condition.

The participants in this study were all in the chronic, stable stage of their illness and felt well enough to respond to an invitation and undertake a one-to-one interview. The relative good health and positive outlook of the participants in this study gives a relevant, useful and interesting perspective to our understanding about living with heart failure in the community and how such patients and their families and caregivers can best be supported. Their lives were impacted by heart failure but they were determined and resolute that they could accommodate the negative impacts of their condition.

The difficulties that patients and their caregivers face in self-managing their condition are well-documented in the literature (5, 45, 69). The experience of patients who are confident and eager to manage their heart failure is less frequently reported. Indeed, a number of the patients in this study discussed the extent to which they were devising their own diet and exercise regimes which were more ambitious than those recommended by their healthcare professionals.

Patients with heart failure are characterised as having a poor quality of life (5, 30, 34), whereas the patients who agreed to take part in this study identified strategies which they used to remain stoical, accepting and optimistic. It may be that patients such as these should receive specific provision to enhance their commitment to manage and live well with heart failure. Heart failure is presenting a significant challenge to health services budgets across the world and much of the cost is due to hospital admissions and re-admissions (11). Supporting patients to stay well in the community is one of the objectives of the Irish Clinical Programme for Heart Failure and the centrality of primary care services to achieve this was cited. However, although most patients spoke highly of their GP, few identified them as having a role in the management of heart failure; these findings reflect the findings of previous studies (62, 75).

The components of good care emerged clearly from the participants. They wanted a timely diagnosis followed by regular follow-ups with health professionals leading to the development of holistic, therapeutic trusting relationships. Patients valued a responsive, flexible service which allows them immediate telephone contact if concerns arise. Such services provide heart failure patients and their caregivers with confidence and a sense of security and reassurance and supports patient self-management of their condition. Almost all examples of good health service provision focused on heart failure clinics, especially from the specialist nurses who are the key personnel in these units. However, heart failure units are unevenly distributed throughout the country leading to lack of equity of care for all patients.

The UK National Institute of Clinical Excellence (65) recommendation that patients with stable chronic heart failure should be reviewed at least every six months to ensure that their medication is working effectively and that their condition is not deteriorating is a point that resonated strongly with the patients in this study. Many patients, including some attending heart failure clinics, expressed concern about the extent of follow-up care. The theme of cancelled appointments and long delays between appointments was a recurring one. Patients spoke of the reassurance that they got from regular reviews and without them patients were trying to manage self-care in a vacuum. Concerns were also expressed about the irregularity of reviews of their medication.

The vision of the Clinical Programme for Heart Failure is for a co-ordinated, multi-disciplinary and patient-focused system of care across the country. Yet the experience of participants in this study provided little evidence of integrated care across hospital and community settings. None of the patients interviewed perceived their GP or community pharmacist to be part of an integrated, multi-disciplinary team and some were clear that their GP was reluctant to engage with them for matters relating to their heart failure, which is a finding consistent with that of other studies (75, 76). This suggests that the Clinical Programme for Heart Failure's vision that heart failure patients' adherence to treatment would be managed by the GP practice and the community pharmacist has not yet be translated into practice throughout the country.

The importance of greater awareness of heart failure was emphasised by the interview participants. Lack of public awareness of the condition was considered to impact on the way in which people respond to the symptoms experienced by heart failure patients. However, particular concern was expressed about the lack of awareness of symptoms by some healthcare professionals in the hospital setting which, participants believed, can result in serious and even life-threatening consequences. Thus, some patients spoke of significant delays in receiving a diagnosis despite experiencing what they now believe are classic heart failure symptoms and a patient described being treated in hospital with intravenous fluids despite being fluid restricted because of heart failure.

The patients and caregivers views about their information needs were very definite. They indicated that they want and need information. However, some experienced 'information overload' at the point of diagnosis and others were critical of the generic nature of the information which they were given. Information was required to be more specific, timelier and given in response to immediate concerns. It was also clear that patients were not homogenous with respect to their preferences and abilities to access information and regard should be paid to the provision of information across the literacy and digital divide. Many patients and caregivers highly valued contact with other patients; in the absence of formal support groups available to the participants in this study, many substituted hospital and clinic waiting rooms as a forum in which to share information and learn from others living with heart failure.

There was a perception apparent from some of the interviews that heart failure had no advocate to raise its profile and lobby on behalf of its patients. Patients incur the costs of a chronic condition including medication and GP visit costs and some argued that greater recognition of heart failure might lead to some financial relief for patients. A strong advocacy group may also have a role in supporting and educating patients to optimise their self-care capacities.

Tully et al. (2009) identified a geographical inequity in service provision across Ireland and a report published in 2015 described the regional disparities as 'profound' (4, 5). A disappointing finding of this current qualitative study is the extent to which this still prevails.

CHAPTER THREE: ALLIED HEALTHCARE PROFESSIONALS SURVEY

The ideal person-centred approach to managing patients with heart failure living in the community has been identified as being rooted in primary care services that are closely integrated with allied health professionals in community-based services (43). Based on the literature previously discussed in Chapter 1, the survey of allied healthcare professionals assessed the experiences and opinions of GPs, nurses, hospice staff and pharmacists to explore what best serves patients with heart failure living in the community. Specifically, health professionals were surveyed in relation to knowledge, opinions and current practice in relation to providing services and support.

Healthcare professionals were sampled to maximise a geographical spread across the country. GPs and pharmacists were randomly selected from the Irish Medical Guide 2015. Nurses were selected from a database of heart failure nurses and cardiac rehabilitation nurses which was initially developed by the Irish Heart Foundation and supplemented by the study researcher through direct contact with respective service providers. Hospices were selected on the basis of geographical location. The health professionals were sent a letter of invitation to participate, a participant information leaflet, a stamped envelope in which to return completed questionnaires and a questionnaire. Reminders were not sent. Return of the completed questionnaires was considered to constitute informed consent.

Table 3.1 *Forty-six healthcare professionals returned the questionnaire which represented an overall response rate of 31%.*

Professional	Questionnaires posted	Questionnaires completed	Response rate %
GPs	100	21	21
Nurses	24	18	75
Pharmacists	25	5	20
Hospice	4	2	50

Professionals' years of experience varied (GPs range: 5-40 years, heart failure nurse range: 1-20 years, hospice team member range: 12-20 years, community pharmacist range: 2-30 years, Total range: 1-40 years. (All questionnaires are available in the Appendix.)

Questions in the healthcare professional survey

Demographics

Age group, gender, geographical location, local telephone area prefix, profession.

Professional contact with heart failure patients

Professionals were asked about their contact with heart failure patients. Professionals were asked to indicate how many heart failure patients they saw daily, weekly, monthly and yearly. Professionals were also asked to indicate the medical card/insurance status of their patients and the stage of heart failure of their patients.

Knowledge of professionals

We assessed professionals' knowledge about heart failure using 8 categories e.g. 'symptoms of heart failure' or 'the pharmacological treatment of heart failure.' Responses ranged from 'Good' to 'None and I would like to know more'. Health professionals were asked about the nature of their interactions with heart failure patients in both a medical and non-medical capacity. Health professionals were also asked what they believed were the key issues in providing a service to heart failure patients.

Barriers in the community

We assessed professional opinions about difficulties and barriers that they may experience when providing care to patients with heart failure. From the literature (75, 76) a list of 15 potential barriers was developed e.g.

'staffing', 'lack of services to refer patients to' and 'time.' Respondents rated their level of agreement with the statements on a 5-point Likert scale ranging from 1 ('no difficulty') to 5 ('great difficulty').

Management in the community

Professionals' views on the barriers that patients with heart failure might experience when seeking and maintaining healthcare were assessed. Twenty-one possible barriers were assessed on a Likert scale ranging from 1 ('no difficulty') to 5 ('great difficulty').

Professionals were asked who they believed should be involved in the healthcare management of patients in the community.

Results

Health professionals were asked to estimate approximately insurance or medical card status of their patients with heart failure and how their symptoms are categorized. Results are displayed in Table 3.2 below.

***Table 3.2** Healthcare professional demographics†*

	GP N=21	Nurse N=18	Hospice N=2	Pharmacist N=5	Total N=46
Female	7 (33%)	1 (6%)	0	1 (20%)	9 (19%)
Male	11 (52%)	16 (88%)	1 (50%)	4 (80%)	32 (70%)
Age					
20-29	0	0	0	2 (40%)	2 (4%)
30-39	3 (14%)	3 (17%)	0	2 (40%)	8 (17%)
40-49	8 (38%)	12 (67%)	1	0	21 (46%)
50-59	7 (33%)	3 (17%)	1	1 (20%)	12 (26%)
60+	3 (14%)	0	0	0	3 (6%)
Working area					
Dublin North East	4 (19%)	5 (28%)	1	2 (40%)	12(26%)
Dublin Midlands	1 (5%)	4 (22%)	0	0	5(11%)
Dublin East	3 (14%)	3 (17%)	0	0	6(13%)
North West	4 (19%)	2 (11%)	0	2 (40%)	8(17%)
West	5 (24%)	2 (11%)	1	1 (20%)	9(20%)
Midwest	0	1 (6%)	0	0	1(2%)
South East	3 (14%)	0	0	0	3(6%)
Years of professional experience (mean)	20	18	16	5	15
Number of patients seen					
Daily	2	8	–	–	10
Weekly	4	28	1	1	34
Monthly	20	117	–	17	154
Type of medical coverage (%/mean)					
Full medical card	83% (17)	75% (14)	100%	80% (5)	84%
GP only card	13% (8)	13% (3)	–	28% (2)	18%
Private	14% (11)	17% (8)	–	15% (3)	15%
Patients who completed structured heart failure program	35% (19)	74% (18)	50%	45% (2)	51%
NYHA II	34% (9)	51% (15)	–	–	58%
NYHA III	30% (10)	45% (14)	80%	90% (1)	52%
NYHA IV	21% (9)	18% (14)	–	–	19%

Healthcare professionals' knowledge of heart failure

The healthcare providers were surveyed about their views and knowledge of community services, depression and other aspects related to heart failure in their patients. The results are presented below in Table 3.3.

The majority of healthcare providers (96%) reported that their knowledge of the symptoms of heart failure was good. Six (29%) GPs reported that they have no knowledge about the NYHA classification of the stages of heart failure. Sixteen (89%) heart failure nurses reported that they had good knowledge about the European Society of Cardiology Clinical Guidelines, while 15 (71%) GPs reported that they would like to know more.

Seventeen (94%) heart failure nurses reported that they had good knowledge about the self-management requirements of heart failure patients while 9 (43%) GPs said that they would like to know more about these requirements. Forty-eight per cent of GPs (10) surveyed stated that they would like to know more about the association between heart failure and depression. Twenty-nine per cent of GPs (6) and 33% (6) of heart failure nurses reported having good knowledge about where heart failure patients can access community health services, while over half (57%) of all healthcare professionals surveyed reported that they would like to know more about this.

Table 3.3 *Healthcare professionals' knowledge of heart failure†*

Knowledge about	GP N = 21	Nurse N =18	Hospice N = 2	Pharmacist N = 5	Total N = 46
The symptoms of heart failure					
Good	21 (100%)	18 (100%)	1 (50%)	4 (80%)	44(96%)
None	–	–	–	–	–
I would like to know more	–	–	–	1 (20%)	1(2%)
Good & I would like to know more	–	–	–	–	–
The NYHA classification of the stages					
Good	13 (62%)	18 (100%)	1 (50%)	1 (20%)	33(72%)
None	1 (5%)	–	–	1 (20%)	2(4%)
I would like to know more	6 (29%)	–	1 (50%)	3 (60%)	10(22%)
Good & I would like to know more	–	–	–	–	–
The European Society of Cardiology Clinical Guidelines					
Good	5 (24%)	16 (89%)	–	–	21(46%)
None	–	–	1 (50%)	1 (20%)	2(4%)
I would like to know more	15 (71%)	2 (11%)	1 (50%)	4 (80%)	22(48%)
Good & I would like to know more	1 (5%)	–	–	–	1(2%)
The pharmacological treatment					
Good	14 (67%)	16 (89%)	–	3 (60%)	33(72%)
None	–	–	–	–	–
I would like to know more	6 (27%)	1 (6%)	1 (50%)	1 (20%)	9(19%)
Good & I would like to know more	1 (5%)	1 (6%)	–	1 (20%)	3(6%)
None & I would like to know more	1 (5%)	–	–	–	1(2%)
The self-management requirements of heart failure patients					
Good	10 (48%)	17 (94%)	1 (50%)	2 (40%)	30(65%)
None	1 (5%)	–	–	1 (20%)	2(4%)
I would like to know more	9 (43%)	1 (6%)	1 (50%)	1 (20%)	12(26%)
Good & I would like to know more	–	–	–	1 (20%)	1(2%)

Knowledge about	GP N = 21	Nurse N =18	Hospice N = 2	Pharmacist N = 5	Total N = 46
The association of heart failure and depression					
Good	9 (43%)	11 (61%)	1 (50%)	–	21(46%)
None	1 (5%)	–	–	–	1(2%)
I would like to know more	10 (48%)	2 (11%)	1 (50%)	4 (80%)	17(37%)
Good & I would like to know more	1 (5%)	5 (28%)	–	1 (20%)	7(15%)
When to refer a heart failure patient for specialist consultation					
Good	13 (62%)	16 (89%)	–	1 (20%)	30(65%)
None	–	–	–	–	
I would like to know more	7 (33%)	–	1 (100%)	2 (40%)	10(22%)
Good & I would like to know more	1 (5%)	2 (11%)	–	1 (20%)	4(9%)
Where heart failure patients can access community health services					
Good	6 (29%)	6 (33%)	1 (50%)	1 (20%)	14(30%)
None	–	–	–	–	–
I would like to know more	13 (62%)	9 (50%)	1 (50%)	3 (60%)	26(57%)
Good & I would like to know more	1 (5%)	3 (17%)	–	–	4(9%)

†*Some figures do not add up to 100% due to rounding or missing values.*

Health professionals were asked, in a free text comment box and therefore not included in Table 3.3, about the nature of their interactions with heart failure patients in both a medical and non-medical capacity. Ten (22%) health professionals stated that their main medical interactions included the prescription and management of medications. Nine health professionals (19%) indicated that their main non-medical interactions with heart failure patients revolved around educating patients and their carers on their diagnosis.

Health professionals were also asked what they believed were the key issues in providing a service to heart failure patients. Twelve (26%) professionals agreed that there was a distinct lack of specialist services in the community for heart failure patients. The locations of those 12 professionals were examined and indicated a regional disparity with 6 (50%) professionals citing lack of specialist services in the West or Northwest counties of Ireland.

Health professionals' opinion on barriers when providing care to patients with heart failure

Two health professionals reported that they experience no barriers when providing care to patients suffering from heart failure. Results indicated that the biggest challenge professional's face is the lack of services to which to refer patients. Thirty-one professionals (67%) agreed that this aspect hinders the provision of care, 27 professionals (59%) reported that patients have difficulties with self-management. Twenty-two (48%) health professionals agreed that time was a barrier when providing care to patients with heart failure. Twenty-two (48%) health professionals described accessing urgent cardiology appointments as a challenge. All barriers are ranked and displayed in Figure 3.1 below.

Differences in responses between the types of health professionals were also explored. Twelve GPs, compared to 5 heart failure nurses reported that the patient being unaware of their diagnosis was a barrier when providing care. Thirteen GPs stated that accessing tests such as B-type Natriuretic Peptide (BNP) testing and echocardiograms was a challenge, whereas five heart failure nurses reported this as a difficulty. Twelve GPs stated that accessing urgent cardiology appointments was a barrier to providing care to heart failure patients, while 7 heart failure nurses cited this as a challenge.

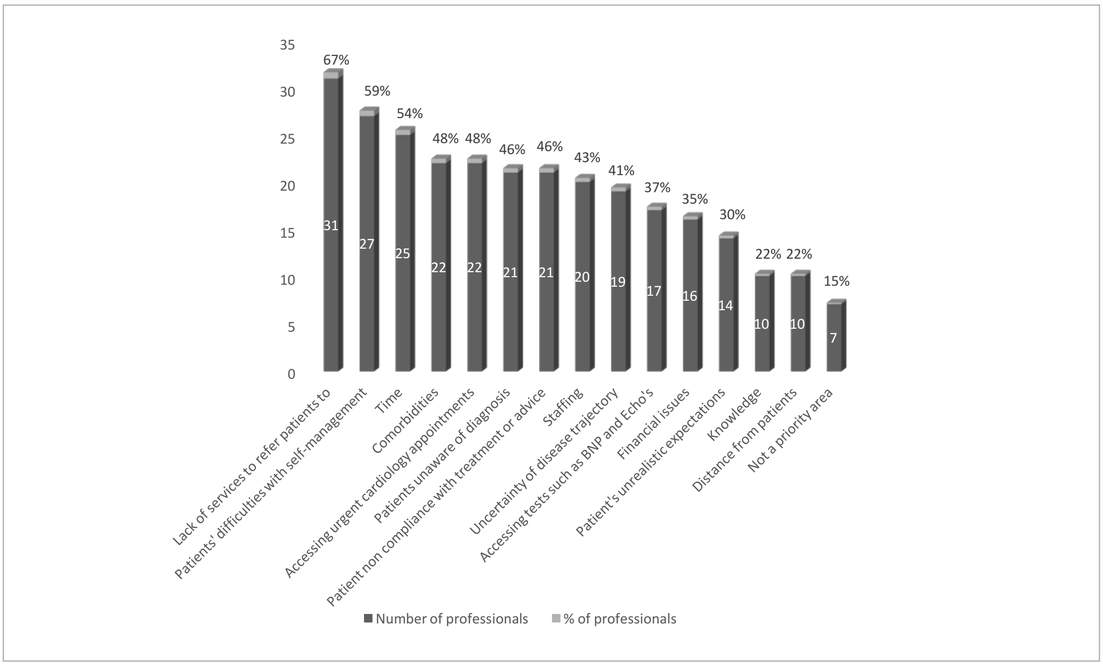

Figure 3.1 *Health professional's opinion about difficulties and barriers that they may experience when providing care to patients with heart failure*

Health professionals' management of heart failure patients

Health professionals' views on the barriers that patients with heart failure might experience when seeking and maintaining healthcare were explored. Twenty-one possible barriers on an ordinal Likert scale from 1 ("no difficulty") to 5 ("great difficulty") were assessed. The percentage of health professionals who indicated that the barrier was a difficulty and the extent of difficulty is outlined in Figure 3.2, with 35 (76%) professionals identifying access to psychological support as the most challenging aspect for patients when receiving health care related to heart failure. Twenty-seven (59%) professionals recognised patients' fear as a barrier to seeking and maintaining healthcare for heart failure patients in the community. Approximately half of the health professionals indicated that lack of co-ordinated/integrated care was a challenge for patients. Complying with medication was the lowest rated barrier (13%).

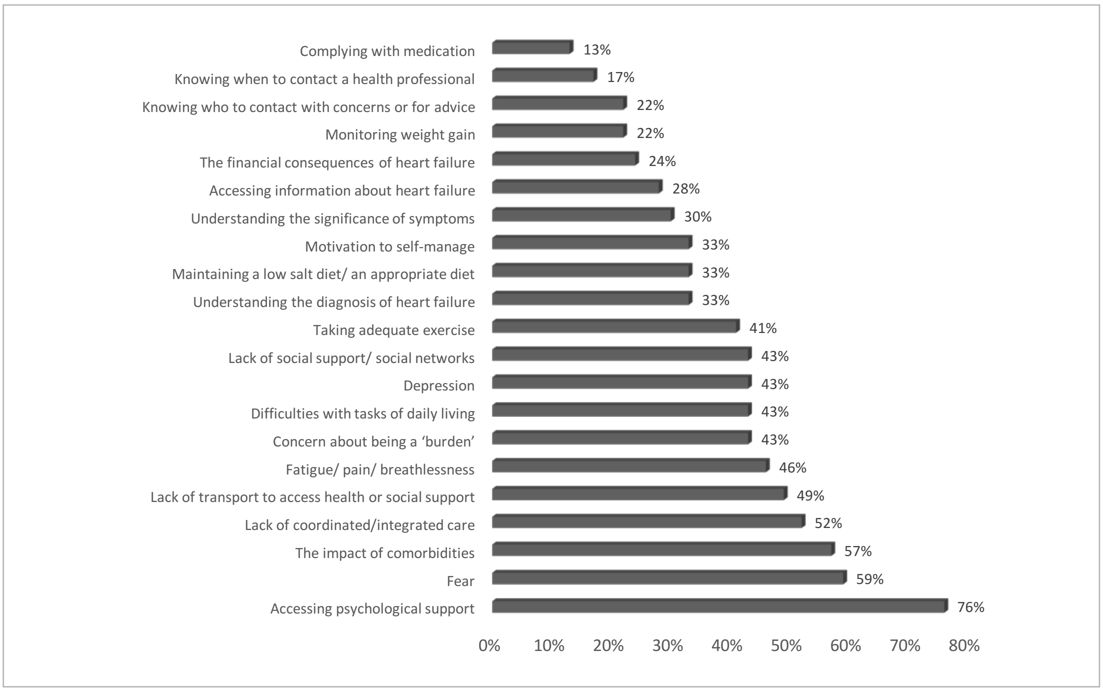

Figure 3.2 *Health professionals' views on the barriers faced by patients with heart failure*

Differences in responses to barriers in patient management between GPs and nurses were also explored and are displayed below in Figure 3.3. Twenty-eight per cent of GPs indicated that difficulties with daily living was a barrier for heart failure patients, however only 9% of heart failure nurses agreed that this was the case. Twenty-four per cent of GPs, compared to 7% of heart failure nurses reported taking adequate exercise as a barrier for heart failure patients. Eighteen per cent of GPs, compared to 6% of nurses stated that accessing information was a challenge for heart failure patients when maintaining healthcare.

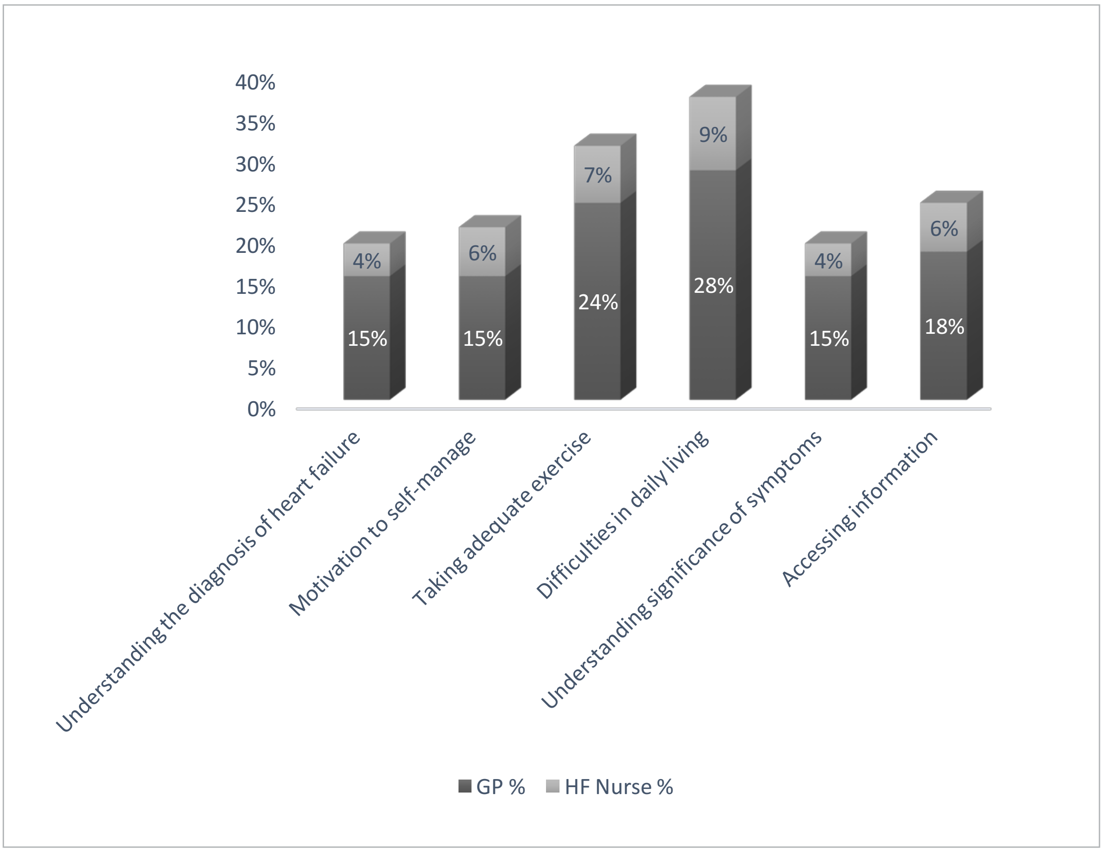

Figure 3.3 *Differences between GPs and nurses when asked about barriers reported by patients to heart failure self-care management*

Health professionals' involvement in the healthcare management of heart failure patients in the community

Health professionals were asked who they believed should be involved in the healthcare management of heart failure patients in the community. All health professionals surveyed (N=46) agreed that GPs should be involved in this trajectory of management. Health professionals (N=39) also indicated that family members, practice nurses and pharmacists should be involved in the healthcare management of heart failure patients in the community. The findings are displayed in Figure 3.4 below.

Seven professionals (15%) suggested by giving a free-text comment, therefore it is not included in the Figure 3.4, that community outreach specialist nurses should play an important role in community care provision.

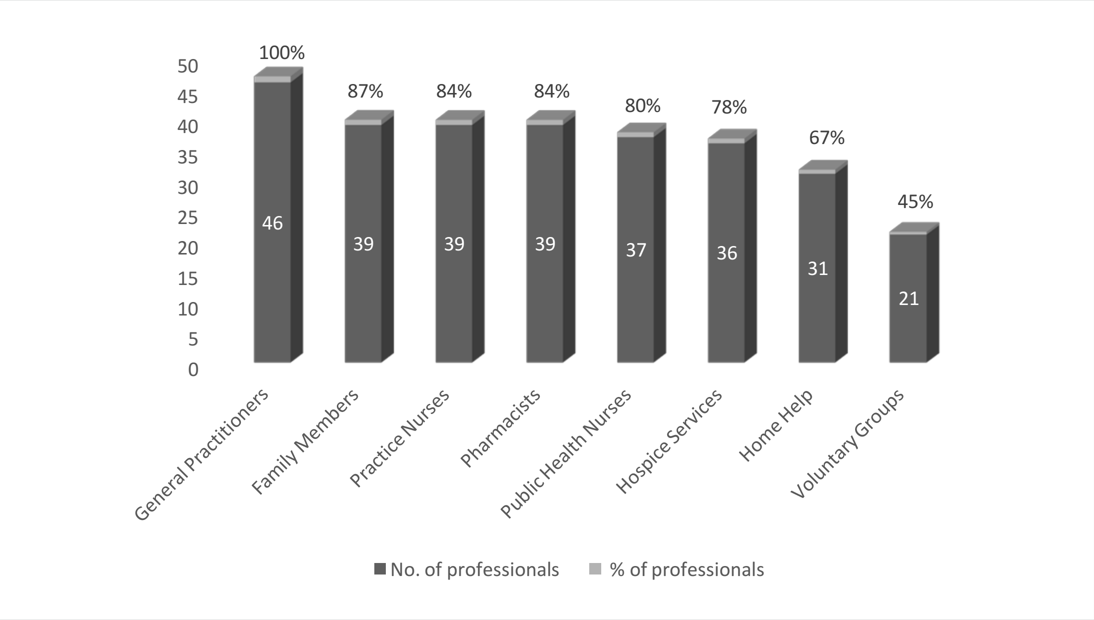

Figure 3.4 *Health professionals' views of who should be involved in the management of heart failure patients in the community*

Support services required by heart failure patients living in the community

Health professionals were asked what support services were required by heart failure patients in the community. The specialist community-based nurses, followed by strengthened linkages between hospital and primary care services and support of carers were appraised as the most essential services, rated respectively by 91% to 87% of the professionals surveyed. The majority of the professionals (> 50%) agreed that the rest of the services are also of significant importance as outlined in Figure 3.5 below.

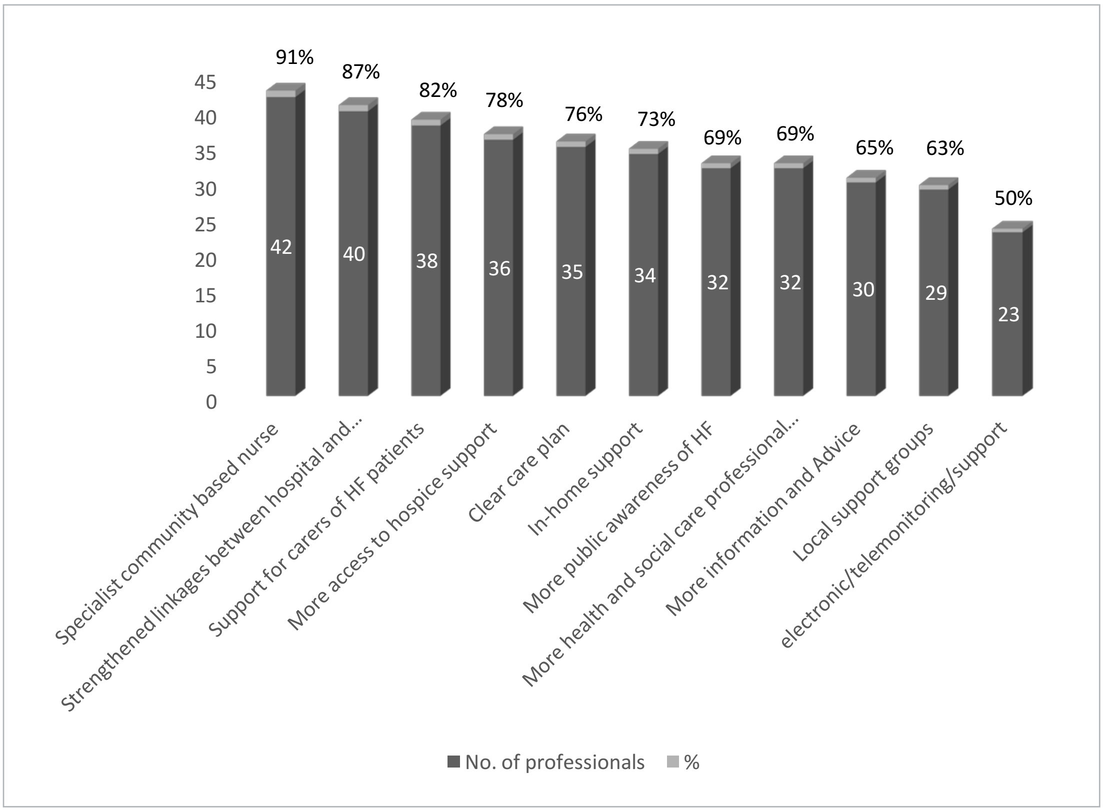

Figure 3.5 *Support services required by heart failure patients according to health professionals*

DISCUSSION AND SUMMARY

The healthcare professionals group comprised mostly of GPs (45%) and heart failure nurses (39%). They had been working for an average of 15 years and 26% respondents were based in the Dublin North East health region.

Health professionals stated that an average of 84% of their patients had a full medical card; an average of 51% of their patients had completed a structured heart failure programme; and the majority (58%) of patients were categorised as having Stage 2 heart failure.

The majority of health professionals (96%) reported that their knowledge of the symptoms of heart failure was good. Six (29%) GPs reported that they have no knowledge of the NYHA classification of the stages of heart failure. Sixteen (89%) heart failure nurses reported that they had good knowledge of the European Society of Cardiology Clinical Guidelines, while 15 (71%) GPs reported that they would like to know more.

Forty-eight per cent of GPs surveyed stated that they would like to know more about the association between heart failure and depression.

Knowledge of GPs

All healthcare professionals surveyed were in agreement that GPs should be involved in the healthcare management of patients with heart failure in the community. However, 29% of GPs surveyed stated that they had no knowledge of the NYHA classifications of heart failure. A further 71% of GPs would like to know more about the European Society of Cardiology Clinical Practice Guidelines. Structured management programmes have been recommended to promote effective integrated use of primary and secondary care services (5, 26). Early detection of heart failure and education about heart failure play an integral role in structured management programmes. The Irish National Cardiovascular Policy 2010-2019 indicates that the role of the GP is integral in providing proactive care in heart failure. Successful treatment of heart failure in the community requires that healthcare professionals receive appropriate training (43). As such, there is a need to increase education of primary care teams to recognise symptoms of heart failure and detect it at an early stage.

Barriers to care

Two thirds of healthcare professionals reported that they would like to know more about where heart failure patients can access community health services. Furthermore, most professionals (67%) agreed that there was a lack of services to which to refer patients, which suggests a poorly integrated and fragmented model of care. The National Cardiovascular Policy highlights the need for a collaborative community-based approach to care, therefore reducing the need for hospital service. However, currently there are gaps in the ways in which heart failure services link between the hospital and the community. The current study found that health professionals would welcome the addition of a specialist community heart failure nurse, which highlights the need for more community-based specialist heart failure services.

Health professionals reported that lack of self-management hindered the provision of care for heart failure patients. Tully et al. (2009) found that self-care behaviour varied among heart failure patients with over 90% of patients reporting taking medication as prescribed. However, much fewer engaged in other important self-management behaviours, such as daily weighing (14%).

The National Cardiovascular Policy outlines a comprehensive process for the initial diagnosis of heart failure. It states that when a patient presents with symptoms suggestive of heart failure, initial investigations including BNP testing and echocardiograms should be carried out. However, in the current study thirteen of the 21 (62%) GPs stated that accessing tests such as these was a challenge, whereas five of the 18 (27%) heart failure nurses reported this as a difficulty, which suggests a variation in the availability of and access to essential resources in the community. For the early detection of heart failure, for treatment to remain in the community and to avoid the costs associated with hospital services, primary care services should have adequate access to necessary testing. Furthermore, patients should universally have access to the latest evidence-based investigations, treatment and resources.

Geographical disparity

The aim of the National Cardiovascular Policy is to increase care in the community for heart failure patients. Of concern, over a quarter of professionals surveyed agreed that there was a distinct lack of specialist services in the community for patients. The locations of professionals expressing these views were further examined and indicated a regional disparity with half stating that they were based in the West or North-West counties of Ireland. Similarly, an Irish report highlighted national variations in the provision of care provided to heart failure patients (4). The report identified a national disparity in services for outpatients' follow-up services between counties. The geographical disparity may make it difficult for patients with heart failure to access specialist services and to receive the continuous care they need to achieve optimal outcomes in treatment and quality of life. For the early diagnosis and for the effective and equitable management of heart failure, resources need to be available to enable delivery of high quality support for patients with heart failure and their caregivers nationwide.

Availability of services

The majority (73%) of professionals indicated that accessing psychological support services was a challenge for heart failure patients. Almost half of the GPs surveyed indicated that they would like to know more about the association between depression and heart failure. Previous research has found that heart failure patients report depression and anxiety (102). Rutledge et al. (2006) reported clinically significant depression was experienced by almost a quarter of heart failure patients (29). The National Institute for Health and Care Excellence (NICE) recommends that a diagnosis of depression be considered in all patients presenting with heart failure (28). There is a need to enhance the knowledge of health professionals about the risk of heart failure and comorbid depression to increase and maintain quality of life among heart failure patients.

CHAPTER FOUR: PATIENT SURVEY

Introduction

It is important to explore how patients experience heart failure and their treatment in relation to their day-to-day living. Gaining an insight into the issues for the provision of healthcare services from the perspective of the user will contribute to the on-going development and improvement of heart failure services in Ireland.

The present study surveyed the experiences and opinions of heart failure patients living in the community to inform how the Irish Heart Foundation can best serve their needs. Specifically, heart failure patients were surveyed in relation to quality of life and care (both self-care and care provision) and quality of care, and satisfaction with healthcare providers. Patient's perceptions of the current level of service provision, including gaps in service provision, were also explored. Some of the measures outlined in the Tully et al. (2009) (5) study and TILDA 2011 (97) were applied to provide a comparison, which are discussed in relation to the findings below.

The patients were recruited through four national regional hospitals and the IHF database. We aimed to recruit approximately 30 patients from each hospital and the IHF, representing a total of 150 patients. Postal questionnaires were returned by 97 patients. Power analysis for the current study was based on the general population TILDA 2011 study (97) in which a sample of 89 participants reported heart failure. We achieved a 65% response rate in relation to our target number of 150 participants.

Ethical approval was granted from each participating hospital. To be included in the survey, patients were required to be over 18, community dwelling and have been diagnosed with heart failure for a minimum period of four months. The patient's consultant in each hospital sent a letter of invite to their patient. Patients were attending outpatient clinics. The invite contained an invite, a patient information leaflet and a consent form. If the patient was interested in receiving a questionnaire, they returned the consent form with their name and address to the researchers in RCSI. They were then forwarded the patient questionnaire. Reminders were not sent to participants to return questionnaires. All data was anonymised and recoded.

Measures

Demographics

Basic patient information relating to age, gender, marital status, medical card/private health insurance and co-morbid illnesses were recorded.

New York Heart Association (NYHA) Functional Classification

The NYHA was used to classify the extent of heart failure symptoms among the heart failure patients. It places patients in one of four categories based on how much they are limited during physical activity. Respondents were asked to choose which was most applicable to them from one of four statements ranging from 'no limitation in physical activity' to 'unable to carry out any physical activity'.

Quality of Life

The Heart Quality of Life (HeartQol) questionnaire was used to assess quality of life among heart failure patients. The HeartQol is a 14-item, self- administered questionnaire comprises 14-items with a 10-item physical scale (e.g. 'In the last four weeks have you been bothered by having to walk indoors on level ground?') and 4-item emotional subscales (e.g. 'In the last four weeks have you been bothered by feeling depressed?') which are scored from 0 (poor HRQL) to 3 (better HRQL) with a global score if needed. The HeartQoL questionnaire has proven to be a reliable instrument with a Cronbach's α between 0.80 and 0.91 for the global score and each subscale, and to be responsive in patients with a wide spectrum of cardiac diagnoses (103).

Psychological well-being

Psychological well-being was measured using the Hospital Anxiety and Depression Scale (HADS) (104). This self-report measure is widely used to determine levels of anxiety and depression in non-psychiatric patients. The HADS is a 14-item measure consisting of two sub-scales (a 7-item Anxiety scale (HADS-A) and a 7 item depression scale (HADS-D)). Items on the Anxiety scale include 'I feel tense or wound up', while items on the Depression scale include 'I can laugh and see the funny side of things'. Responses are rated on a scale of 0-3 with a score of 3 indicating a higher symptom frequency. Anxiety and depression items are scored separately and scores for each subscale range from 0-21. Scores are categorised as follows: 0-7 indicates 'non-case', 8-10 indicates 'possible case' and a score of 11 or above indicates a 'probable/definite case' of anxiety or depression. The HADS is a commonly used brief measure of psychological distress.

Self-care

Self-care behaviour among heart failure patients was measured using the European Heart Failure Self-Care Behaviour Scale (EHFSCBS) (105). This is a 12-item, self-administered questionnaire containing statements about heart failure self-care such as 'If I get short of breath, I take it easy'. Patients rated their agreement with the statements on a 5-point Likert Scale ranging from 1 ('I completely agree') to 5 (I do not agree at all') with total scores ranging from 12 to 60. The European Heart Failure Self-Care Behaviour Scale has been found to be a reliable (Cronbach's alpha=0.81), valid and practical scale for measuring the self-reported self-care of heart failure patients (105).

Satisfaction with GP

Satisfaction with the quality of care provided by GPs was assessed using 11 statements such as 'My GP is not very good at explaining my health problems' (5). Patients rated their agreement with statements on a 5-point Likert Scale ranging from 1 ('strongly agree') to 5 ('do not agree'). This was developed by Tully et al. (2009) (5).

Health Service Use

Health service use was assessed by way of an open response comment section. Patients were asked to indicate how often they had attended their GP and how often they had attended the Emergency Department (ED) in the hospital in the past 6 months.

Activities of Daily Living (ADL) and Instrumental Activities of Daily Living

The Katz Index of Independence in Activities of Daily Living (ADL) (106) was used to assess the functional status of the patient's ability to perform activities of daily living independently. The Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring and feeding. Respondents are scored 'yes/no' for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment and 2 or less indicates severe functional impairment. Patients indicated who helped them in their daily activities by choosing one of the following options: 'I don't require assistance,' 'Partner assists me,' 'Son or daughter assists me,' 'Home help or other,' 'Paid Carer,' 'Other, please say who.' The scale is widely used and is used extensively to identify functional capabilities of older adults in clinical and home environments.

The Lawton Instrumental Activities of Daily Living (IADL) Scale (107) was used to assess independent living skills. These skills are considered more complex than the basic activities measured by the Katz Index of ADL. The instrument identifies how a person is functioning at the present time. It measures eight domains of functioning including: ability to use telephone, shopping, food preparation, housekeeping, laundry, transport, medication and finances. A summary score ranges from 0 (Low function, dependent) to 8 (High function, independent). The assessment is widely used in research and clinical practice.

Services involved in care

Guidelines (23, 35) indicate that a range of health professionals should be involved in the optimal care of patients with heart failure. Patients were asked what services were involved in their care or that they would like to be involved in their care. A list of 14 services (e.g. social work, psychology and home-help services provided by the HSE) was developed and patients chose from the following options: 'Involved in my care,' 'Not involved in my care, 'or 'Not involved in my care BUT I would like them to be.'

Patients were asked to indicate if anything had prevented them attending any services involved in their care and if they received services as often as they needed by way of a free text comment section. Patients were also asked if they felt there were any other services that they should be receiving.

Social support

Social support was measured using the Berkman-Syme Social Network Index (SNI) (108). The Berkman-Syme Social Network Index is a self-reported questionnaire that is a composite measure of four types of social connections: marital status (married vs. not); sociability (number and frequency of contacts with children, close relatives, and close friends); church group membership (yes vs. no); and membership in other community organizations (yes vs. no). Items assessing an individual's sociability include: 'Is there someone available to give you good advice about a problem?' Items were scored using the protocol reported by Loucks et al. (2006) which is as follows: Married (no = 0; yes = 1); close friends and relatives (0-2 friends and 0-2 relatives = 0; all other scores = 1); group participation (no = 0; yes = 1); participation in religious meetings or services (less than or equal to every few months = 0; greater than or equal to once or twice a month = 1). The latter two categories are mutually exclusive from each other. Scores were summed: 0 or 1 being the most isolated category; and 2 being moderately isolated; 3 being moderately integrated and 4 being socially integrated (109).

Patient information

Patients were asked if any information they had received had answered all their questions about heart failure, and if not why they felt this was the case. Patients were also asked to indicate where they had received the information; what format they received it in; and what information they believe patients needed to have.

Patients were also asked what they believed the Irish Heart Foundation could do to help people with heart failure living in the community in relation to support services, education, information and advice.

Patients were asked a number of questions which they could answer in a free text comment section. Questions included: 'What could IHF do to help people with heart failure living in the community in relation to: Support services; Education; Information and Advice'. Answers to the free text comments were analysed using thematic analysis.

Comparison of the current study findings with previous Irish studies

The following section describes the findings of the present study and, where possible, we compare the results with findings from the Irish Longitudinal Study on Ageing (TILDA, 2011), a large-scale national study of people aged fifty and over living in Ireland. The study aims to document all aspects of ageing including health, social, psychological and economic conditions in those over fifty in Ireland. The study involves waves of data collection every two years and is representative of an older population in Ireland. There were 89 people who reported having a diagnosis of heart failure in the TILDA study (97). Findings from the Tully et al. (2009) study of 98 Irish heart failure patients recruited from outpatient departments of two large urban Dublin hospitals were also compared where possible (5).

Patient Demographics

Results

Demographic characteristics are displayed below in Table 4.1 Ninety seven patients returned the questionnaires. Respondents were primarily male (63% male and 36% female). A quarter of the sample had completed some secondary education. Half of the sample reported having NYHA class II heart failure.

Table 4.1 *Demographic and clinical characteristics of heart failure patients from three Irish studies†*

Socio-demographic and clinical characteristics	Current study N = 97 N (%)/mean	TILDA (2011) N= 89	Tully (2009) sample N = 98
Gender			
Male	61 (63%)	66%	83%
Female	35 (36%)	34%	17%
Age (years) (SD)	70 (10.07)	67 (9.4)	69.4 (8.8)
Marital Status			
Married	70 (72%)	70%	77%
Widowed	16 (16%)	19%	15%
Separated/Divorced	5 (5%)	6%	4%
Single/Never Married	5 (5%)	6%	4%
Socio-demographic and clinical characteristics	**Current study N = 97 N (%)/mean**	**TILDA (2011) N= 89**	**Tully (2009) sample N = 98**
Education			
No schooling	2 (2%)	44%	n/a
Primary education only	34 (35%)	17%	n/a
Some secondary education	23 (24%)	18%	n/a
Complete secondary	14 (14%)	16%	n/a
Some third level	17 (17%)	5%	n/a
Complete third level	7 (7%)	–	n/a
Location			
Northwest	30 (33%)	n/a	n/a
West	19 (20%)	n/a	n/a
South East	25 (26%)	n/a	n/a
IHF varied	17 (17%)	n/a	–
East	4 (4%)	–	–
NYHA status			
Class I	8 (8%)	n/a	28%
Class II	50 (52%)	n/a	47%
Class III	27 (28%)	n/a	18%
Class IV	11 (11 %)	n/a	8%
Medical Coverage of heart failure Patients:			
Full Medical Card	70 (72%)	74%	n/a
GP only card	2 (2%)	–	n/a
Private Insurance	19 (19%)	20%	n/a
Not covered	–	6%	n/a

† *Some figures do not add up to 100% due to rounding or missing values.*

Heart failure patients were given a list of other health conditions and were asked to indicate whether they had been told if they had any of these. Results are displayed below in Table 4.2 Eighty per cent of patients reported being told that they had heart failure. Forty per cent and 36% were told that they had high blood pressure and high cholesterol, respectively. Thirty two per cent of respondents reported being told that they had had a heart attack.

Table 4.2 *Health conditions*

Health problems	N= 97
COPD	6%
Stroke	7%
Depression	8%
Chronic Kidney Failure	8%
Angina	19%
Diabetes	18%
Heart attack	32%
High Cholesterol	36%
High BP	40%
Heart Failure	80%

Diagnosis of heart failure

Patients were asked who had given them the diagnosis of heart failure. Eighty per cent of respondents reported that a hospital doctor had given them the diagnosis; 8% indicated that their GP had done so, while 3% reported that a hospital nurse had given them the diagnosis. Nine per cent did not respond to this question.

Quality of life

The scores on the HeartQoL scale indicated that patients were experiencing more emotional deficits in the last four weeks than physical problems due to their illness (lower mean scores indicate a lower quality of life in relation to heart failure). See Table 4.3 below for mean scores.

Table 4.3 *HeartQoL Scores*

	Mean	Mean score as % of total HeartQoL domain score
Physical (0-30)	11.1	37%
Emotional (0-12)	5	42%
Total HeartQol (0-42)	15.2	36%

There was a small, negative correlation between age of the patients and HeartQoL scores (r = -.281; p <.05) with older patients experiencing lower HeartQoL scores. There was no difference in HeartQoL scores between males and females (r = 0.99; p = .370). Disease severity was negatively correlated with HeartQol scores (r = -.499; p <.001), with higher NYHA classification associated with lower HeartQoL scores.

There was a small, positive correlation between level of education and HeartQoL scores for patients (r =.282; p <.001), with those completing higher levels of education experiencing higher HeartQoL scores.

Psychological well-being

HADS scores were categorised as being in the range for ‘non-case’ of anxiety/depression, a ‘possible’ case of anxiety/depression or a ‘probable/definite’ case of anxiety/depression. Results are displayed below in Figure 4.1. Nine per cent of respondents had HADS-A scores indicating ‘probable/definite’ anxiety disorder while 6% of patients had HADS-D scores indicating ‘probable/definite’ depression.

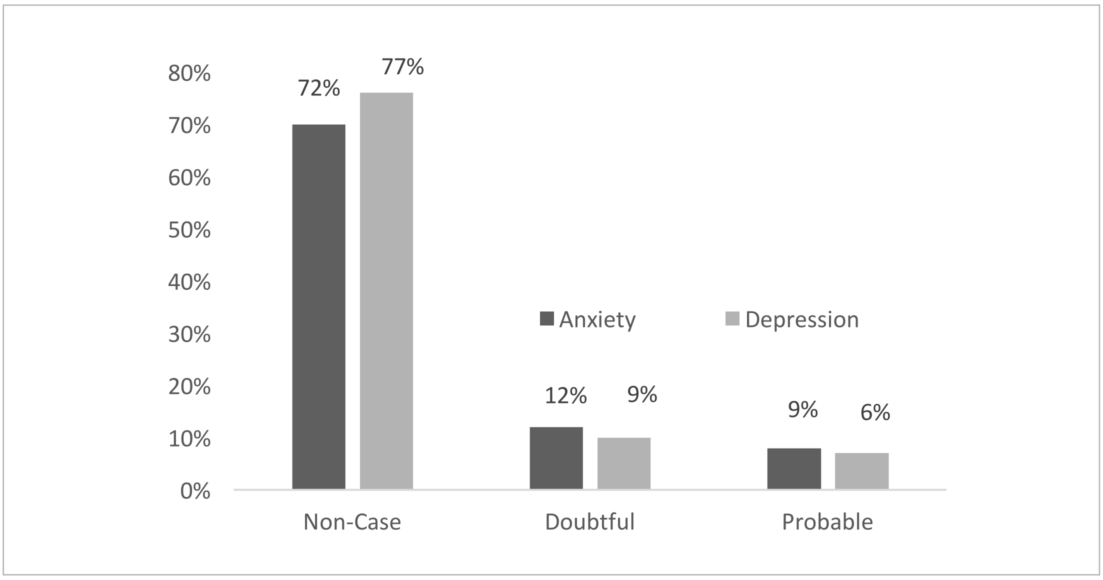

Figure 4.1 *Patient depression and anxiety (HADS) scores (N = 97)*

Self-care behaviour

Patients were asked about how they take care of their needs, see figure 4.2 below. Ninety-five per cent of patients reported taking their medication as prescribed, 87% reported receiving the flu vaccine annually and 81% stated that if they become short of breath, they take it easy. Sixty per cent of respondents in the present study reported weighing themselves daily. Over half (55%) of patients reported exercising regularly. The lowest rated self-care behaviours included contacting a doctor 'If I gain weight, I call my doctor or nurse' (45%) and 'If I experience fatigue, I call my doctor or nurse' (29%).

Patients were asked, by way of a free text comment section, to indicate who they would turn to for medical advice if they had a concern about their heart failure. The most common response reported by 34% of participants was that they would contact their GP if they had any concerns, while 9% indicated they would contact their heart failure nurse.

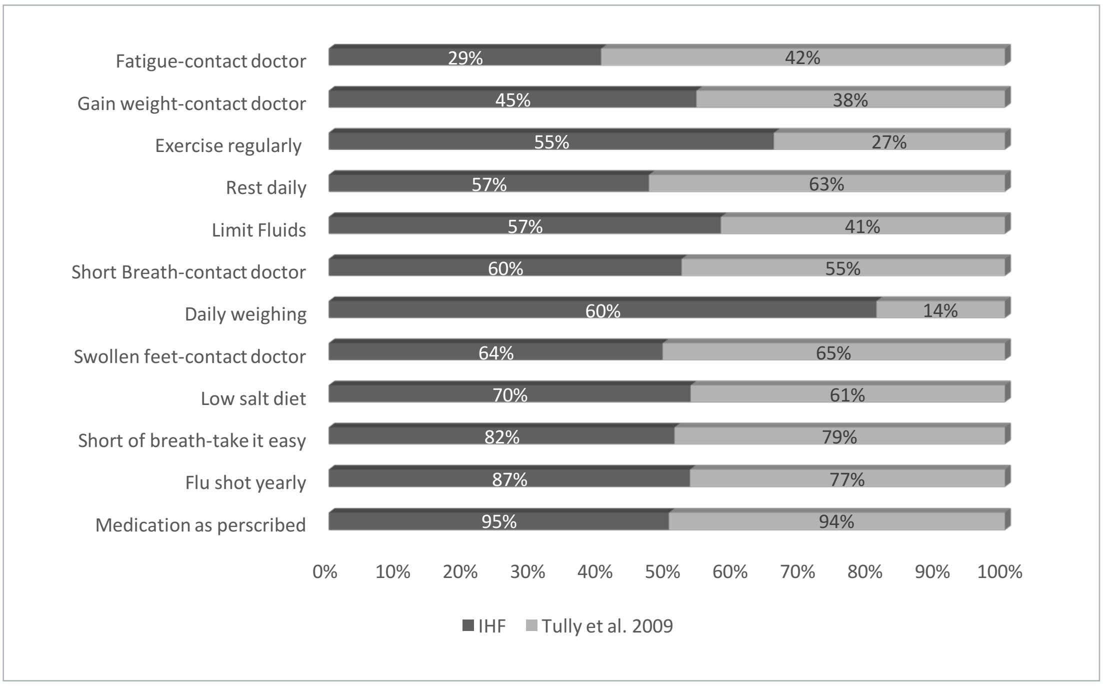

Figure 4.2 *Patient adherence by item on the EHFSCBS (n = 97) compared to Tully et al.*

Daily activities

The majority (92%) of patients did not report any difficulties in activities of daily living (ADL). Four per cent reported moderate impairment, while 2% reported severe functional impairment in daily activities. Respondents who indicated that they required some assistance in activities of daily living reported that their partner assisted them. Seven per cent reported that their partner assisted them in bathing. Forty-two (43%) of respondents who indicated a level II NYHA classification of heart failure stated that they were fully functioning and did not require assistance in activities of daily living, while 17 respondents who indicated a level III NHYA classification of symptoms reported that they did not require assistance in ADL.

Twenty-three (24%) respondents who indicated a level II NYHA classification of heart failure stated that they were fully independent and did not require assistance in instrumental activities of daily living (IADL). Six (6%) respondents reported severe difficulty in IADLs. Respondents most frequently indicated that they needed assistance from their partner with laundry (25%) and housework (22%). Gender differences were also explored (see Figure 4.3 below); males required more assistance than females in all measures of instrumental activities of daily living, e.g. twenty males (40%) compared to two (4%) females with a level II NYHA classification of heart failure reported needing assistance from their partner with laundry, 16 (32%) males reported needing assistance with food preparation compared to two (4%) females.

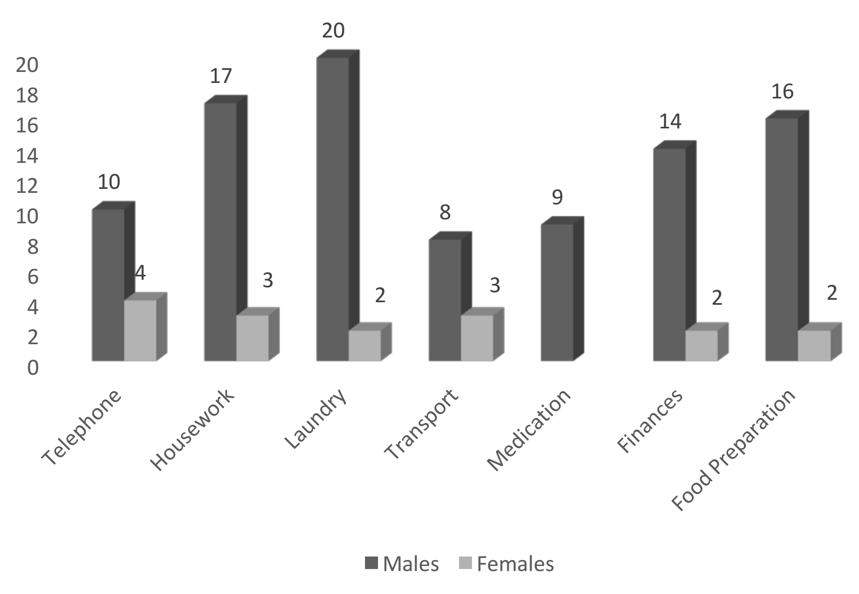

Figure 4.3 *Gender differences in instrumental activities of daily living*

Services involved in care

Patients were asked about what services were involved in their care or what services were not currently involved in their care but they would like to have them involved. Results are displayed below in Table 4.4. Sixty-nine per cent of patients reported that a heart failure clinic was involved in their care, while 16% reported heart failure clinics were not involved in their care. Thirty-nine per cent indicated that a community pharmacist was involved in their care while 46% reported that a community pharmacist was not involved in their care. Twenty-six per cent reported that a public health nurse was involved in their care, while 59% stated that a public health nurse was not involved in their care. Five per cent of patients indicated that a psychologist was involved in their care, while 78% reported a psychologist was not involved in their care.

Table 4.4 *Services involved, not involved and preference for access to care†*

	Involved in my care N (%)	Not involved in care N (%)	Not involved in care but I would like them to be N (%)
Social work services	**5 (5%)**	**72 (74%)**	**5 (5%)**
Home help provided by HSE	**11 (11%)**	**71 (73%)**	**4 (4%)**
Home help (private)	**4 (4%)**	**78 (80%)**	**2 (2%)**
Community pharmacist	**38 (39 %)**	**45 (46%)**	**2 (2%)**
HSE physiotherapist	**11 (11%)**	**64 (66%)**	**7 (7%)**
Physiotherapist (private	**4 (4%)**	**77 (79%)**	**2 (2%)**
HSE dietician	**12 (12%)**	**66 (68%)**	**6 (6%)**
Dietician (private)	**1 (1%)**	**79 (81%)**	**3(3%)**
Psychologist	**5 (5%)**	**76 (78%)**	**3 (3%)**
Psychologist (Private)	**1 (1%)**	**79 (81%)**	**3(3%)**
Hospice/Palliative care	**1 (1%)**	**80 (82%)**	**2 (2%)**
Public Health Nurse	**25 (26%)**	**57 (59%)**	**6 (6%)**
Heart failure Clinic (patients were recruited from hospitals)	**67 (69%)**	**16 (16%)**	**5 (5%)**
Counselling Service	**5 (5%)**	**70 (72%)**	**8 (8%)**

†Some figures do not add up to 100% due to rounding or missing values.

Barriers to care

Patients were asked in an open comment section if they experience any barriers to accessing or attending services. The majority (78%) of patients reported that they did not experience any barriers to accessing or attending services. Sixty-five per cent of respondents reported that they received services that they need as frequently as they require them, while 22% reported that they did not receive services as frequently as they needed. Patients were asked, by way of an open comment section, what services they believed patients with heart failure should receive. Twenty-six per cent of respondents reported that there are other services that patients should receive. A small number (7%) reported transport to and from appointments was problematic.

Social support

Social connectedness was assessed using the Berkman-Syme Social Network Index (108). Nine per cent of patients were classified as 'socially isolated', while 20% were classified as being 'moderately isolated'. Most patients with heart failure (37%) were categorised as being 'moderately socially integrated', while 17% of patients reported being socially integrated. Approximately 17% of participants did not respond to this question.

Support groups

Patients were asked, by way of an open comment section, their opinions about attending a support group for heart failure. Eighty-four per cent of respondents stated that they did not attend a support group, while 10% reported that they did attend one. When asked why they had not attended a group 48% reported that there was no such group in their area. Seventy per cent of patients with heart failure reported that a support group for people with heart failure would be helpful. When asked why they believed a support group would be helpful, 19 (20%) reported that it would allow them to meet other people with the same experiences and, as such, they would not feel alone in their condition.

Use of GP services

Patients with heart failure were asked how many GP visits they had over the last six months. Almost half (47%) of the respondents made 1-3 visits to the GP in the last six months, while 35% had made four or more visits. Sixteen per cent had not visited their GP. Visits were not necessarily related to the respondent's heart failure. There were no differences in mean number of visits to the GP based on NYHA classification.

Emergency department visits

Patients were also asked approximately how many ED visits they had experienced over the last six months. Over half (55%) of patients had not been admitted to ED in the past six months, while 18% had visited ED twice or more in the last six months. Visits were not necessarily related to the respondent's heart failure.

Satisfaction with GP services

The majority of respondents (92%) either strongly agreed or agreed that they were satisfied that their concerns were taken seriously by their GP. The majority (87%) of patients either strongly agreed or agreed that it was generally easy to get an appointment when they wanted. The main area of dissatisfaction for patients was receiving feedback on the progress of their condition with 17% either disagreeing or strongly disagreeing that they were satisfied with the feedback they receive. See Table 4.5 below for full results.

Table 4.5 *Satisfaction with GP by heart failure patients†*

	Strongly agree (%)	Agree (%)	Neither agree nor disagree (%)	Disagree (%)	Strongly Disagree (%)
I'm satisfied that my concerns are taken seriously by the GP	63	29	5	2	–
My GP sees older people as being a high priority group	33	29	27	6	1
My GP is not very good at explaining my health problems	12	12	12	35	23
My GP gives me feedback on the progress of my condition	32	35	12	12	5
My GP's surgery caters well for the needs of patients e.g. wheelchair access	40	38	5	10	2
It is generally easy to get an appointment at the time I want	46	41	8	3	–
I am satisfied that information is given to me by my GP in a sensitive and reassuring way	57	32	5	3	–
I am satisfied with the quantity of information received from my GP about my health	48	35	10	3	–
After I see my GP I feel my problems are understood	42	40	11	4	–
In my GP surgery, information given to reception staff remains confidential	51	39	6	–	–

† *Some figures do not add up to 100% due to rounding*

Heart failure information for patients

Ninety-one (94%) heart failure patients agreed that the information they received answered all of their questions about living with heart failure. Twenty-four per cent of respondents reported receiving the information about heart failure from a heart failure nurse. Patients received information in a variety of ways, 30% of respondents reported receiving information from one-to-one discussion with a health professional, 20% reported receiving information from leaflets, while 19% reported accessing information from the internet.

Patients were asked for their suggestions for the kinds of information they felt they should be receiving. The most frequent response was information relating to diet and exercise. Another frequent suggestion included information about the signs and symptoms of heart failure.

DISCUSSION AND SUMMARY

The aim of the patient survey was to assess quality of life, wellbeing, self-care, activities related to daily living, social connectedness and support group participation. Several questions also assessed areas of interest to the IHF. This sample of patients was similar to that in the Tully et al. study, in that participants were mostly male, married and had heart failure NYHA classification II (53% in current study compared to 47% in Tully et al.).

The respondents were on average 70 years old; primarily male (63%) and a majority married (72%). Half (52%) were classified as NYHA class II heart failure and the majority (72%) had a full medical card. Thirty-three per cent of respondents were recruited from hospitals in the Northwest; 26% from South East; 20% from West; 17% of responses were received from the IHF; and 4% were received from Dublin.

Eighty per cent of patients reported being told that they had heart failure. Forty per cent and 36% were told that they had high blood pressure and high cholesterol, respectively. Thirty-two per cent of respondents reported being told that they had had a heart attack.

Patients with more advanced heart failure (NHYA III and IV classifications) were lower in the Tully et al. study than in the current study (18% v 28% and 8% v 11% respectively).

Respondents reported experiencing more emotional deficits rather than physical problems in the last four weeks due to their illness. Older respondents had globally poorer quality of life scores than those reported by Tully et al. Those with more severe symptoms experienced poorer quality of life. Respondents with higher levels of education reported experiencing higher quality of life. There were no gender differences in quality of life scores.

Eight per cent of respondents had scores indicating 'probable/definite' anxiety disorder, while 7% of patients had HADS-D scores indicating 'probable/definite' depression. These scores are somewhat lower than those reported by Tully et al. They found that clinically significant anxiety and depression was present in 18% and 16% of patients respectively. Depression is linked to social isolation and poor adherence to medication and ultimately higher hospital admissions. This is a recurrent theme from the literature (24, 29). Thirty-seven per cent of patients were categorised as being 'moderately socially integrated' which is a positive finding. However, consideration must be given to nine per cent of patients who were classified as 'socially isolated and the relatively high percentage (20%) of patients reported as 'moderately isolated'. Eighty four per cent of respondents stated that they did not attend a support group. When asked why they had not attended a group 48% reported that there was no such group in their area. Seventy per cent of patients reported that a support group for people with heart failure would be helpful. When asked why they believed a support group would be helpful, one-fifth reported that it would allow them to meet other people with the same experiences and, as such, they would not feel alone in their condition.

Ninety five per cent of patients reported taking their medication as prescribed, compared to 90% in the Tully et al. study, while over half (55%) of patients reported exercising regularly. Sixty per cent of patients weighed themselves daily. Patients reported that they did not attend their GP for changes in symptoms related to weight or fatigue. This according to the literature could be problematic as patients who do not respond to symptom change have poorer outcomes (40).

Similar levels of satisfaction with GP services were reported in both studies. The number of GP visits in the current study were estimated to be higher than the Tully et al. study, 32% of their patients reporting that they visited a GP 1-3 times in the last year compared to 47% of current study participants in the previous six months. Levels of non-attendance at ED was reported in both studies, with 75% reported in Tully et al. in the past year, and compared to 55% in the past six months in the current study.

Sixty-nine per cent of patients reported that a heart failure clinic was involved in their care. Thirty-nine per cent indicated that a community pharmacist was involved in their care. Respondents were asked which services were not involved in their care that they would like to have involved, however the response rate was generally low. This may be a reflection of the fact that the majority of patients reported a low class of heart failure symptoms which may not require the use of such services.

The majority (78%) of patients reported that they did not experience any barriers to accessing or attending services. Transport was mentioned in both studies as a barrier but the numbers reporting this were low. However, the above findings indicate that the current sample were currently not in need of such services and as such are representative of the relatively mild level of heart failure among respondents.

In summary, the current study reflects a similar patient profile to the Tully et al. study, with some positive differences, especially in relation to lower rates of depression.

CHAPTER FIVE: CAREGIVERS SURVEY

Introduction

The quality of a patient's close personal relationships can influence the outcome in heart failure. Due to the considerable effect of heart failure on the individual, patients can often rely on their family to assist them in carrying out their everyday activities. Depending on the severity of the heart failure diagnoses, caregivers may also have to deal with a wide range of difficulties including; fluctuating symptoms, restricted and reduced social life and caregiver burnout (60). The combination of these factors may potentially adversely impact on the caregiver's overall quality of life and subsequently the quality of care provided to the person experiencing heart failure.

Despite an increasing prevalence of heart failure in Ireland and a growing body of research that details the adverse effects of caregiving for other chronic conditions such as dementia and stroke, little research exists into the effects of caregiving for people with heart failure. As such, there is a need to examine the physical, psychological and emotional impact of caring for those with heart failure. There is also a need to examine how caregivers of people with heart failure manage the condition in the community.

The present study surveyed the experiences and opinions of caregivers of people with heart failure living in the community to inform how the Irish Heart Foundation can best serve caregivers and patients. Specifically, caregivers were surveyed in relation to knowledge, opinions and current practice on providing support to patients.

Methods

Caregivers were recruited through the patients. When the questionnaire was posted to the patients, an envelope was included and the patient was requested to give that envelope to a caregiver or family member involved in their care. The envelope contained a letter of invitation addressed to the caregiver or family member, an information leaflet giving details of the study and contact details for the research team, consent forms and a pre-paid envelope for the return of the completed questionnaire.

Measures

Psychological well-being

Psychological well-being among caregivers was measured using the Hospital Anxiety and Depression scale (HADS). This has been described above.

Quality of Life

Quality of Life among caregivers was assessed using the CASP-19 (110). The CASP-19 is a brief measure of quality of life comprising four domains ('control', 'autonomy', 'pleasure' and 'self-realisation'). Items in each of the domains include:

- Control: 'I feel that what happens to me is out of my control'
- Autonomy: 'I can do the things I want to do'
- Pleasure: 'I feel that my life has meaning'
- Self-Realisation: 'I feel full of energy these days'

Each scale item was rated on 4-point Likert scale, with responses ranging from 0 (never) to 3 (often). The scale comprises both positively and negatively worded items. The negatively worded questions were reverse coded so that all item responses are in the same direction. The total scores range from 0 to 57 with higher indicating better quality of life. The CASP-19 has been shown to be a reliable and valid measure (111).

Caregiver burden

Caregiver burden among carers of people with heart failure was measured using the Caregiver Burden Questionnaire (CBQ-heart failure) (112). The CBQ-heart failure is a 26 item, self-administered instrument measuring the burden associated with caregiving in the following domains: physical, emotional/psychological, social, and impact on caregiver's life. Items in each of the domains include:

- Physical: 'How much has caregiving made you physically tired?'
- Social: 'How much has caregiving made you feel stressed?'
- Emotional/Psychological: 'How guilty have you felt because the time you spent caregiving limited what you can do for others?'
- Impact of caregiver's life: 'How much have you felt like you have no time for yourself?'

Participants rated their level of agreement with the statements on a 5 point Likert scale ranging from 0 ('Not at all') to 5 ('A lot').

Involvement in daily activities

Caregivers were asked about their involvement in daily activities of the person they care for. They ask whether the person that they care for required assistance with these activities (e.g. dressing and shopping) and who, in the main, provides this assistance.

Services involved in care

Caregivers were asked what services supported them in their care for a person with heart failure or they would like to support them in caring for a person with heart failure. A list of 14 services (e.g. social work, psychology and home help services provided by the HSE) was developed and caregivers chose from the following options: 'Supports my caring,' 'does not support my caring,' 'does not support my caring BUT I would like.'

Patients were also asked if they felt there were any other services that caregivers of people with heart failure should be receiving support from.

Activities of Daily Living (ADL) and Instrumental Activities of Daily Living

The Katz Index of Independence in Activities of Daily Living (ADL) was used to assess the functional status of the patient's ability to perform activities of daily living independently. The scale is widely used and is used extensively as a flag signalling functional capabilities of older adults in clinical and home environments. This has been described in Chapter 4.

The Lawton Instrumental Activities of Daily Living (IADL) Scale (1969) was used to assess independent living skills. These skills are considered more complex than the basic activities measured by the Katz Index of ADLS. The instrument identifies how a person is functioning at the present time. A summary score ranges from 0 (low function, dependent) to 8 (High function, independent). The assessment is widely used in research and clinical practice and has been described in more detail in the section above.

Patient information

Caregivers were asked if any information they had received had answered all their questions about heart failure, and, if not, why they felt this was the case. Caregivers were also asked to indicate what format they received the information in and what information they believe carers of people with heart failure needed to have.

Caregivers were also asked what they believed the IHF could do to help caregivers of people with heart failure living in the community in relation to: support services, education, information and advice.

Caregiver survey results

Table 5.1 *Demographic characteristics of caregivers*

Socio-demographic and clinical characteristics	N = 31N (%)/mean
Gender	
Male	7 (23%)
Female	24 (79%)
Age (years) (SD)	63 (13.17)
Marital Status	
Married	29 (94%)
Single/Never Married	2 (6%)
Education	
Primary education only	5 (16%)
Some secondary education	6 (19%)
Complete secondary education	9 (29%)
Some third level	5 (16%)
Complete third level	6 (19%)
Location	
North west	15 (48%)
West	6 (19%)
IHF varied location	8 (26%)
Dublin	2 (6%)
NYHA status of person you care for:	
Class I	8 (25%)
Class II	15 (48%)
Class III	4 (13%)
Class IV	3 (10 %)
Current Situation:	
Retired	12 (39%)
Employed	7 (23%)
Permanently sick	1 (3%)
Looking after home	3 (10%)
Part time carer	6 (19%)
Relationship to person you care for:	
Spouse	20 (64%)
Neighbour	1(3%)
Daughter	2(6%)
Son	2(6%)
Carer's Allowance:	
Full rate	1 (3%)
Half rate	2(6%)
No Carer's Allowance	24 (77%)

Respondents were primarily female (79% female and 21% male). The mean age of was 63 (range 25-79). The majority of respondents were spouses of the person they cared for. A quarter of the sample had completed some secondary education. Just under half of the sample (48%) reported the person they cared for as having NYHA class II heart failure. Twelve (39%) of respondents were retired. The majority (77%) of caregivers did not receive any Carer's Allowance.

Health conditions of caregivers

Caregivers were asked to name any conditions they had been told that they had. Results are displayed below in Table 5.2, 42% of caregivers reported being told that they had high blood pressure. Thirteen per cent of respondents reported being told that they had had a heart attack. Six per cent of caregivers reported having heart failure themselves. Caregivers were also asked what conditions the person they care for had been told they had. Eighty-four per cent of caregivers reported that the person they care for had been told they had heart failure. Thirty-nine per cent of caregivers reported that the person they cared for had had a heart attack, while 32% had high blood pressure.

Table 5.2 *List of caregiver health conditions*

Conditions	Caregivers reported they had the following conditions (%)	Caregivers reported that the people they cared for had the following conditions: (%)
Depression	3%	7%
Angina	3%	26%
Diabetes	3%	11%
Heart attack	13%	39%
High Cholesterol	23%	32%
High BP	42%	32%
Heart Failure	6%	84%
COPD	–	11%
Stroke	–	7%
Kidney disease	–	11%

Psychological well-being

Results are displayed below in Figure 5.1. Thirteen per cent of caregivers had HADS-A scores indicating 'probable/definite' anxiety disorder. There was no relationship between marital status and scores on the HADS.

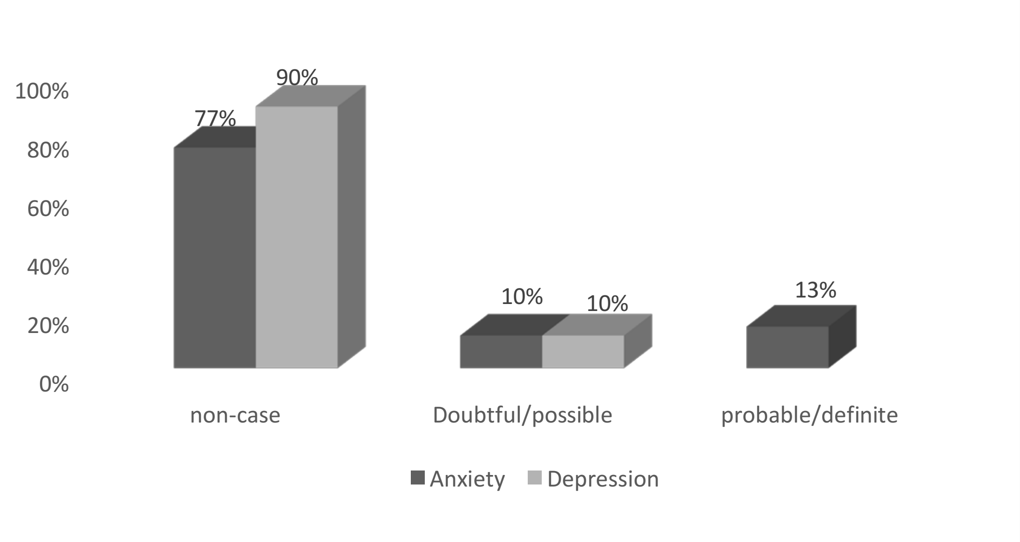

Figure 5.1 *Caregiver's depression and anxiety (HADS) scores (n = 31)*

Caregiver burden

The CBQ-heart failure consists of subscales which reflect different domains of caregiver burden and can be used independently. For each subscale, the total score was computed as the average of the subsequent item scores, ranging from 1–5, with a higher score representing a higher burden. Total scores range from 1 (low burden) to 130 (high burden). See Table 5.3 below for full results. The mean score for caregiver burden on the CBQ-heart failure is 45 representing 35% of the total score. This is a very positive finding indicating that overall, respondents are experiencing low levels of reported caregiver burden.

Table 5.3 *CBQ-heart failure scores*

	Mean	Mean score as % of total CBQ-heart failure domain Score
Physical well-being (1-25)	8.3	33%
Emotional well-being (1-75)	27	36%
Social life and relationships(1-10)	3	30%
Lifestyle (1-20)	7	35%
Total CBQ-heart failure (1-130)	45	35%

Quality of Life

The mean score for quality of life on CASP-19 is 44 (Table 5.4 below), representing 77% of the total score. This is a very positive finding indicating that overall, this caregiver population experiences high levels of quality of life. In terms of the CASP-19 domains, respondents reported particularly high scores on the pleasure domain, with relatively lower scores on the control domain. The high score on the pleasure domain suggests that the caregivers derive considerable enjoyment from life. Scores were compared with a general sample from the first wave of the TILDA (2011) which reported a CASP-19 mean of 43.3.

Table 5.4 *Caregiver CASP-19 Quality of Life mean score with TILDA mean scores for comparison*

	Mean	Mean score as % of total domain CASP-19 Score	TILDA Mean
Control (0-12)	9.9	82%	8.1
Self-Realisation (0-15)	14.6	91%	10.8
Pleasure (0-15)	11.2	74%	10.7
Total CASP-19 (0-57)	44	78%	43.3

Services involved in care

Caregivers were asked what services were already supporting their caring or what services were not currently supporting their caring but they would like them to be involved. Results are displayed below in Table 5.5. Thirty-nine (12%) indicated that a community pharmacist supported their care, while 48% (15) reported that a community pharmacist did not support their care. Thirty-two (10%) reported that a public health nurse supported their care, while 45% (14) stated that a public health nurse was not involved in their care. Seventy-seven per cent of caregivers indicated that a psychologist did not their support care.

Table 5.5 *Services involved with caregivers*

	Supports my caring N (%)	Does not support my caring N (%)	Not involved my caring but I would like them to be N (%)
Social work services	4 (13%)	23 (74%)	2 (6%)
Home help provided by HSE	3(10%)	20 (64%)	2 (6%)
Home help (private)	2 (6%)	22 (71%)	–
Community pharmacist	12 (39 %)	15 (48%)	2 (6%)
HSE physiotherapist	7 (23%)	20 (64%)	1 (3%)
Physiotherapist (private)	–	24 (77%)	–
HSE dietician	6 (19%)	19 (61%)	3 (10%)
Dietician (private)	–	25 (80%)	–
Psychologist	1 (3%)	24 (77%)	–
Psychologist (Private)	–	24 (77%)	–
Hospice/Palliative care	–	25 (81%)	–
Public Health Nurse	10 (32%)	14 (45%)	3 (10%)

Daily activities

Caregivers were asked whether the person they cared for required assistance with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). Twenty-four (77%) caregivers indicated that the person they cared for did not require assistance with activities of daily living. Six (19%) caregivers reported that the person they were caring for did not require any assistance in IADL, while 4 (13%) reported severe impairment in IADL. Caregivers indicated that they most frequently assisted the person with laundry (52%) and housework (52%). See Table 5.6 below for full results.

Table 5.6 *Patient ADL and IADL scores*

	Person does not require assistance N (%)	Caregiver assistance N (%)
Getting across a room	28 (90%)	3 (10%)
Dressing	26 (84%)	4(13%)
Bathing	25 (81%)	6 (19%)
Eating	31 (100%)	-
Getting out of bed	29 (94%)	2 (6%)
Using the toilet	29 (94%)	1 (3%)
Using the telephone	28 (90%)	1 (3%)
Shopping	20 (65%)	7 (23%)
Food preparation	18 (58%)	10 (32%)
Housework	10 (32%)	16 (52%)
Laundry	11 (35%)	16 (52%)
Transport	20 (65%)	10 (32%)
Taking medication	20 (65%)	10 (32%)
Handling Finances	19 (61%)	10 (36%)

Patient information

Eleven (35%) respondents reported receiving the information about heart failure from a heart failure nurse. Caregivers of people with heart failure received information in a variety of ways. Twenty six per cent (8) of respondents reported receiving information from one to one discussion; 23% (7) reported receiving information from leaflets, while 23% (7) reported receiving information from the internet.

Respondents were asked what the Irish Heart Foundation could do to help caregivers of people with heart failure living in the community in relation to support services. Suggestions (7%) included the introduction of support groups. Caregivers were asked what kinds of information do caregivers of people with heart failure need to have. Twenty two per cent of respondents agreed that caregivers required information on the signs of symptoms of heart failure and what to do in case of emergency.

DISCUSSION AND SUMMARY

The caregivers sample derived through the patients had a total of 31 respondents. The sample was primarily female (23% male and 77% female). The mean age of caregivers was 63 (range 25-79). The majority of respondents were the spouse of the person they cared for. Just under half of the sample (48%) reported the person they cared for as having NYHA class II heart failure. The majority (77%) of caregivers did not receive any Carer's Allowance.

Response rate

There was a relatively small response rate for the present study (N= 31). This may reflect the fact that the majority of the heart failure respondents indicated that they were NYHA class II patients and as such may not need a great deal of formal/informal caregiving. Current research into chronic conditions points to the adverse effects of caregiving such as psychological distress and burn out (60). As such, it is important that future research continue to explore the effects of caregiving at every stage of heart failure.

The majority (64%) of the sample were spousal caregivers which according to the literature is unusual as the majority of heart failure patients are either single or widowed (113).

Forty-two per cent of the caregivers reported receiving a diagnosis of high blood pressure and 23% reported having a diagnosis of high cholesterol. Eighty-four per cent of caregivers reported that the person they care for had been told they had heart failure.

Psychological well-being

The present study found that 13% of caregivers had HADS-A scores indicating 'probable/definite' anxiety disorder. While this result is relatively low, previous findings have found that informal caregiving is often associated with increased levels of psychological distress (60). The low finding in the current study may be reflective of the low severity of symptoms experienced by the patients. Additionally, length of time providing care was not assessed so there is no way of telling if the caregiver was relatively new to the role and as such may not experience the levels of psychological distress associated with providing long term care. The results may also be reflective of the small sample size and sampling bias with caregivers with more severe levels of psychological distress being underrepresented.

Caregiver burden

The current study found that caregiver burden was quite low among respondents. While this is positive result, suggesting that respondents were experiencing low levels of burden, the sample size was quite small and as such those experiencing higher levels of caregiver burden may be underrepresented.

Regarding psychological well-being, 13% of caregivers had HADS-A scores indicating 'probable/definite' anxiety disorder.

The mean score for quality of life on CASP-19 was 44 representing 77% of the total score. This is a very positive finding indicating that; overall, the carer population experiences high levels of quality of life.

Caregivers indicated that the majority of services (e.g. public health nurse, heart failure clinic and social work services) do not support their caregiving. Caregivers were asked to indicate if they would like the above services to be involved in their care however, the response rate was relatively low for each.

Twenty-four (77%) of caregivers indicated that the person they cared for did not require assistance with activities of daily living such as dressing, bathing and eating. Six (19%) caregivers reported that the person they were caring for did not require any assistance in IADL, while 4 (13%) reported severe impairment in IADL. Caregivers indicated that they most frequently assisted the person with laundry (52%) and housework (52%).

Regarding information received about heart failure, twenty-three (74%) caregivers agreed that any information they received answered all of their questions about with heart failure, while four (13%) were dissatisfied with the information they had received.

With regards to what the IHF can do to help caregivers of people with heart failure, respondents (22%) most frequently agreed that caregivers required information on the signs of symptoms of heart failure and what to do in case of emergency.

CHAPTER SIX: CONCLUSION

This study aimed to find answers to the following questions:

1. What are the patients' experiences of living in the community with heart failure?
2. What are the experiences of the caregivers of patients with heart failure?
3. What are the allied health service providers (including nurses, general practitioners and pharmacists, hospice staff) views and attitudes and knowledge of community services for heart failure patients and their families?
4. What support can the Irish Heart Foundation provide for people with heart failure?

Key findings and recommendations

Study one: Qualitative interviews

- Sixteen patients and two caregivers were interviewed.
- Patients with heart failure value timely diagnosis with regular follow-up, so as to build rapport and trusting relationships with healthcare staff.
- Patients felt their GPs and pharmacists were not part of their integrated care plan.
- Some patients reported some GPs had a lack of knowledge and awareness of heart failure symptoms.
- Information overload following a patient's initial diagnosis and the use of generic educational material was problematic.

Study two: Healthcare professionals

- A total of 46 healthcare providers returned questionnaires, 21 of whom were GPs, 18 nurses and 5 pharmacists and two hospice staff.
- GPs agreed there was a geographic disparity in equity of service provision for heart failure patients.
- Two-thirds of GPs reported that they would like to know more about clinical guidelines, while 27% were unsure about the New York Heart Association (NHYA) classification of heart failure.
- Half of the GPs surveyed indicated that they would like to know more about the association between depression and heart failure.
- GPs reported a sense of reluctance or felt unable to manage heart failure with the complexity of co-morbidities and the amount of time required supporting their patients, preferring to refer the patient back to hospital-based services.
- GPs perceived that some of their patients could manage their self-care better than others.
- Over half of all healthcare professionals surveyed reported that they would like to know more about where patients can access community health services.
- Two-thirds of allied health professionals indicated that accessing psychological support was a challenge.
- Pharmacists appear to be an unrecognised resource in the community for patients with heart failure.

Study three: Patient survey

- A total of 97 patients returned questionnaires.
- Patients were generally well in this survey, over half were classified as having heart failure NYHA stage II (slight limitation of physical activity; comfortable at rest; ordinary physical activity results in fatigue, palpitation, dyspnoea (shortness of breath)).

- Many patients reported no major issues of self-care and management of their disease.
- Patients were satisfied with the cardiac care they received, with almost two-thirds attending a heart failure clinic.
- Some patients expressed feelings of vulnerability when treated in hospital Emergency Departments (EDs) by non-cardiac specialists. They perceived that such doctors lacked knowledge and expertise about the care of heart failure patients.
- Nine per cent of respondents reported a probable/definite anxiety disorder while 6% of patients indicated probable/definite depression levels.
- Patients with heart failure were at risk of social isolation; almost 30% reported being isolated or moderately isolated.
- Patients reported contacting their doctor or nurse in two situations in particular – if they gained weight, or if they experienced fatigue; these were the lowest rated self-care behaviours.
- Recognition of serious symptoms such as sudden weight gain or fatigue, which could lead to acute episodes, were problematic and hampered patients in decision-making of when to seek help.
- Eighty-four per cent of patients stated that they did not attend a support group, with half of patients stating a support group was not available in their area. Two-thirds of patients reported that a support group for people with heart failure would be helpful.

Study four: Caregiver survey

- Thirty-one caregivers returned questionnaires.
- Recognition of heart failure symptoms and when to seek help was identified as a problem for caregivers.
- Thirteen per cent of caregivers reported a probable/definite anxiety disorder.
- Overall, reflecting the patient sample, respondents reported experiencing low levels of caregiver burden.

We have provided key recommendations based on these findings and in direct response to the key research questions. A number of the recommendations are outlined below for patients, caregivers and healthcare providers, with further detail provided in the executive summary:

1. Greater awareness of available patient resources is required. Patients reported a need for information about everyday health behaviours with clearly identified goals or targets on how best to optimise their health in an easy to remember manner.
2. Nationwide support groups would be appreciated by both patients and caregivers to alleviate social isolation.
3. Caregivers require specific educational information to (a) include recognition of potentially harmful symptoms (b) when and how to seek health professional advice and (c) how to recognise the potential side-effects of medications.
4. Caregivers require practical, everyday training in skills for heart failure management. Useful skills including preparation of healthy food and weight management, simple everyday safe exercise regimes and the importance of balancing this with rest periods.
5. Implementation of an integrated care plan with resources is required for GPs.
6. Education relating to heart failure symptoms and management should be made accessible to all non-cardiology healthcare staff with whom patients may come into contact, such as those in emergency departments and pharmacists, who are often the first point of contact for patients experiencing an acute episode.

The overarching aim of this research was to document the experiences of patients diagnosed with heart failure and those who care for them while living in the community. The main focus of the study was to speak to patients who are not in the acute phase of heart failure, but living in their respective communities. It is important to explore the manner in which patients cope with their condition, how they manage their everyday lives and what they need to improve their quality of life. There is a limited amount of research conducted on quality of life with heart failure patients in Ireland.

The study methodology reflected a mixed method approach led by the literature. Key findings and recommendations are presented which reflect the views of this relatively well group of patients and engaged healthcare providers.

Previous research conducted by Tully et al. reported on quality of life with 98 patients in rural and urban locations in Ireland. A number of established survey instruments were used to assess patients' wellbeing and experiences. The current study sought to report on an updated vision of heart failure patients lives in 2015, including many of the measures previously used. Results have been discussed in Chapter 4.

The number of patient surveyed was very similar in both studies and is reflective of the numbers in general population surveys who reported heart failure conducted by TILDA 2011 and 2014 respectively as 89 and 54 (114).

Combining views from healthcare providers and caregivers provides a comprehensive unique insight into living with heart failure in 2015 in Ireland. Six years after the call from Tully et al. for integrated service provision and shared care, some changes are evident, there has been the role out of heart failure clinics and service provision has improved. Yet, there remains an inequity of provision across the country. Primary and secondary care provision is not ideal with many GPs not fully integrated into a structured care plan for heart failure patients.

Recommendations from the current study are provided based on the needs and views of the survey participants. These are a relatively well group of patients who were motivated to share their mainly positive outlook. There is also a cohort of patients with heart failure who do not have access to heart failure clinics, and also those who do not respond to surveys and crucially their needs are not being well documented, especially those who are in the later stages of their illness. A call for a national database documenting heart failure patients was called for by Tully et al. in order to benchmark service provision; to date this has not been implemented. Such a database would allow for specific, targeted patient surveys which would greatly improve our knowledge of the experience of patients and ultimately improve health care provision.

Limitations of this study

Ethical approval from one of the hospitals took more than six months to be heard by their research ethics committee which had an impact on the length of time available for recruitment and return of questionnaire.

Several hospitals in the Dublin region were invited to take part but declined for a variety of reasons, one of which included current on-going research with heart failure patients.

Patients were recruited from four regional hospital databases, identified through their consultants as being four months post diagnosis and the IHF databases. This may have biased our sample and excluded patients who are not attending heart failure clinics. Those patients who are feeling well are more likely to contribute to research and this led the results of this study to be representative of patients who appear to be coping well in the community. As in other studies, women were underrepresented in the study sample.

Response rates from GPs are generally low in surveys; our sample reflects this, although those who responded may have an interest in contributing to the knowledge base.

In summary

The overarching conclusion from these studies is that the heart failure patients with whom we spoke reported good health and remained highly motivated and capable of managing their diagnosis within the community. The respondents in this report were a relatively 'well treated' population, most of whom had access to good heart failure services. Many patients do not have access to this level of care and therefore their needs may not be reflected in this report.

Caregivers did not perceive their role as burdensome, however both groups expressed a greater need for clear guidelines on support services, symptom recognition and what to do in an emergency.

In addition, allied healthcare professionals identified a significant need for more community resources, referral systems and education for healthcare professionals.

Six years after the call from Tully et al. for integrated service provision and shared care, some changes are evident, there has been the role out of heart failure clinics and service provision has improved. Yet, there remains an inequity of provision across the country. Primary and secondary care provision is not ideal with many GPs not fully integrated into a structured care plan for heart failure patients.

REFERENCES

1. K M. Irish Cardiac Society calls for rapid Community Heart Failure diagnosis. Irish Cardiac Society 2016.
2. James S, Barton D, O'Connell E, Voon V, Murtagh G, Watson C, et al. Life expectancy for community-based patients with heart failure from time of diagnosis. International Journal of Cardiology. 2015;178:268-74.
3. Department of Health and Children. Changing Cardiovascular Health. National Cardiovascular Health Policy 2010 - 2019. 2010.
4. The Heartbeat Trust. The cost of heart failure in Ireland. The social, economic and health implications of Heart Failure in Ireland. Dublin: The Heartbeat Trust, 2015.
5. Tully N, Morgan K, McGee H, Burke H. Quality of Life and Quality of Care in Heart Failure: Perspectives of Irish Patients. Dublin: Department of Psychology Division of Population Health Sciences Royal College of Surgeons in Ireland, 2009.
6. Gallagher J. Challenges and opportunities in heart failure: unmet clinical needs,economic burden, and impact on society. Milan Italy 2015.
7. Heartbeat Trust. www.heartbeat-trust.ie [cited 2016 July].
8. Croí west of Ireland Cardiac Foundation. www.croi.ie [cited 2016 July].
9. Cowie MR, Anker SD, Cleland JGF, Felker GM, Filippatos G, Jaarsma T, et al. Improving care for patients with acute heart failure: before, during and after hospitalization. ESC Heart Failure. 2014;1(2):110-45.
10. Jaarsma T, Nikolova-Simons M, van der Wal MHL. Nurses' strategies to address self-care aspects related to medication adherence and symptom recognition in heart failure patients: An in-depth look. Heart & Lung: The Journal of Acute and Critical Care. 2012;41(6):583-93.
11. Tully N, Morgan K, Burke H, McGee H. Patient Experiences of Structured Heart Failure Programmes. Rehabilitation Research and Practice. 2010:157939.
12. Feltner C, Jones CD, Cene CW, Zheng ZJ, Sueta CA, Coker-Schwimmer EJL, et al. Transitional Care Interventions to Prevent Readmissions for Persons With Heart Failure A Systematic Review and Meta-analysis. Annals of Internal Medicine. 2014;160(11):774-+.
13. The Mayo Clinic. Diseasess and conditions, Heart Failure http://www.mayoclinic.org/diseases-conditions/heart-failure/basics/causes/con-20029801 [cited 2016].
14. Ponikowski P, Voors AA, Anker SD, Bueno H, Cleland JGF, Coats AJS, et al. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure.The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC)Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. European Heart Journal 2016;37(27):2129-200.
15. Sperry BW, Ruiz G, Najjar SS. Hospital readmission in heart failure, a novel analysis of a longstanding problem. Heart Fail Rev. 2015;20(3):251-8.
16. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE, Drazner M, H, et al. 2013 ACCF/AHA guidelines for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. Circulation 2013 128.
17. Lang CC, Mancini DM. Noncardiac comorbidities in chronic heart failure. Heart. 2007;93(6):665-71.
18. Greenberg B. Acute Decompensated Heart Failure Treatments and Challenges. Circulation Journal. 2012;76(3):532-43.
19. Collins S, Storrow AB, Albert NM, Butler J, Ezekowitz J, Felker GM, et al. Early Management of Patients With Acute Heart Failure: State of the Art and Future Directions. A Consensus Document From the Society for Academic Emergency Medicine/Heart Failure Society of America Acute Heart Failure Working Group. Journal of Cardiac Failure. 2015;21(1):27-43.
20. Jaarsma T, Larsen T, Strömberg A. Practical guide on home health in heart failure patients. International Journal of Integrated Care. 2013;13(4).
21. Takeda A, Taylor SJC, Taylor RS, Khan F, Krum H, Underwood M. Clinical service organisation for heart failure. Cochrane Database of Systematic Reviews. 2012(9):159.
22. Bui AL, Horwich TB, Fonarow GC. Epidemiology and risk profile of heart failure. Nature reviews Cardiology. 2011;8(1):30-41.
23. Dickstein K, Cohen-Solal A, Filippatos G, McMurray JJV, Ponikowski P, Poole-Wilson PA, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2008. European Heart Journal. 2008;29(19):2388-442.
24. Jeon YH, Kraus SG, Jowsey T, Glasgow NJ. The experience of living with chronic heart failure: a narrative review of qualitative studies. BMC Health Serv Res. 2010;10:77.
25. Browne S, MacDonald S, May CR, MacLeod U, Mair FS. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. PLoS One. 2014;9(3):e93288.

26. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. European Journal of Heart Failure. 2009;11(5):433-43.
27. Health Services Executive & Irish Hospice Foundation. PALLIATIVE CARE FOR ALL Integrating Palliative Care into Disease Management Frameworks. Joint HSE and IHF Report of the Extending Access Study. 2008.
28. National Institute for Health and Clinical Excellence. Chronic heart failure: management of chronic heart failure in adults in primary and secondary care. 2010.
29. Rutledge T, Reis VA, Linke SE, Greenberg BH, Mills PJ. Depression in heart failure a meta-analytic review of prevalence, intervention effects, and associations with clinical outcomes. J Am Coll Cardiol. 2006;48(8):1527-37.
30. Heo S, Lennie TA, Okoli C, Moser DK. Quality of Life in Patients With Heart Failure: Ask the Patients. Heart & Lung : The Journal of Critical Care. 2009;38(2):100-8.
31. Dobre D, de Jongste MJL, Haaijer-Ruskamp FM, Sanderman R, van Veldhuisen DJ, Ranchor AV. The enigma of quality of life in patients with heart failure. International Journal of Cardiology. 2008;125(3):407-9.
32. Hobbs FD, Kenkre JE, Roalfe AK, Davis RC, Hare R, Davies MK. Impact of heart failure and left ventricular systolic dysfunction on quality of life: a cross-sectional study comparing common chronic cardiac and medical disorders and a representative adult population. Eur Heart J. 2002;23(23):1867-76.
33. Zuluaga MC, Guallar-Castillón P, López-García E, Banegas JR, Conde-Herrera M, Olcoz-Chiva M, et al. Generic and disease-specific quality of life as a predictor of long-term mortality in heart failure. European Journal of Heart Failure. 2010;12(12):1372-8.
34. O'Loughlin C, Murphy NF, Conlon C, O'Donovan A, Ledwidge M, McDonald K. Quality of life predicts outcome in a heart failure disease management program. International Journal of Cardiology. 2010;139(1):60-7.
35. McMurray JJV, Adamopoulos S, Anker SD, Auricchio A, Böhm M, Dickstein K, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. European Heart Journal. 2012;33(14):1787-847.
36. Lam C, Smeltzer SC. Patterns of Symptom Recognition, Interpretation, and Response in Heart Failure Patients: An Integrative Review. Journal of Cardiovascular Nursing. 2013;28(4):348-59.
37. Bos-Touwen I, Jonkman N, Westland H, Schuurmans M, Rutten F, de Wit N, et al. Tailoring of Self-Management Interventions in Patients With Heart Failure. Current Heart Failure Reports. 2015;12(3):223-35.
38. Ditewig JB, Blok H, Havers J, van Veenendaal H. Effectiveness of self-management interventions on mortality, hospital readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure: A systematic review. Patient Education and Counseling. 2010;78(3):297-315.
39. Siabani S, Driscoll T, Davidson PM, Leeder SR. A randomized controlled trial to evaluate an educational strategy involving community health volunteers in improving self-care in patients with chronic heart failure: Rationale, design and methodology. SpringerPlus. 2014;3:689.
40. Moser D, Dickson V, Jaarsma T, Lee C, Stromberg A, Riegel B. Role of Self-Care in the Patient with Heart Failure. Current Cardiology Reports. 2012;14:265-75.
41. Health Information and Quality Authority. Health technology assessment of chronic disease self-management support interventions. Heart Failure (extracted from main report). 2015.
42. Rasmusson K, Flattery M, Baas LS. American Association of Heart Failure Nurses Position Paper on Educating Patients with Heart Failure. Heart & Lung: The Journal of Acute and Critical Care. 2015;44(2):173-7.
43. Jaarsma T, Brons M, Kraai I, Luttik ML, Strömberg A. Components of heart failure management in home care; a literature review. European Journal of Cardiovascular Nursing. 2012;12(3):230-41.
44. Strachan PH, Currie K, Harkness K, Spaling M, Clark AM. Context Matters in Heart Failure Self-Care: A Qualitative Systematic Review. Journal of Cardiac Failure. 2014;20(6):448-55.
45. McGreal M, Hogan M, Walsh-Irwin C, Maggio N, Jurgens C. Heart failure self-care interventions to reduce clinical events and symptom burden. Research Reports in Clinical Cardiology. 2014;5:243—57.
46. Jaarsma T, Strömberg A. Heart Failure Clinics Are Still Useful (More Than Ever?). Canadian Journal of Cardiology. 2014;30(3):272-5.
47. Stamp K. Women with Heart Failure: Do They Require a Special Approach for Improving Adherence to Self-Care? Current Heart Failure Reports. 2014;11(3):307-13.
48. Buck HG, Harkness K, Wion R, Carroll SL, Cosman T, Kaasalainen S, et al. Caregivers' contributions to heart failure self-care: A systematic review. European Journal of Cardiovascular Nursing. 2015;14(1):79-89.
49. Buck HG, McAndrew L, Dionne-Odom JN, Wion R, Riegel B. What were they thinking? Journal of Hospice and Palliative Nursing. 2015;17(3):249-56.
50. Granger BB, Sandelowski M, Tahshjain H, Swedberg K, Ekman I. A Qualitative Descriptive Study of the Work of Adherence to a Chronic Heart Failure Regimen: Patient and Physician Perspectives. Journal of Cardiovascular Nursing. 2009;24(4):308-15.
51. Clark AM, Savard LA, Spaling MA, Heath S, Duncan AS, Spiers JA. Understanding help-seeking decisions in people with heart failure: A qualitative systematic review. International Journal of Nursing Studies. 2012;49(12):1582-97.

52. Sethares KA, Chin E, Jurgens C. Predictors of Delay in Heart Failure Patients and Consequences for Outcomes. Current Heart Failure Reports. 2015;12(1):94-105.

53. Sethares KA, Sosa M, Fisher P, Riegel B. Factors associated with delay in seeking care for acute decompensated heart failure. Journal of Cardiovascular Nursing 2014;29(5):429-38.

54. Ponikowski P, Anker SD, AlHabib KF, Cowie MR, Force TL, Hu S, et al. Heart failure: preventing disease and death worldwide. ESC Heart Failure. 2014;1(1):4-25.

55. Lambrinou E, Protopapas A, Kalogirou F. Educational Challenges to the Health Care Professional in Heart Failure Care. Current Heart Failure Reports. 2014;11(3):299-306.

56. Albano MG, Jourdain P, De Andrade V, Domenke A, Desnos M, d'Ivernois JF. Therapeutic patient education in heart failure: do studies provide sufficient information about the educational programme? Arch Cardiovasc Dis. 2014;107(5):328-39.

57. Boyde M, Peters R. Education Material for Heart Failure Patients: What Works and What Does Not? Current Heart Failure Reports. 2014;11(3):314-20.

58. Kang X, Li Z, Nolan MT. Informal Caregivers' Experiences of Caring for Patients With Chronic Heart Failure: Systematic Review and Metasynthesis of Qualitative Studies. Journal of Cardiovascular Nursing. 2011;26(5):386-94.

59. Dunbar SB, Clark PC, Quinn C, Gary RA, Kaslow NJ. Family Influences on Heart Failure Self-care and Outcomes. The Journal of cardiovascular nursing. 2008;23(3):258-65.

60. Hooker SA, Grigsby ME, Riegel B, Bekelman DB. The Impact of Relationship Quality on Health-Related Outcomes in Heart Failure Patients and Informal Family Caregivers: An Integrative Review. Journal of Cardiovascular Nursing. 2015;30(4S):S52-S63.

61. Wingham J, Frost J, Britten N, Jolly K, Greaves C, Abraham C, et al. Needs of caregivers in heart failure management: A qualitative study. Chronic Illness. 2015.

62. Wakefield BJ, Boren SA, Groves PS, Conn VS. Heart Failure Care Management Programs: A Review of Study Interventions and Meta-Analysis of Outcomes. Journal of Cardiovascular Nursing. 2013;28(1):8-19.

63. Seferović PM, Stoerk S, Filippatos G, Mareev V, Kavoliuniene A, Ristić AD, et al. Organization of heart failure management in European Society of Cardiology member countries: survey of the Heart Failure Association of the European Society of Cardiology in collaboration with the Heart Failure National Societies/Working Groups. European Journal of Heart Failure. 2013;15(9):947-59.

64. Krum H, Jelinek MV, Stewart S, Sindone A, Atherton JJ. 2011 update to National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Guidelines for the prevention, detection and management of chronic heart failure in Australia, 2006. Med J Aust. 2011;194(8):405-9.

65. National Institute for Health and Care Excellence (NICE). Chronic heart failure in adults:management 2016. Available from: https://www.nice.org.uk/guidance/cg108?unlid=695360523201691714358.

66. Willey RM. Managing Heart Failure: A Critical Appraisal of the Literature. Journal of Cardiovascular Nursing. 2012;27(5):403-17.

67. Cooper LB, Hernandez AF. Assessing the Quality and Comparative Effectiveness of Team-Based Care for Heart Failure: Who, What, Where, When, and How. Heart Failure Clinics. 2015;11(3):499-506.

68. Price A, Baker R, Krause J, Keen C. Organisation of services for people with cardiovascular disorders in primary care: transfer to primary care or to specialist-generalist multidisciplinary teams? BMC Family Practice. 2014;15(158):158.

69. Jaarsma T, Luttik ML. Home care in heart failure: towards an integrated care model. Eur J Heart Fail. 2011;13(8):823-4.

70. Luttik MLA, Jaarsma T, van Geel PP, Brons M, Hillege HL, Hoes AW, et al. Long-term follow-up in optimally treated and stable heart failure patients: primary care vs. heart failure clinic. Results of the COACH-2 study. European Journal of Heart Failure. 2014;16(11):1241-8.

71. Holland R, Battersby J, Harvey I, Lenaghan E, Smith J, Hay L. Systematic review of multidisciplinary interventions in heart failure. Heart. 2005;91(7):899-906.

72. Stewart S, Carrington MJ, Horowitz JD, Marwick TH, Newton PJ, Davidson PM, et al. Prolonged impact of home versus clinic-based management of chronic heart failure: Extended follow-up of a pragmatic, multicentre randomized trial cohort. International Journal of Cardiology. 2014;174(3):600-10.

73. Inglis S, Clark R, Dierckx R, Prieto-Merino D, Cleland J. Structured telephone support or non-invasive telemonitoring for patients with heart failure. . Cochrane Database of Systematic Reviews 2015.

74. Näsström L, Jaarsma T, Idvall E, Arested K, Strömberg A. Heart failure patients' descriptions of participation in structured home care. Health Expectations. 2013:n/a-n/a.

75. Hancock HC, Close H, Fuat A, Murphy JJ, Hungin APS, Mason JM. Barriers to accurate diagnosis and effective management of heart failure have not changed in the past 10 years: a qualitative study and national survey. BMJ Open. 2014;4(3):e003866.

76. Peters-Klimm F, Natanzon I, Müller-Tasch T, Ludt S, Nikendei C, Lossnitzer N, et al. Barriers to guideline implementation and educational needs of general practitioners regarding heart failure: a qualitative study. GMS Zeitschrift für Medizinische Ausbildung. 2012;29(3):Doc46.
77. Scott I, Jackson C. Chronic heart failure management in Australia. Time for general practice centred models of care? Australian Family Physician 2013;42(5):342-6.
78. Cramm JM, Nieboer AP. Chronically ill patients' self-management abilities to maintain overall well-being: what is needed to take the next step in the primary care setting? BMC Family Practice. 2015;16(1):1-8.
79. O'Donovan K. Nursing care of acute and chronic heart failure. Continuing Education 2010;19(1):33-5.
80. Grange J. The role of nurses in the management of heart failure. Heart. 2005;91(suppl 2):ii39-ii42.
81. Lambrinou E, Kalogirou F, Lamnisos D, Sourtzi P. Effectiveness of heart failure management programmes with nurse-led discharge planning in reducing re-admissions: A systematic review and meta-analysis. International Journal of Nursing Studies. 2012;49(5):610-24.
82. McLaughlin D, Hoy L, Glackin M. Heart failure nurse specialist crisis interventions and avoided hospital admissions. British Journal of Cardiac Nursing. 2015;10(7):326-33.
83. Price A. Specialist nurses improve outcomes in heart failure. Nurse Times. 2012;108(40):22-4.
84. Radhakrishnan K, Jacelon C. Impact of Telehealth on Patient Self-management of Heart Failure: A Review of Literature. Journal of Cardiovascular Nursing. 2012;27(1):33-43.
85. Glogowska M, Simmonds R, McLachlan S, Cramer H, Sanders T, Johnson R, et al. Managing Patients With Heart Failure: A Qualitative Study of Multidisciplinary Teams With Specialist Heart Failure Nurses. The Annals of Family Medicine. 2015;13(5):466-71.
86. Cheng JWM, Cooke-Ariel H. Pharmacists' Role in the Care of Patients with Heart Failure: Review and Future Evolution. Journal of Managed Care Pharmacy. 2014;20(2):206-13.
87. Koshman SL, Charrois TL, Simpson SH, McAlister FA, Tsuyuki RT. Pharmacist care of patients with heart failure: A systematic review of randomized trials. Archives of Internal Medicine. 2008;168(7):687-94.
88. Molloy GJ, O'Carroll RE, Witham MD, McMurdo MET. Interventions to Enhance Adherence to Medications in Patients With Heart Failure: A Systematic Review. Circulation: Heart Failure. 2012;5(1):126-33.
89. Holland R, Brooksby I, Lenaghan E, Ashton K, Hay L, Smith R, et al. Effectiveness of visits from community pharmacists for patients with heart failure: HeartMed randomised controlled trial. 2007;334(7603):1098.
90. World Health Organisation. Definition of Palliative Care. 2002. Available from: http://www.who.int/can- cer/palliative/definition/en/.
91. Health Service Executive, Foundation IH. Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks. Dublin: HSE and IHF, 2008.
92. Gadoud A, Kane E, Macleod U, Ansell P, Oliver S, Johnson M. Palliative Care among Heart Failure Patients in Primary Care: A Comparison to Cancer Patients Using English Family Practice Data. PLoS ONE. 2014;9(11):e113188.
93. Johnson M. Breaking the Deadlock. British Journal of Cardiology 2015;22(10).
94. McDevitt R, Bates M, Buckley U, Lucey M, Lynch M, Mahon N, et al. Action Research Project for the Integration of Palliative Care into Heart Failure Management Update as of June 2011 Department of Cardiology, Mater Misericordiae University Hospital, Dublin, Department of Cardiology, Connolly Hospital, St Francis Hospice, Raheny, Family GP Practice, North Dublin & Irish Hospice Foundation. Dublin2011.
95. Irish Hospice Foundation. Heart Failure and Palliative Care. http://hospicefoundation.ie/wp-content/uploads/2015/05/Heart-Failure-Report.pdf; 2015.
96. Wagner E, Austin HB, Korff MV. Organizing Care for Patients with Chronic Illness. The Milbank Quarterly 1996;74(4):511-44.
97. Barrett A, Savva G, Timonen V, Kenny R. Fifty Plus in Ireland 2011, First results from the Irish Longitudinal Study on Ageing (TILDA). Trinity College Dublin 2011.
98. Deswal A, Bozkurt B. Comparison of Morbidity in Women Versus Men With Heart Failure and Preserved Ejection Fraction. The American Journal of Cardiology. 2006;97(8):1228-31.
99. Shah RU, Klein L, Lloyd-Jones DM. Heart failure in women: epidemiology, biology and treatment. Women's Health. 2009;5(5):517-27.
100. Frazier CG, Alexander KP, Newby LK, Anderson S, Iverson E, Packer M, et al. Associations of Gender and Etiology With Outcomes in Heart Failure With Systolic Dysfunction: A Pooled Analysis of 5 Randomized Control Trials. Journal of the American College of Cardiology. 2007;49(13):1450-8.
101. Taylor AL. Heart Failure in Women. Current Heart Failure Reports. 2015;12(2):187-95.
102. Johansson P, Dahlstrom U, Brostrom A. Factors and interventions influencing health related quality of life in patients with heart failure: a review of the literature. European Journal of Nursing. 2006;5(1).
103. Oldridge N, Höfer S, McGee H, Conroy R, Doyle F, Saner H, et al. The HeartQoL: Part I. Development of a new core health-related quality of life questionnaire for patients with ischemic heart disease. Eur J Prev Cardiol. 2014;21:90-7.

104. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale Acta Psychiatrica Scandinavia. 1983;69(6):361-70.

105. Jaarsma T, Stromberg A, Martensson J, Dracup K. Development and testing of the European Heart Failure Self-Care Behaviour Scale. European Journal of Heart Failure 2003;5:363-70.

106. Katz S. Assessing self-maintenance: Activities of daily living, mobility and instrumental activities of daily living. Journal of the American Geriatrics Society. 1983;31(12):721-6.

107. Lawton M, Brody E. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969;9:179-86.

108. Berkman LF, Syme SL. Social networks, host resistance and mortality: a nine year follow-upstudy of Alameda County residences American Journal of Epidemiology. 1979;109:186-204.

109. Loucks EB, Sullivan LM, D'Agostino Sr RB, Larson MG, Berkman LF, Benjamin EJ. Social networks and inflammatory markers in the framingham heart study. Journal of Biosocial Science. 2006;38(06):835-42.

110. Hyde M, Wiggans R, Higgs P, Blane D. A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP- 19). Ageing Mental Health. 2003;7(3):186-94.

111. Wiggins R, Higgs P, Hyde M, Blane D. Quality of life in the third age: key predictors of the CASP-19 measure. Ageing and Society. 2004;24:693-708.

112. Blackburn S, Strömberg A, Humphrey A, Maguire L, Deschaeaux C. The caregiver burden questionnaire for chronic heart failure (CBQ-HF): development and validation. Journal of Cardiac Failure 2012;18(83).

113. Lum HD, Lo D, Hooker S, Bekelman DB. Caregiving in heart failure: Relationship quality is associated with caregiver benefit finding and caregiver burden. Heart & Lung: The Journal of Acute and Critical Care. 2014;43(4):306-10.

114. Irish Longitudinal Study on Ageing. TCD2016. Available from: http://tilda.tcd.ie/.

APPENDICIES

Appendix 1: Letter from hospital consultant to patient

Good morning

Your consultant, [name], has kindly agreed to send you this invitation on our behalf.

We are researchers from the Royal College of Surgeons Ireland (RCSI), who are conducting a study looking at the experiences of heart failure patients, their families and caregivers and healthcare providers following heart failure patients' discharge from hospital and your return to the community.

This study is commissioned by the Irish Heart Foundation (IHF), who are interested to learn more about how they can support heart failure patients and their caregivers through information, education and advice.

We would like to invite you to participate in a survey by completing a postal questionnaire. This would take approximately 40 minutes and you can return this to us in a free stamped address envelope. Your responses are completely confidential and there is no way you can be or will be identified in any reporting of the results. All of the information you provide will be aggregated with the other participant's information and presented in a report, which will inform the Irish Heart Foundation on your views and requirements.

We will also send you information to give to a caregiver of your choice. This will be in a separate envelope and will contain an information leaflet and a consent form for the caregiver to return to us in a separate free post envelope if they wish to receive a questionnaire to complete.

I enclose further information about the survey. Please contact us on the free phone number provided if you have any questions about this survey or this invitation. If you would like to complete this survey please sign the enclosed form and include your address. We will send you a questionnaire in the next week. If you do not wish to take part in the survey, we will not contact you again.

Thank you for reading this letter and we look forward to hearing from you.

Freephone number:

Email:

Appendix 2: Letter to patients who returned a consent form

Good morning,

Thank you for returning the consent form and agreeing to take part in the survey. I enclose a questionnaire for you to complete and a stamped addressed envelope for you to return the survey to us. We would greatly appreciate if you could return the questionnaires within a two week period.

I also enclose an envelope with a request that you give it to a family member or friend who gives you any help that you may need as a result of your heart failure. The envelope contains an invitation to fill in a caregiver's questionnaire, an information leaflet, consent forms and a questionnaire for the caregiver to return to us in the separate free post envelope provided if they are happy to complete the caregiver's survey.

If you have any questions about the surveys or if you would like some telephone assistance with filling it in then please phone xx on a Wednesday, Thursday or Friday between 9am and 5pm. Her number is xx and this is a Freephone number so the call won't cost you any money.

Thank you once again and we look forward to receiving the completed questionnaire.

Appendix 3: Letter to caregivers

Dear caregiver or family member,

The person you care for has kindly agreed to send you this invitation on our behalf.

We are researchers from the Royal College of Surgeons Ireland (RCSI), who are conducting a study looking at the experiences of heart failure patients, their families and caregivers and healthcare providers following heart failure patients' discharge from hospital and their return to the community.

This study is commissioned by the Irish Heart Foundation (IHF), who are interested to learn more about how they can support heart failure patients and their caregivers through information, education and advice.

We would like to invite you to participate in a survey by completing a postal questionnaire. This would take approximately 40 minutes and you can return this to us in a free stamped address envelope. Your responses are completely confidential and there is no way you can be or will be identified in any reporting of the results. All of the information you provide will be aggregated with the other participant's information and presented in a report, which will inform the Irish Heart Foundation on your views and requirements.

I enclose the questionnaire and two informed consent forms. Please contact us on the free phone number provided if you have any questions about this survey or this invitation. If you would like to complete this questionnaire please sign the enclosed consent form and return it together with the completed questionnaire using the enclosed envelope. If you do not wish to take part in the survey, we will not contact you again.

Appendix 4: Letter to health professionals

Good morning,

The Royal College of Surgeons Ireland (RCSI), commissioned by the Irish Heart Foundation, has initiated a research project which aims to document the experiences of heart failure patients, their families and carers and healthcare providers following patients' discharge from hospital and their return to the community.

This study will document how the Irish Heart Foundation (IHF) can best serve the patient's needs in relation to support, information, education and advice. This will inform the IHF how to deliver important social, personal and informational services beyond the remit and expertise of the HSE.

An important component of the study is to include opinions, views and experiences of professionals connected with patients with a diagnosis of heart failure. We have developed a short questionnaire for professionals and invite you to complete it.

I enclose the questionnaire and further information about the project. If you have further questions, please contact us.

Your contribution to this important study will be very much appreciated.

Appendix 5: Participants Information Leaflet

Principal investigator's name:

Principal investigator's title:

Telephone number of principal investigator:

You are being invited to take part in a research study to be carried out by the Royal College of Surgeons Ireland.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

This information is to help you understand what this study is about so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. If you decide not to take part it won't affect your future medical care.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You can call, text or speak to the researcher and say that you do not want to continue, you don't have to give us a reason and you will not be contacted again.

Why is this study being done?

Increasing numbers of people are living with heart failure. Irish health policy recommends that the care of people with heart failure should take place mainly in the community and that patients should only be in hospital during acute phases of their illness.

Who is organising and funding this study?

Little is known about what it is like for people with heart failure living in the community and whether the support and services that they need are there for them. This study aims to document the experiences of heart failure patients, their caregivers and health professionals who work with people with heart failure. It will inform the Irish Heart Foundation about how it can best support people with heart failure and their families.

The Irish Heart Foundation has commissioned this project and it is being carried out by a team of researchers from the Royal College of Surgeons Ireland (RCSI).

Why am I being asked to take part?

You are being asked to take part because your consultant has identified you as a person with heart failure. We are interested in your views and experiences of living with heart failure.

How will the study be carried out?

There are a number of parts to this study. You are being invited to complete a questionnaire which we will post to you if you agree to consent to take part. The questionnaire has a number of questions about you, your experience of having heart failure, your health, wellbeing and quality of life. It will also ask you about the services that you receive and about any services that you think should be put in place to support people with heart failure living in the community. The survey will take about 40 minutes to complete. Your involvement is voluntary and you are free to change your mind once you receive the questionnaire and are under no obligation to complete the survey.

What will happen to me if I agree to take part?

If you would like to take part, please complete the enclosed consent form and return it in the stamped addressed envelope provided when you return the questionnaire.

What are the benefits?

While there may be no direct benefit to you, others may benefit following the outcome of this survey. However, taking part in the survey will help the Irish Heart Foundation to get a clear picture of what it is like to live with heart failure in Ireland today. In this way you may be helping to improve services for future patients with heart failure.

What are the risks?

There are no foreseeable risks for you in taking part in this project. If you would like to discuss any aspect of the questionnaire, you can do so at any time.

Will it cost me anything to take part?

No, it won't cost you anything to take part. Postage is paid for to return the questionnaire.

Is the study confidential?

Only members of the research team will see the returned questionnaires. All the returned questionnaires will be given code numbers and the information given in the questionnaire will be stored in a way that protects the identity of the people who complete the survey. Those who kindly agree to participate in the survey will not be identified in the report or in any other publication. Nor will their consultant or any other member of their care be aware of their responses.

The results of the study

If you would like to receive the report that will be produced at the end of the study, please let us know.

Consent

Along with the letter of invite which you have received from your consultant, you have been provided with this participant information leaflet and a consent form to sign and return to the researcher.

Where can I get further information?

If you have any further questions about the study or if you need any further information now or at any time in the future, please Freephone:

Appendix 6: Consent form

Please read the letter of invite and the information leaflet. If you are interested in completing a questionnaire please read and sign and return this consent form. You have received two copies; please keep one for your own records.

We will then send you a questionnaire which you can return in the stamped address envelope which we will provide.

You can opt out of this survey at any time.

If you have any queries please do not hesitate to contact either:

I have read and understood the Information Leaflet about this survey. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes ☐	No ☐
I understand that I do not have to take part in this study and that I can opt out at any time. I understand that I do not have to give a reason for opting out.	Yes ☐	No ☐
I have been given a copy of the Information Leaflet and this completed consent form for my records.	Yes ☐	No ☐
Storage of information: I give my permission for the survey questionnaire to be stored or electronically processed for the purpose of this research project.	Yes ☐	No ☐

Name: ____________________

Address: ____________________

To be completed by the researcher.

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have invited them to ask questions on any aspect of the study that concerned them.

Researcher signature ____________________

Researcher name ____________________

Date ____________________

2 copies to be made: one to be returned in the post and the other to be retained by the participant

Appendix 7: Allied Health Professional Questionnaire

The Royal College of Surgeons Ireland (RCSI), commissioned by the Irish Heart Foundation, aims to document the experiences of patients with heart failure , their families and carers and healthcare providers following patients' discharge from hospital and their return to the community. We would like to invite you, as a healthcare provider, to take part in this short survey which will take approximately 10 minutes to complete. Through completion of this survey we can include your opinions, views and experiences as professionals connected with patients with a diagnosis of heart failure. Your responses will be completely confidential and no participants will be identifiable in the published reports. Ethical approval for this study has been granted by RCSI.

Please return this questionnaire in the stamped addressed envelope provided by

If you have any questions about this questionnaire or the project, please contact

SECTION ONE: Please tell us the following details about yourself

1a: Are you: Male ☐ Female ☐

1b: Please indicate your age bracket?

20-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60+ ☐

1c: Where do you work?

Dublin North East ☐
Dublin Midlands ☐
Dublin East ☐
West/North ☐
West ☐
Midwest ☐

1d: What is your local telephone area prefix: (eg 091, 01) ______________________________

1e: What is your profession?

GP ☐
Heart Failure nurse ☐
Hospice team member ☐
Community pharmacist ☐
Public health nurse ☐
Other, please specify ☐

1f: How long have you worked in this field/profession? __________ months __________ years

SECTION TWO: What is your professional contact with heart failure patients

2a: How many patients with heart failure, would you estimate you see:

Daily	Weekly	Monthly	Yearly

2b: In your estimation, what percentage of the heart failure patients who you see have a

Full medical card	GP only card	Private	Don't know

2c: In your estimation, what percentage of the heart failure patients who you see have completed a structured heart failure programme? __________ %

2d: In your estimation, what percentage of the heart failure patients who you see are categorised according the NYCA classification? __________ %

2e: In your estimation, what percentage of your heart failure patients are categorised as NYHA stage of heart failure:

stage 2	stage 3	stage 4	unknown stage

2f: How would you rate your knowledge about each of the following, you can tick two columns here especially if you have no knowledge and would like to know more:

	Good	None	I would like to know more
The symptoms of heart failure	☐	☐	☐
(NYHA) Classification of the stages of heart failure	☐	☐	☐
The European Society of Cardiology Clinical Practice Guidelines	☐	☐	☐
The pharmacological treatment of heart failure	☐	☐	☐
The self-management requirements of heart failure patients	☐	☐	☐
The association between heart failure and depression	☐	☐	☐
When to refer a heart failure patient for specialist consultation	☐	☐	☐
Where heart failure patients can access community health services other than your service	☐	☐	☐

2g: Can you tell us a little more about the nature of your interaction with heart failure patients

2g1: medical interaction ______________________________

2g2: non-medical interactions ______________________________

2h: What, IF ANY, are the key issues for YOU in providing a service to heart failure patients?

____

____

____

2i: We are interested in possible difficulties and barriers you may experience when to providing care to patients with heart failure, please tick all which of the following that may apply

There are no barriers		Not a priority area	
Distance from patients		Patients may be unaware of their diagnosis	
Time		Lack of services to refer patients to	
Financial		Patients difficulties with self-management	
Staffing		Patients non-compliance with treatment or advice	
Knowledge		The uncertainty of the disease trajectory	
Comorbidities		Patients unrealistic expectations	
Accessing tests such as BNP testing, echocardiograms		Accessing urgent cardiology appointments	
Other, please specify			

SECTION THREE: Your views about the management of heart failure patients living in the community

3a: We are interested in understanding the barriers TO SEEKING AND MAINTAINING HEALTHCARE that patients with heart failure may face. Please indicate to what extent the patients you meet experience difficulties with any of the following on a scale from 1= no difficulty to 5 = great difficulty:

	Please tick one choice on each line	**1** **No difficulty**	**2**	**3**	**4**	**5** **Great difficulty**
1	Complying with prescribed medication	☐	☐	☐	☐	☐
2	Maintaining a low salt diet/ an appropriate diet	☐	☐	☐	☐	☐
3	Monitoring weight gain	☐	☐	☐	☐	☐
4	Taking adequate exercise	☐	☐	☐	☐	☐
5	Motivation to self-manage	☐	☐	☐	☐	☐
6	Fatigue/ pain/ breathlessness	☐	☐	☐	☐	☐
7	Knowing when to contact a health professional	☐	☐	☐	☐	☐
8	Knowing who to contact with concerns or for advice	☐	☐	☐	☐	☐
9	Understanding the diagnosis of heart failure	☐	☐	☐	☐	☐
10	Accessing information about heart failure	☐	☐	☐	☐	☐
11	Accessing psychological support	☐	☐	☐	☐	☐
12	Fear	☐	☐	☐	☐	☐
13	Concern about being a ‘burden’	☐	☐	☐	☐	☐
14	The financial consequences of heart failure	☐	☐	☐	☐	☐
15	The impact of comorbidities	☐	☐	☐	☐	☐
16	Understanding the significance of symptoms	☐	☐	☐	☐	☐
17	Lack of social support/ social networks	☐	☐	☐	☐	☐
18	Difficulties with tasks of daily living	☐	☐	☐	☐	☐
19	Lack of coordinated/integrated care	☐	☐	☐	☐	☐
20	Depression	☐	☐	☐	☐	☐
21	Lack of coordinated/integrated care	☐	☐	☐	☐	☐
22	Lack of transport to access health or social support	☐	☐	☐	☐	☐
23	Other, please specify					

3b: Who should be involved in the healthcare management of heart failure patients in the community? Please tick all that apply:

General Practitioners		Hospice services	
Practice nurses		Voluntary groups	
Public Health Nurses		Home help	
Pharmacists		Family members	
Other, please specify			

3c: What support services do heart failure patients living in the community require? Please tick all that apply:

More information/advice ☐
Local support groups ☐
More public awareness of heart failure ☐
More health and social care professional awareness of heart failure ☐
Specialist community-based nurses ☐
Electronic/tele monitoring/support ☐
More access to hospice (palliative) care ☐
Strengthened linkages between hospital and primary care services ☐
In-home support (e.g. home help; meals on wheels) ☐
Support for carers of heart failure patients ☐
Clear care plan ☐
Other, please specify ☐

4: Is there anything that you would like to add?

Thank you for taking the time to complete this survey. The results will be disseminated to all those who return a questionnaire. Please return in the stamped addressed envelope provided and we would greatly appreciate if you could do this within the next two weeks.

Appendix 8: Patient Questionnaire

Thank you for consenting to take part in this important survey

This survey asks questions about you and your experience of living with Heart Failure

There are no right or wrong answers to the questions.

Your answers are very important to us and will help us to understand the experiences and the needs of people with heart failure. In this way services in the future may be improved.

When you have completed the survey please return it, by post, in the stamped and addressed envelope provided.

If you have any difficulties with the questions or would like some help to complete the questionnaire, or you would prefer to complete the questionnaire over the phone then please contact. This is a free phone number and is available Wednesday to Friday 9.00am – 5.00pm

Thank you.

SECTION A Demographics

A1. Gender

Male ☐ 1
Female ☐ 2

A2. What age are you?

_______ Years

A3. What was your highest level of education? Please tick one

No schooling ☐ 1
Primary school education only ☐ 2
Some secondary education ☐ 3
Complete secondary education ☐ 4
Some third level education ☐ 5
Complete third level education ☐ 6

A4. What is your present marital status? Please tick one

Married ☐ 1
Living with partner ☐ 2
Widowed ☐ 3
Separated ☐ 4
Divorced ☐ 5
Single/never married ☐ 6

A5. Do you have a medical card or private health insurance? Please tick one

Yes – full medical card ☐ 1
Yes – GP only card ☐ 2
Yes – private insurance [VHI/BUPA/VIVAS] ☐ 3
No ☐ 4

A6. Have you ever been told by a doctor that you have or have had any of the following? Please tick all that apply

Angina ☐
Heart attack ☐
High blood pressure ☐
Stroke ☐
COPD ☐
Diabetes) ☐
High cholesterol ☐
Depression ☐
Chronic Kidney Disease ☐
Heart Failure ☐

Any other condition not mentioned above: ____________________

A7. Who gave you the diagnosis of heart failure?

GP	☐	1
Hospital doctor	☐	2
Hospital nurse	☐	3
Other, please specify	☐	4

A8. Please tick one box, which best describes how you feel at the moment

No limitation of physical activity	☐	1
Slight limitation of physical activity	☐	2
Marked limitation of physical activity	☐	3
Unable to carry out any physical activity	☐	4

SECTION B

B1. On each line please tick one response that best describes how your heart problem has bothered you in the last four weeks

In the last four weeks have you been bothered by having to:		No	A little	Some	A lot
1	Walk indoors on level ground	☐	☐	☐	☐
2	Garden, vacuum or carry groceries	☐	☐	☐	☐
3	Climb a hill or a flight of stairs without stopping	☐	☐	☐	☐
4	Walk more than 100 yards/metres at a brisk pace	☐	☐	☐	☐
5	Lift or move heavy objects	☐	☐	☐	☐
In the last four weeks have you been bothered by:		No	A little	Some	A lot
6	Feeling short of breath	☐	☐	☐	☐
7	Being physically restricted	☐	☐	☐	☐
8	Feeling tired, fatigued or low on energy	☐	☐	☐	☐
9	Not feeling relaxed and free of tension	☐	☐	☐	☐
10	Feeling depressed	☐	☐	☐	☐
11	Being frustrated	☐	☐	☐	☐
12	Being worried	☐	☐	☐	☐
13	Being limited in doing sports or exercise	☐	☐	☐	☐
14	Working around the house or yard	☐	☐	☐	☐

B2: Please reply to the item which comes closest to how you have been feeling in the past week. Don’t take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. Please tick one box in each question.

B2.1. I feel tense or ‘wound up’

Most of the time	☐
A lot of the time	☐
From time to time, occasionally	☐
Not at all	☐

B2.2. I still enjoy the things I used to enjoy:

Definitely as much ☐
Not quite as much ☐
Only a little ☐
Hardly at all ☐

B2.3. I get sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly ☐
Yes, but not too badly ☐
A little, but it doesn't worry me ☐
Not at all ☐

B2.4. I can laugh and see the funny side of things:

As much as I always could ☐
Not quite so much now ☐
Definitely not so much now ☐
Not at all ☐

B2.5. Worrying thoughts go through my mind:

A great deal of the time ☐
A lot of the time ☐
From time to time but not too often. ☐
Only occasionally ☐

B2.6. I feel cheerful:

Not at all ☐
Not often ☐
Sometimes ☐
Most of the time ☐

B2.7. I can sit at ease and feel relaxed

Definitely ☐
Usually ☐
Not often ☐
Not at all ☐

B2.8. I feel as if I am slowed down:

Nearly all of the time ☐
Very often ☐
Sometimes ☐
Not at all ☐

B2.9. I get a sort of frightened feeling like butterflies in the stomach:

Not at all ☐
Occasionally ☐
Quite often ☐
Very often ☐

B2.10. I have lost interest in my appearance:

Definitely ☐
I don't take as much care as I should ☐
I may not take quite as much care ☐
I take just as much care as ever ☐

B2.11. I feel restless as if I have to be on the move:

Very much indeed ☐
Quite a lot ☐
Not very much ☐
Not at all ☐

B2.12. I look forward with enjoyment to things:

As much as ever I did ☐
Rather less than I used to ☐
Definitely less than I used to ☐
Hardly at all ☐

B2.13. I get sudden feelings of panic:

Very often indeed ☐
Quite often ☐
Not very often ☐
Not at all ☐

B2.14. I can enjoy a good book or radio or TV programme:

Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

SECTION C

C1. These questions are about how you take care of your needs. Please tell us how you would rate your self-care in these areas from 1 = I completely agree to 5 = I completely disagree

Please tick one choice on each line		1 completely agree	2	3	4	5 completely disagree
1	I weigh myself every day	☐	☐	☐	☐	☐
2	If I get short of breath I take it easy	☐	☐	☐	☐	☐
3	If shortness of breath increases I contact my doctor or nurse	☐	☐	☐	☐	☐
4	If my legs/feet are more swollen, I contact my doctor or nurse	☐	☐	☐	☐	☐
5	If I gain weight I contact my doctor or nurse	☐	☐	☐	☐	☐
6	I limit the amount of fluids	☐	☐	☐	☐	☐
7	I take a rest during the day	☐	☐	☐	☐	☐
8	If I experience fatigue, I contact my doctor or nurse	☐	☐	☐	☐	☐
9	I eat a low salt diet	☐	☐	☐	☐	☐
10	I take my medication as prescribed	☐	☐	☐	☐	☐
11	I get a flu shot every year	☐	☐	☐	☐	☐
12	I exercise regularly	☐	☐	☐	☐	☐

C2.1 If you had a concern about your Heart condition, to whom would you turn for medical advice and why?

____

____

C3. These questions ask about your daily activities and any help you may need. Please tick <u>one response on each line</u> (Tick for the person who is MOST LIKELY to help you)

	Please tick one choice on each line	I don't require assistance	Partner assists me	Son or daughter assists me	Home help or other paid carer	Other, please say who
a	Getting across a room	☐	☐	☐	☐	☐
b	Dressing	☐	☐	☐	☐	☐
c	Bathing	☐	☐	☐	☐	☐
d	Eating	☐	☐	☐	☐	☐
e	Getting out of bed	☐	☐	☐	☐	☐
f	Using the toilet	☐	☐	☐	☐	☐
g	Using the telephone	☐	☐	☐	☐	☐
h	Shopping	☐	☐	☐	☐	☐
i	Food preparation	☐	☐	☐	☐	☐
j	Housework	☐	☐	☐	☐	☐
k	Laundry	☐	☐	☐	☐	☐
l	Transport	☐	☐	☐	☐	☐
m	Taking medication	☐	☐	☐	☐	☐
n	Handling finances	☐	☐	☐	☐	☐

C4. The next questions ask about other services that are involved in your care or that you would like to be involved in your care

	Please tick all that apply	Involved in my care	Not involved in my care	Not involved in my care BUT I would like them to be
1	Social work services	☐	☐	☐
2	Home help services provided by the HSE	☐	☐	☐
3	Home help services that I pay for privately	☐	☐	☐
4	Community pharmacist	☐	☐	☐
5	HSE Physiotherapist	☐	☐	☐
6	Physiotherapist who I pay for privately	☐	☐	☐
7	HSE dietician	☐	☐	☐
8	Dietician who I pay for privately	☐	☐	☐
9	Psychologist	☐	☐	☐
10	Psychologist who I pay for privately	☐	☐	☐
11	Hospice/palliative care	☐	☐	☐
12	Public Health Nurse	☐	☐	☐
13	Heart failure Clinic	☐	☐	☐
14	Counselling service	☐	☐	☐

C5. Are there other services that you receive <u>that are not listed above</u>? If yes, please tell us what these are

____

____

C6.1 Do you experience any barriers to accessing or attending any of the services involved in your care? Please tick one:

Yes ☐ No ☐

C6.2 If you do experience barriers to accessing or attending services please tell us what these barriers are?

____

____

C6.3 Do you receive the services that you need as frequently as you feel you need them? Please tick one:

Yes ☐ No ☐

Please explain your response

____

____

C7. Are there other services that you feel that patients with heart problems should receive? If yes, please tell us what these are?

____

____

____

____

C8. The following questions ask about your social support. Please read the following questions and circle the response that most closely describes your current situation.

C8.1. How many close friends do you have, people that you feel at ease with, can talk to about private matters?

None	☐
1 or 2	☐
3 to 5	☐
6 to 9	☐
10 or more	☐
Unknown	☐

C8.2. How many of these close friends do you see at least once a month?

None	☐
1 or 2	☐
3 to 5	☐
6 to 9	☐
10 or more	☐
Unknown	☐

C8.3. How many relatives do you have, people that you feel at ease with, can talk to about private matters?

None	☐
1 or 2	☐
3 to 5	☐
6 to 9	☐
10 or more	☐
Unknown	☐

C8.4. How many of these relatives do you see at least once a month?

None	☐
1 or 2	☐
3 to 5	☐
6 to 9	☐
10 or more	☐
Unknown	☐

C8.5. Do you participate in any groups, such as a senior centre, social or work group, religious-connected group, self-help group, or charity, public service, or community group?

No	☐
Yes	☐
Unknown	☐

C8.6. About how often do you go to religious meetings or services?

Never or almost never	☐
Once or twice a year	☐
Every few months	☐
Once or twice a month	☐
Once a week	☐
More than once a week	☐
Unknown	☐

C8.7. Is there someone available to you whom you can count on to listen to you when you need to talk?

No-one ☐
1 or 2 ☐
3 to 5 ☐
6 to 9 ☐
10 or more ☐
Unknown ☐

C8.8. Is there someone available to give you good advice about a problem?

No-one ☐
1 or 2 ☐
3 to 5 ☐
6 to 9 ☐
10 or more ☐
Unknown ☐

C8.9. Is there someone available to you who shows you love and affection?

No-one ☐
1 or 2 ☐
3 to 5 ☐
6 to 9 ☐
10 or more ☐
Unknown ☐

C8.10. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?

No-one ☐
1 or 2 ☐
3 to 5 ☐
6 to 9 ☐
10 or more ☐
Unknown ☐

C8.11. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?

No-one ☐
1 or 2 ☐
3 to 5 ☐
6 to 9 ☐
10 or more ☐
Unknown ☐

C9.1 Do you attend a support group for patients with heart failure?

Yes ☐ No ☐

If not, why not?

C9.2. Do you think that a support group for people with heart failure would be helpful?

Yes ☐ No ☐

Please say why you answered in this way?

SECTION D

This section asks about your GP and about your Emergency Dept visits.

D1. In the past 6 months approximately how many GP visits have you had?

____

____

D2. In the past 6 months how approximately many Emergency Department visits have you had?

____

____

D3. The following questions relate to your satisfaction with your general practitioner service

	Please tick one on each line	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
1	I'm satisfied that my concerns are taken seriously by the GP	☐	☐	☐	☐	☐
2	My GP sees older people as being a high priority group	☐	☐	☐	☐	☐
3	My GP is not very good at explaining my health problems	☐	☐	☐	☐	☐
4	My GP gives me feedback on the progress of my condition	☐	☐	☐	☐	☐
5	My GP's surgery caters well for the needs of patients e.g. wheelchair access	☐	☐	☐	☐	☐
6	It is generally easy to get an appointment at the time I want	☐	☐	☐	☐	☐
7	I am satisfied that information is given to me by my GP in a sensitive and reassuring way	☐	☐	☐	☐	☐
8	I am satisfied with the quantity of information received from my GP about my health	☐	☐	☐	☐	☐
9	After I see my GP I feel my problems are understood	☐	☐	☐	☐	☐
10	At my GP's surgery, information given to reception staff remains confidential	☐	☐	☐	☐	☐

SECTION E

This last section is about information, support, and what the Irish Heart Foundation can do to help people with heart failure

The Irish Heart Foundation is the national charity fighting heart disease and stroke and it is funded 92% by public donations.

Some of the services the Irish Heart Foundation provides includes providing information on heart health to the public and media, supporting patients in managing heart disease and stroke and advocating better patient treatment and services.

E1. Do you think that the information you received answered all your questions about living with heart failure?

Yes ☐ No ☐

If Yes – Where and from whom did you get this information about heart failure?

____

If No – why do you think this information did not meet your needs?

____

E2. In what format did you receive any information that you were given? Please tick all that apply

One to one discussion ☐
Leaflet ☐
Internet site ☐

Other, please specify ______________________________

The next questions ask for your opinions about what the Irish Heart Foundation could do for you?

E3. The Irish Heart Foundation would like to help people with a diagnosis of heart failure. In your opinion, what could they do to help people with heart failure living in the community in relation to?

E3.1 Support services

____

E3.2 Education

____

E3.3 Information

____

E3.4 Advice

____

E4.In your opinion, what kinds of information do people with Heart Failure need to have?

____

E5. Would any of the following help you to manage your heart failure? Please tick all that apply

A telephone helpline ☐
Information leaflets ☐
An internet forum ☐
Home visits from a community nurse ☐
A support group ☐
A log book for recording symptoms ☐
A colour coded chart to help to monitor symptoms ☐
A smart-phone App ☐
Telemedicine ☐
Other, please specify

Appendix 9: Caregiver questionnaire

This survey asks questions about you and your experience of living with Heart Failure. There are no right or wrong answers to the questions. answers are very important to us and will help us to understand the experiences and the needs of people with heart failure. In this way services in the future may be improved. When you have completed the survey please return it, by post, in the stamped and addressed envelope provided. If you have any difficulties with the questions or would like some help with it, then please phone XXX free phone: XXXX *(Wednesday – Friday 9.00am -5.00pm)

SECTION A

A1. Gender

Male ☐ 1
Female ☐ 2

A2. What age are you?

Years

A3. What was your highest level of education? Please tick one

No schooling ☐ 1
Primary school education only ☐ 2
Some secondary education ☐ 3
Complete secondary education ☐ 4
Some third level education ☐ 5
Complete third level education ☐ 6

A4. What is your present marital status? Please tick one

Married ☐ 1
Living with partner ☐ 2
Widowed ☐ 3
Separated ☐ 4
Divorced ☐ 5
Single/never married ☐ 6

A5. Do you have a medical card or private health insurance? Please tick one

Yes – full medical card ☐ 1
Yes – GP only card ☐ 2
Yes – private insurance ☐ 3
No ☐ 4

A6. Which of these best describes your current situation? Please tick one

Retired ☐ 1
Employed ☐ 2
Self-employed (including farming) ☐ 3
Unemployed ☐ 4
Permanently sick or disabled ☐ 5
Looking after home or family ☐ 6
In education or training ☐ 7
Full time or part time carer ______________ ☐ 8
Other, please specify ☐ 9

A7. What is your relationship to the person you care for (eg spouse, friend, cousin, neighbour)?

____

A8. Do you receive:

Full rate Carers Allowance ☐ 1
Half-rate Carers Allowance ☐ 2
No Carers Allowance ☐ 3

A9. Have you ever been told by a doctor that you have or have had any of the following? Please tick all that apply

Angina ☐
Heart attack ☐
High blood pressure ☐
Stroke ☐
COPD ☐
Diabetes ☐
High cholesterol ☐
Depression ☐
Anxiety ☐
Heart Failure ☐

A10. Has the person you care for ever been told by a doctor that they have or have had any of the following? Please tick all that apply

Angina ☐
Heart attack ☐
High blood pressure ☐
Stroke ☐
COPD ☐
Diabetes) ☐
High cholesterol ☐
Depression ☐
Chronic Kidney Disease ☐
Heart Failure ☐

A11. Please tick one category which best describes the level of physical activity of the person you care for.

No limitation of physical activity ☐ 1
Slight limitation of physical activity ☐ 2
Marked limitation of physical activity ☐ 3
Unable to carry out any physical activity ☐ 4

SECTION B

This section asks about your general health.

Please tick the item which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

B1. I feel tense or 'wound up':

Most of the time ☐
A lot of the time ☐
From time to time, occasionally ☐
Not at all ☐

B2. I still enjoy the things I used to enjoy:

Definitely as much ☐
Not quite as much ☐
Only a little ☐
Hardly at all ☐

B3. I get sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly ☐
Yes, but not too badly ☐
A little, but it doesn't worry me ☐
Not at all ☐

B4. I can laugh and see the funny side of things:

As much as I always could ☐
Not quite so much now ☐
Definitely not so much now ☐
Not at all ☐

B5. Worrying thoughts go through my mind:

A great deal of the time ☐
A lot of the time ☐
From time to time but not too often. ☐
Only occasionally ☐

B6. I feel cheerful:

Not at all ☐
Not often ☐
Sometimes ☐
Most of the time ☐

B7. I can sit at ease and feel relaxed

Definitely ☐
Usually ☐
Not often ☐
Not at all ☐

B8. I feel as if I am slowed down:

Nearly all of the time ☐
Very often ☐
Sometimes ☐
Not at all ☐

B9. I get a sort of frightened feeling like butterflies in the stomach:

Not at all ☐
Occasionally ☐
Quite often ☐
Very often ☐

B10. I have lost interest in my appearance:

Definitely ☐
I don’t take as much care as I should ☐
I may not take quite as much care ☐
I take just as much care as ever ☐

B11. I feel restless as if I have to be on the move:

Very much indeed ☐
Quite a lot ☐
Not very much ☐
Not at all ☐

B12. I look forward with enjoyment to things:

As much as ever I did ☐
Rather less than I used to ☐
Definitely less than I used to ☐
Hardly at all ☐

B13. I get sudden feelings of panic:

Very often indeed ☐
Quite often ☐
Not very often ☐
Not at all ☐

B14. I can enjoy a good book or radio or TV programme:

Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

SECTION C

The following questions ask you about what it is like caregiving for someone with heart failure.

By 'Caregiving' we mean all the things you do to help a relative or friend with heart failure, for which you are not paid.

If that person has other health conditions, please try to think about their heart failure first.

For each question, think about how caregiving for a person with heart failure has affected you during the past 4 weeks.

Tick only one box for each question that best reflects how you feel.

Your Physical Well-Being

	Not at all	A little	Somewhat	Quite a lot	A lot
During the past 4 weeks, how much has caregiving made you feel physically tired?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you neglect your own health?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving been physically hard work?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made it difficult to sleep?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving caused you aches and pains?	☐	☐	☐	☐	☐

Your Emotional Well-Being

	Not at all	A little	Somewhat	Quite a lot	A lot
During the past 4 weeks, how much have you felt like you need to do more for the person you care for?	☐	☐	☐	☐	☐
During the past 4 weeks, how much have you felt the person you care for asks too much of you?	☐	☐	☐	☐	☐
During the past 4 weeks, how guilty have you felt because the time you spent caregiving limited what you can do for others?	☐	☐	☐	☐	☐
During the past 4 weeks, how guilty have you felt because you cannot do enough for the person you care for?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel frustrated?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel stressed?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel sad?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made it difficult to focus or concentrate on other things?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you worry about the person you care for?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel mentally tired?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel emotionally drained?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel overwhelmed?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made you feel lonely?	☐	☐	☐	☐	☐

	Not at all	A little	Somewhat	Quite a lot	A lot
During the past 4 weeks, how much support have you had from family or friends?	☐	☐	☐	☐	☐
During the past 4 weeks, how much have you enjoyed caregiving?	☐	☐	☐	☐	☐

Your Social Life & Relationships

	Not at all	A little	Somewhat	Quite a lot	A lot
During the past 4 weeks, how much has caregiving caused problems in your relationship with the person you care for?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving limited the time you spent with partner, family or friends?	☐	☐	☐	☐	☐

Your Lifestyle

	Not at all	A little	Somewhat	Quite a lot	A lot
During the past 4 weeks, how much have you felt like you have no time for yourself?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving caused you to change your plans or made you avoid making plans?	☐	☐	☐	☐	☐
During the past 4 weeks, how much have you felt you cannot be away from the person you care for?	☐	☐	☐	☐	☐
During the past 4 weeks, how much has caregiving made it difficult to do paid work?	☐	☐	☐	☐	☐

SECTION D

This section asks about your life and how you feel. Here is a list of statements that people have used to describe their lives and how they feel. We would like to know how often, if at all, you think that these apply to you. Please tick the which one most applies.

		Often	Sometimes	Not often	Never
1	My age prevents me from doing the things I would like to	☐	☐	☐	☐
2	I feel that what happens to me is out of my control	☐	☐	☐	☐
3	I feel free to plan the future	☐	☐	☐	☐
4	I feel left out of things	☐	☐	☐	☐
5	I can do the things I want to do	☐	☐	☐	☐
6	Family responsibilities prevent me from doing what I want to do	☐	☐	☐	☐
7	I feel that I can please myself what I can do	☐	☐	☐	☐
8	My health stops me from doing things I want to do	☐	☐	☐	☐
9	Shortage of money stops me from doing things I want to do	☐	☐	☐	☐
10	I look forward to each day	☐	☐	☐	☐
11	I feel that my life has meaning	☐	☐	☐	☐
12	I enjoy the things that I do	☐	☐	☐	☐
13	I enjoy being in the company of others	☐	☐	☐	☐
14	On balance, I look back on my life with a sense of happiness	☐	☐	☐	☐
15	I feel full of energy these days	☐	☐	☐	☐
16	I choose to do things that I have never done before	☐	☐	☐	☐
17	I feel satisfied with the way my life has turned out	☐	☐	☐	☐
18	I feel that life is full of opportunities	☐	☐	☐	☐
19	I feel that the future looks good for me	☐	☐	☐	☐

SECTION E

E1. The next questions ask about other services that support you in caring for a person with HF or that you would like to support you in caring for a person with heart failure. Please tick the answer that applies.

		Supports my caring	Does not support my caring	Does not support my caring BUT I would like them to be involved
1	Social work services	☐	☐	☐
2	Home help services provided by the HSE	☐	☐	☐
3	Home help services paid for privately	☐	☐	☐
4	Community pharmacist	☐	☐	☐
5	HSE Physiotherapist	☐	☐	☐
6	Physiotherapist paid for privately	☐	☐	☐
7	HSE dietician	☐	☐	☐
8	Dietician paid for privately	☐	☐	☐
9	Psychologist	☐	☐	☐
10	Psychologist paid for privately	☐	☐	☐
11	Palliative care	☐	☐	☐
12	Public Health Nurse	☐	☐	☐

E2. Are there other services that support that are not listed above?
If yes, please tell us what these are

E3. Are there other services that you would like to receive support from?
If yes, please tell us what these are?

SECTION F

The next questions are about daily activities, they ask whether the person that you care for requires assistance with these activities and who, in the main, provides this assistance. Please tick one choice on each line.

		Person does not require assistance	I assist	Other, please say who
a	Getting across a room	☐	☐	☐
b	Dressing	☐	☐	☐
c	Bathing	☐	☐	☐
d	Eating	☐	☐	☐
e	Getting out of bed	☐	☐	☐
f	Using the toilet	☐	☐	☐
g	Using the telephone	☐	☐	☐
h	Shopping	☐	☐	☐
i	Food preparation	☐	☐	☐
j	Housework	☐	☐	☐
k	Laundry	☐	☐	☐
l	Transport	☐	☐	☐
m	Taking medication	☐	☐	☐
n	Handling finances	☐	☐	☐

Please add any other assistance you may provide:

SECTION G

This last section is about information, support, and what the Irish Heart Foundation can do to help carers of people with heart failure.

The Irish Heart Foundation is the national charity fighting heart disease and stroke and it is funded 92% by public donations.

The Irish Heart Foundation provides information on heart health to the public and media, supports patients in managing heart disease and stroke, advocating better patient treatment and services.

G.1 Do you think you got the information that answered all your questions about heart failure?

Yes ☐ No ☐

If Yes – Where and from whom did you get this information about heart failure?

If No - why do you think this information did not meet your needs?

G.2 In what format did you receive any information that you were given? Please tick all that apply

One to one discussion	☐
Leaflet	☐
Internet site	☐

Other, please specify

The next questions ask for your opinions about what the Irish Heart Foundation could do for you?

G.3 The Irish Heart Foundation would like to help carers of people with heart failure. In your opinion, what could they do to help carers of people with heart failure living in the community in relation to?

G3.1 Support services

G3.2 Education

G3.3 Information

G3.4 Advice

G4. In your opinion, what kinds of information do carers of people with heart failure need to have?

G5. Would any of the following help you to support the person with heart failure? Please tick all that apply?

A telephone helpline	☐
Information leaflets	☐
An internet forum	☐
Home visits from a community nurse	☐
A support group	☐
A log book for recording symptoms	☐
A colour coded chart to help to monitor symptoms	☐
A smart-phone App	☐
Telemedicine	☐

Other, please specify

Is there anything else that you would like to tell us?

Appendix 10: Qualitative interview schedule

5.1: patient interviews

How long ago were you diagnosed with heart failure?

Who gave you the diagnosis?

How did you feel when you were told that you had heart failure?

Did you participate in a structured programme following your diagnosis?

Yes ☐ No ☐

If no, why not?

If yes, did you find it helpful?

How does having heart failure impact on your daily life?

Activities of daily living?

Social activities?

Quality of life?

Self-care regime?

Which health professionals are involved with your heart failure care?

How often would receive services from these professionals?

Hospital services?

GP?

Pharmacy?

Home help?

Other?

Are you happy with the health services that you receive?

Yes ☐ No ☐

Why/why not?

Barriers?

What could be improved, if anything?

Do you need help with any aspect of life because of your heart failure?

Yes ☐ No ☐

Who gives that help?

Does that work well? Why/why not?

Would you like to receive more help?

Yes ☐ No ☐

If yes, what help? ________________________________

From whom? ________________________________

When you were diagnosed with heart failure:

How much information were you given about heart failure?

Who gave you the information? In what form? Was it useful? Is there any other information that you would like to have been given that you weren't given?

The Irish Heart Foundation is the national charity fighting heart disease and stroke and it is funded 92% by public donations. Some of the services the Irish heart Foundation provides include providing information on heart health to the public and the media, supporting patients in managing heart disease and stroke and advocating for better patient treatment and services.

In your opinion:

What would best help people with heart failure living in the community?

How would heart failure patients like to receive information and advice?

Is there anything that you would like to tell me that we haven't covered?

5.2: caregiver interview schedule

Did you know anything about heart failure before your husband/wife/father/mother……. was diagnosed with the condition?

What information did you receive about heart failure?

Who gave you this information?

Was it enough/useful?

What assistance does the person you care for need?

Do you feel equipped to give this care? Please explain?

Do you receive help with the care-needs of the person you care for?

Who gives this help?

Is it enough?

How is your own health?

Do your caring demands impact on your own health? Please explain

The Irish Heart Foundation is the national charity fighting heart disease and stroke and it is funded 92% by public donations. Some of the services the Irish Heart Foundation provides includes providing information on heart health to the public and media, supporting patients and their families and carers in managing heart disease and stroke and advocating better patient treatment and services.

What services do you think that the Irish Heart Foundation could provide that would improve the quality of life of carers of patients with heart failure in terms of:

The financial impact of the diagnosis?

The emotional impact of the diagnosis?

The social support needs of carers?

Is there anything else that you would like the Irish Heart Foundation to provide information about? Is there anything that you would like to tell me that we haven't covered?

Appendix 11: Qualitative interview schedule

The interviews were semi-structured and included questions about the experiences of heart failure patients living in their community relating to the medical and non-medical needs of heart failure patients based on:

Tully et al 2009 questions:

1. What constitutes good quality of life for people in Ireland living with heart failure, and which factors are most important to them?
2. What is the quality of life currently experienced by people living with heart failure?
3. What are patients' current experiences of heart failure health services in areas with and without specialised heart failure services?
4. What are patients' views on what is important for good quality of care in heart failure services and how such services should be developed and delivered to optimise their quality of life?

Specific areas included:

- Day to day living with HF
- Support following discharge - primary and specialist services
- Support services in the community, such as home help and how this is accessed
- Information relating to the impact of HF on family, work and social activities
- Information relating to the financial and emotional impact of HF
- How is educational material and advice on living with heart failure accessed?

IRISH HEART FOUNDATION
Fighting Heart Disease & Stroke

Irish Heart Foundation
50 Ringsend Road, Dublin 4
Phone: +353 1 668 5001
Email: info@irishheart.ie
Heart & Stroke Helpline: Freephone 1800 25 25 50
Web: www.irishheart.ie